

1992

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Recommended Citation

Charles B. Gurd *Whether a Generic Defect Is a Disability under the Americans with Disabilities Act: Preventing Genetic Discrimination by Employers*, 1 *Annals Health L.* 107 (1992).

Available at: <http://lawcommons.luc.edu/annals/vol1/iss1/9>

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Whether a Genetic Defect Is a Disability Under the Americans With Disabilities Act: Preventing Genetic Discrimination by Employers

*Charles B. Gurd**

The Americans with Disabilities Act (“ADA”)¹ provides important rights for individuals with disabilities. Title I of the ADA prohibits employers from discriminating against qualified individuals with disabilities. Although Title I does not guarantee employment, it does give a qualified individual with a disability an equal opportunity to a particular job.² Under the Act, a “qualified individual with a disability” is an individual with a disability who, with or without reasonable accommodation, can perform the essential functions of the job that the individual holds or desires.³ It is unlawful to discriminate against a “qualified individual with a disability” in all aspects of the employment relationship including recruitment, hiring, upgrading, promotion, transfer, termination, rates of pay, or job assignments.⁴

The ADA and the corresponding regulations allow several defenses to a charge of discrimination.⁵ An employer has a defense to a charge of discrimination based on disparate treatment if the employer can show that the “action is justified by a legitimate, nondiscriminatory reason.”⁶ An employer has a defense to a charge of discrimination based on disparate impact if the employer can show “that a uniformly applied standard, criterion, or policy [is] job-related and consistent with business necessity”⁷ and that a

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1. Americans With Disabilities Act of 1990, 42 U.S.C.A. § 12101-12213 (West Supp. 1992).

2. CHARLES D. GOLDMAN, *DISABILITY RIGHTS GUIDE* 22 (2d ed. 1991).

3. 42 U.S.C.A. § 12111(8).

4. 29 C.F.R. § 1630.4 and appendix § 1630.4 (1992).

5. 29 C.F.R. § 1630.15 and appendix § 1630.15 (1992).

6. 29 C.F.R. § 1630.15(a).

7. *Id.* at 1630.15(c).

requested or necessary accommodation would impose an undue hardship”⁸ on the employer, such as excessive cost.⁹

The question arises: does the ADA prohibit an employer from discriminating against a qualified individual because his or her genetic make-up contains a defective gene or a particular physical or mental trait? In his article entitled *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, Larry Gostin provides an excellent and comprehensive analysis of genetic screening, testing, and discrimination in the workplace.¹⁰ He analyzes the legality of genetic discrimination under the ADA, Title VII of the 1964 Civil Rights Act, and other legislation. Mr. Gostin also provides an excellent analysis of the social, political, ethical, and medical aspects of the Human Genome Project.¹¹ Larry Gostin concluded his paper stating: “While the ADA is a powerful tool to combat genetic discrimination, its construction [concerning genetic discrimination] should not be left to the uncertainty of future judicial decisions.”¹² In reviewing federal and state statutes, the Office of Technology Assessment (“OTA”) concluded that these statutes do not fully prohibit genetic discrimination.¹³ Further, the OTA report states: “Whether a genetic marker or a trait constitutes an ‘impairment’ under [the] ADA is unclear [The] ADA language, however, does not specifically address genetic monitoring or screening.”¹⁴

Larry Gostin proposes an amendment to the ADA to cover genetic discrimination. The present article examines his proposed amendment and explains why it is insufficient to protect against all genetic discrimination. The article then proposes a National Genetic Anti-Discrimination Act, which prohibits genetic discrimination by employers.

GENETIC SCREENING AND GENETIC DISCRIMINATION

To determine the type and extent of genetic monitoring (testing)

8. *Id.* at 1630.15(d).

9. Appendix to 29 C.F.R. § 1630.2(p).

10. 17 AM. J.L. & MED. 109 (1991) [hereinafter Gostin].

11. The goals of the Human Genome Project are to identify or “map” all human genes and all human DNA.

12. Gostin, *supra* note 10, at 142.

13. Congress of the United States, Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* 15-17 (OTA-BA-455, 1990) [hereinafter OTA Report].

14. *Id.* at 16.

and screening¹⁵ in the workplace, OTA surveyed the 500 largest United States companies (Fortune 500), the 50 largest utilities, and several major labor unions, first in 1982 and again in 1989.¹⁶ The OTA “found 20 companies had used genetic monitoring or screening in 1989, as compared to 18 companies in 1982.”¹⁷ In its 1989 survey, the OTA asked respondents whether they expected to do genetic screening in the future. The OTA concluded that “the 1989 . . . survey appears to indicate fewer companies anticipate using genetic monitoring or screening [in the future].”¹⁸

The 1989 survey indicates the extent and type of genetic monitoring and screening that employers are reporting. Despite these survey results, it is likely that genetic screening and genetic discrimination will increase in the future as the mapping of human genes continues. For example, Professor Gostin writes: “American industry is likely to turn to genetic diagnosis in the future for many of the same reasons that have driven the sharp increases in drug, polygraph and general medical testing in the workplace.”¹⁹ Genetic screening in employment could be used to deny applicants and to transfer employees to certain departments if they are “susceptible to certain occupational diseases”; employers could also use genetic screening to ensure that “workers most susceptible to a specific risk [are working] in the least hazardous environments.”²⁰ According to the OTA, employers might use genetic screening to “improve employee productivity” and to lower health insurance costs.²¹ Employers may want to terminate employment for employees whose genetic make-ups may make them susceptible to a particular disease or whose genetic traits are undesirable. In their book *Genome*, Jerry E. Bishop and Michael Waldholz write:

Employers also may demand to see or even to require genetic tests of their workers and/or job applicants. It is quite likely that

15. Genetic screening, in most cases, requires a one-time test to detect a single trait in a worker or job applicant, while [genetic] monitoring generally involves multiple tests of a worker over time. Most importantly, in genetic screening the focus is on the preexisting genetic makeup that workers or job applicants bring to the job. This is distinct from genetic monitoring, where the focus is on changes in the genetic material induced from hazardous exposure at the workplace

Id. at 32.

16. *Id.* at 20-22. The OTA report contains a detailed analysis of the results and conclusions of these surveys.

17. *Id.* at 23.

18. *Id.* at 24.

19. Gostin, *supra* note 10, at 116.

20. OTA Report, *supra* note 13, at 32.

21. *Id.*

as genetic tests uncover an increasingly wide spectrum of genetic susceptibilities, at least some people will be excluded from certain jobs Corporate managements well may want to know if a candidate for promotion to a key management job is susceptible to alcoholism, mental illness, or Alzheimer's disease.²²

However, a particular action may be non-discriminatory if related and relevant to job performance. For example, Dr. Knoppers, a geneticist, has stated that "genetic screening may be legal if it is 'directly related to qualifications for doing the task or if necessary for employee safety. However, refusal or termination of employment should only be permitted on grounds of the employee's current capabilities and not on the grounds of predicted future incapacities.'"²³ Every person's rights are threatened if an employee's genetic constitution or genotype is used to evaluate the employee's ability to perform a job or task. Yet, society seeks to protect against discrimination based upon traits that do not affect job performance.²⁴

In analyzing genetic discrimination under the ADA, a general understanding of genetics is required. The gene is the basic physical and functional unit of heredity; chains of DNA (deoxyribonucleic acid) comprise this gene unit. The DNA's linear arrangement of paired bases in triplets provides the blueprint for protein synthesis. These proteins ultimately control all human structure and function.²⁵

Genetic screening is the process of scanning an individual's genetic composition to determine whether that individual has genetic material rendering him or her susceptible to developing or transmitting a genetic defect or disease.²⁶ Three general types of genetic screening exist. Fetal or prenatal screening seeks to identify genetic defects and disease in the fetus, newborn screening seeks to identify genetic defects and disease in the newborn, and carrier screening seeks to identify those individuals whose genes are responsible for genetic disease.²⁷

22. JERRY E. BISHOP & MICHAEL WALDHOLZ, *GENOME* 300 (1990).

23. Peter T. Rowley, *Genetic Discrimination: Rights and Responsibilities of Tester and Testee: Summary of a Workshop Sponsored by the Social Issues Committee, American Society of Human Genetics, November 2, 1986*, 43 AM. J. HUM. GENETICS 105 (1988).

24. DAVID T. SUZUKI & PETER KNUDTSON, *GENETHICS: THE CLASH BETWEEN THE NEW GENETICS AND HUMAN VALUES* 142-143 (1989).

25. ARTHUR L. BEAUDET ET AL., *INTRODUCTION TO HUMAN BIOCHEMICAL AND MOLECULAR GENETICS* 6-8 (1990).

26. SUZUKI & KNUDTSON, *supra* note 24, at 144.

27. Peter T. Rowley, *Genetic Screening: Marvel or Menace?*, 225 SCIENCE 138 (1984).

AMERICANS WITH DISABILITIES ACT AND GENETIC DEFECTS

The Americans with Disabilities Act extends the Rehabilitation Act of 1973,²⁸ which only prohibits discrimination by the federal government, federal contractors, and institutions receiving federal funds.²⁹ The ADA prevents discrimination by private employers who hire more than 15 employees. Also, the ADA prohibits discrimination based on a disability; the 1973 Rehabilitation Act prohibits discrimination based on a handicap. However, the definitions of handicap and disability are similar: “the ADA’s definition of disability is designed to track the definition under the Rehabilitation Act, with some modifications and clarifications.”³⁰

Categories of Disability Under the ADA

The ADA defines an individual with a disability as one who “has a physical or mental impairment that substantially limits one or more of the major life activities of [that] individual,” has “a record of such an impairment,” or is “regarded as having such an impairment.”³¹ The ADA regulations define physical or mental impairment as “any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, . . . endocrine; or any mental or psychological disorder”³²

Impairments are physiological disorders—physical or mental. The Equal Employment Opportunity Commission (“EEOC”) emphasizes that “[t]he definition [of impairment] does not include characteristic predisposition to illness or disease.”³³ This is significant because, while the ADA regulations fail to mention genetic screening or genetic disease, the definition appears to exclude genetic defects or traits.

28. 29 U.S.C.A. § 701-796i (West 1985 & Supp. 1992). See generally Jack F. Williams, *A Regulatory Model for Genetic Testing in Employment*, 40 OKLA. L. REV. 181 (1987) and Ellen R. Pierce, *The Regulation of Genetic Testing in the Workplace: A Legislative Proposal*, 46 OHIO ST. L.J. 771 (1985) for an excellent analysis of genetic testing and discrimination in employment and discussion of how the 1973 Rehabilitation Act and Title VII of the Civil Rights Act of 1964 do not adequately prevent all genetic discrimination. Each proposes federal legislation governing genetic testing and discrimination in light of these two pieces of legislation.

29. Chai Feldblum, *The Americans With Disabilities Act: Definition of Disability*, 7 LAB. LAW. 11 (1991).

30. *Id.*

31. 42 U.S.C.A. § 12102(2).

32. 29 C.F.R. § 1630.2(h) (1992).

33. Appendix to 29 C.F.R. § 1630.2.

A "major life activity" is defined as a routine daily function "such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working."³⁴ "The term substantially limits means [an inability] to perform a major life activity that the average person in the general population can perform."³⁵

First Category of Disability Under the ADA

Under the first category of disability, the ADA requires that a two prong test be met. The first prong requires that the individual have a physiological impairment; the second prong requires that the impairment substantially limits a major life activity. Genetic discrimination may not be covered because either one or both of these prongs may not be satisfied.

A genetic defect may satisfy the first prong if it leads to a physiological impairment. However, a genetic defect, including a chromosomal abnormality, would not satisfy the impairment requirement in any of the following situations. First, the genetic defect has not yet given rise to a physiological disorder even though it might give rise to a physiological disorder in the future. Second, the individual is a carrier or a possible carrier of a defective gene; for example, even though the cystic fibrosis gene has been found, it is "impossible to develop a convenient prenatal screening test which would detect all forms of the gene" because there are more than 40 different mutations that can cause cystic fibrosis.³⁶ Third, the individual has a disabling disorder but he or she is being treated in order to prevent the expression of the gene causing the disabling disorder. For instance, human growth factor is used to prevent pituitary dwarfism.³⁷ Fourth, the individual has a family member with a defective gene and could be discriminated against because of family history. For example, if a member of an employee's family has Huntington's Disease, it is impossible to know whether that employee has the disease unless a test is performed or until the disease occurs in mid-life;³⁸ a child has a 50 percent chance of inheriting the Huntington's Disease gene if one parent has the disease. Since it is expensive to test for this gene or the test may not be available in a particular community, one may

34. 29 C.F.R. § 1630.2(i) (1992).

35. 29 C.F.R. § 1630.2(j) (1992).

36. THOMAS F. LEE, *THE HUMAN GENOME PROJECT: CRACKING THE GENETIC CODE OF LIFE* 12, 190 (1991).

37. *THE MERCK MANUAL* 2221 (Robert Berkow ed., 16th ed. 1992).

38. LEE, *supra* note 36, at 191-193 (1991).

not know whether or not he has the gene. Fifth, an individual may have a “multifactorial disorder in which his disorder is caused by a complex interaction of his genes with his environment.”³⁹

While the first prong requires an impairment, the second prong requires that the individual’s impairment substantially limits a major life activity. Until testing or screening is performed, an individual may be unaware that he has the defective gene. Furthermore, if the individual is a carrier of the defective gene, he or she is usually not affected; it is his or her offspring who may be affected. Finally, assuming that the defect is present, it may not substantially, or even minimally, limit a major life activity.

Second Category of Disability Under the ADA

Under the second category of disability, a person can be defined as disabled if he or she has a record of an impairment. This means that the individual “has a history of, or has been misclassified as having, a mental or physical impairment that substantially limits one or more major life activities.”⁴⁰ This category prohibits discrimination because an individual has a history of a disability, such as having had cancer, or was misclassified as being disabled. For example, “individuals misclassified as learning disabled are protected from discrimination on the basis of that erroneous classification.”⁴¹ This category of disability probably does not cover those genetic defects that fluctuate (such as acute intermittent porphyria).⁴²

Third Category of Disability Under the ADA

Under the third category of disability, the ADA protects those persons who are “regarded” as having a physical or mental impairment. The ADA regulations define regarded as having a physical or mental impairment as

- 1) [having] a physical or mental impairment that does not substantially limit major life activities but is treated by [an employer] as constituting such limitation;
- 2) [having] a physical or mental impairment that substantially limits major life activities only as a result of the attitudes of others toward such impairment; or
- 3) [having] none of the impairments [that are specifically stated] . . . but [being] treated by [an employer] as having a substan-

39. BEAUDET, *supra* note 25, at 18.

40. 29 C.F.R. § 1630.2(k) (1992).

41. Appendix to 29 C.F.R. § 1630.2(k).

42. THE MERCK MANUAL, *supra* note 37, at 1031.

tially limiting impairment.⁴³

It is questionable whether every genetic defect would fall within this definition; it is equally questionable whether a court would prohibit genetic discrimination since neither the ADA nor the regulations specifically mention genetic discrimination.

STATE STATUTORY PROHIBITIONS AGAINST GENETIC DISCRIMINATION

Some states, such as Florida, Illinois, Louisiana, New Jersey, New York, and California, have enacted state legislation to protect employees from genetic discrimination. Larry Gostin has carefully reviewed these state statutes and has determined that some are more limited than others.⁴⁴ For example, Florida's statute protects against discrimination based on one particular trait. It states: "No person, firm, corporation, . . . state agency, . . . or any public or private entity shall deny or refuse employment to any person or discharge any person from employment solely because such person has the sickle cell trait."⁴⁵

California's Hereditary Disorders Act is more expansive. This Act encourages certain public screening programs to detect various genetic ("hereditary") disorders and requires that results be kept strictly confidential in order to prevent abuse. This Act prohibits discrimination for "carriers of most deleterious genes."⁴⁶ However, it, too, is limited as it only prevents discrimination for persons involved in the State's hereditary disorders programs.⁴⁷ As Larry Gostin writes: "A review of current state statutes reveals a patchwork of provisions which are incomplete, even inconsistent, and which fail to follow a coherent vision for genetic screening, counseling, treatment and prevention of [genetic] discrimination."⁴⁸

REMEDIES FOR PREVENTING GENETIC DISCRIMINATION

Since the ADA does not cover all genetic discrimination, and the states' legislation is a patchwork, many employers could engage in genetic discrimination against their employees. Larry Gostin seeks to amend the ADA to expand the definition of disability

43. 29 C.F.R. § 1630.2(l) (1992).

44. Gostin, *supra* note 10, at 141-142.

45. FLA. STAT. ANN. § 448.075 (West 1981).

46. CAL. HEALTH & SAFETY CODE § 150(f) (West 1990).

47. *Id.* at § 150 (1990).

48. Gostin, *supra* note 10, at 142.

to include “having a genetic or other medically identified potential of, or predisposition toward, such an impairment.”⁴⁹ While Gostin’s amendment expands the impairment requirement, it does not address the second prong that requires that the impairment must “limit a major life activity.”

Also, Gostin’s amendment prohibits employers from engaging in genetic discrimination only if an impairment or disease is present. His amendment fails to prohibit genetic discrimination based on a genetic profile; an individual’s genetic profile may not relate to any particular disease but rather to a general physiological, mental, or psychological trait. As studies on the human genome become more accessible, such genetic profiles are a distinct possibility.

Thus, since neither the ADA nor Gostin’s amendment prohibits all genetic discrimination, I propose the following National Genetic Anti-Discrimination Act. This Act is designed to prohibit genetic discrimination, establish a joint commission with the power to promulgate rules and regulations, set forth what constitutes genetic discrimination, specify the burden of proving discrimination, and provide for compensatory and punitive damages.

NATIONAL GENETIC ANTI-DISCRIMINATION ACT

To prevent genetic discrimination by employers.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SHORT TITLE

Section 1. This Act may be cited as the “National Genetic Anti-Discrimination Act.”

FINDINGS AND PURPOSES

Section 2. (a) The Congress finds that—

(1) The right to privacy is a personal and basic right protected by the Constitution of the United States;

(2) The collection, maintenance, use and dissemination of genetic information can threaten an individual’s right to privacy;

(3) Detecting genetic defects and diseases through screening can prevent or help to treat these diseases;

(4) There are different levels of severity for genetic diseases, some genetic diseases have little effect on the normal functioning of

49. *Id.* at 143.

individuals, and some genetic diseases may be wholly or partially prevented or treated through medical intervention and treatment;

(5) Carriers of these defective genes are sometimes discriminated against and stigmatized;

(6) The increasing use of genetic screening and testing creates the potential danger that employers will discriminate against individuals because of their genetic make-up; and

(7) In order to protect individuals from being discriminated against by employers, under the Commerce and Necessary and Proper Clauses, the Congress is empowered to regulate such employment practices.

(b) The purpose of this Act is to prevent genetic discrimination by employers, unless allowed by law, by—

(1) Establishing a Joint Commission on Genetic Screening and Testing within the Department of Health and Human Services. This Joint Commission will consist of one member from each of the following: (a) National Institutes of Health, National Center for Human Genome Research, (b) Department of Energy, Human Genome Program, (c) Equal Employment Occupational Commission, (d) National Academy of Sciences and (e) National Institute of Occupational Safety and Health;

(2) Providing this Joint Commission on Genetic Screening and Testing with the authority to establish guidelines and regulations promulgated in the Federal Register, and having the force of law;

(3) Creating an administrative cause of action for genetic discrimination, which can be brought by the Joint Commission against employers; and

(4) Creating a private right of action for genetic discrimination, which can be brought by individuals against employers.

PART A—DEFINITIONS

Section 3. For purposes of this Act:

(a) the term “complaining party” means the Joint Commission, the Attorney General, or a private party;

(b) the term “demonstrates” means meets the burdens of production and persuasion;

(c) the term “employment practices” means a combination of employment practices that produces one or more decisions with respect to employment, employment referral, or admission to a labor organization or apprenticeship;

(d) the term “employer” means a person engaged in an indus-

try affecting commerce, including the United States and any department, division, or commission;

(e) the term “genetic discrimination” means any action based on genetic information that is unrelated and irrelevant to job performance;

(f) the term “genetic screening” means the process of scanning the genetic make-up of individuals to determine whether they are likely to develop or transmit a genetic defect or disease;

(g) the term “genetic testing” means the test or tests done on individual persons for the purpose of determining whether they are likely to develop or transmit a genetic defect or disease;

(h) the term “disability” in the Americans With Disabilities Act shall include “having a genetic defect” if that defect is identified, pursuant to regulations, as creating or predisposing an individual to an identifiable impairment.

PART B—NOTICE OF UNLAWFUL PRACTICES

Section 4. Pursuant to this Act, it shall be unlawful for employers to discriminate against carriers of a genetic trait or defect, unless the employer can demonstrate that carrier trait or defect directly impairs or interferes with the person’s ability to perform the job or occupation.

Section 5. Pursuant to this Act, it shall be unlawful for employers to discriminate against persons having a genetic defect, mutated gene, or disease susceptible gene, unless the employer can demonstrate that gene directly impairs or interferes with the person’s ability to perform the job or occupation.

Section 6. In order for employers to alter their employment practices based on genetic screening and genetic testing, they must first inform affected individuals so that the individuals can respond and either negotiate with the employer or file a complaint with the Joint Commission as the complaining party.

Section 7. In order for the employer to have access to an individual’s genetic test results, that individual must first grant written permission. However, under emergency situations established by regulations, health officials may obtain confidential genetic information without the individual’s consent.

REMEDY

Section 8. Compensatory and punitive damages may be awarded for such violations.

EFFECTIVE DATE

Section 9. Effective Date:

CONCLUSION

The foregoing analysis of the ADA and its regulations demonstrates that all cases of genetic discrimination are not prohibited. The ADA prohibits employers from discriminating against individuals who have, or have had a history of, a disability that involves a mental or physical impairment that limits a major life activity. Because of these two requirements, many individuals who have or might have a genetic defect are not covered. The ADA may also be inapplicable to carriers or individuals receiving treatment to prevent gene expression. Also, the ADA does not apply to discrimination based on an individual's genetic profile. Since the ADA would not apply in these cases, employers would be free to discriminate against these employees.

Congress should enact legislation that would complement the ADA to prohibit genetic discrimination. Congressional action would promote uniformity and would balance the rights of individual employees as against the rights of employers. The proposed Act does not unduly burden employers and will not interfere with their rights. If the employer can demonstrate that an employee's trait or defect directly impairs or interferes with that person's job performance, then the employer's actions are lawful and not discriminatory. Although some states have enacted legislation to prohibit some types of genetic discrimination, the statutory framework is ad hoc and inconsistent to protect applicants and employees from genetic discrimination. In order to prohibit genetic discrimination by employers without unduly interfering with employers' rights, Congress should take action.