Genetic Discrimination and the Employment Provisions of the Americans With Disabilities Act:
Emerging Legal, Empirical, and Policy Implications

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Abstract

The Americans with Disabilities Act of 1990 (ADA) is the most comprehensive federal civil rights law addressing employment discrimination against potentially millions of Americans. The Human Genome Project (HGP) is a federally funded research effort which seeks to map and sequence every human gene. This Article is meant to contribute to the emerging dialogue on the interplay between the HGP and the employment provisions of the ADA, set forth in Title I of the act. The broader relevance of the HGP to emerging legal questions, including those arising under Title I and recent EEOC guidelines, is described. Thereafter, empirical issues are discussed, and directions for future investigation of genetic discrimination under the ADA are explored.
I. INTRODUCTION

This article addresses emerging issues regarding the relationship between genetic discrimination and the antidiscrimination legislation embodied in the employment provisions of the Americans with Disabilities Act of 1990 (ADA), set forth in Title I of the act.¹ Under Title I of the ADA, genetic discrimination occurs when, on the basis of real or perceived differences in their genomes, qualified individuals are denied employment rights or privileges that are available to others.²

The Human Genome Project (HGP) has engendered a revolution in diagnosis of human genetic conditions. More than 50 new genetic tests have been identified in the past five years with potential for discovering the causes of inheritable diseases.³ The rapid advances in genetic testing, therapy, and technology, however, have increased the possibility of stigmatization and discrimination against qualified individuals with current and possible future genetic disorders in the employment context and in other areas of daily life.


² See Peter David Blanck, Reflections on the Law and Ethics of the Human Genome Project, in Genes and Human Self-Knowledge, 185 (Robert F. Weir, Susan C. Lawrence, and Evan Fales, eds., 1994).

In this context, researchers and policy makers are beginning to explore how the ADA and its judicial and legislative progeny may act as a safeguard against genetic discrimination in the employment relationship in particular, and in the provision of insurance and health care benefits in general.\(^4\) Insurance companies, private employers, governments, and educational institutions each have a legitimate interest in promoting genetic screening to help identify and treat appropriately individuals with genetic disorders.\(^5\) Moreover, identifying potential health risks or heightened susceptibility to injury from particular workplace exposures identified by an individual's genetic composition is an application central to the advancing knowledge of the HGP.\(^6\)

In situations where employers, insurers or others use medically-related information from genetic testing to deny equal employment opportunity, exclude qualified individuals from work or work-related benefits, or limit health care coverage to qualified individuals, the antidiscrimination provisions of


Title I of the ADA are implicated. Such adverse and unfair employment-related decisions are particularly harmful when rendered on the basis of false assumptions or attitudes, and not based on systematic study regarding the nature, accuracy, and predictability of genetic tests.

This article is meant to help replace with emerging information the many myths and misconceptions regarding persons with genetic disabilities, in the employment context and elsewhere. Empirical study is needed on the attitudes, myths, and stereotypes in society that may be the source of genetic discrimination by employers, insurers, or the general public. The next section describes emerging legal questions concerning the HGP under ADA Title I law. Section III examines the developing empirical research that has attempted to address the relation of the HGP to the ADA. Finally, section IV explores implications for future study in this area.

II. EMERGING LEGAL IMPLICATIONS

A. Genetic Discrimination Under Title I of the ADA: Overview

Title I of the ADA prohibits covered entities from discriminating against a qualified person with a disability in any aspect of employment.7 Despite attempts at clarification by the EEOC and guidance from developing case law, there remains some ambiguity in the concept of discrimination with regard to ADA Title I compliance.8


8. See George Rutherglen, Discrimination and Its Discontents,
as to meaning of ADA's terms). As a consequence, interpretations of Title I as an employment antidiscrimination law often have been misguided and incomplete.9 For instance, some commentators incorrectly view the ADA as extending the guarantees of equal employment opportunity well beyond the scope of previous anti-discrimination laws.10 To help resolve this ambiguity, the EEOC has issued guidelines for analysis of the statutory definition of disability.11

Under the ADA, a person with a disability covered by the law has a known physical or mental condition or impairment that "substantially limits major life activities," "a record of" a physical or mental condition, or is "regarded as" having such a condition.12 The third prong of the ADA disability definition


10. See Donohue, supra note 9, at 2608-2611.


12. 42 U.S.C. § 12102(2) (1993). ADA Title I also prohibits discrimination on the basis of an association with a person with a disability (e.g., denying employment opportunity to a qualified employee because of a family member with a genetic condition. 42 U.S.C. § 12112(b)(4) (1993).
(i.e., perceived disability) is particularly relevant to the emerging study of genetic discrimination. The United States Supreme Court has stated expressly that in enacting the perceived disability standard, "Congress acknowledged that society's accumulated myths and fears about disability and diseases are as handicapping as are the physical limitations that flow from actual impairment."\textsuperscript{13} Thus, people who are regarded or perceived as having a genetic disability, but who are as equally qualified for a particular job as those without disabilities, "are analogous to capable workers discriminated against because of their skin color or some other vocationally irrelevant characteristic."\textsuperscript{14}

To prevail on an ADA Title I claim under the third prong of the definition of disability, a plaintiff must show that the defendant employer perceives the plaintiff as having a genetic condition or impairment that substantially limits one or more of the plaintiff's major life activities (e.g., the ability to work).\textsuperscript{15} A prevailing plaintiff must prove that an employer made an employment decision because of a perception of disability, based on myth, fear or stereotype, and not related to the plaintiff's actual abilities.\textsuperscript{16} Presently, there are no ADA Title I cases alleging genetic discrimination as a perceived disability. Analogous case law, however, suggests that an


\textsuperscript{14} Vande Zande v. State of Wis. Dep't of Admin., 44 F.3d 538, 541 (7th Cir. 1995).


\textsuperscript{16} Id.
employer likely would violate Title I in circumstances in which it unjustifiably regards an employee or job applicant as disabled solely due to a genetic condition or impairment.\footnote{Compare EEOC v. Texas Bus Lines, 1996 WL 210760 (S.D. Tex.)} (April 23, 1996) (finding that employer's unsubstantiated perception of obesity as a disability constitutes disability discrimination under the ADA) with Smaw v. Commonwealth of Va. Dep't of State Police, 862 F. Supp. 1469 (E.D. Va. 1994) (rejecting state trooper's perceived disability claim because she failed to meet weight limit and therefore was "unqualified").

The concept of a "qualified individual" with a disability is central to the ADA's goal of equality of economic opportunity.\footnote{Peter D. Blanck, Employment Integration, Economic Opportunity, and the Americans with Disabilities Act: Empirical Study from 1990-1993, 79 Iowa L. Rev. 853, 864-66 (1994) [hereinafter Empirical Study].} In establishing employment qualifications and essential job functions, the applicant's experience and skills are considered without the provision of workplace accommodations. An individual with a disability is qualified for purposes of the ADA if the individual satisfies the prerequisites for the job, such as educational background or employment experience, and can perform essential job functions.\footnote{29 C.F.R. § 1630.2(m & n) (1991).}

Information is beginning to emerge on the relation between the type of disabling condition and essential skills

\footnote{Compare EEOC v. Texas Bus Lines, 1996 WL 210760 (S.D. Tex.)}
required to perform certain jobs or work functions.\(^{20}\) In the absence of such information, however, employment qualification decisions for many persons with genetic disabilities likely will be based on myths and misconceptions about an individual's current and future potential. To date, the most common approach employed by the courts has been to define qualifications retroactively, on a case-by-case basis.\(^{21}\)

Title I also requires employers to "reasonably accommodate" the needs of qualified persons with disabilities.\(^{22}\) Reasonable accommodations ensure equal opportunity to the application process, enable qualified employees with disabilities to perform essential job functions, and allow employees with disabilities to enjoy the same benefits as


\(^{21}\) See generally Empirical Study, supra note 18. See e.g., Miller v. United States Bancorp, 1996 WL 277768 (D. Ore May 16, 1996) (ruling for first time that person who collects social security benefits for permanent disability is precluded from making ADA claim as "qualified" employee).

\(^{22}\) 29 C.F.R. § 1630.2(o) (1991). See also 42 U.S.C. § 12111(9)(B) (1993) (a qualified employee may request reasonable accommodation of being transferred to another vacant and similar position with the employer).
employees without disabilities. The ADA does not require accommodation if it would impose an "undue hardship" on the employer; that is, an action by an employer requiring significant difficulty or expense in relation to the nature of the accommodation and the size and financial resources of the company.

Under Title I, persons with genetic disabilities may be determined to be "unqualified" for a job if they pose a direct safety or health threat to themselves or others in the workplace. Patronizing assumptions, generalized attitudes or


fears, and speculative or remote risks of incurring a genetic condition or disease would not be sufficient to constitute a "direct threat" defense to a Title I claim. Those lawfully excluded from employment because of a direct threat of harm often involve individuals with potential sudden onset conditions (e.g., epilepsy), not those who may become disabled at some point in the future.

Title I prohibits disability-related preemployment inquiries and medical examinations, except those examinations conducted after a conditional job offer has been made. Medically-related employment examinations must be given to all employees regardless of disability, and with limited exceptions, the information obtained must be treated as confidential. Title I regulations provide that medical test results from a post-conditional offer of employment or results obtained during employment may not be used to exclude an individual from the job unless the exclusion is shown to be job-related, consistent with

infected orthopedic surgeon in lawsuit involving non-staff hospital privileges because of possible safety threat to patients).


29. Id. § 12112(d)(3)(A), (B) (1993).
business necessity, and not amenable to reasonable accommodation.  

The ADA expressly allows insurance companies to underwrite, classify and administer medical health risks. Classifications must be consistent with state law practice and based on sound actuarial data. Third party insurers or employers self-funding their insurance plans may classify employees with regard to health insurance coverage on the basis of their medical and health histories. The employer, however, cannot use actual or perceived medical histories as a pretext.


32. Id.

33. 29 C.F.R. § 1630.16(f) (1991).

34. Because the ADA's legislative history only addresses health insurance, it is uncertain whether employees may be denied life and disability insurance provided by employers. See S. Rep. No. 101-116, 101st Cong., 1st Sess. 29 (1989); Natowicz et al., supra note 4, at 471. See also Can Benefits for Mental Illness Be Limited to Two Years Under the ADA?, 96 Law. Wkly. USA 512 (June 3, 1996) (discussing new EEOC position on mental illness benefits as extending beyond health insurance plan to disability plan).
for refusing to hire, firing, or taking other adverse action against a qualified applicant or employee.\textsuperscript{35}

Although the results of genetic screening conducted as part of a post-offer medical examination alone may not be used to withdraw an offer of employment to a qualified applicant, the results may be used to modify health care coverage provided through the employer's self-funded benefits plan. Limitations on health insurance coverage or exclusions of certain genetic conditions from coverage is permitted under the ADA as long as they are not a "subterfuge" for disability-based discrimination.\textsuperscript{36} For example, a self-funded employer may offer a health insurance policy to all employees that does not cover experimental treatment for Huntington's disease. However, under the ADA, a self-insured employer with an employee whose child develops cystic fibrosis may not withdraw dependent coverage for that particular employee on the basis of that disability.

As described above, employment discrimination under Title I of the ADA includes unequal treatment on the basis of a genetic condition or disability in any terms, conditions and privileges of employment.\textsuperscript{37} Employment decisions made solely upon information obtained from genetic tests may deny currently qualified individuals equal employment opportunity on the basis of a "status" over which they have no control.\textsuperscript{38} Scientific and legal debate over employers' use of properly obtained genetic information is evolving. For example, it is unclear for purposes of ADA analysis whether an employer may refuse to hire

\textsuperscript{35} 42 U.S.C. § 12112(c) (1993).

\textsuperscript{36} Id.

\textsuperscript{37} 42 U.S.C. § 12112(a) (1993).

\textsuperscript{38} Billings et al., supra note 5, at 477.
a qualified individual, even though asymptomatic, if occupational exposure to certain substances is likely to increase the employee's known genetic susceptibility to disease, even with the provision of reasonable accommodations. Yet, few instances of genetic conditions that require differential treatment in the workplace have been documented or studied systematically.

More commonly, genetic testing by an employer is motivated by cost and benefit analyses. In cases where


40. Natowicz et al., supra note 4, at 467.

41. Office of Technology Assessment, U.S. Congress, Medical Monitoring and Screening in the Workplace 3 (1991) (reporting that 42% of large corporate respondents considered a job applicant's health insurance risks a factor in determining employability and 36% actively engaged in health insurance risk assessments of job applicants); Ask Comp Carrier to Pay for Return-to-Work Accommodations, 1 Successful Job Accommodations Strategies (April 1996)
companies self-fund their insurance coverage for their employees, in effect acting as the insurer, economic considerations often provide a strong incentive to use genetic testing to avoid or limit future insurance costs and compensation claims. Nevertheless, an employer's culture, perceptions, and attitudes play a role in a decision not to hire an applicant who is qualified for the job but who is perceived likely to develop a genetic disease.\textsuperscript{42} Untested and often unfounded beliefs by employers about employees with genetic conditions include fears of increased absenteeism, decreased productivity, and higher health care costs.\textsuperscript{43}

Finally, the health insurance system generally has been implicated in the debate involving genetic discrimination because the system often has denied coverage to individuals who

\footnotesize{(discussing trend to shift responsibility for accommodations to worker' compensation insurance carriers); Velida Starcevich, Workplace: Designer Genes Only, Please, The Observer, June 2, 1996, at 8 (discussing EEOC estimate that 5\% of large companies test their employees' genes).}

\textsuperscript{42} Cf. Sears II, supra note 23, at 42 (discussing employer attitudes).

are in most need of insurance.\textsuperscript{44} Without careful study, any inequities in health insurance coverage for people with genetic conditions may be magnified, particularly if the use of genetic test results for insurance purposes become commonplace. In the absence of systematic study, the use of genetic testing by employers and insurers may result in qualified individuals not being able to obtain needed insurance, or having to pay exorbitant premiums, and thereby not being able to attain and retain employment. Study is needed of the psychological, medical, social and economic consequences of genetic testing by employers and insurers.\textsuperscript{45}

B. EEOC and Legislative Guidance on Genetic Discrimination Under Title I

Recently, the United States Equal Employment Opportunity Commission (EEOC) issued an amended compliance manual that extended ADA Title I protections to qualified people who experience employment discrimination on the basis of their genetic profiles.\textsuperscript{46} The EEOC expressly acknowledged the possibility that covered entities may discriminate against


\textsuperscript{46}. EEOC, supra note 11, at 43-45.
qualified individuals on the basis of actual or perceived genetic conditions or impairments.\footnote{Id.}

The EEOC manual presents a hypothetical scenario about a qualified job applicant whose asymptomatic genetic profile reveals an increased susceptibility to colon cancer but where no actual link to the development of the disease is present.\footnote{Id. See also infra notes 92-93 and accompanying text (discussing types of employment-related genetic discrimination).}

After making the qualified applicant a conditional offer of employment, the employer learns from genetic testing about the applicant's increased susceptibility. The employer withdraws the job offer because of generalized concerns about the applicant's future productivity, insurance costs, and absences from work. The EEOC determined that the applicant is covered by the third prong of the definition of "disability" because the employer is regarding and treating the asymptomatic applicant as having an impairment that substantially limits the major life activity of work. The actual prevalence of such behavior and attitudes by employers is an important area for future study discussed in Section III.

The EEOC guidelines raise other issues capable of study, such as those related to privacy and test results use. Increasingly, employees are subjected to urine and blood tests to screen for alcohol or substance use.\footnote{Patricia A. Montgomery, Workplace Drug Testing: Are There Limits?, 32 Tenn. B.J. 20 (1996).} Employers also may sponsor genetic screening, or more likely, obtain the results of genetic testing from other medical tests and potentially use that information to restrict the employment opportunities of
qualified applicants and employees. Federal and state legislation affecting confidentiality issues arising from the use of genetic information in the workplace is likely to be proposed over time. Although access to genetic information may not violate the ADA, more study is needed of related issues involving privacy, informed consent, and information use.

At present, no federal statutes prohibit genetic discrimination in employment-related settings, but four bills currently are pending in Congress. In addition, twelve states

50. Rothstein, supra note 27, at 62-68 (this information may be obtained through releases by employees, health insurance claims, or voluntary medical examinations and wellness programs).


have enacted legislative protections for persons against being
denied health insurance based solely on genetic status.\textsuperscript{53} State
laws do not provide protection for those who obtain their health
insurance coverage through employer-based plans, because the
Federal Employee Retirement Security Act (ERISA) exempts self-
funded plans from state oversight.\textsuperscript{54}

The EEOC guidelines and proposed legislation have
stimulated discussion of complex issues while helping to deter
genetic discrimination under Title I of the ADA. Systematic
study of the scientific, legal, and policy issues surrounding
genetic discrimination in the employment context is required.
The next section examines emerging empirical research, that is

\begin{itemize}
\item \textit{(1996); S. 1694, 104th Cong., 1st Sess. (1996); H.R. 3160, 104th
Cong., 1st Sess. (1996) (same as Senate Bill 1028).}
\end{itemize}

10123.3 (West 1996); \textit{Colo. Rev. Stat.} § 10-3-1104.7 (West 1995);
(West 1995); \textit{Md. Code Ann., Ins.} § 223 (West 1994); \textit{Minn. Stat.}
§ 72A.139 (West 1996); \textit{Mont. Code Ann.} § 33-18-206 (West 1994);
§§ 3901.49, 3901.50 (West 1996); \textit{Or. Re. Stat.} §§ 659.705,
746.135 (West 1995); \textit{Wis. Stat. Ann.} §§ 111.32, 631.89 (West
1993). Additionally, 20 state legislatures have proposed bills
to prohibit genetic discrimination, see e.g., \textit{N.J. S.} 695, 207th

beginning to replace myths with facts, about the nature of genetic discrimination under ADA Title I.

III. EMERGING EMPIRICAL STUDY OF GENETIC DISCRIMINATION AND ADA TITLE I

Prior studies suggest that myths, stereotypes, and misperceptions in society contribute to the potential for genetic discrimination by employers, insurers, and the general public. Preliminary empirical research has identified five core implications that are relevant to debunking myths related to genetic discrimination under Title I of the ADA:

(1) ADA Title I does not require employers to hire unqualified employees with genetic conditions or disabilities;

(2) The benefits of workplace accommodations for qualified employees with genetic conditions or disabilities outweigh the costs;

(3) ADA Title I has not resulted in extensive and costly litigation and has provided a framework for dispute avoidance and resolution;

(4) Genetic testing does not establish that all individuals with a genetic predisposition for a condition or disease will inevitably contract that disease; and

(5) Attitudes toward individuals with a genetic condition or disease often are based on stereotypes and misperceptions.

This section discusses the relevance of these five implications and the emerging empirical research that supports them. Additional systematic study is necessary, however, to

inform policymakers, insurers, employers, employees, and others about issues central to Title I implementation in relation to genetic discrimination. Such study helps to replace myths about genetic conditions with facts, foster meaningful and informed dialogue about the ADA, raise awareness about the lives, capabilities, and needs of qualified people with genetic conditions and disabilities, and forestall or minimize legal disputes about ADA Title I implementation by providing information to improve communication.56

A. ADA Title I Does Not Require Employers to Hire Unqualified Employees With Genetic Conditions or Disabilities

Critics of the ADA argue increasingly that when a person with a disability is hired, it is often because of the disability, not the individual's qualifications.57 Without reliance on hard data, the ADA is cast as a preferential treatment initiative, that is costly and economically inefficient.58 Contrary to these popular misconceptions, ADA Title I does not require employers to hire individuals with disabilities who are not qualified, or to hire qualified


57. Sears II, supra note 23, at 42.

individuals with disabilities over equally qualified individuals without disabilities.\textsuperscript{59}

In fact, almost half of all legal claims brought under the ADA are dismissed because the plaintiff alleging discrimination failed to show that he or she is qualified for the position.\textsuperscript{60} As of September 30, 1995, forty percent of all ADA claims filed with the EEOC were dismissed for having no reasonable cause.\textsuperscript{61} Another forty-three percent were closed for

\textsuperscript{59} 29 C.F.R. § 1630.2 (m & n) (1991); Sears I, supra note 23, at 30-40; Sears II, supra note 23, at 42. See also Helen L. v. DiDario, 46 F.3d 325, 334 (3d Cir. 1995) (the ADA ensures that qualified individuals be treated in "a manner consistent with basic human dignity, rather than a manner which shunts them aside, hides, and ignores them.").

\textsuperscript{60} Although this is not the best measure of preferential treatment under the ADA, the high rate of dismissals suggests that many cases are brought where the person is not otherwise qualified. See e.g., Ellison v. Software Spectrum, Inc., 1996 WL 284969 (5th Cir. May 30, 1996) (holding that woman treated for breast cancer with daily radiation therapy did not have a disability under the ADA); Kuehl v. Wal-Mart Stores, Inc., 909 F. Supp. 794 (D. Colo. 1995) (holding that individual who rejected a reasonable accommodation was not a qualified individual with a disability).

\textsuperscript{61} Lisa J. Stansky, \textit{Five Years after its Passage, the Americans with Disabilities Act Has Not Fulfilled the Greatest Fears of}
administrative reasons, including claims that they were withdrawn or were closed because the complaining parties failed to cooperate with the agency.\textsuperscript{62}

Despite these and other emerging trends, many of the legal concepts central to Title I implementation are evolving through the operation of the law in practice and through interpretation by the courts. More study is needed of the hiring practices concerning employees with disabilities. Presently, there is no empirical evidence to suggest that Title I implementation distorts the market value of American labor, requiring employers to take "affirmative" and costly measures to accommodate unqualified persons with disabilities.

To the contrary, recent longitudinal studies examining the employment profiles of individuals with disabilities highlight an emerging workforce of young, qualified individuals with disabilities.\textsuperscript{63} This emerging workforce reflects a new generation of persons with disabilities who have experienced mainstreamed education and whose families have advocated for their rights. Many qualified individuals with disabilities in the workforce show appropriate job skills, often have their accommodation needs met in reasonable ways, live more independently, are more involved in self-advocacy, and have

\textsuperscript{62}. Id.

rising incomes.\textsuperscript{64} Consistent with these findings, a study by the National Academy of Social Insurance found that many qualified Americans with disabilities prefer to work and only use social security disability benefits as a last resort.\textsuperscript{65}

In addition, surveys show that many executives have favorable views toward the employment of qualified people with disabilities. A 1995 Harris Poll of business executives found that 79\% of those surveyed believe that the employment of qualified people with disabilities is a boost to the economy, while only 2\% believe it poses a "threat to take jobs" from people without disabilities.\textsuperscript{66} Thus, the developing empirical


\textsuperscript{65}. 2 \textit{Successful Job Accommodations Strategies} (June 1996). See also William B. Gould IV, Employee Participation and Labor Policy: Why the Team Act Should be Defeated and the National Labor Relations Act Amended, speech before Creighton University School of Law on June 7, 1996, as reported in (BNA) \textit{Daily Labor Report}, _ DLR _ (__, 1996) (the opportunity to work is essential to one's sense of self worth, both by providing material goods and by expanding one's horizons, hopes, and aspirations).

evidence does not reflect a trend under Title I of the ADA toward preferential treatment in the workplace, at the expense of employee qualifications, economic efficiency, workplace health and safety, and business sense.

B. The Benefits of Workplace Accommodations for Qualified Employees with Genetic Conditions or Disabilities Outweigh the Costs

Some commentators argue that when the absolute right to refuse employment or insurance is denied, without exception, the employer or insurer is forced into a losing economic position.67 Others assert that the costs to employers of complying with the ADA outweigh the benefits provided to persons with disabilities.68 Still others argue that the costs of the accommodations will be especially high for large employers who will be held accountable for more extensive accommodations due to their greater financial resources.69 Thus, often in the


absence of systematically collected information, it is no
surprise that many employers believe that the costs of workplace
accommodation outweigh the benefits provided to employers,
society, and even individuals with disabilities themselves.

Emerging empirical information on the long-term
economic value of reasonable accommodations and "ADA
transcendence" in the workplace suggests otherwise. Companies
that are effectively and proactively implementing Title I
demonstrate the ability to look beyond mere compliance of the
ADA to transcendence of the law, in ways that make strong
economic sense. The low costs of accommodations for employees
with disabilities has been shown to produce substantial economic
benefits to companies, in terms of increased work productivity,
injury prevention, reduced workers' compensation costs, and
workplace effectiveness and efficiency.70

In a series of studies conducted at Sears, Roebuck and
Co., from 1978 to 1996, a time period before and after Title I's
July 26, 1992 effective date, nearly all of the almost 500
workplace accommodations sampled required little or no cost.71
From 1993 to 1996, the average cost for workplace accommodations
was $45, and from 1978 to 1992 the average cost for
accommodations was $121.72 Moreover, workplace accommodations
for people with disabilities often create a ripple effect
throughout an organization, as they lead to cost-effective

70. Sears II, supra note 23, at 11.

71. Specifically, 72% required no cost, 17% cost less than $100,
10% cost less than $500, and only 1% cost more than $500, but
not more than $1,000. Id. at 17.

72. Id. at 16-24.
applications that increase the productivity of employees without disabilities.\textsuperscript{73}

Consistent with these findings, other studies demonstrate benefits to employers of workplace accommodations for qualified employees. For instance, more than two-thirds of effective workplace accommodations implemented as a result of a Job Accommodation Network (JAN) consultation cost less than $500, and almost two-thirds of the workplace accommodations implemented result in savings to the company in excess of $5,000.\textsuperscript{74} The savings associated with effective workplace accommodations tracked by JAN include lower job training costs, increased worker productivity, lowered insurance claims, and reduced rehabilitation costs after injury on the job.\textsuperscript{75} Likewise, the results of a 1995 Harris Poll of more than 400 executives show that: (1) more than three-quarters of those surveyed report minimal or low increases in costs associated with the provision of workplace accommodations; (2) three-quarters of those surveyed report that the average cost of employing a person with a disability is not greater than employing a person without a disability; (3) the median cost for the provision of a accommodations was $233 per employee; and (4)

\textsuperscript{73} Id. at 35-36.

\textsuperscript{74} President's Committee on Employment of People with Disabilities, \textit{Job Accommodation Network (JAN) Reports} (October-December 1994) (Washington, D.C., 1994) (JAN provides information on accommodations for employees with disabilities).

\textsuperscript{75} Id. (reporting that for every dollar invested in an effective accommodation, companies realized an average of $50 in benefits).
from 1986 to 1995, the proportion of companies surveyed providing workplace accommodations rose from 51% to 81%. Studies show that the effective low cost workplace accommodations include assistive technology, physical access, changed schedules, assistance by others, and changed job duties. (March, 1996) (unpublished manuscript, on file with author). Additionally, many companies make informal and undocumented workplace accommodations that require minor cost-free workplace adjustments and that are implemented directly by

76. Harris Study, supra note 66. Companies are beginning to realize the benefits of helping employees deal with job pressures and pressures outside of work. For example, stressing a business-driven focus on improving productivity and competitiveness, the E.I. du Pont de Nemours and Company has developed "work-life programs" to help employees deal with such pressures. Hal Clifford, The Perfect Chemistry: DuPont's Work-Life Program, *Hemispheres* 33, 34 (1996) (claiming a 637 percent return on expenditures for its LifeWorks program, based on its estimated value of resulting increased performance, employee retention, stress reduction, and reduced absenteeism).

77. Mary C. Daly & John Bound, Worker Adaptation and Employer Accommodation Following the Onset of a Health Impairment, 51B *J. Gerontology* S53 (1996); Martha J. McAughey et al., Implementation of the Americans with Disabilities Act: Perceptions and Experiences of Individuals with Disabilities,
an employee and his or her immediate supervisor.\textsuperscript{78} Study is needed of the accommodation costs associated with the many qualified employees with genetic conditions and diseases.

In studying future employment strategies, examination is needed of both direct and indirect costs and benefits associated with ADA implementation for those with genetic disabilities, such as staff time related to the planning of an accommodation or the positive impact of an accommodation on training and safe workplace practices for fellow employees without genetic disabilities.\textsuperscript{79} As discussed next, the emerging empirical evidence indicates that employers also may reduce potential future costs by using Title I to provide a framework to avoid costly genetic discrimination litigation.

C. ADA Title I Has Not Resulted in Extensive and Costly Litigation and Has Provided a Framework for Dispute Avoidance and Resolution

When the ADA was passed, it was predicted that it would foster extensive and costly trial litigation.\textsuperscript{80} Some

\textsuperscript{78} Sears II, \textit{supra} note 23, at 19-24. Additionally, any necessary accommodations for qualified employees with asymptomatic genetic conditions would be minimal.


commentators continue to make these arguments.81 Far from creating onerous legal burdens, however, the ADA had provided employers and employees a framework for effective dispute avoidance and resolution. Studies show that corporations may avoid litigation and create an environment of cooperation, rather than confrontation, in managing health-related and disability issues in the workplace.82

The findings from the Sears study show that from January 1, 1990 to August 10, 1995, 141 Title I complaints were filed with the EEOC against Sears.83 Roughly 80% of the informal ADA inquiries sampled were resolved successfully, including through the provision of reasonable accommodations, the revision of corporate or store policies, and the development of training and awareness programs regarding Title I compliance. Moreover, the overwhelming majority of formal Title I charges (98%) were resolved without resort to protracted litigation. The most effective resolutions involved compensatory payments and the provision of accommodations enabling qualified employees to return to work.

81. Willis, supra note 68, at 728-729. Cf. Special Supplement to the Council Updater: Andy Miller of the Atlanta Journal-Constitution Discusses Disability Issues with Speaker of the House Newt Gingrich (Feb. 23, 1996) (Gingrich commenting that although the ADA has too much regulation and too many opportunities for litigation, overall it has been successful).


83 See Sears II, supra note 23, at 31.
Workplace strategies also can lead to streamlined dispute resolution and enhanced workplace safety for employees with and without disabilities.\textsuperscript{84} Sears provides a "help line" to employees for guidance on ADA-related policy.\textsuperscript{85} Inquiries are confidential, and advice and follow-up information is provided by trained personnel. Although many of the accommodations addressed by the help-line appear to involve simple and common sense business strategies, similar accommodation requests in other corporate settings have fostered Title I litigation.\textsuperscript{86}

Consistent with the Sears study, another study suggests that individuals with disabilities are less likely to perceive discrimination if they are able to negotiate job-related problems successfully.\textsuperscript{87} The study asked respondents with a disability whether they had resolved a problem related to discrimination without filing an ADA complaint. The respondents reported resolving problems substantially more times than they

\textsuperscript{84} Francine S. Hall & Elizabeth L. Hall, \textit{The ADA: Going Beyond the Law}, 8 \textit{Acad. Mgmt. Executive Rev.} 17 (1994); Talbert & Karp, supra note 82, at 638-42.

\textsuperscript{85} Sears II, supra note 23, at 11.

\textsuperscript{86} See, e.g., Fritz v. Mascotech Automotive Sys. Group, Inc., 914 F. Supp. 1481 (D. E.Mich. February 13, 1996) (finding that employee's shortcomings in attendance and punctuality due to heart condition could have been accommodated by a flexible work schedule).

\textsuperscript{87} McGaughey et al., supra note 77, at 16.
reported experiencing discrimination. Moreover, 59% of those who attempted informal negotiation activities resolved the problem successfully through informal means.

Viewing the empirical evidence as a whole, the studies suggest that a corporate commitment to Title I dispute resolution of genetic discrimination claims may generate positive effects. The empirical findings suggest that the degree to which companies respond to qualified persons with genetic conditions and impairments may have more to do with their corporate cultures and attitudes than with the demands of the law. Systematic study is needed on corporate practices, such as establishing training awareness programs about genetic discrimination, and their effectiveness. As discussed next, study also is needed on the misconceptions surrounding the usefulness and interpretation of genetic test results.

D. Genetic Testing Does Not Establish That All Individuals With a Genetic Predisposition For a Condition or Disease Will Inevitably Contract That Disease

88. *Id.* at 16-17 (depending on the type of job discrimination, between 5.4% to 11.4% reported job discrimination and between 8.7% and 18.6% reported problem resolution).

89. *Id.* at 18.

Misconceptions about the usefulness of genetic testing may lead to increased discrimination against people with genetic impairments and their relatives. In the employment realm, genetic discrimination based on misinformation may preclude qualified people from being hired, hold people hostage to their current employment because of a reluctance to seek a new job without new health insurance, or serve as a basis for firing. In the insurance arena, such discrimination may result in the denial of coverage, inequitable premiums, or unwarranted exclusions for particular genetic conditions. Given the rapid advances in the development of genetic tests, the economic incentives for insurance companies and employers to use them, and the presence of certain abnormal genes in all individuals, increasing numbers of qualified individuals may be in jeopardy of encountering genetic discrimination.91

Genetic discrimination involving health and life insurance may include discrimination against asymptomatic individuals or their relatives once a genetic diagnosis has been

established or the failure of group insurance plans to provide equitable coverage for qualified individuals with a genetic diagnosis or their relatives.\textsuperscript{92} Extensive qualitative studies suggest that many people who are currently healthy and asymptomatic are being denied health insurance and employment opportunities based solely on predictions that they may become "unhealthy" in the future.\textsuperscript{93} Inconsistent with the spirit and law of the ADA, many healthy, asymptomatic individuals are treated as if they were presently disabled or chronically ill.

There are several flaws with equating the presence of a particular genotype with the existence of a severe illness and the lack of effective treatment. First, contrary to popular belief, many genetic conditions and diseases are variable in expressivity; that is, not all individuals with the genotype develop clinical manifestations of the disease.\textsuperscript{94} Moreover, with the continued growth in therapies for genetic conditions, it is likely that additional therapies may be available by the time an asymptomatic person actually contracts a predicted genetic disease.

Second, when decisions regarding insurance and employment are based solely on a diagnostic label, the severity or range of the individual's condition is disregarded. However, the course and severity of many diseases vary widely among

\textsuperscript{92} Geller et al, supra note 91, at 75.

\textsuperscript{93} Billings et al., supra note 5, at 481; Geller, et al., supra note 91, at 82.

\textsuperscript{94} Alper et al., supra note 91, at 353 (e.g., at least 25% of those with the genotype for hemochromatosis, a relatively common recessive iron storage disorder, do not develop symptoms of the disease).
individuals, and the presence of a gene cannot foretell how disabling a genetic condition or disease may be to a specific person.\textsuperscript{95} Nevertheless, the worst possible scenario often is used as the standard for policy decisions regarding persons with genetic conditions or impairments.\textsuperscript{96}

Third, few genetic conditions and diseases are caused by a single gene.\textsuperscript{97} Many common health conditions, such as coronary disease and cancer, have been shown to have many causes. Focusing solely on the role of genetics also minimizes the impact of other social conditions, such as poverty, or environmental conditions, such as pollution, that have been shown to be related to poor health and higher mortality rates.\textsuperscript{98} Thus, an attitudinal bias or overemphasis on genetic conditions may divert researchers and resources from addressing these underlying economic and social mediating factors.\textsuperscript{99}

Finally, errors in testing and interpretation occur.\textsuperscript{100} Because of a high rate of false positive test results, the

\textsuperscript{95}. Billings et al., \textit{supra} note 5, at 479-80.

\textsuperscript{96}. \textit{Id.}


\textsuperscript{98}. See McGoodwin, \textit{supra} note 3.

\textsuperscript{99}. \textit{Id.}; see infra notes 103-05 and accompanying text (discussing base-rate fallacy).

\textsuperscript{100}. Alper et al., \textit{supra} note 91, at 352-53. The same is true for degrees of mental illness as commonly measured by the Minnesota Multiphasic Personality Inventory (MMPI). The predictive
medical records of individuals who do not have a particular genetic condition sometimes suggest treatment for the disease.\textsuperscript{101} False positive tests may have a dramatic impact on an individual's life.\textsuperscript{102} Psychometric studies from statisticians, actuaries, psychologists, and others are needed on the predictive validity of each genetic test. In addition to the unfounded beliefs surrounding the usefulness and meaning of the genetic tests, there are other misperceptions about persons with genetic impairments, which are addressed next.

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validity of the MMPI and other psychological tests has been questioned. \textit{See, e.g.}, Gary F. Coulton & Hubert S. Feild, \textit{Using Assessment Centers in Selecting Entry-Level Police Officers: Extravagance or Justified Expense?}, 24 \textit{Pub. Personnel Mgmt.} 223 (June 22, 1996). Other analogies may be drawn between genetic disabilities and mental disabilities based on their "hidden" and often asymptomatic nature.

\textsuperscript{101} Alper et al., \textit{supra} note 91, at 353.

E. Attitudes Toward Individuals With a Genetic Condition or Disease Often Are Based on Stereotypes and Misperceptions

Research suggests that the chance of developing a genetic condition or disease is perceived differently than a similar probability of contracting an illness not produced primarily by genetic factors.103 People commonly commit base-rate judgment errors when attempting to predict the outcome of events on the basis of fallible data.104 The phenomenon of base-rate error has been demonstrated empirically in studies about the prediction of disease onset.105

103. Billings et al., supra note 5, at 480. There is evidence that persons with disabilities are perceived differently in general. One study reported that more than half (53%) of Americans believe their co-workers would treat them differently if they had disabilities. 5 BNA ADA Manual 62 (May 23, 1996).


105. See, e.g., Ward Casscells et al., Interpretation by Physicians of Clinical Laboratory Results, 299 New Eng. J.M. 999-1000 (1978). Students and staff at Harvard Medical School were asked, "If a test to detect a disease whose prevalence is 1/1000 has a false positive rate of 5%, what is the chance that a person found to have a positive result actually has the disease, assuming you know nothing about the person's symptoms or signs?"
In a study of state insurance commissioners, the findings showed that respondents repeatedly ignored base rate information about the prevalence and onset of genetic conditions.106 For instance, regardless of actual risk, the commissioners treated applicants who were at genetic risk for developing breast cancer or coronary artery disease less harshly than those with other genetic conditions, such as Huntington's disease or cystic fibrosis.107 The respondents also reported

\[ \text{Id. at 999. Almost half of the respondents said 95\%, while less than 20\% of the participants gave the appropriate response of 2\%. Id.} \]

106. Jean E. McEwen et al., A Survey of State Insurance Commissioners Concerning Genetic Testing and Life Insurance, 51 Am. J. Hum. Genetics 785 (1992) (measuring whether responding commissioners would allow life insurers to refuse coverage, charge higher premiums, or provide exclusion for applicants who were at genetic risk for developing certain diseases).

107. Id. at 791 (this finding might reflect the commissioners' biases or perceptions that breast cancer and coronary artery disease, being more common in the population than the other conditions, are not genetic disorders). It is not in violation of the ADA for insurers or employers to charge higher premiums for certain conditions, to exclude certain conditions, to exclude dependents or to limit coverage of certain conditions, as long
that they were as willing to permit the denial of insurance to an adult with spina bifida as to an adult with cystic fibrosis, even though a young adult with spina bifida has a significantly higher life expectancy.\textsuperscript{108}

Improper and uninformed genetic testing also may encourage a "blame the victim" mindset, where society condemns people with "faulty" genes solely on the basis of that status.\textsuperscript{109} Psychological studies have examined the "defensive attribution" as a tendency to blame victims for their misfortune, in part so that the blamer feels less likely to be victimized in a similar way.\textsuperscript{110} Blaming victims for their afflictions causes the victims

\textsuperscript{108} McEwen, et al., supra note 106, at 791.

\textsuperscript{109} See McGoodwin, supra note 3; Statement of EEOC Commissioner Paul Steven Miller (May 24, 1996), at 3 (on file with author) [hereinafter EEOC Statement] (referring to first ADA case filed by EEOC involving individuals with developmental disabilities as "a particularly egregious case of blaming the victim").

to be viewed negatively by themselves and others.\textsuperscript{111} Misinformed perceptions of persons with genetic disabilities as being sickly and having poor health habits may lead to unwarranted derogation and those individuals actually having less concern for their health and self-worth, thereby enhancing the probability for disease onset.

Another stereotype is that the onset of a genetic condition or disability usually indicates the end of one's productive work life. A recent study that examined the extent to which workers, through their own actions or their employer's accommodations, adjust to their health limitations and continue working, found that only about one-quarter of those who become impaired while employed exited the labor force on a permanent basis.\textsuperscript{112} Over half of the individuals studied remained with their employer, and the remaining individuals continued to work for different employers.\textsuperscript{113} Moreover, significantly more employees who remained with their employer after the onset of their impairment reported receiving accommodation from their employer.\textsuperscript{114}


\textsuperscript{112} See Daly & Bound, supra note 77, at S54 (respondents who reported that they had "any impairment or health problem that limits the kind or amount of paid work" they could do were classified as disabled).

\textsuperscript{113} Id. at S55-S56.

\textsuperscript{114} Id. at S55-S56. See also Sears II, supra note 23, at 25-27.
Stereotypes and misperceptions have a psychological impact on potential targets of genetic discrimination. People who have experienced one or more episodes of genetic discrimination commonly report a loss of self-esteem, alienation from family members and others, and alterations in family dynamics.\textsuperscript{115} There also are psychological implications concerning genetic testing itself.\textsuperscript{116} (discussing fears about health, insurance, and employment based on gene predicting increased risk of cancer). Study is needed of these effects, as well as the medical, social, and economic consequences of the use of genetic test results by employers and insurers. These emerging research issues are discussed in the final part of this article.

\textsuperscript{115} Geller et al., supra note 91, at 78, 80-81.

IV. EMERGING ISSUES AND A CALL FOR RESEARCH

Genetic discrimination by employers and insurers often is caused as much by attitudinal biases and ignorance as it is by institutional or governmental policy.\textsuperscript{117} Insurance companies, employers, policymakers, and regulatory bodies need to be aware of the existence of discriminatory practices and the costly effects of these practices.

Qualified employees and job applicants also must be educated regarding their rights under the law.\textsuperscript{118} Although individuals who face genetic discrimination often must seek the assistance of state regulatory agencies, many qualified persons who are susceptible to genetic discrimination lack either the information or the resources to address the problem. One study found that only one-third of individuals who reported having experienced genetic discrimination knew of the existence of state insurance commissions.\textsuperscript{119} Additionally, less than 50% of the general population with disabilities reported being aware of

\textsuperscript{117} Geller et al., supra note 91, at 81-82 (examining causes of genetic discrimination in various settings).

\textsuperscript{118} See Bob Dole, Are We Keeping America's Promises to People with Disabilities--Commentary on Blanck, 79 Iowa L. Rev. 925, 927-28 (1994) (stating that society has an obligation to know how well the ADA is working and whether people affected by the ADA are aware of their rights and responsibilities).

\textsuperscript{119} Geller, et al., supra note 91, at 81.
the ADA in 1994, four years after its enactment.\textsuperscript{120} This lack of consumer awareness likely is one reason why studies of state insurance commissions find regulators to be unaware of genetic discrimination faced by many qualified individuals.\textsuperscript{121} Study needs to be conducted also on the legal remedies, informal and formal, available to those who experience genetic discrimination.\textsuperscript{122}

\textsuperscript{120}. Louis Harris and Associates, Survey of Americans with Disabilities (New York, 1994). A 1996 study reported that 58\% of one sample of persons with disabilities, and 98\% of a highly educated sample, were aware of the ADA. McGaughey, et al., supra note 77, at 14. Two-thirds of the highly educated sample reported that they knew how to file an ADA-related discrimination complaint, compared with only 8\% of a less educated sample. Id. at 18.

\textsuperscript{121}. McEwen et al., supra note 106, at 790 (finding only 2 out of 42 state insurance commissioners reported receiving formal complaints about genetic discrimination). See also Geller et al., supra note 91, at 81 (discussing evidence that even when individuals are aware of regulatory agencies, they do not attempt to challenge the discrimination); infra note 136, and accompanying text (discussing research issues relevant to vulnerable populations).

\textsuperscript{122}. See Sears II, supra note 23, at 33-37 (examining use of alternative dispute resolution to resolve disputes).
The need for a comprehensive examination of genetic discrimination and a educational program for interested parties requires a systematic study of issues surrounding genetic discrimination under Title I of the ADA. In this section, we discuss how this study may be interdisciplinary in nature, and illustrate emerging research issues in the areas of employment and insurance, attitudes, and vulnerable populations.

A. Interdisciplinary Study of Genetic Discrimination under ADA Title I

Genetic discrimination in the employment context cannot be resolved solely by strict enforcement of the ADA. No law, even one as far-reaching as the ADA, can be the sole impetus for social change. Complex questions about the potential for genetic discrimination in the workplace must be examined within the context of other emerging national debates, such as those on welfare and health care reform.123

The existing health care system is facing major challenges. In 1988, there were over 33.6 million Americans without health insurance coverage, and by 1992, that number had

123. See Gould, supra note 65, at ___ (providing incentives to work as part of welfare package require an investment in job training, education, and child care, and adequate minimum wage).

climbed to 38.9 million.\textsuperscript{124} In addition, health care costs have skyrocketed, increasing the importance of adequate health insurance.\textsuperscript{125}

There are several options for studying the potential impact of genetic testing on the availability of health insurance. First, study is needed by political scientists of actual or proposed legislation prohibiting genetic testing or the use of genetic test results by employers and insurers to prevent discrimination.\textsuperscript{126} Study is needed of prohibitions that would prevent insurers from requiring genetic testing during the application process, and from acquiring and improperly using the results of genetic tests performed for other purposes. Analysis of these studies may aid in an understanding of the incentives for individuals to avoid genetic tests recommended by physicians or conducted for research purposes, possibly out of fear that they would not be able to acquire health insurance.

Second, legal scholars may study the ways to appropriately regulate the use of genetic information acquired by insurers. An integral part of any proposed regulation involves the evaluation and approval of specific tests by a regulatory authority to assure test reliability. Moreover, study is needed of the extent to which individuals who undergo

\textsuperscript{124}. Charles M. Madigan, Health Care's Huge Appetite; Special Interests Snarl Reform, Chi. Trib., Aug. 7, 1994, at 1.

\textsuperscript{125}. Id. Spending on health care in the United States in 1993 was $903.4 billion, 14.4 percent of the nation's gross national product.

\textsuperscript{126}. See supra notes 52-53 and accompanying text (discussing proposed legislation).
genetic testing have a right to be made aware that insurance coverage may be denied or limited based on the test results, and the nature of informed consent to the genetic test required by the insurer. Third, study is needed by economists of the financial impact on insurance companies choosing to insure people at risk for genetic diseases. Cost/benefit analyses are needed, involving people with inherited conditions over time. Study is needed also of the costs and benefits of detection that may aid in disease or injury prevention, which in turn would help control health care costs.

There are additional areas of study involving other disciplines that need to be explored. Ethicists and those in the medical community must address potential uses of genetic testing. Organizational behavioral experts and sociologists are needed to study the role of corporate cultures in defining how employers relate to those with genetic conditions and disabili-

127. See Genetic Testing for Cancer Susceptibility ASCO Statement Published, PR Newswire, May 1, 1996 (The American Society of Clinical Oncology advises clinical oncologists on genetic testing issues, recommends that counseling be provided for individuals at risk for inheriting a cancer susceptibility gene, and that patients and their families be informed about the potential for genetic discrimination by insurers or employers).

128. McGoodwin, supra note 3, at C03. Some commentators have suggested that a universal health system is needed to address the larger problem of the uninsured. See e.g., Billings et al., supra note 5, at 481-82; Natowicz et al., supra note 4, at 473-74.
ties. Developmental psychologists may study childrens' attitudes toward those with genetic disabilities and how those attitudes change over time.

Each of these areas of interdisciplinary study implicate several of the possible health insurance reforms that may help protect against genetic discrimination in the employment context. Before any of these proposals are implemented on a national basis, however, their potential impact on society must be studied in a systematic way. This empirical work is needed to provide guidance for insurers, employers, policymakers, courts, and others to effectively evaluate ADA Title I implementation and determine whether future legislation is required in the area of genetic discrimination.

As mentioned in Parts II and III above, the use of genetic tests by employers and insurers also raises issues capable of study concerning informed consent, privacy, and confidentiality in research, diagnosis, and therapy. Issues


130. A recent study showed that preschoolers who have a disabled classmate are more likely to accept others with disabilities. Karen Diamond, Topics in Early Childhood Special Education, 22 Special Education Report (CPI) (Winter 1996) (forthcoming).

131. See supra notes 29, 49-51, and accompanying text; On-Line Service Checks Job Applicant Histories, Charleston Newspapers, April 18, 1996 (prospective employers may access online information about an applicant's past workers' compensation claims and
involving confidentiality are increasingly prominent as medical and other records are put into computer data bases that are accessible to a large number of individuals and companies.\(^{132}\) Some commentators have proposed the use of anonymous genetic counseling and testing.\(^ {133}\)

As more studies on the presence and effects of genetic discrimination are reported, it will be helpful also to begin to


summarize the literature meta-analytically.\textsuperscript{134} Meta-analysis is a set of concepts and procedures employed to summarize quantitatively a domain of research to provide a more accurate, comprehensive, and statistically more powerful understandings.\textsuperscript{135} These analyses will help standardize research protocols and help prevent the piecemeal presentation of evidence that contributes to the resolution of the issues surrounding genetic discrimination in employment and insurance.

Other empirical problems with regard to the future study of genetic discrimination in employment context include:

(1) How to assess the economic and social impact that genetic discrimination has on employment opportunity and advancement for qualified persons with genetic disabilities;

(2) How to study and assess empirically whether individuals with asymptomatic genetic disorders are regarded or perceived as having a disability for purposes of coverage under the ADA;

(3) How to assess whether substantial limitations in work abilities change over time for individuals with different genetic conditions and disabilities;

(4) How to examine longitudinally whether families, vulnerable populations, or other subgroups in society with prevalent genetic disorders are excluded from equal employment opportunities and privileges; and


(5) How to assess whether courts, legislators, and regulators are redressing present and future harms resulting from actual or perceived abuses of genetic testing or therapy. These and many other questions need to be addressed to facilitate systematic study of genetic discrimination in employment and insurance. This study is needed to ensure that genetic discrimination does not render large numbers of qualified persons in society unemployable or uninsurable.

B. Attitudinal Research

As mentioned above, there exist attitudinal biases and misperceptions about persons with genetic impairments in the workforce and elsewhere. Standardized methods to measure attitudes about genetic discrimination and persons with genetic impairments are needed. Prior studies by social psychologists on attitudes towards race, gender, and other classifications have much to contribute to the developing understanding of attitudes toward genetic discrimination.136 Additional empirical questions with regard to the perceptions and attitudes surrounding genetic discrimination in employment include:

(1) How are the risks for genetic conditions or diseases perceived differently by employers, insurers, or others than those of other conditions or diseases not produced by genetic factors?

136. See, e.g., Harlan Hahn, Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective, 14 Behav. Sci. & Law 41 (1996); Martin Fishbein & Icek Ajzen, Belief, Attitude, Intention and Behavior: An Introduction to Theory and Research (1975). See also EEOC Statement, supra note 109, at 4 ("the EEOC will not tolerate bigotry and subterfuge to deprive disabled persons of their livelihoods").
(2) What are the common attitudes and attributions by
employers, insurers, or others toward the employment abilities
of those with different genetic conditions or impairments?
(3) What impact do actual or perceived genetic
conditions or disabilities have on employers' attitudes toward
employment qualifications (e.g., career advancement and work
life) for employees with genetic disabilities?
(4) To what extent do unfounded attitudes by
employers, insurers, or others towards employees with genetic
disabilities contribute to actual disease onset (e.g., increased
susceptibility or self-fulfilling prophecies)?, and
(5) What intervention strategies are effective to
educate employers, insurers, employees, and others of their
rights and obligations with regard to genetic information?

These and many other questions need to be addressed as
part of the investigation of attitudes toward persons with
genetic disabilities. Identifying the common myths and
stereotypes surrounding persons with genetic disabilities is an
important step toward reducing genetic discrimination.

In addition to attitudinal research, systematic
attention must be devoted toward the ethical and legal rights of
vulnerable populations, such as persons with disabilities,
children, patients, persons in poverty, and those disen-
franchised from society with little voice in research or regula-
tion.137 Many legal and ethical dilemmas related to genetic

137. See Billings, et al, supra note 5, at 479 (the poor, unedu-
cated foreign nationals, and others may not be as willing or
able to pursue legal redress of genetic discrimination); Blanck,
supra note 2, at 184 (with increased exposure to unemployment,
health risk, substance abuse, and abuse and neglect, vulnerable
testing research and intervention that involve vulnerable populations, as a distinct subgroup of genetic research and intervention, may be formulated, including:

(1) What legal and ethical responsibility or duty of care do researchers, employers, or others have to inform third parties (e.g., spouses, other employees, insurers) of potentially harmful genetic facts?

(2) What constitutes valid informed consent for testing or intervention involving vulnerable populations with genetic conditions or disorders, particularly when monetary compensation is provided?

(3) What legal and ethical guidelines should be followed by the parents of minors with genetic conditions or other disorders in regard to decisions about their long-term familial involvement in genetic research and intervention?

(4) What are the independent responsibilities of researchers and employers to the children of qualified employees who consent to participate in genetic testing or studies?, and

(5) What role will state, federal, and institutional review boards play in the monitoring of longitudinal genetic testing and research protocols by employers, researchers, insurers, and others?

populations are the focus of increased research efforts and legal protections).
IV. Conclusion

Persons with genetic disabilities often are excluded from society and subjected to deep-rooted biases and prejudices, myths, and stereotypes about their job-related needs and abilities. The HGP offers tremendous promise for aiding in the intervention in and treatment of genetic conditions and disorders. The advances of the HGP, however, raise new research, ethical and legal questions that require close attention.

The antidiscrimination legislation embodied in the ADA holds great promise for promoting equal opportunity for qualified persons with genetic disabilities in employment. The current dialogue on the HGP and the ADA, including the recent EEOC guidelines, highlight the potential that the ADA has to help eliminate genetic discrimination in employment and in the provision of health insurance to qualified persons. More empirical information about the behavior and attitudes of persons with and without genetic conditions and disabilities, their employers, insurance providers and others is needed.