

Chapter 7

Ethical Issues

CONTENTS

	<i>Page</i>
ETHICAL DIFFERENCES BETWEEN GENETIC MONITORING AND SCREENING	140
MORAL CONSIDERATIONS FOR WORKERS AND EMPLOYERS	141
The Decision To undergo Genetic Monitoring or Screening	142
Access to Information Gained From Genetic Monitoring and Screening	143
The Communication and Interpretation of Test Results	143
ADDITIONAL CONSIDERATIONS	145
Reducing the Incidence of Occupational Disease	145
Protecting Privacy	146
Fair Treatment of Individuals	147
Economic Efficiency and Competitiveness	147
CRITERIA FOR WORKPLACE GENETIC MONITORING AND SCREENING PROGRAMS	147
HOW MAY GENETIC MONITORING AND SCREENING RESULTS BE USED TO PROTECT WORKER HEALTH?	151
SUMMARY AND CONCLUSIONS	153
CHAPTER PREFERENCES	154

Boxes

<i>Box</i>	<i>Page</i>
7-A. The Social Value of Work	142
7-B. An International Survey of Attitudes of Medical Geneticists Toward Workplace Genetic Screening and Access to Results	144
7-C. Sex Discrimination and Fetal Protection Policies	148
7-D. Using Workplace Genetic Screening as Power	149
7-E. Protection of Others: A Case for Workplace Screening?	152

Chapter 7

Ethical Issues

The benefits of genetic monitoring and screening in the workplace lie in their potential to provide reliable, long-range predictions about the health risks that employees and job applicants face. These predictions could benefit employees, job applicants, and employers by allowing workers to avoid situations likely to cause illness, thereby maintaining their productivity and defraying health care costs. However, the workplace acquisition and use of this predictive knowledge raise important ethical questions. Under what circumstances, if any, could genetic monitoring and screening programs be required of employees or job applicants? Who should have access to test results? To what purposes may such knowledge be applied?

The rights and responsibilities of individual employees, job applicants, employers, and society in such programs are not clearly defined. Several values embedded in U.S. culture conflict with each other as a result of genetic monitoring and screening: autonomy of employees, job applicants, and employers; privacy and confidentiality of medical information; rights to a safe workplace; fairness and equality of opportunity; and efficiency in the workplace and industrial competition.

Ethical and legal issues surrounding genetic monitoring and screening in the workplace share common ground. Legal and ethical arguments often express common concerns and in some instances use common language. Several laws discussed in chapter 6 confer rights or responsibilities to various parties or identify and promote moral values shared by society. For example, the Occupational Safety and Health Act (OSH Act) (Public Law 91-596) protects workers from exposure to toxic substances, ensures they are provided with information about occupational health risks, and guarantees employees access to the results of any medical tests performed in the workplace. This law could therefore be interpreted as legal enforcement of a moral obligation to provide a safe work environment and a legal “right to know” that reflects the moral value of respect for autonomy. Similarly, the Americans with Disabilities Act (ADA) (Public Law 101-336) may prevent workplace discrimination based on genetic factors.

The overlap between law and ethics, however, is limited. Law does not reflect all moral values held by members of society, nor can it necessarily be used to resolve ethical dilemmas. Ethical arguments about the use of genetic monitoring and screening in the workplace often address obligations, rights or values not explicitly covered by law, and are used to express incumbency the law does not acknowledge.

Currently, employers might not be constrained by existing statutes to always use genetic monitoring and screening in ways that reinforce human values or for purposes that are directly related to worker health protection. Employers could find that performing certain genetic screening tests on workers provides information useful in limiting workers’ compensation claims or decreasing insurance premiums. These same tests, however, may be a way to fulfill legal obligations if they provide the only effective protection for the sensitive worker against irremedial damage. In this case, ethical and legal concerns will come into conflict.

The relationship between law and ethics is dynamic. Awareness of the ethical issues surrounding new technology is essential for formulating and implementing policies that reflect the greatest possible regard for human values. The formulation of new public policies often reflects ethical concerns, and new ethical issues often arise from the implementation or interpretation of law.

Although the ethical issues have not changed considerably since the Office of Technology Assessment (OTA) studied them in 1983 (17), the emphasis placed on some concerns about genetic monitoring and screening has shifted. Increased pessimism is being expressed in public debate about the risks genetic screening could have for employees’ autonomy and privacy. Attention has shifted from the uncertain technical efficacy of genetic monitoring and screening in predicting or identifying illness to the potential abuses of genetic monitoring and screening in the workplace. In 1983, genetic monitoring and screening were perceived to be ethically justified to the extent they would enhance worker health in a manner consistent with established moral principles. Considerable concern that these principles cannot be upheld has developed since that time.

Because current U.S. law does not address these ethical considerations, they are discussed in this chapter.

For the most part, the ethical issues surrounding genetic monitoring and screening involve concerns about the social rules for and the implications of their use, not the intrinsic properties of the technologies themselves. Two kinds of ethical concerns are discussed in this chapter: problems that arise as testing procedures create moral dilemmas for one or another party, and possible problems that could stem from the misuse of test results (3). The former type of concern stems from the uncertain roles of the various parties involved in testing programs, and from the fact that not all current genetic monitoring or screening tests developed are indisputably valid means of determining either genetically determined traits for illness or chromosomal damage (see chs. 4 and 5).

This chapter presents ethical issues raised by genetic monitoring and screening based on the perspectives of employees, job applicants, employers, and society. These perspectives describe possible considerations from each point of view, and will address the overall questions: Should genetic monitoring and screening be performed in the workplace? Should the tests be used in employment decisions? May these tests be used to deny access to jobs? How might potential policies affect employees, job applicants, employers, or society?

In discussing the interests of job applicants, workers and employers, three principal issues exist:

- the implementation of genetic monitoring and screening tests in the workplace and the use of the information they generate,
- the dissemination and storage of information gained from genetic monitoring and screening, and
- the role of genetic counseling for both employers and employees in genetic monitoring and screening programs.

Some ethical issues presented by genetic monitoring and screening in the workplace go beyond the interests of individual workers and employers to affect society as a whole. Not all the social issues discussed in this chapter are strictly ethical: some have moral significance because they create conflict among widely held values. For example, both the health of the workforce and economic competitive-

ness can be regarded as valued goods that should be protected, although neither has moral value in itself. If employers are held responsible for conducting genetic monitoring or screening to protect the health of the workforce, some sacrifice could be involved for both employers and society. Employers could bear the expense of monitoring and screening and taking necessary action to protect employees, and society may sacrifice some economic advantage. Values such as economic competitiveness will be included in this discussion because they often affect decisionmaking and weigh against ethical concerns.

ETHICAL DIFFERENCES BETWEEN GENETIC MONITORING AND SCREENING

The ethical issues associated with genetic monitoring and screening in the workplace vary according to whether the test performed is genetic monitoring for chromosomal damage, genetic screening for susceptibilities to occupational illness, or genetic screening for inherited conditions or traits unrelated to the workplace.

Genetic monitoring can be effective to the extent that it detects previously unrecognized hazardous environments or identifies incipient damage in exposed workers. This form of surveillance, however, differs from traditional environmental or biological monitoring, as it is intended to detect indirect evidence of an adverse health effect that could occur in the future rather than present levels or pathological effects of the hazardous substance itself. Indirect evidence often limits the utility of genetic monitoring tests, making it unclear how to use the information gained from these tests if its predictive value is uncertain.

Genetic screening can be used for two purposes in the workplace. First, as indicated previously, it can identify genetic susceptibilities to workplace exposures. The same conditions that make genetic screening effective, however, make these tests potential threats to workers' privacy. Information obtained from genetic screening is likely to be seen by employees as extremely private, sensitive information. Because genes provide much of the basis of human individuality, information about a person's genes is likely to be seen as intensely private. Since genetic screening is meant to detect "defects" in genetic makeup, genetic disease may also carry a stigma. Genetic screening for workplace susceptibil-

ities is more controversial than genetic monitoring, but it maybe ethically justified in some situations.

Genetic screening can also be used by employers to identify genetic traits or susceptibilities unrelated to the workplace, but which indicate likelihood of future disease. Because genetic disease can affect a company's productivity or profit in terms of sick leave taken, workers' compensation, disability, early retirement, health and life insurance expenses (if these are provided by the employer), and liability for illness and injury, employers might want to know as much as possible about workers' genetic makeup. Genetic screening for traits unrelated to the workplace is controversial and many find it ethically inappropriate to conduct these tests in an employment setting.

MORAL CONSIDERATIONS FOR WORKERS AND EMPLOYERS

To the extent that genetic tests are able to detect and prevent genetic disease, both workers and employers could find genetic monitoring or screening in the workplace desirable. From the points of view of both workers and employers, however, genetic monitoring and screening raise several moral considerations.

A worker's motivation for participating in a genetic monitoring or screening program would most likely be self-benefit. While a mandatory genetic monitoring or screening program might benefit employees by preventing occupational disease, such a program could also deprive them of fair treatment or the ability to make free choices. Workers are likely to want to judge for themselves what actions serve their benefit and act freely toward this end. In many cases, workers want to work and do not want their employment opportunities to be curtailed (see box 7-A). Workers therefore have an interest in maximizing their autonomy and thus their freedom.

For the purposes of this chapter, "autonomy" refers to the freedom and ability to make choices concerning one's own welfare. From the employee's perspective, autonomy consists in the liberty to make free choices about the work he or she performs, but autonomy also requires information about occupational health and safety risks so that informed decisions can be made. Autonomy depends on being able to plan and act deliberately, based on one's

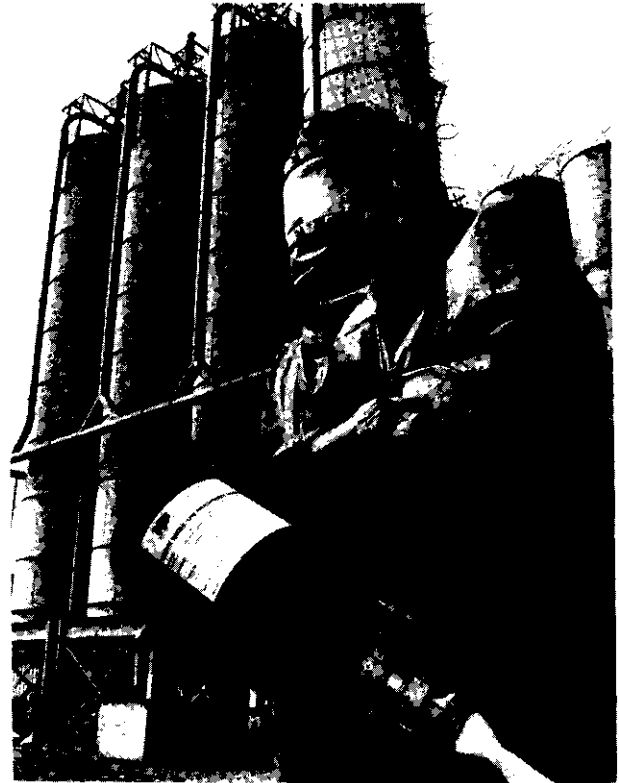


Photo credit: Earl Dotter

A worker wearing protective clothing.

judgment about the consequences of certain behaviors and their value or utility to oneself or others. This leads to the notion that individuals should be free to act as they wish, regardless of how their actions appear to others and without interference by others, so long as their actions do not harm or interfere with the liberty of others. In this light, an employee might see genetic monitoring or screening as a way to obtain information necessary to make informed choices about accepting or remaining in a job.

At the same time, employers want the freedom to protect the interests of the company, and genetic monitoring and screening might benefit employers by reducing costs. A balance must be struck between promoting one party's autonomy and compromising that of the other. If employers are free to implement and enforce genetic monitoring or screening policies, the autonomy of employees will be limited. Conversely, giving the employee complete freedom to protect his or her own interests would restrict the freedom of the employer and in some instances present risk to co-workers or family. Employer and

Box 7-A—The Social Value of Work

Most persons find it is in their best interest to work. In most American social, economic, and political thought, labor tends to be regarded exclusively as an economic activity. Work has many dimensions, however, since it has always been connected to moral and ethical, as well as economic values. For example, work ties into religious perspectives, such as Puritanism which is based on a concept of work and faith in continuous tension with each other. Secular and religious meanings of work are often inseparable.

While the range of feelings about the role and meaning of work in human life is broad, work is typically viewed as a matter of practical necessity. Work is expected of those who participate in society, and adults who do not work are often regarded with some suspicion. In the Marxist view, labor determines economic value. On a more personal level, employment gives an individual dignity which is often reflected in the esteem of professional peers. Whatever the reason for employment, a number of reasons exist for why a person needs employment: to survive, to fulfill social expectations, or to maintain self-esteem.

Despite workers' compelling reasons for obtaining and retaining jobs, in the United States, decisions about beginning and terminating employment are usually left to employers. Although U.S. laws and moral codes do not specifically recognize a right to work they do acknowledge strong protectable interests in fair work opportunities and freedom from occupational injury and illness which might prevent a person from working. Genetic monitoring and screening present a moral dilemma in that these tests could meet one aim, but violate the other: they could protect workers from occupational illness but also be used to deny them employment. Different opinions are held about how to resolve this conflict.

SOURCES: Office of Technology Assessment, 1990, based on F. Battaglia, 'Work' Dictionary of **the History of Ideas** (New York NY: Charles Scribner's Sons, 1973); and A.J. Vidich, 'The Morel, Economic, and Political Status of Labor in American Society,' *The Environment of the Workplace and Human Values*, S.W. Samuels (ed.) (New York, NY: Alan R. Liss, Inc., 1986).

employee interests can conflict at three points in the processes of genetic monitoring and screening:

- the decision to undergo genetic monitoring or screening;
- the access to information gained from genetic monitoring or screening; and
- the communication and interpretation of genetic monitoring or screening results.

The Decision To Undergo Genetic Monitoring or Screening

Who decides whether an employee or job applicant undergoes genetic monitoring or screening?

Given employers' legal obligations to prevent harmful workplace exposures and workers' interests in acting autonomously, there may be disagreement about whether employers should be able to require workers to undergo genetic monitoring or screening. Some workers will want to undergo genetic monitoring or screening to make informed decisions about the benefits of any current or potential job (e.g., the income from having that job) against risks of that job (e.g., any heightened risk of developing occupational illness). Based on genetic monitoring or screening results, they could decide to continue

working at a job or take a job in spite of health hazards because they feel it is the best option available to them. Alternatively, they might decide against working in a hazardous environment, and seek transfer to another job. Other workers, however, will prefer not to be tested. They might not want to know psychologically burdensome information, or might choose to work in a job regardless of health hazards. Any of these choices could be seen as maximizing autonomy because the worker has made the decision.

Employers, however, might want to be free to conduct monitoring or screening programs and establish the conditions for employee participation and consequences for those who refuse to participate. Such practice would be consistent with current preemployment medical testing practices. Employers weigh the benefits (e.g., minimizing the costs of or liability for occupational disease) against the costs (e.g., the cost of the monitoring and screening program).

The degree of conflict between worker and employer interests varies according to whether a genetic monitoring or a genetic screening program is implemented.

Access to Information Gained From Genetic Monitoring and Screening

Who should have access to the information obtained from genetic monitoring or screening? Are workers entitled to test results? Are employers? Are others?

Because information from genetic monitoring or screening could provide the first indication that an individual is at risk for genetic disease, workers need to know test results in order to take action to protect their health. Withholding test results deprives the worker of autonomy by making it impossible for him or her to make informed choices. Thus an employee will likely find no reason to undergo genetic monitoring or screening unless test results are shared with him or her.

When patients have requested the test, medical test results are usually given to patients by their doctors. This tradition should not be taken for granted, however, if genetic monitoring or screening are performed in the workplace, especially if tests are done at the employer's expense. Unless the genetic monitoring and screening programs are established by the employer as part of an employee wellness program, employers may find no reason to provide genetic monitoring and screening results to workers.

Rather than notifying workers, employers might choose to protect employee interests paternalistically by preventing them from working in unhealthy environments. While this approach fulfills a responsibility to provide a safe workplace, such action denies the worker autonomy. Although there may be no legal compulsion to provide workers with genetic monitoring or screening results, a moral reason for doing so probably exists based on a right to information about one's own medical condition, an obligation to respect the autonomy of persons, and the social benefit of open communication between persons tested and those who conduct medical tests. Whatever the explanation, compelling ethical reasons are present to ensure that workers who undergo genetic monitoring or screening receive test results.

Whether an employer chooses to receive worker test results depends on the motivations for implementing genetic monitoring or screening programs. If genetic monitoring or screening is offered as a health promotion service (e.g., a voluntary sickle cell screening program), the employer might spon-

sor such programs without expecting to see the results. If genetic monitoring or screening is offered for economic or legal reasons, however, the employer will most likely want to see the results and may want to retain the information. Indeed, the OSH Act requires employers to keep medical records on their employees.

The OSH Act, however, has no specific language requiring occupational health professionals to protect the confidentiality of those records. Employers have unrestricted access to them and may, in certain circumstances, distribute genetic information to third-parties (10). Thus, employees might not want genetic monitoring and screening results from voluntary wellness programs to be disseminated to employers. Employees could feel that all genetic information should remain confidential under any circumstance, especially if it might be used to deprive them of a job, health insurance, or other benefit (see box 7-B).

The Communication and Interpretation of Test Results

How should test results be communicated to workers and employers?

Even if workers receive genetic monitoring and screening results, using them to make informed choices could be problematic unless the communication of genetic information is accompanied by appropriate interpretation. Results from genetic monitoring and screening need to be placed in context—unless their significance is properly communicated, there is much room for misunderstanding. Results delivered without adequate or accurate interpretation could harm workers by causing them extreme and, in some cases, undue concern about their health. In other situations, some workers who are found to be susceptible to workplace exposures may continue to work in an unhealthy environment unknowingly if the implications of the test results are misunderstood. While it is impossible to ensure that all workers make truly informed decisions, failure to communicate the results of genetic monitoring and screening tests in a clear, thorough, and responsible manner curtails employee autonomy by not enabling workers to make informed choices. Thus genetic counseling appears necessary for employees to fully understand the results of genetic monitoring or screening and to use this knowledge appropriately. Currently, however, employers are

Box 7-B—An International Survey of Attitudes of Medical Geneticists Toward Workplace Genetic Screening and Access to Results

A survey on mass genetic screening was sent to 1,053 medical geneticists in 18 nations, of whom 677 responded. Geneticists strongly preferred voluntary over mandatory workplace screening, by a 72 percent majority. In the United States, there was consensus (>75 percent) that screening should be voluntary. Geneticists who thought screening should be voluntary cited the worker's autonomy or right to decide (74 percent), and the danger of stigmatization, discrimination in employment, or misuse of information by institutional third-parties (41 percent). Advocates of mandatory screening cited protecting the individual worker's health (64 percent), protecting public health (51 percent), and efficiency or cost-benefit arguments (22 percent). Nine percent of those who advocated voluntary screening and 12 percent of those who advocated mandatory screening based their responses in part on concern for economic interests of employers.

In advocating voluntary versus mandatory screening, a clear difference of opinion on whose welfare the respondent placed foremost was reported. Ninety-seven percent who advocated voluntary screening and 58 percent who advocated mandatory screening placed the worker's welfare as most important. Three percent who advocated voluntary screening and 37 percent who believed in mandatory screening placed societal interests first. Only 1 percent placed the employer's welfare first.

Advocates of voluntary screening were more likely than supporters of mandatory screening to describe a conflict of interest between worker and employer; 34 percent described such conflicts, as opposed to 13 percent who advocated mandatory screening. A majority of both groups, however, described no conflicts.

Ninety-eight percent of respondents said the worker should have access to test results, including 86 percent who said the worker should be told the results even if he or she did not ask for them. When asked whether the employer should have access to genetic screening results, 81 percent said employers should have no access without the worker's consent, including 22 percent who believed that employers should have no access at all.

Thirty percent of respondents who gave reasons for their choices about access believed it would be to the worker's benefit if the employer had some form of access, e.g., employers could shift susceptible workers to less dangerous jobs. Only 6 percent of respondents, however, thought that working conditions in general would be improved. Nineteen percent described **potential economic discrimination, stigmatization, or other misuse of test results by employers. Ten percent based their responses on the economic interests** of the employer.

when asked whether government **health departments should have access, 68 percent said there should be** no access without worker consent. There was a strong consensus on this issue in six nations, including the United States.

These differences in perception indicate that geneticists—those in a position to conduct genetic screening tests—share concerns about how genetic screening might be used in the workplace. A large majority of geneticists ranked the interests of workers and society above those of employers in importance, but they disagree about how these interests can be best protected. Many geneticists believe that workplace screening should be voluntary and that workers should make autonomous decisions about whether to undergo genetic screening. Almost all geneticists believed workers should receive genetic screening results, but that employers' access should be restricted. They expressed concern that genetic screening results may be used to justify personnel actions that may stigmatize or discriminate against some workers.

SOURCE: D.C. Wertz and J.C. Fletcher, "An International Survey of Attitudes of Medical Genetics Toward Mass Screening and Access to Results," *Public Health Reports* 104(1):35-44, 1989.



Photo credit: University of South Carolina School of Medicine

A genetic counselor discussing results with clients.

under no legal obligation to have genetic monitoring or screening results interpreted for workers by a qualified genetic counselor. If test results are shared with employees, the employer might suggest the worker have them interpreted by a genetic counselor, but is not required to provide one. (See ch. 8 for further discussion of genetic counseling.)

Employers, too, would likely benefit from professional interpretation of genetic monitoring and screening results, but might see no reason to obtain a genetic counselor's interpretation of test results. An employer might not want or need to know the exact levels of sensitivity or predictiveness for individual workers before taking personnel actions based on genetic tests. The employer could find it sufficient to rely on aggregate or imprecise data in making employment decisions without regard for false positive or false negative results. Although genetic monitoring and screening are not sensitive or predictive enough to identify every worker at risk of genetic disease, employers might still find the procedures beneficial on a population basis.

Without qualified interpretation of test results, however, employers might deny individuals jobs that would never cause them disease. This denial would then constitute unfair treatment of employees, and could reduce the efficiency of the workplace--thereby failing to serve the interests of the employer. Having a genetic counselor interpret genetic moni-

toring and screening results appears to be of both moral and economic value to employers.

ADDITIONAL CONSIDERATIONS

A number of factors either promote or violate the autonomy of workers and employers when ethical considerations of genetic monitoring and screening are analyzed. In some cases, genetic monitoring and screening programs appear to benefit both workers and employers; other programs likely function to the detriment of one or both. But genetic monitoring and screening in the workplace can affect societal interests as well. Because genetic monitoring and screening are likely to have impact beyond the workplace, societal interests must also be balanced against the interests of various parties.

Reducing the Incidence of Occupational Disease

Occupational disease might be prevented in three ways: increasing the safety of the work environment; identifying workplace-induced genetic changes early so as to minimize future damage; or removing susceptible employees from a hazardous environment. Genetic monitoring is intended to address the second goal; genetic screening the third. Some argue that the first goal, providing a safe workplace, is the employer's responsibility and that the use of genetic monitoring and screening to remove employees from high-risk jobs does not release employers from their obligation to improve the safety of working conditions.

Under the OSH Act, the employer is responsible for minimizing the potential for disease or physical harm in the workplace by providing the safest possible environment. When removing all risks is not possible, engineering protections may be required. If employers use genetic screening to identify individuals most likely to be affected by workplace conditions, they might consider it more expedient to relocate those workers rather than remove the hazards. Although ADA precludes excluding workers from jobs based on genetic characteristics, its coverage of genetic traits, susceptibilities, or disease is unclear. To minimize the costs of occupational illness, the most effective prevention could result from a safe workplace, either alone or in combination with genetic monitoring or screening.



Photo credit: American Philosophical Society

Eugenic and Health Exhibit, Kansas Free Fair, 1929.

Protecting Privacy

Protecting the privacy of workers undergoing genetic monitoring and screening is important not only to individuals, but to society as well. By protecting the privacy of workers and the confidentiality of genetic information, workers who otherwise would be unwilling to undergo genetic monitoring or screening in the workplace (even if such tests can protect their health) might choose to be tested. The value placed on the confidentiality of medical information is seen as early as the Hippocratic oath, and is confirmed in the Patient's Bill of Rights adopted by the American Hospital Association in 1973 and other principles and codes of medical ethics (2). The value society places on confidential-

ity is also seen in other contexts, such as the careful protection traditionally given to the records of adopted children.

Although a number of medical organizations have dealt with the issue of protecting patients' confidentiality in their codes of medical ethics (e.g., American Medical Association, World Medical Association), different views exist about whether medical procedures performed in the workplace are subject to the same constraints. Occupational health professionals might not consider the worker as a patient and thus not see obligations to workers being "as comprehensive or as stringent as the responsibilities that apply in a typical physician-patient relationship" (2). While law does not prevent workplace

physicians from notifying employers of employees' medical conditions, the American College of Occupational Medicine's Code of Medical Ethics emphasizes the importance of confidentiality of employees' medical information (see ch. 6). Similar viewpoints have been expressed by other groups (5), indicating a general interest in protecting the privacy of individuals and the confidentiality of medical information regardless of where it is obtained.

Society probably also has an interest in allowing employers access to genetic monitoring and screening results. If employers are prevented from examining results, they may unknowingly hire or retain workers who have genetic susceptibilities to workplace risk, which could eventually increase the costs of occupational illness to society. It could be argued that, if all medical testing results must remain confidential, genetic monitoring and screening in the workplace should not be considered medical testing or that these results should be considered an exception to the confidentiality rule.

No clear answer exists to whether a privacy right overrides the risk that might be presented to society in maintaining confidentiality of workplace test results. Currently, the matter is often resolved according to who requests or pays for the tests: when the employer pays for the test, the employer receives the results.

Fair Treatment of Individuals

Certain legislation expresses the societal belief that nondiscrimination promotes general well-being (see ch. 6). Title VII of the Civil Rights Act, for instance, states that denying jobs to qualified individuals for race, sex, or disability is prohibited (see box 7-C). Since a person's genetic endowment, whether or not it causes an obvious disability, is also beyond individual control, it might be unfair, although not expressly illegal, to use the results of genetic monitoring or screening as the basis for hiring and firing decisions. Some believe existing law does not protect workers from discrimination on the basis of genetic endowment. It might be appropriate to explicitly include genetic susceptibilities and traits among the conditions listed in Title VII or ADA (see ch. 6) if it is found that employers use the results of genetic monitoring or screening to stigmatize certain workers for genetic traits.

Some question whether the results of genetic monitoring and screening tests should be used as a

basis for hiring or retention decisions if they show that members of certain racial, ethnic, or gender groups are more likely to be susceptible or potentially susceptible. It is not clear whether genetic monitoring or screening would be a socially acceptable means of reducing occupational illness regardless of its impact on such groups, or whether such testing would provide a means of justifying discrimination against such groups. Decisions to hire or fire members of racial, ethnic, or gender groups that already struggle for equality in the workplace, on the basis of the results of genetic monitoring and screening might be interpreted as discrimination (See box 7-D).

Economic Efficiency and Competitiveness

Capitalist economy depends on competition. One of the variables that determines successor failure for a business is management style, including hiring and firing policies and overall treatment of employees. Apart from preventing blatant discrimination in hiring practices, the law has largely left employers free to make decisions in this regard. This freedom is generally viewed as serving a societal interest by promoting economic efficiency and productivity within companies and competitive markets (9).

CRITERIA FOR WORKPLACE GENETIC MONITORING AND SCREENING PROGRAMS

Under ideal circumstances, genetic monitoring and screening could benefit workers, employers, and society by improving the health of the workforce. Workers would gain maximal information about risks of mutagenicity through genetic monitoring and screening and would be provided with protective measures or reasonable work alternatives when test results indicate such action is necessary. Employers would benefit by reducing the costs of occupational illness and increasing productivity.

To protect the interests of all parties two factors are necessary: a mechanism for deciding when it is appropriate to use genetic monitoring and screening in the workplace, and guidelines for how these results are to be applied. No guarantee exists that genetic monitoring or screening will be used to reduce occupational illness or that such testing will be conducted in an ethical manner. Therefore, guidelines for the use of genetic monitoring and screening in the workplace have been proposed.

Box 7-C-Sex Discrimination and Fetal Protection Policies

Some companies have fetal protection policies (FPPs) that deny women of childbearing age jobs to prevent harmful exposures to developing or future fetuses. Recently, several of these policies have been challenged, and courts have found that an FPP that applies only to women constitutes sex discrimination.

Because battery production involves exposure to lead (a known hazard to fetal development), Johnson Controls, Inc. has an FPP. Its policy denies all battery production jobs to women of childbearing age who lack medical evidence of infertility except those fertile women who prove they can keep their blood lead level below a specific minimum level.

Until 1982, Johnson Controls had a voluntary FPP that informed workers of the potential risks of lead exposure to fetal health during pregnancy and encouraged female workers to consult their doctors. The company based its voluntary policy on its view that fetal protection "is the immediate and direct responsibility of the prospective parents . . . [it would] appear to be illegal discrimination" to have an FPP that treated all fertile female employees "as though they will become pregnant." The company found that the voluntary policy was ineffective because women refused to leave jobs which threatened exposure to hazardous amounts of lead.

Several court cases have been brought against Johnson Controls--one by a female employee in Johnson Controls' Globe Battery Co. plant in San Francisco, CA, who was denied a battery assembly job in 1983, although she was not pregnant or planning to be. A lower court ruled that Johnson Controls' FPP constitutes "overt gender-based discrimination" founded in "unscientific stereotypic notions about women." The decision was based in part on the facts that exposure to lead can affect fertile male workers as well as fertile women, and that Federal and State work safety agencies ban both male and female workers from job sites if their blood lead levels rise. Johnson Controls disputed the claim's scientific basis but in May 1990, the California Supreme Court upheld the ruling.

Another case has been brought against a Johnson Controls plant in Minnesota by the Auto Workers Union and eight Johnson Controls employees. The plaintiffs include a woman who was sterilized *to remain in a job she considered desirable, several women who had been transferred to lower-paying jobs, and a man who desired a leave of absence to lower his blood lead level before he became a father. The workers and union argued* Johnson Controls' FPP is explicit sex discrimination because it singles out women for less favorable treatment on the basis of a factor that has nothing to do with their ability to do the job. Johnson Controls' FPP was upheld by the Circuit Court which said the plaintiffs failed to prove the FPP was discriminatory. The case is now before the U.S. Supreme Court, and a ruling is expected in 1991.

Other companies' FPPs have been challenged. General Motors (GM) has one "intended to protect fetuses that women may be carrying knowingly or unknowingly" and "to protect [GM] from possible lawsuits alleging that workplace lead exposures caused **birth defects.**" **This policy** was challenged by a female iron pourer at GM's Defiance foundry in Cincinnati in a case currently under consideration by the **U.S. Court of Appeals, sixth** Circuit.

Neither case is new or unique, but both illustrate the ongoing problem with job discrimination and the confusion that can result in job bias litigation from introducing risk assessment technologies to the workplace. Scientific progress in identifying risks associated with exposure to hazardous workplace agents has been the basis for these policies, yet the teratogenic effects of exposures seem to be poorly understood by employers.

Whether employers would use genetic monitoring or screening results to justify FPPs is unclear, since exposure to lead and the detection of genetic sensitivities are not completely analogous. There is a crucial conceptual difference between measuring intrinsic genetic traits that might confer risk and measuring the effects of external workplace agents on fetal development. Detecting a susceptibility to workplace exposures in a female worker does not necessarily identify risk to a future fetus because offspring would not be adversely affected unless the susceptibility was inherited from both parents, the trait was expressed, and workplace exposure could affect the fetus in utero. While genetic monitoring that identified genetic changes might better indicate actual risk to a future fetus, the gametes of both male and female workers would have to be affected, thus an FPP aimed at women would be clearly discriminatory.

SOURCES: Office of Technology Assessment, 1990; based on L. Denniston, "High Court To Consider Fetal *Safety: Workers' Choice at Center of Case,*" **Baltimore Sun**, p. 1, Feb. 18, 1990; B. Egelko, "California Court Rebuffs Ban on Women From Jobs That Could Harm Fetuses," Associated Press, May 18, 1990; J. Nolan, Associated Press, Mar. 16, 1990; U.S. Congress, Office of Technology Assessment, **Reproductive Health Hazards in the Workplace** OTA-BA-266 (Washington, DC: US. Government Printing Office December 1985).

Box 7-D-Using Workplace Genetic Screening as Power

Some persons believe political power and social status influence employers' uses of genetic screening. To illustrate this claim, two authors present a scenario in which the roles of employers (the party the authors believe are most likely to advocate occupational genetic screening programs) and workers are reversed.

"Imagine that an administrative committee, composed of some of the least powerful members of a population of workers--racial minorities, non-English-speaking immigrants, poorly educated youth--have suddenly been granted full authority to impose a genetic screening program on their more highly paid employers. The goal: to design and implement a test that will weed out 'genetically defective' business executives and mid-level managers. These genetic misfits are then to be efficiently eliminated from corporate payrolls in an effort to improve the company's lagging profits.

First this powerful committee might decide to provide corporate research funds to spur studies into human genetic variation in areas that might affect the job performance of managers. The search might encompass genes thought to influence the development of a wide range of diseases that are approaching epidemic levels in the ranks of executives, including alcoholism, drug abuse, heart disease, sexual dysfunction and mental illness, to name a few. In time, it is likely that ambitious genetics researchers in both private and public laboratories, flushed by the sudden influx of research grants, would find such DNA sequences or at least identify genetic markers that could be used to signal their presence in genetic screening tests.

Later, other researchers might suggest techniques to carry out low-cost screening programs on the chromosomes of these harried executives, who by now would almost certainly find themselves growing increasingly uneasy over rumors of the committee's benevolent plans to improve their genetic hygiene. As soon as these experimental genetic tests began to promise a degree of predictive value for the target occupational diseases, the committee, emboldened by the new scientific findings, might brashly demand that all managers submit to a series of genetic tests designed to ferret out their 'bad' genes. Those managers whose genetic profiles revealed any 'undesirable' DNA sequences might then be asked-for their own good health, of course, as well as for the economic health of the corporation--either to transfer to a less stressful position in the company or to seek more 'genetically suitable' employment elsewhere.

The pool of genetic information on these unfortunate would then be freely shared with other workers' committees controlling other firms, in the hope that epidemics of alcohol and drug addiction, heart disease and emotional disturbances could finally be controlled. No effort would be made to modify environmental factors that might be contributing to the deterioration of these 'executive diseases'--excessive work loads, social stresses, dietary practices and so forth. The diligent genetic screening task force would **singlcminedly devote its efforts** to identifying what they perceived as disease-prone managers and plucking them unceremoniously from the workplace.

The utter improbability of this imaginary role reversal underscores the imbalance of power that traditionally exists between employers and employees in our society. But this thought experiment also reveals the potential for the abuse of genetic knowledge by any special-interest group, regardless of its ideology, whenever information is used to dictate important decisions to individuals, rather than to enlighten their own personal decisionmaking processes."

SOURCE: D. Suzuki and P. Knudtson, "Genetic Screening" *Genethics* (Cambridge, MA: Harvard University Press 1989).

These guidelines call for the development of workplace genetic monitoring and screening programs that produce maximal benefits to all parties by minimizing occupational illness without threatening privacy and confidentiality, denying equality of opportunity, or stigmatizing workers:

- **Employers should demonstrate the need for a genetic monitoring or screening program** (14). Employers should be able to prove a high prevalence of genetic disease among the workforce and an increased risk of morbidity (12).

. Purposes for conducting **genetic monitoring or screening in the workplace should be attainable and clearly articulated before implementation. The purpose of any workplace genetic monitoring or screening program should be to protect employee health and reduce the burdens of occupational illness to workers, employers, and society (7,10).** This zeal should be communicated to workers before testing to avoid misunderstanding and heightened expectations for intervention that could be neither intended nor feasible. Only

scientifically valid tests should be used, and the ability of genetic monitoring or screening tests to meet these ends should be determined before implementing programs. Tests chosen should be subject to minimal misinterpretation and provide maximal, medically relevant information for protecting employee health (10).

- Participation of both individual workers and the workforce in general should be voluntary. For ethical reasons as well as purposes of efficacy, maximal involvement of the workforce in designing and implementing workplace genetic monitoring or screening programs is desirable (8,10,18). Voluntary participation requires that workers who choose not to undergo genetic monitoring or screening do not jeopardize employment opportunities (7). If possible, alternative protective measures should be provided for workers who do not wish to participate in diagnostic genetic monitoring or screening. Workers should be free to discontinue participation in monitoring. Voluntary participation recognizes the autonomy of workers: it provides opportunity for workers to gain information about job risks if they so choose, but does not compel participation.
- Any program of genetic monitoring and screening in the workplace should apply equally to all workers. Providing equal access to monitoring or screening lessens the possibility of such programs being used or perceived as devices to discriminate against certain workers (10). Particular attention should be given to ensuring that screening for genetic conditions normally concentrated in specific ethnic groups (e.g., glucose-6-phosphate dehydrogenase deficiency or sickle cell anemia) be made available to other members of the workforce on an equal basis and that consistent action be taken for all persons who test positive for a trait in order to avoid disparate impact of workplace testing policies.
- Informed consent should be obtained from any worker undergoing genetic monitoring or screening for any reason. Meaningful informed consent for genetic monitoring or screening should be solicited whether genetic monitoring or screening is performed at the worker's request, for research, or for diagnostic purposes. Informed consent forms should enumerate the purposes of the test, including a description of any ambiguities inherent in the test design, all projected uses of the results, and plans for disclosure of resulting data.
- Any worker undergoing genetic monitoring and screening in the workplace should have access to results. All results should be made available to workers who participate in genetic monitoring or screening programs, including those who are involved in preemployment testing (10). Since genetic monitoring does not clearly indicate risk to individuals, denying access might not limit employee autonomy, but the restricted access to results should be made clear to the employee before tests are performed, and employees should receive genetic monitoring results if they still want them. Genetic screening results should always be provided to workers.
- Professional interpretation of genetic monitoring and screening results should be provided for both workers and employers so that genetic monitoring and screening can be used in accordance with their intended ends. Genetic monitoring results should be interpreted by a genetic counselor so that statistical evidence of workplace hazards are completely understood. Genetic counseling should be provided for all workers who undergo genetic screening, especially when genetic screening indicates increased risk of genetic disease. Genetic screening results should also be conveyed to employers by a professional counselor, and "special care should be taken not to perpetuate past instances of misinformation and stigmatization of particular groups" (8).
- Genetic monitoring and screening results should be confidential. Workers should have the ability to restrict access to genetic monitoring and screening results. Ideally, the results of genetic monitoring and screening would be provided only to tested employees, and could only be provided to employers with the worker's explicit consent or without identifying individual subjects (8). In this regard, genetic monitoring and screening would be like any other form of medical testing service that individuals receive from their own physicians.

HOW MAY GENETIC MONITORING AND SCREENING RESULTS BE USED TO PROTECT WORKER HEALTH?

Once genetic monitoring or screening has been performed, what actions should be taken to protect worker health? If genetic screening identifies a susceptible individual, do employers have a responsibility to reduce the hazards in the workplace, or do they have a right to remove workers at risk? How can worker, employer, and societal interests be promoted equally in making these decisions?

This chapter and chapter 6 describe ethical and legal duties for employers to provide a safe work environment, but this obligation could be impossible to fulfill for persons genetically susceptible to workplace exposures. If engineering protections cannot provide adequate protection for these workers, removing them from sites of dangerous exposure could be the only recourse (16). Some workers are likely to view this preventive measure to their benefit; others, however, will take issue with what they perceive as restriction of their free choice and autonomous action.

Current employees who experience genetic changes or who are found genetically susceptible to occupational illness might be eligible for medical removal protection, which requires employers to transfer an at-risk employee to a safer job without loss of pay or benefits. Job applicants, however, might only be protected from genetic susceptibilities if employers install only genetically "safe" workers in hazardous environments: if genetically susceptible persons are denied employment in hazardous jobs altogether they will certainly be protected from exposure. An employment policy that excludes some workers from job opportunities based on genetic monitoring or screening results could be considered discrimination against handicap, where the disability is genetic susceptibility.

Some employees and job applicants might be willing to risk adverse health effects despite genetic monitoring and screening results. If freedom to make informed decisions about acceptable personal risks is a condition of autonomy, should autonomy ever be limited by preventing individuals from taking risks? The answer depends on whether other persons are affected. People are generally free to

take risks in our society. Many people who engage in dangerous hobbies, for example, risk their health by doing so. When those risks affect others, however, there is usually cause to prevent them.

Workers who agree to work in hazardous conditions, or employers who hire workers with genetic susceptibilities, might be assuming risks not only for themselves but for others. Society might be responsible for medical care for workers if they become ill, and for disability payments if they cannot work. Family members can also suffer financially or emotionally if the worker is injured or becomes ill.

There could be health or safety risks involved for others as well. If a worker's decision to risk genetic disease threatens the well-being of other persons, there may be reason to curtail his or her autonomy in choosing to take chances. The safety of co-workers or consumers of a company's products or services could be threatened if genetic disease impairs an individual's job performance.

A similar dilemma about whether to deny jobs on the basis of predictive screening tests was a recent source of controversy in the passage of ADA. Both houses of Congress initially agreed the protections of ADA should not be extended to food service workers who have acquired immunodeficiency syndrome (AIDS). This decision was endorsed by the restaurant and food service industry, which shared congressional concern that restaurants would lose customers if patrons learned a chef or other employee had AIDS (1,6). The exclusive language was later removed from the bill as it became clear there is no scientific evidence that the handling of food by persons with AIDS presents a public health risk (1) (see box 7-E).

Since employees are free to take other risks, such as dangerous hobbies, despite the effects on others, should employees known to be genetically susceptible to workplace exposures be allowed to acceptor remain in jobs that increase the risk of disease? The answer depends on several conditions, including whether it is technically possible to reduce workplace hazards so that workers with predisposing traits can work safely, and whether alternative, acceptable forms of employment are readily available for those with a specific genetic predisposition (11). In other words, it might only be justifiable to prevent a worker from taking risks if the employer has already done everything possible to make the workplace safe and protect employees from harm.

Box 7-E—Protection of Others: A Case for Workplace Screening?

Workplace screening for HIV infection and genetic susceptibilities to occupational illness are somewhat analogous situations. Both types of screening tests are predictive rather than diagnostic tests intended to detect possible future health problems that do not affect a worker's job performance at the time the test is performed. Employers might want to avoid hiring workers with HIV infection for similar reasons they might not want to hire a person with a genetic susceptibility to occupational illness: economic effect, stigma attached to the disease, or perceived risk to co-workers or the public. Like genetic screening, HIV screening provides personal information most workers want to be kept confidential.

Because HIV can only be transmitted through intimate contact or infected blood, it is generally acknowledged that protection of public safety cannot be used to justify mandatory AIDS screening in the workplace. In some cases, however, genetic susceptibilities may in fact present risk to others. If such is the case, would infringements of autonomy and privacy inherent in mandatory workplace genetic screening ever be justified by protecting public safety?

Some persons argue that the protection of others might justify workplace genetic screening for nonoccupational illness. A common example used to illustrate this possibility is an airline pilot who develops Alzheimer's disease. As the early symptoms of the disease incrementally affect his or her judgment and memory, aircraft passengers could be endangered by the pilot's behavior. A gene for a disease, however, is not the disease itself, and should not be treated as one, since other factors can influence the gene's expression. If the development of a genetic disease, especially one that takes effect rapidly, can affect co-workers or the public, the potential for genetic disease could justify exclusion from job opportunities.

Significant risk to others must be ascertained before workplace genetic screening can be used for the protection of others. Employers should consider the predictive value of the test, how far in the future a detected trait would likely take effect, and the consequences of a trait becoming manifest. Identification of a genetic susceptibility to sudden heart failure might justify workplace genetic screening if expression of that trait could injure others and if no other ways of identifying the risk exist. For other illnesses, however, especially those that develop gradually and can be detected through other means, genetic screening might not be warranted. Further discussion is needed to identify the conditions that should exist for genetic screening in the workplace to be justified by public safety considerations.

SOURCES: *Office of Technology Assessment*, 1990, based on AS. Leonard, "AIDS in the Workplace," H.L. Dalton, S. Burris, and the Yale AIDS Law Project (eds.), *AIDS and the Law: A Guide for the Public* (New Haven, CT: Yale University Press, 1987); M.A. Rothstein, *Medical Screening and the Employee Health Cost Crisis* (Washington, DC: Bureau of National Affairs, Inc., 1989); M.A. Rothstein, "Screening Workers for AIDS," H.L. Dalton, S. Burris, and the Yale AIDS Law Project (eds.), *AIDS and the Law: A Guide for the Public* (New Haven, CT: Yale University Press, 1987).

Many jobs present risks of illness or injury, and the possible impact on others has seldom been accepted as reason to deny employment. It is impossible to organize society so that the individuals who make the decisions bear all of the risks themselves (15).

Should genetic screening be used in hiring decisions if they have a disparate impact on groups politically protected against workplace discrimination? Some maintain that such impact might be justified if it is generally accepted that it is necessary for the safety of the worker and there are no equally protective alternatives. Others argue that since "the law has traditionally viewed with disfavor any differentiation in treatment based on immutable characteristics like race, sex, alienage, and legitimacy . . . a person's genetic or environmentally-

induced predisposition to occupational illness, which does not affect 'present ability' to perform the job, should not be permitted to result automatically in an adverse employment decision' (13). The tension between protecting the health of workers and avoiding discrimination illustrates the need for values to be balanced.

If the risk of occupational illness only affects the individual worker there may be no ethical reason to prevent employment on that basis. As long as co-workers and family cannot be harmed directly or indirectly, many argue that individual autonomy should not be limited. Some argue that genetically susceptible workers are responsible for their own health as long as they are informed of risks, even if alternative employment is available (4).

Employers could ask workers to sign waivers indicating they are aware of possible health risks and will not hold the employer liable. It has been argued, however, that this practice limits employee autonomy by limiting the range of options available to employees: forcing workers to relinquish benefits and protections normally provided by employers constitutes coercion (13). For many workers, a job is primarily a source of income and other benefits that provides security for themselves and their families and is essential to their well-being. Workers might be willing to risk their health in order to ensure continued income. Thus, a worker might feel pressure to keep a job even if it requires assuming health risks. On the other hand, waivers could provide a means for employers and employees to learn about possible health risks without employers being held liable for workers' autonomous decisions to accept health risks.

SUMMARY AND CONCLUSIONS

The interests of workers, employers, and society need to be addressed and balanced with respect to each other. Employees and employers will strive to maximize their autonomy and reduce their economic or personal costs, while certain social values might need to be protected. There is no consensus about how ethical issues related to genetic monitoring and screening in the workplace should be decided or whether any group's particular interests override another's. Ethical arguments can be made for and against a number of different options.

Since genetic monitoring and screening in the workplace might, depending on circumstances, identify workplace hazards and function to benefit all the parties involved, the ideal solution would be to develop programs that minimize occupational illnesses while avoiding potentially harmful consequences from such testing, including the threat to privacy, confidentiality, and equality of opportunity, and the unfair stigmatization of employees. Striking balance among different interests poses a considerable challenge, since it is difficult to give equal emphasis to all the personal and social benefits and hazards that may derive from genetic monitoring and screening.

Some of the interests of different parties overlap considerably. Genetic monitoring can be ethically justified to the extent that it provides a verifiable and

useful index of workplace risks and employers are willing to take action to improve the safety of the workforce based on the results. Genetic monitoring in the workplace currently might not be perceived as a threat to employee privacy. Although it indicates genetic damage in individuals, genetic monitoring cannot accurately predict specific health effects. If the proper conditions are fulfilled, genetic monitoring could mutually benefit employers, employees, and society by reducing the burden of occupational disease.

Issues related to genetic screening are less easily resolved, since genetic screening in the workplace is more controversial than genetic monitoring. On one hand, it can provide the most accurate and sensitive detection of risks to individuals. On the other hand, genetic screening results can be easily misused by employers. Employers could implement workplace genetic screening to protect their own interests without regard for the interests of job applicants and employees.

An additional problem with genetic screening in the workplace perceived as most serious is that employers can test for traits unrelated to workplace exposures, i.e., traits that have no medical relevance for the workplace. While identifying genetic susceptibility to occupational illness might motivate the employer to improve workplace conditions, genetic samples collected for that purpose could be put to other uses. Genetic screening for nonoccupational disease in the workplace does not protect workers against occupational illness, could violate the privacy and autonomy of job applicants and employees, and will not lower occupational health costs for society although it may lower health-related costs for employers.

Many of the standards suggested for an ideal workplace testing program are likely to be difficult to uphold while allowing the interests of workers, employers, and society to be met. It is not clear how conflicts of interest should be resolved, and there is little agreement about whether workplace hazard removal should be accomplished by denying employment to genetically susceptible individuals. For now, ethical questions surrounding genetic monitoring and screening in the workplace can only be answered on a case-by-case basis.

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