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CAN EMPLOYERS PUT GENETIC INFORMATION TO GOOD USE?

KATHLEEN C. ENGEL¹

I. INTRODUCTION

In my talk today I am going to try to answer the question: Can employers put genetic information to good use? Preparing this talk was a challenge because it required me to switch sides of the table. Having represented plaintiffs in employment discrimination cases for ten years, my inclination is to focus on the ways that employers can use genetic information to the detriment of their workers. I chose to talk about the value of genetic information from the employers' perspective because I wanted to force myself to engage in a disciplined study of the issues, rather than simply don the hat of an employee advocate.

Many employee advocates argue that employers should never have any access to their employees' genetic information. What I want to do today is identify situations in which employers could use employees' genetic information to benefit themselves and their employees. In giving these examples, I am not advocating that employers have unlimited access to employees' genetic information. Rather, I am suggesting that with adequate controls there is the potential for employers to utilize employees' genetic information in ways that are socially valuable.

For the purposes of this talk, I am focusing on employees whose genetic propensities for certain diseases are not yet expressed, understanding, of course, what Dr. Zahka said earlier, that this can be a hard line to draw. There are two ways to think about using genetic information in the employment context. One is to look at an individual employee's genetic information, and the other is to focus on the genetic traits represented by a pool of employees.²

II. ACCESS TO INDIVIDUAL EMPLOYEE'S GENETIC INFORMATION

I will turn first to genetic information about individual employees. Employers could use genetic information to identify "costly" employees, *i.e.* those employees whose genome indicates that they could develop diseases that could lead to increased health insurance costs, absenteeism, disability claims, and workers' compensation claims.³ Clearly, without the threat of sanctions, many employers will use this information to refuse to hire or to terminate employees who are likely to become

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²Employers can obtain collective information about their employees by, for example, having a third party test the employees and then create a genetic profile of the group of employees.

³Elaine Draper, *The Screening of America: the Social and Legal Framework of Employers' Use of Genetic Information*, 20 BERKELEY J. EMP. & LAB. L. 286, 289 (1999).

expensive in these ways. I think we can agree that no good comes from this sort of genetic discrimination.

When, in this talk, I highlight ways that employers could put genetic information to good use, I am not advocating for these discriminatory employment practices. Indeed, we should not even consider endorsing “good” uses for genetic information until effective protections against genetic discrimination are in place.

A. Identifying Employees Who are Susceptible to Developing Specific Diseases

Employers could use employees’ genetic information to provide preventative medical care. For example, if a genetic test revealed that an employee was at risk for developing diabetes, an employer could refer the employee to an employee assistance plan that could recommend preventative measures that might actually decrease the odds of the employee developing diabetes.⁴ Several years ago, Wells Fargo implemented a twenty-four hour disease management program for its employees with diabetes.⁵ Although the Wells Fargo employees were already symptomatic, there is no reason why similar programs could not be implemented proactively with the goal of reducing the expression of genetic diseases.

The potential benefits of proactive programs are obvious. Employers could experience a reduction in their health and disability insurance claims, lower absenteeism and turnover, increased worker productivity, and better returns on any investments they make in training employees. It is also possible that insurance companies would discount insurance premiums for employers who implemented these types of programs. From the employees’ perspective, employer-sponsored medical assistance programs could improve their overall well-being and, in some cases, prolong their lives. Society would benefit as well. Whenever we can reduce the likelihood that diseases will develop, we generate savings for the social welfare system. Lastly, to the extent that employees would depend on family members or friends for care taking if they became ill, testing and early interventions could relieve the potential burden on caretakers.

B. Identifying Employees Who are Particularly Vulnerable to Workplace Hazards

If employers were able to identify employees with genetic traits that make them unusually susceptible to developing diseases if exposed to workplace toxins or if engaged in specific activities, employers could make job assignments that would reduce these employees’ exposure to the suspect toxins or activities.⁶ For example,

⁴*Cf.* Kathy Farmer, *Medical Confidentiality: While it Carries Strong Humanistic Appeal, The Notion of Sealing Off Employee Medical Records Has a Huge Potential Downside For Benefits Management*, EMPLOYEE BENEFIT NEWS, Jan. 1, 1999, (discussing the impact medical confidentiality laws have on employers’ ability to provide medical screening and preventative health care programs to employees).

⁵*Id.*

⁶Mark Rothstein, *The Use of Genetic Information for Nonmedical Purposes*, 9 J. L. & HEALTH 109, 111 (1994-95); *see also*, Melinda Kaufmann, *Genetic Discrimination in the Workplace: an Overview of Existing Protections*, 30 LOY. U. CHI. L.J. 393, 393-94 (1999) (citing evidence that a handful of employers are already screening employees for genetic susceptibilities to workplace toxins).

as Commissioner Miller mentioned yesterday, there is evidence that some people may have a genetic predisposition to developing beryllium disease.⁷ Beryllium is a metal that is used in the manufacture of a wide range of products, from fluorescent lights to automobile circuit boards. Genetic testing for the propensity to develop beryllium disease would enable employers to place vulnerable employees in positions where they would not be exposed to beryllium.

Arguably, the Americans with Disabilities Act (ADA)⁸ and the Occupational Safety and Health Act (OSHA)⁹ already require this type of intervention to protect employees from workplace hazards. Under the ADA, employers are required to make reasonable accommodations for employees with disabilities.¹⁰ If genetic predispositions constitute “disabilities” under the ADA, employers may have an obligation to insulate workers, who because of their genetic makeup, are susceptible to developing certain diseases if exposed to workplace toxins or hazards. Likewise, an OSHA requirement that employers eliminate significant workplace hazards arguably includes the requirement to test employees to determine whether they are unusually vulnerable to workplace toxins.¹¹

C. Genetic Monitoring of Employees Who are Exposed to Workplace Hazards

Genetic monitoring of employees who are exposed to workplace hazards could also be beneficial. For example, monitoring the genetic makeup of employees could permit employers to establish if and when employees exceed acceptable levels of exposure.¹² Similarly, genetic monitoring could enable employers to identify workplace hazards that have not yet been identified as toxic. For example, if

⁷At least one company, Brush Wellman, is providing employees with the option of having third parties test them for genetic traits that could increase the employees’ risk of developing diseases if exposed to workplace toxins. See generally, T. Shawn Taylor, *Mapping of Human Genome Could Make Way for Genetic Testing by Employees*, CHI. TRIB., Sept. 12, 2001. The employer pays for the tests, but only the third party testers and the employees know the results. *Id.*

I somewhat cynically believe that when employers offer this test, they are motivated in part by the possibility that the testing could help them defend any future tort claims brought by workers who elected not to take the test or by workers who tested positively for the genetic traits and continued to work in positions that entailed exposure to the particular toxins. This situation bears some similarity to the United States Supreme Court’s decision in *Johnson Controls*. *Automobile Workers v. Johnson Controls, Inc.*, 499 U.S. 187 (1991). Johnson Controls excluded pregnant and fertile women from working with lead, in part, because it wanted to insulate itself from tort claims that might arise if women who worked with lead had children with lead-related disabilities. *Id.* at 191-92. The Supreme Court required Johnson Controls to give women the choice whether to work with lead. *Id.* at 211. In the process, the Court likely provided the company with a strong defense to future tort claims based on injuries arising from fetal exposure to lead.

⁸42 U.S.C. §§ 12101, *et seq.* (1999).

⁹42 U.S.C. §§ 651, *et seq.*

¹⁰42 U.S.C. § 12112(b)(5)(A).

¹¹Kaufmann, *supra* note 6, at 425-26.

¹²*Id.* at 398-99.

employees underwent regular genetic testing and the testing revealed unexplained changes in the employees' genetic makeup, this information could be helpful in identifying toxins in the workplace.

D. Access to Genetic Information for Use in Health Emergencies

Genetic information could also be valuable when an employee becomes seriously ill on the job. If an employer knew that a particular employee had a genetic susceptibility to a given disease and then the employee exhibited symptoms consistent with that disease, the employer's knowledge could be helpful in an emergency situation. For example, if an employer knew that an employee carried a gene that made her susceptible to developing diabetes and the employee passed out on the factory floor, the employer's knowledge of the employee's genetic propensity for diabetes could be valuable to emergency and other medical personnel.

III. POOLED GENETIC INFORMATION

A. Identifying Diseases That a Significant Number of Employees are Susceptible to Developing

Many of the concerns about genetic discrimination disappear if employees' genetic information is pooled, *i.e.*, when employers do not know the genetic traits of any individual employee, but instead have an overall genetic profile of their workers. There are a number of ways that pooled information could be valuable. If employers knew, for example, that a significant number of their employees were susceptible to developing heart disease, they could put educational programs in place, have a nutritionist speak to employees about diet, or subsidize employees' memberships to health clubs, all of which would have the same benefits as interventions based on individual level information without the accompanying risk of discrimination.¹³ The downside for employers of using pooled information is that, without knowing the specific individuals at risk, they would have to extend the benefits to all employees, not just those truly at risk. Thus, interventions based on pooled information would not be as cost effective as individualized interventions. On the other hand, promoting the overall health of all employees could be cost effective if it reduced absenteeism and healthcare costs.

B. Using Pooled Information to Reduce Insurance Costs

Pooled information could be particularly valuable when it comes to insurance. Insurance is a system of cross-subsidies: healthy insureds subsidize less healthy insureds.¹⁴ If all employers pay the same rate for insurance regardless of the health risks presented by their employees, there can be an adverse selection problem. For employers whose employees have an increased likelihood of becoming ill, the marginal benefit of insurance exceeds the marginal cost. Conversely, for employers

¹³Of course, if the pooled risk was high enough, employers could fire all their employees and hope that the next pool of employees presented a reduced genetic risk.

¹⁴Naomi Obinata, *Genetic Screening and Insurance: Too Valuable an Underwriting Tool to Be Banned from the System*, 8 SANTA CLARA COMPUTER & HIGH TECH. L.J. 145, 146 (1992).

whose employees have a relatively low risk of becoming seriously ill, the marginal cost of insurance often exceeds the marginal benefit. In response to this phenomenon, employers with relatively healthy employees may elect to not provide health insurance coverage at all, and instead increase employees' wages with resources that would otherwise be spent on health insurance. Insurance companies, left with the less healthy workers, will in turn raise premiums to cover the cost of insuring the most risky people. A second adverse selection problem arises if some employers provide health insurance coverage and others do not: Workers who are ill or likely to become ill will flock to the employers who offer health insurance.¹⁵

One way to eliminate or reduce this adverse selection problem would be to establish a risk-based pricing program, where employers' insurance premiums would be based on the pooled risk presented by their cluster of employees. Risk-based pricing is well established in the life and automobile insurance industries. When you are older, you pay more for life insurance because you are more likely to die. In most states, young males pay a premium for automobile insurance because collectively they present a greater risk of causing an accident than their female counterparts.

The more accurately insurance companies assess risk, the more efficiently they can price policies and pass any savings on to customers.¹⁶ Genetic information has the potential to be a valuable tool for engaging in more accurate risk assessment and risk-based pricing. For example, if insurance companies reviewed the genetic profile of each employer's employees, they could then set prices based on the relative risk presented by each group of workers. Employers whose employees had a relatively low pooled risk would pay less for their insurance.¹⁷ If employers were paying premiums based on the actual risk posed by their employees, the incentive for employers to elect not to provide health insurance on efficiency grounds is reduced. The downside of risk-based pricing is the less affluent tend to be less healthy, and poor health can trigger expression of genetic diseases. Thus, charging on the basis of risk could create situations where those with the least assets pay the most for insurance.¹⁸ In addition, employers whose employees present a relatively high level of risk may opt to not provide any health insurance because of the cost.

¹⁵Rothstein, *supra* note 6, at 113.

¹⁶Draper, *supra* note 3, at 289.

¹⁷Other options include pricing insurance based on experience or community rating. The problem with experience ratings is that they create an incentive for employers to deny employees health care, for example, by making the claims and approval processes cumbersome.

Community rating is also not foolproof, but for different reasons. With community rating, insurance costs are based on the prevailing medical and hospital costs in the area in which the insureds reside. Under a community rating system, people who live in urban areas, where the cost of space and labor is higher, likely will pay higher premiums. In areas where class and geography are closely linked, less affluent urban residents would pay more than their more affluent suburban counterparts.

¹⁸There is another, more subtle, fairness issue. People cannot control their genetic make-ups as they can with other risk factors, such as smoking. The question is whether it is fair to add the burden of higher insurance premiums on people who already have the burden of wondering whether they are going to develop potentially life-threatening diseases.

One solution to this problem would be to establish a discounting program in which employers who implement preventative health care programs in response to genetic information about their employees would receive a discount on their insurance premiums.¹⁹ This has the potential to reduce some of the cost differential between the high-risk and low-risk groups.²⁰ I am not aware of anyone who has tested or modeled this idea and suspect that even the best of preventative health care programs will not sufficiently eliminate the cost difference. Another option would be for the federal government to play a role, either by picking up the premium cost differential for employers whose employees present high risk levels or by establishing federally-sponsored high-risk pools that would provide health insurance coverage for workers at risk of developing serious diseases.

IV. CONCLUSION

This exercise in switching sides of the table has made me realize that it is premature to endorse an all-out prohibition on employers' access to any form of genetic information about their employees. I say this for two reasons. First, with adequate safeguards, employers could use genetic information in ways that would benefit employees, employers, and society. Second, genetic testing is in its infancy.²¹ At this point, employers are not engaging in widespread genetic testing and discrimination so there is no immediate need to impose a ban to protect workers. During this period of learning and experimenting, there is an opportunity for us to craft a solution to the problem of genetic discrimination before it comes a reality. And, in so doing, I suggest that we keep in mind the possibility that employers could use genetic information for socially productive purposes.

¹⁹Auto insurance companies and health insurance companies offer rate reductions on an individualized basis, *e.g.*, reduced rates for drivers whose cars have airbags, and health insurance rate reductions for non-smokers. Obinata, *supra* note 14, at 60.

²⁰Of course, the cost differential might persist if the insurer offered the same rate discounting program to employers whose employees were not high risk.

²¹See T.H. Cushing, *Should There Be Genetic Testing in Insurance Risk Classification?*, 60 DEF. COUNS. J. 249, 252 (1993) (discussing the limited utility of extant genetic testing).