Genetic Information and Discrimination in Employment: A Psycho-legal Perspective

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I. INTRODUCTION

The fruits of the Human Genome Project (HGP) will soon enable people to have simple tests that provide information about their genetic propensities for various disorders, both mental and physical. This new information could thus give people the ability to
make important decisions related to their health; however, it could also result in misinterpretation and misuse by others, such as employers. Ongoing legal and ethical debates suggest that information about people’s genetic propensities could result in discrimination, with commentators disagreeing over how effective current jurisprudence is for preventing and/or remediating such violations. This debate begs fundamental questions that psychological research could address, such as “Would employers even utilize genetic information, should they gain access to it?” This article reviews relevant literature on genetics and disability discrimination and outlines some psycho-legal issues and avenues for research.

II. GENETIC INFORMATION AND DISCRIMINATION IN EMPLOYMENT: A PSYCHO-LEGAL PERSPECTIVE

The desire to make inferences about human nature based on biology is not without precedent or merit. History is rife with examples of attempts to categorize and predict human diseases and behaviors, both for good purposes (e.g., to improve health) and for bad (e.g., eugenics, which sought to “weed out the weak”).¹ The Human Genome Project (HGP) is the newest in a series of technological improvements that will allow us to persist in efforts to improve ourselves. Proponents of the HGP argue that it will allow us to identify the genetic mutations that cause disease and unhealthiness and ultimately remedy those problems.² However, past experience demonstrates that we sometimes place more faith in the conclusiveness and accuracy of our latest technology than is warranted.³

For example, during the eugenics movement of the early twentieth century, people with low cognitive functioning were often

³. Sarah Cunningham-Burley & Mary Boulton, The Social Context of the New Genetics, in THE HANDBOOK OF SOCIAL STUDIES IN HEALTH AND MEDICINE 173, 174-75 (Gary L. Albrecht et al. eds., 2000) (discussing a social context analysis of genetic developments as well as a sociohistorical overview of the growth of genetics during the twentieth century).
sterilized because they were seen as incapable of caring for children and their intellectual limitations were seen as unworthy traits.\textsuperscript{4} Contradicting these assumptions, research from the latter half of the twentieth century demonstrates that many people with low cognitive functioning can raise children with the aid of social support and skills training.\textsuperscript{5} For another example, males with an extra Y chromosome (XYY chromosomes instead of XY chromosomes) were argued to be more likely to be mentally ill, aggressive and criminal;\textsuperscript{6} it is now recognized that many of the studies leading to those conclusions suffered from bias in sampling techniques, among other problems.\textsuperscript{7} Based on history, it seems prudent to be cautious when interpreting new information that purports to link heredity to behavioral outcomes in a conclusive way, because two risks exist: (1) that the information will be inaccurate or misinterpreted,\textsuperscript{8} or (2) that the information will be accurate and understood, but misused.

Already, advances in our understanding of the genetic precursors for heritable diseases have led to new genetic tests.\textsuperscript{9} For example, one can now obtain a test for cystic fibrosis, Tay-Sachs Disease, hereditary breast and colon cancer, coronary artery disease, late-onset Alzheimer’s, bipolar disorder, multiple sclerosis,

\begin{itemize}
\item \textsuperscript{5} See, e.g., Maurice A. Feldman et al., \textit{Using Self-Instructional Pictorial Manuals to Teach Child-Care Skills to Mothers With Intellectual Disabilities}, 23 BEHAV. MODIFICATION 480, 481 (1999).
\item \textsuperscript{6} See, e.g., Lissy F. Jarvik et al., \textit{Human Aggression and the Extra Y Chromosome: Fact or Fantasy?} 28 AM. PSYCHOL. 674, 675 (1973).
\item \textsuperscript{7} See, e.g., Nkanginieme Ike, \textit{Current Thinking on XYY Syndrome}, 30 PSYCHIATRIC ANNALS 91, 92-93 (2000).
\item \textsuperscript{8} Richard S. Cooper, \textit{Race and IQ: Molecular Genetics as Deus ex Machina}, 60 AM. PSYCHOL. 71 (2005); see generally Norman B. Anderson & Kim J. Nickerson, \textit{Genes, Race, and Psychology in the Genome Era: An Introduction}, 60 AM. PSYCHOL. 5 (2005) (stating that with the advance of the HGP, the field needs to understand the issues and implications of the research); Ainsley Newson, \textit{The Nature and Significance of Behavioral Genetic Information}, 25 THEORETICAL MED. 89 (2004) (discussing how behavioral genetic information is distinguished from other genetic information).
\end{itemize}
Parkinson’s and schizophrenia—which are just some of the available tests. Advances in genetic testing, as a result of new technological and scientific breakthroughs derived from the HGP, may lead to a new form of employment discrimination based on the perception of the increased likelihood of disease occurrence from tests assessing genetic susceptibility. For example, employers may be concerned about the future costs of an employee who has tested positive on a genetic test. These perceived future costs could take the form of lost time/absenteeism, lost productivity, higher turnover, and expensive accommodations. Employment discrimination would follow if employers decided to control these perceived future costs by not hiring people who tested positive for disorders.

David Wiesenthal and Neil Wiener outline the way previous scientific advances in understanding the biochemical nature of humans has indeed been used to make biological and behavioral inferences, often in a discriminating manner (such as the aforementioned example of believing that having the chromosomal abnormality XYY predicted pathologically violent behavior). They predict that the likelihood of this type of genetic information misuse is likely to continue in the new era of genetic information availability. They also suggest that the pressure to make use of the available information will become increasingly strong, citing the “Law of the Hammer” which states, “[O]nce a tool is developed there are considerable pressures for implementation.”

The wealth of general knowledge resulting from the HGP will provide the opportunity for individualized health information to be obtained through simple medical tests (e.g., blood tests) in a way that will make the diagnostic information seem more concrete and dispositive than previous technology. The air of determinism that might be associated with the availability of this new type of health information could have serious, deleterious consequences if it is misinterpreted, over-interpreted, and/or misused (e.g., for purposes of potentially unlawful discrimination).

12. See Wiesenthal & Wiener, supra note 1.
13. See id. at 196-98.
14. Id. at 196.
The history of interpreting traits as being strongly determined by heredity demonstrates our inability to account for environmental influences that may alter outcomes.\textsuperscript{15} The reality is that many genes operate according to a diathesis-stress model whereby “disease” is not expressed unless an environmental stressor “activates” the gene expression. For example, one may have a genetic predisposition (the diathesis) for schizophrenia, but whether or not a given person develops schizophrenia will depend on many different environmental factors (the stressors) that could bring it about.\textsuperscript{16} Thus, there are a number of considerations, aside from the mere presence of a positive genetic test, that need to be accounted for when one tries to interpret the risk of genetic expression and make decisions (e.g., health-related behaviors or hiring decisions) based on that interpretation. Incorrectly making decisions about people’s propensities for genetic expression of disorders could lead to unfair assumptions about their future health and result in discriminatory treatment.

Concern about the misuse of health information and the rights of ordinary citizens is warranted and not without precedent. Employers have used a range of techniques varying in intrusiveness to evaluate potential employees, from simple personality tests to physiological tests (blood or urine) to rule out drug abuse. Case law examples demonstrate that employers have been willing to use permissible drug tests to obtain illegal information about medical conditions of current and potential employees in making hiring and dismissal decisions.\textsuperscript{17} There is a heated debate in legal literature regarding whether existing legislation would protect job applicants and employees from genetic discrimination.\textsuperscript{18} However, even if employers have permissible access to employees’ and applicants’ medical information, decisions based on genetic tests are unfounded to the degree that most of them currently offer no

\textsuperscript{15} See Cunningham-Burley & Boulton, supra note 3, at 178.


\textsuperscript{17} See, e.g., Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260 (9th Cir. 1998) (involving governmental employer who conditioned start of employment upon a “health evaluation” that included testing for medical and genetic information such as syphilis, sickle cell trait, and pregnancy).

diagnostic value in the evaluation of future job performance. As Blanck and Marti 19 indicate, genetic precursors to a disease do not necessarily confirm that a disease will arise in the future, much less how severe the expression of the disease will be. Single gene diseases are rare; the majority of diseases are explained by the multiple interactions of several genes and the environment. 20 Furthermore, diseases have the potential to be ameliorated by a number of environmental factors, such as behavior modification (i.e., engaging in healthy activities) or medical treatment programs; but employers, as well as medical professionals, may place an over-emphasis on genetic predetermination and consequently ignore environmental factors. 21

This article reviews literature relevant to the topic of genetic information misinterpretation and misuse, particularly in the employment context. More specifically, it will briefly review relevant legislation and examples from case law of genetic and health-based discrimination. 22 Next, literature on people’s knowledge of the HGP, perceptions about testing, and genetic discrimination will be reviewed. 23 Since there is little empirical examination of actual genetic discrimination, the related literature of disability discrimination will be briefly reviewed. 24 The focus of the article is the potential for use of genetic information in an employment decision-making context; thus, consideration will be given to the literature on how employers (or more often, potential employers engaged in hiring) make decisions. The article culminates in a call for research that empirically examines whether health-based information, such as genetic test results, would be used by people making hiring decisions if they had access to it, as well as for research examining the boundary conditions under which such information would be used. 25

22. See infra Part III.
23. See infra Part IV.
24. See infra Part V.
25. See infra Part VI.
III. WHY STUDY THE POTENTIAL FOR GENETIC DISCRIMINATION—LEGAL ISSUES AND EXAMPLES OF ACTUAL GENETIC DISCRIMINATION

A. Legislative and Judicial Response

The legal community has recognized the potential for genetic discrimination in employment. Psycho-legal scholars believe that there is insufficient legislation to protect against genetic discrimination in employment. Legal scholars have not yet reached a consensus. Some argue that legislation aimed specifically at the problem of genetic discrimination, and legislation aimed generally at the problem of disability discrimination, should address the potential problem of genetic discrimination. Other legal scholars disagree about the adequacy of the legislation, as Executive Order 13,145 applies only to federal employees and the Americans with Disabilities Act (ADA) does not explicitly cover presymptomatic individuals, such as those with a genetic predisposition but not yet a full-blown disorder.

26. E.g., Wiesenthal & Wiener, supra note 1; Yoon et al., supra note 10; Blanck & Marti, supra note 11; Nance et al., supra note 18.
29. See, e.g., Paul S. Miller, Genetic Discrimination in the Workplace, 26 J.L. MED. & ETHICS 189 (1998) (discussing the fears of genetic discrimination and the existing case law and legislation in place to accommodate it); Paul S. Miller, Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace, 3 J. HEALTH CARE L. & POL’Y 225 (2000) (discussing the fears of genetic discrimination, genetic privacy, and the existing case law and legislation in place to accommodate both, including an executive order by the President).
Indeed, recent decisions by the U.S. Supreme Court have interpreted the ADA in a way that some critics consider narrow and likely to substantially limit plaintiffs’ ability to bring actions. For example, in one trilogy of cases, the Court made it clear that if a plaintiff has taken action to mitigate a disability, then such mitigation is to be considered by the courts, and the courts can reasonably conclude that plaintiffs are not “substantially limited in a major life activity.” This would then mean that they are not disabled under the ADA. Yet another trilogy of recent cases from the Supreme Court has continued in the same vein of making it difficult for plaintiffs to bring and succeed with ADA claims, either by showing (1) they have a disability within the meaning of the ADA, (2) their request for reasonable accommodation should not be subordinate to employer policies, or (3) their employer is using their own disability against them.

These rulings, and others by the Supreme Court, have served to limit the applicable scope of the ADA and suggest that the Court may be reticent to recognize the applicability of the Act to genetic


33. See, e.g., Albertson’s Inc. v. Kirkingburg, 527 U.S. 555, 567-68 (1999) (holding that a plaintiff with amblyopia fired for not meeting Department of Transportation vision standards was not disabled by his condition since his visual system provided mitigation by allowing him to see with one eye whereas others typically see with two eyes); Murphy v. United Parcel Service, Inc., 527 U.S. 516, 523 (1999) (holding that a plaintiff with hypertension who was denied a position driving a commercial vehicle for UPS because he failed Department of Transportation certification standards, regarding high blood pressure, was not disabled since medication controlled the condition); Sutton v. United Air Lines, Inc., 527 U.S. 471, 493 (1999) (holding that plaintiffs who were denied commercial airline pilot positions and who had myopia that could be corrected with lenses were not disabled).

34. Toyota Motor Mfg., Ky., Inc. v. Williams, 534 U.S. 184, 202 (2002) (holding that a plaintiff with carpal tunnel syndrome who, among other things, could not always dress herself and had to limit time spent with her children was not sufficiently restricted in major life activities so as to be disabled).


36. Chevron U.S.A., Inc. v. Echazabal, 536 U.S. 73, 87 (2002) (holding that it was not impermissible discriminatory action for a contractor to lay off an employee whose condition made it likely that working for the contractor’s employer in the employer’s refinery would expose the plaintiff to toxins exacerbating the plaintiff’s health condition).
discrimination. However, the Equal Employment Opportunity Commission (E.E.O.C.) has interpreted the ADA to apply to genetic discrimination, so the potential for courts to adopt this interpretation and apply the ADA to presymptomatic individuals exists—although it seems unlikely that courts will do so,\textsuperscript{37} particularly considering the Supreme Court’s recent decisions demonstrating that the E.E.O.C.’s interpretations of the ADA will not necessarily be followed. What is apparent is that the problem of genetic discrimination has been recognized and that the adequacy, or inadequacy, of remedies is being debated.

Aside from legislation that provides a basis for filing actions after discrimination is alleged to occur, there is the potential for existing legislation to provide protections that prevent genetic information from being acquired in the first place.\textsuperscript{38} For example, the Health Insurance Portability and Accountability Act (HIPAA) protects the privacy of medical information and prevents disclosure of medical information without the patient’s consent.\textsuperscript{39} However, the adequacy of its protections is still being tested, and some suggest that there are those who may nonetheless avoid predictive testing because of a fear that results will fall into the hands of those who would use the information discriminatorily.\textsuperscript{40} Indeed, during hearings related to the reauthorization of the 1996 amendments to the Fair Credit Reporting Act (FCRA), panelists raised concerns that medical information that could be obtained via credit reports or thorough background checks may not be covered by HIPAA.\textsuperscript{41}

In addition, there are legitimate ways that employers can gain access to employee or applicant medical information. One of the most obvious ways is through direct testing of biological materials voluntarily turned over by employees (e.g., blood or urine). Employees will submit to testing when company policy or law

\textsuperscript{37} See, e.g., Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260 (9th Cir. 1998) (holding that ADA safeguards protecting information on job applicant’s medical condition or history are adequate); see also Americans with Disabilities Act § 102, 42 U.S.C. § 12112(d)(3) (2000).


\textsuperscript{39} Id.


requires it, as in the case of drug testing conducted on employees. Drug testing has been upheld by the Supreme Court as permissible so long as it is reasonable and there is a “special need,” such as when Customs Officers are being promoted to positions where they may intercept illegal drug transportation, or when public safety demands it as with the case of drug testing railway employees.

Acquiescence to permissible testing does not, however, mean that further testing of the biological materials is necessarily allowed. Such further testing would include genetic testing, which is a separate issue and governed by different legal principles. One example of permissible genetic testing involves chemical sensitivity. For example, employers in industries involving exposure to beryllium may monitor groups of employees via genetic testing to make sure that exposure to beryllium will not be a health problem for the employees, and that the chemical exposure is not harming them. In the majority of situations, however, genetic monitoring and/or testing is impermissible, as when employers exceed the scope of permission they have been given by employees for testing (e.g., testing for something other than drugs or chemical sensitivities). Such impermissible testing can then predicate employment discrimination by leading to decisions not to hire, to fire, or not to promote a given employee based on the results of the impermissible tests.

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42. See Nat’l Treasury Employees Union v. Von Raab, 489 U.S. 656 (1989) (holding that Customs Service did not need a warrant to conduct a drug testing requirement).
44. See Brian Bornstein, Seize This Urine Test: The Implications of Ferguson v. City of Charleston for Drug Testing During Pregnancy, 6 J. MED. & L. 65 (2001) (discussing Ferguson v. City of Charleston, 532 U.S. 67 (2001), which ruled that urine tests were searches within the meaning of the Fourth Amendment and that the tests, along with subsequent reporting of positive results to the police, were unreasonable searches absent patients’ consent).
45. Beryllium is a lightweight metal to which some people have a genetic sensitivity. Gary E. Marchant, Genetics and Toxic Torts, 31 SETON HALL L. REV. 949, 966 n.79 (2001).
47. Marisa Pagnattaro, Genetic Discrimination and the Workplace: Employee’s Right to Privacy v. Employer’s Need to Know, 39 AM. BUS. L. J. 139, 169-70 (2001) (explaining that the Occupation Health and Safety Administration requires an employer to protect employees from hazardous chemicals and that employers may perform blood tests to determine whether an employee is absorbing harmful levels of a chemical).
48. See Bornstein, supra note 44.
B. Actual Genetic/Health-Based Discrimination—Examples and Survey Data

In *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, employees of Lawrence Berkeley Laboratory sued their employer, because they found out that blood and urine samples voluntarily submitted during standard preemployment and postemployment health exams had been tested for sickle cell anemia, pregnancy, and syphilis.\(^{49}\) According to the district court, by submitting to routine medical exams, and answering questions about such diseases on a medical history form, the employees had given permission to test for such traits.\(^{50}\) The Ninth Circuit disagreed, holding that submission to routine medical exams does not *per se* amount to submission for genetic and pregnancy testing.\(^{51}\)

In another case, the Equal Employment Opportunity Commission (E.E.O.C.) sued the Burlington Northern and Santa Fe Railroad Company after employees found out they were being genetically tested for a carpal tunnel syndrome marker.\(^{52}\) The company was trying to determine which employees would be likely to suffer from repetitive stress injuries, which were becoming a financial burden for the company.\(^{53}\) The complaint alleged that Burlington Northern even retaliated against employees who refused to submit to genetic testing.\(^{54}\) The company ultimately agreed to settle out of court.\(^{55}\)

Other anecdotal evidence exists in the form of survey studies of patients or workers, which have more pointedly explored the issue of perceived discrimination.\(^{56}\) Geller et al. conducted a survey through national organizations, which included respondents who were at risk, presymptomatic, or asymptomatic for hemochromatosis, phenylketonuria, mucopolysaccharidosis

\(^{49}\) 135 F.3d at 1265.
\(^{50}\) Id. at 1266.
\(^{51}\) Id. at 1269.
\(^{53}\) Id. at *1.
\(^{54}\) Id.
\(^{55}\) Id. at *2.
disorders, and Huntington disease. An initial mailed survey screened for people who reported perceived discrimination, and follow-up interviews were then conducted with that subsample; of the 917 mailed surveys, 206 people were chosen to be interviewed. Respondents identified the institutions that had discriminated against them as health and life insurers, clinical professionals, employers, blood banks, and public institutions, such as the government and military.

In addition to asking who was discriminatory, and how, people were also asked to indicate if they had taken any steps to avoid discrimination. Respondents voiced concerns about the possibility of discrimination in both hiring and firing. Some respondents also reported that they refused to accept more desirable jobs or relocate for new jobs fearing that health insurance would be unobtainable in the new job. Thus, although employers may not be listed as the most discriminatory, they are clearly linked to the group (insurers) that is perceived as the most discriminatory; and any discriminatory actions by insurers could affect actions taken by employers.

In order to avoid discrimination, many of the respondents to the Geller et al. survey reported taking various actions that gave them a sense of control over the situation and their genetic information. They obtained insurance prior to any genetic testing, received testing that could not be linked back to them personally, only partially disclosed relevant information, and personally paid for testing that would ordinarily be covered by insurers (to avoid results of the test falling into the insurers’ hands). Thus, they not only took passive control (avoidance of testing), but active control as well.

Lapham et al. found results very similar to those of Geller et al. They also surveyed members of support groups, specifically those who were affiliated with the Alliance of Genetic Support Groups, and had a total of 332 respondents. They found that 25%

57. Geller et al., supra note 56, at 250-52.
58. Id. at 251-52.
59. Id. at 252.
60. Id. at 252, 257.
61. Id. at 255.
62. Id.
63. Id. at 257.
64. Id.
65. Lapham, Kozma & Weiss, supra note 56; Geller et al., supra note 56.
of their sample believed they were denied life insurance, 22% believed they were denied health insurance, and 13% believed they were not hired or were fired all because of their genetic status or that of a family member. They also found that in order to avoid being discriminated against, people took steps such as avoiding testing (89%) or keeping information from insurers and employers (80%).

Survey data, anecdotal evidence, and some case law suggest that genetic discrimination has already occurred. These sources also suggest that both employees and employers have some awareness of the existence of technologies like genetic testing and the HGP. The next section reviews data on the extent to which laypeople are, in fact, familiar with these concepts.

IV. CURRENT AWARENESS OF THE HGP AND ITS IMPLICATIONS: PERCEPTIONS OF TESTING

The degree to which people are even aware of the availability of genetic information could affect its use or the perception that such information is being used. How aware are people of the HGP? How aware are people that genetic tests could be used to diagnose their potential for disorders? How aware are people that such information could be used against them, and if they are aware of the potential, how fearful are they? All these questions bear examination.

A. Awareness of the HGP

Poll data demonstrate that most people indeed are aware of the HGP and the concept of genetic testing. In fall 2001, Virginia Commonwealth University conducted a poll of United States adults, finding that of the 1122 respondents, roughly half were aware of the HGP.66

A June 2002 Harris Interactive poll67 asked several questions...
about genetics; of 1013 respondents, 70% indicated that they were “somewhat familiar” or “very familiar” with the meaning of genetic testing, and 81% believed it was a “good thing” to be able to use such testing to find out which diseases people were at high risk of getting. In order to find out such information, of course, people would need access to someone in the medical field who could conduct such testing; 90% of Harris poll respondents indicated that they would feel comfortable with their regular doctor knowing genetic information about them. Interestingly, only 25% of those polled would want their life insurance company to have access to genetic information, 39% would allow their health insurance company access, and only 17% of those polled would want their employer (who would usually be paying for part of the health insurance and, thus, technically have access to such information) to have access to the results of genetic tests.

A poll analysis conducted by the Gallup Organization showed that “most” Americans did not want their genetic information to get into the hands of employers or insurers. Both the Harris and Gallup polls demonstrated that most people do not want employers to have access to genetic information; it was unclear if this desire is due to a fear that the information will result in discrimination, but the data is certainly consistent with that notion.

B. Perceptions of Testing

Cunningham-Burley and Boulton approached the issue of using genetic information from a different angle. By examining the lay response to new genetic technology, such as the ability to screen for various genetic predispositions to disease, they found that people were slow to incorporate the new technologies into their lives by making use of the screenings. One reason posited for this finding was that people want to avoid the psychological consequences of “knowing”; in other words, people may fear having to live with the knowledge that they could become symptomatic, so they engage in avoidant behavior. If this assumption is true, it means that people place a lot of weight on the predictive power of a genetic test. In a hiring context, this means that an employer might be as likely to discriminate against a person

68. Id.
69. Cunningham-Burley & Boulton, supra note 3, at 179-80. Compare Wiesenthal, supra note 1, with Alper, supra note 20.
with a *predisposition* for a disability as she would be to discriminate against a person with an *actual* disability.

The medical, genetic therapy, and genetic counseling literature presents examples of patients’ fear of genetic testing. In a survey of physicians who had requested information on a genetic test for breast cancer, Cho et al.\(^70\) found that 70% of physicians who offered the genetic test had at least one patient who refused to take it. The physicians reported that 68% of patients declining the test did so out of fear that confidentiality would not be maintained, 52% feared the actual results of the test, and 42% did not think they could afford it.

In a review of the literature on genetic testing, Lerman et al.\(^71\) examined three different types of genetic testing: prenatal genetic testing (which tests the fetus), carrier testing (which tests parents for autosomal recessive traits that require the “defective” gene to be inherited from both parents in order for the trait to be expressed), and predictive genetic testing (which focuses on the participant’s own risk). They concluded that, although research did not reveal broad adverse psychological effects of choosing to have tests, subgroups of people with certain psychological traits appeared to be more vulnerable to psychological stress than others. For example, they found that women with “information-seeking” coping styles were more susceptible to negative effects in some situations. Indeed, research seems to be moving toward identifying vulnerable subgroups rather than focusing on the possibility that everyone who considers genetic testing may be adversely affected; for example, the Multidimensional Impact of Cancer Risk Assessment (MICRA) identifies subgroups of people who choose to be genetically tested for cancer risk and may be vulnerable to psychological distress after learning their test results.\(^72\)

Yet another complicating factor of the use of predictive genetic test information by applicants, employees, or employers involves the effect of individual difference variables like gender.\(^75\)

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70. Cho et al., *supra* note 9, at 160.
73. Miller, *supra* note 29, at 191 (regarding Title VII of the Civil Rights Act, “genetic discrimination may have a disparate impact based on race, color, religion, sex, or national origin”).
Two studies have indicated a potential gender effect. Harman examined attitudes about the use of genetic information and genetic engineering, finding that women were less likely than men to want genetic tests and enhancements. Napolitano and Ogunseitan found similar results when examining gender differences in attitudes toward genetic engineering in the area of reproduction. They replicated Harman’s findings that women are more cautious than men, with women less accepting of genetic engineering as a legitimate way to alter characteristics of unborn children in utero. This suggests that gender may be a moderating variable that affects the interpretation and use of genetic information. Thus, male employees might be more likely than female employees to submit to genetic testing. From an employer’s perspective, men making hiring decisions might react differently than women to applicants who have tested positive for a genetic predisposition to disease. Research examining genetic discrimination, perceived and actual, would benefit from moderating analyses that examine gender and other individual difference variables.

In an examination of participants’ reasons for and against genetic testing, Wroe et al. investigated in more detail how people felt about taking genetic tests. More specifically, they asked participants to predict their likelihood of developing given diseases, the likelihood that they would take genetic tests for those diseases, and the reasons for their decisions. Despite being given population base rates (e.g., “4% of people develop Disease X”) for various diseases, all participants overestimated their risk of developing diseases. Students reported likelihoods of having genetic tests from 28% to 62% for a variety of diseases, reflecting the ratio between the pros and cons that they listed. Diseases that student participants were more likely to obtain genetic tests for

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77. Id. at 605-06.
78. Id. at 607.
79. Id. at 607-09.
included diabetes, rheumatoid arthritis, heart disease, weak bones, and breast cancer (with likelihoods greater than 50%), and diseases that student participants were less likely to obtain genetic tests for included colon cancer, Alzheimer’s disease, and schizophrenia (with likelihoods of less than 50%).

Another group of participants, one that identified itself as having contemplated genetic testing in the past, reported higher likelihoods of obtaining genetic tests, ranging from 56% to 84% across a variety of diseases.

The predictability of one’s likelihood to take a genetic test, however, is more complex than this account indicates. In a review of decision-making studies dealing with genetic risks and tests, Shiloh presented many examples of contradictory findings. Decisions varied according to several factors, including when the studies were conducted; how the risk was presented to participants; how researchers operationalized or framed the “decision” that participants had to make; and who was asked to make the decision about genetic tests (e.g., patients versus parents, spouses, families, and different cultural groups).

It has been shown that one’s role affects one’s perspective when making decisions, as does framing. Additional research suggests that certainty in the predictability of genetic tests is important, as is the control one has over the progression of the disease at issue. Clearly, the picture is a complex one, and findings need to be interpreted within the context of how the research was conducted.

80. Id. at 608.
81. Id. at 609.
83. Id.
85. See generally CHOICES, VALUES, AND FRAMES (Daniel Kahneman & Amos Tversky eds., 2000); HEURISTICS AND BIASES: THE PSYCHOLOGY OF INTUITIVE JUDGMENT (Thomas Gilovich et al. eds., 2004).
87. See generally Shiloh, supra note 82.
V. PREVIOUS RESEARCH ON DISABILITY AND DISCRIMINATION

Psycho-legal writers have convincingly demonstrated the potential for genetic discrimination; however, experimental examination of the phenomenon is lacking. In order to better understand how genetic test information might be used discriminatorily, it is instructive to look at the related literature on discrimination due to disability. This well-developed body of literature not only shows how discrimination occurs, but also suggests important variables to consider and methodologies to use in the study of discrimination.

Statistical data suggests that the disabled are treated inequitably in the job market, as evidenced by a comparison of the employment and pay rates of disabled and non-disabled individuals. The salaries of the working disabled are up to 35% lower than those who are in the same jobs and not disabled.\(^{88}\) According to the Department of Labor, the disparity is caused in large part by employers’ stereotypes and attitudes toward the disabled and by employers’ expectations that disabled employees will contribute to higher bottom-line costs with absenteeism, poorer performance, turnover, accommodation necessities,\(^ {90}\) lower productivity, and higher workers’ compensation rates.\(^ {91}\) Based on the aforementioned concerns, it would seem that employers take two different measures to combat the supposed higher costs of employing disabled people: not hiring the disabled in the first place or paying them less.

According to Stone and Colella,\(^ {92}\) perception of disabled people begins with their immediate categorization. Categories automatically bring to mind stereotypes of the disabled and associated expectancies with those stereotypes.\(^ {93}\) For example,

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93. Id.
Fichten and Amsel found that the physically disabled are perceived as “quiet, honest, gentle hearted, non-egotistical, benevolent, helpless, hypersensitive, inferior, depressed, distant, shy, unappealing, unsociable, bitter, nervous, unaggressive, insecure, dependent, unhappy, aloof, and submissive” more often than non-disabled people.

Despite these broad stereotypes, not all disabilities are viewed in the same way. The majority of the evidence appears to demonstrate that sensory disabilities (e.g., blindness and deafness) and cognitive disabilities (e.g., mental retardation and mental illness) are viewed less favorably than physical disabilities.

It has been suggested that the reason for the difference in how sensory and cognitive impairments are viewed, as compared to physical impairments, lies in the fact that physical impairments are seen as more consistent and predictable over time. Following from that, it may be that genetic tests that are positive for mental disabilities may also be seen as less stable and predictable than genetic tests that are positive for physical disabilities. Conversely, if people are attuned to the fact that genetic tests are not determinative, then they may see positive genetic tests for any disorder as analogous to an actual mental disability: unstable over time and unpredictable.

Research examining disabled people in the workplace has not just looked at whether disabled people are perceived differently, but also whether they are treated differently. Analog research models

94. Id. (citing Catherine S. Fichten & Rhonda Amsel, Trait Attributions about College Students with a Physical Disability: Circumplex Analyses and Methodological Issues, J. APPLIED SOC. PSYCHOL., 16:410-27 (1986)).
96. Fuqua, supra note 91, at 41.
have determined that disabled applicants receive fewer callbacks for interviews, less favorable hiring recommendations, lower salary recommendations, and that they are generally rated lower than non-disabled applicants along a variety of dimensions such as competence. Consistent with the stereotype research, individuals with physical disabilities are discriminated against less in the employment context than those with mental or neurological disabilities. In 1979, Rose and Brief examined the differences in hiring rates and other employment-related treatment between epileptics and the physically disabled (e.g., paraplegics and amputees). They found that amputees were offered lower salaries than non-disabled people and that epileptics were offered lower salaries than the amputees. Stone and Sawatzki compared groups of applicants who were non-disabled, physically disabled, and psychiatrically disabled. They found no differences between the non-disabled and physically disabled in terms of the probability of being hired, but they did find that the group of applicants with psychiatric disabilities fared worse. This result has been replicated elsewhere and occurs even when participants rate the physically and mentally disabled as having equivalent work qualifications.

In general, unfavorable information about a job applicant is given greater weight than other information, and it appears that a disability is clearly perceived as unfavorable information. Disabilities, along with ethnicity and gender, are one of the

97. Ravaud et al., supra note 95, at 954.
100. Bell & Klein, supra note 95.
101. See generally Stone & Colella, supra note 90.
102. Rose & Brief, supra note 99.
103. Stone & Sawatzki, supra note 98.
105. Bordieri & Drehmer, supra note 95.
"stigmas in organizations."107

The literature on disability discrimination is instructive because people may perceive a positive genetic test (i.e., the potential for disability) to be “as good as” having a disability. The literature on perceptions of predictive genetic testing and the likelihood of having genetic tests indicates that this may be the case, since fear of the results suggests an overly deterministic interpretation of a positive genetic test. Thus, if genetic information is given great weight, it could lead to discrimination against people with positive results by operating much the same way that having an actual disability does. It would be interesting to see how closely the perceptions match by determining whether a person with a positive genetic test for higher risk of a mental disability (e.g., depression) is discriminated against more often than a person with a positive genetic test for higher risk of a physical disability (e.g., carpal tunnel syndrome). Such a finding would show that people perceive the potential for different disabilities in the same way they perceive actual different disabilities.

Thus, if one has the option of hiring someone who has tested positive for high risk of a disease over someone who has not tested positive—and the person who has tested positive is equally qualified for the job—it seems likely that the person who did not test positive would be hired. In such a case, the hiring decision would be discriminatory. Should it be demonstrated that such discriminatory decisions are made, the calls for legislation protecting those who test positive for genetic disorders would have more force than they do currently, in the absence of research.

VI. GENETIC DISCRIMINATION: WHAT DO PSYCHOLOGY AND LAW HAVE TO OFFER?

Clearly, the bulk of the literature supports the notion that genetic discrimination is a potential problem. What can psychology and law offer to address this problem? “Social analytic jurisprudence” provides a framework for studying the interaction of

law and social science, especially psychology,\textsuperscript{108} which can be applied to the topic of genetic discrimination. The first stage in the approach is analysis of doctrine, policy rules, or legal procedures, carefully looking for assumptions that the law makes about human behavior. With respect to genetic discrimination, there are clear indications of concern that employers could misuse genetic information if it is available.\textsuperscript{109}

The second stage of social analytic jurisprudence is a careful psychological analysis of law and policy, in which the psycho-legal scholar identifies the theories, research results, and methodologies that are most suitable to answer legal and policy questions.\textsuperscript{110} Research documenting the consistency with which genetic discrimination could occur can serve as the foundation upon which arguments for preventative or punitive legislation are made. The employee selection and disability discrimination literature contains numerous examples of analog research in which participants simulate the task of employers in making decisions such as hiring and salary recommendations.\textsuperscript{111} This methodology, which provides a means of systematically investigating the impact of relevant variables (e.g., type of disability) in a controlled fashion, yields results that comport well with those of more naturalistic studies.\textsuperscript{112} It could easily be adapted to the study of genetic discrimination by incorporating a predisposition for a disability (i.e., a positive genetic test) instead of an actual disability.


\textsuperscript{109} E.g., Walker & Diforio, supra note 16; Yoon, supra note 10.

\textsuperscript{110} \textit{Social Sexual Conduct}, supra note 108, at 55.

\textsuperscript{111} E.g., Bell & Klein, supra note 95; Bordieri & Drehmer, supra note 95; Michael A. Hitt & Steven H. Barr, \textit{Managerial Selection Decision Models: Examination of Configural Cue Processing}, 74 J. Applied Psychol. 53 (1989) (evaluating hiring possibilities based on age, sex, race, education, and experience); Rose & Brief, supra note 99; Stone & Sawatzki, supra note 98.

\textsuperscript{112} Ravaud et al., supra note 95.
The disability discrimination literature generally follows the analog paradigm in which student samples are given descriptions of jobs and told that their task is to review applicant material and select someone for the position. Factors such as the disability of the applicant, the nature of the disability, and the nature of the job are frequently manipulated variables.

There are, however, examples of studies on disability discrimination that are notable for being more realistically designed. Ravaud et al.\(^{113}\) conducted a field study in which a representative, stratified sample of 2228 French companies’ different branches were mailed application materials. The researchers manipulated the type of disability, as well as the job qualification of the applicants, and their dependent measure was the number of callbacks for interviews that the applicants received. When analyzing their results in a weighted manner such that company size was accounted for, they found that disability did have a negative effect on the number of callbacks received and that larger companies discriminated more than smaller companies. Thus, both analog and field studies demonstrate discrimination toward people with disabilities.

The third stage of social analytic jurisprudence follows directly from the first two. A psycho-legal analysis of the knowledge base related to an area of law or public policy, such as genetic discrimination and the HGP, is likely to point out gaps in our understanding of the psychological and social realities that underlie legal assumptions. “In the third stage of social analytic jurisprudence, psycho-legal scholars conduct research that tests the psychological . . . models that they applied to answer the empirical issues identified in stages 1 and 2.”\(^{114}\) It is at this stage that the topic of genetic discrimination affords numerous empirical avenues. For example, to what extent do employers rely on genetic information? How do they use this information relative to other health information (e.g., family history) or job-relevant information (e.g., work experience)? Is the information used more in some types of employment decisions than others (e.g., hiring decisions versus post-hiring decisions like personnel evaluations)? Does reliance on genetic information vary as a function of individual characteristics (e.g., decision makers’ race, gender, or job position), company

\(^{113}\) See id.
\(^{114}\) Social Sexual Conduct, supra note 108, at 72.
characteristics (e.g., size), or type of genetic information (e.g., predisposition for a mental versus a physical disability)? Do organizational policies effectively prevent the use of such information when salient? Experimental psychological research that manipulates some of these variables within a simulated employment context could provide a wealth of information on whether legal assumptions about genetic discrimination are warranted.

In addition to influencing policy, social science research on the law can measure law’s impact on the behavior of citizens. If people fear—as research suggests they do—that employers and others would use the results of such screenings to discriminate against them, they might avoid predictive screening (and thus miss the opportunity for early diagnosis and treatment) altogether, which it has been suggested might occur or already is occurring. It is important to assess whether such discrimination is in fact taking place. Aside from preventing discrimination in the event that it is occurring, protective legislation could help allay people’s fears even if it is not occurring.

115. Id. at 74.
116. E.g., Hellman, supra note 30.
118. Geller et al., supra note 56, at 247; Lapham et al., supra note 56, at 621.