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COMMENTS

FEDERAL GENETIC NONDISCRIMINATION LEGISLATION: THE NEW “RIGHT” AND THE RACE TO PROTECT DNA AT THE LOCAL, STATE, AND FEDERAL LEVEL

Katherine A. Hathaway⁺

When the Human Genome Project (HGP) officially began in 1990,¹ it was overshadowed by the Americans with Disabilities Act (ADA),² the new federal legislation aimed at combating discrimination based on a person's disability. While the ADA was the result of a massive legislative effort to extend protection to people with physical or mental impairments,³ few were discussing the legal implications of the Human

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1. See Daniel Drell, *The Human Genome Project: What a Legal Assistant Needs to Know*, 27 J. LEGAL ASSISTANTS 2 available at <http://www.ornl.gov/hgmis/publicat/miscpubs/legalasst.html> (Aug. 2, 2000); see also National Human Genome Research Institute, *The Human Genome Project*, at <http://www.genome.gov/page.cfm?pageID=10001694> (last visited Aug. 18, 2002). The Human Genome Project began in 1986 with funding from the U.S. Department of Energy. See Drell, *supra*. In 1990, a joint effort was launched by the Department of Energy and the National Institutes of Health. See *id.*

2. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (2000).

3. See 42 U.S.C. § 12101(a). Congress enacted the ADA because it found that discrimination against disabled individuals was taking place in “such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services.” *Id.* § 12101(a)(3). Additionally, Congress found that disabled individuals persistently encountered discrimination in many forms, including “outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers;” the failure to make modifications to building structures; exclusionary practices; “relegation to lesser services, programs, activities, benefits[, and] jobs.” *Id.* § 12101(a)(5). Congress also found that “individuals with disabilities are a discrete . . . minority who have been faced with restrictions and limitations” and “relegated to a position of political powerlessness in . . . society, based on characteristics beyond their control, which results in stereotypic assumptions not indicative of the individual.” *Id.* § 12101(a)(7). Congress needed to enact legislation because unfair discrimination denies disabled persons “the opportunity to compete on an equal basis and to pursue opportunities for which our free society is justifiably famous.” See *id.* § 12101(a)(9). The purpose of the ADA is:

Genome Project.⁴ More than a decade later, with the HGP having accomplished its first major goal, disability discrimination is no longer the only evil.⁵ Possibly more pervasive and wide-reaching than disability discrimination,⁶ genetic discrimination has quickly surfaced as the unwanted by-product of a heralded scientific milestone.⁷ Today, discrimination based on one's genetic make-up presents individuals with more serious privacy concerns, more pressing and immediate legal issues,

to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
 to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
 to ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities.

Id. § 12101(b).

4. See National Human Genome Research Institute, *About ELSI*, at <http://www.nhgri.nih.gov/ELSI/aboutelsi.html> (last visited Aug. 18, 2002) (noting that in 1989, the National Institutes of Health-Department of Energy Joint Working Group on Ethical, Legal, and Social Implications of Human Genome Research was only beginning to anticipate the potential ramifications of the HGP); see also Ari Patrinos and Daniel W. Drell, *Introducing the Human Genome Project: Its Relevance, Triumphs, and Challenges*, 36 JUDGES' J. 3 (1997) (tracking the development of the HGP and noting the early recognition of the legal issues related to mapping the human genome, while stating that many of the issues ELSI deals with are not new to medicine), available at http://www.ornl.gov/TechResources/Human_Genome/publicat/judges/drell.html (last visited Aug. 18, 2002). The National Institutes of Health's National Human Genome Research Institute established, and the Department of Energy funded, the Ethical, Legal and Social Implications of the Human Genome Project (ELSI) in 1989 to "anticipate and address the implications for individuals and society of mapping and sequencing the human genome." See National Human Genome Research Institute, *About ELSI*, *supra*.

5. See Rick Weiss & Justin Gillis, *Teams Finish Mapping Human DNA: Clinton, Scientists Celebrate 'Working Draft' of Human Genetic Blueprint*, WASH. POST, June 27, 2000, at A1 (reporting the dual achievement reached by the HGP and Celera Genomics in identifying and placing in order between ninety-seven and ninety-nine percent of the molecular "letters" of the DNA in virtually every type of human cell). On June 26, 2000, President Clinton announced that the human genome had been mapped by two research groups, the federally funded Human Genome Project, and a private company, Celera Genomics, Inc. See *id.* The goal of the HGP was "to uncover the entire genetic architecture of human chromosomes." Richard S. Fedder, *To Know or Not to Know: Legal Perspectives on Genetic Privacy and Disclosure of an Individual's Genetic Profile*, 21 J. LEGAL MED. 557 (2000) (footnote omitted). The "working draft" that was announced in June 2000 revealed the location and order of 3.12 billion base pairs of the human genome. *Id.* at 557-58.

6. See Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(a)(1) (2000) (finding that at the time of the ADA's enactment, 43 million Americans had disabilities).

7. See *Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment: Hearings on S.318 Before the Senate Comm. on Health, Educ., Labor and Pensions*, 107th Cong. (July 25, 2001) (statement of Kathleen Zeitz, National Breast Cancer Coalition) [hereinafter 107th Congress HELP Hearing], available at National Breast Cancer Coalition Web Page, <http://www.natlbcc.org/bin/index.asp?strid=475&depid=3> (last visited Aug. 29, 2002).

and a growing sense of caution with regard to daily activities than any other time in recent memory.⁸ The “old” evil of disability discrimination is being revisited and put on center stage, albeit in a different form.⁹

Despite a host of immense legal implications, the sequencing of the human gene has proven to be one of the most important scientific breakthroughs in modern times.¹⁰ The significance for the medical community has been astounding, as researchers have been successful in determining the genetic cause and hereditary factors of, for example, heart disease, diabetes, Parkinson’s disease, bipolar illness, and asthma.¹¹ According to Dr. Francis S. Collins, Director of the National Human Genome Research Institute (NHGRI):

We are daily gaining insights into the mysteries of the human cell, how it works, and why sometimes . . . it doesn’t. . . . These revelations hold within them the promise of a true transformation of medical practice. Quite possibly before the end of the first decade of this new millennium, each of us may be able to learn our individual susceptibilities to common disorders, in some cases allowing the design of a program of effective individualized preventive medicine focused on lifestyle changes, diet and medical surveillance to keep us healthy.¹²

The advantage of knowing the sequence of human genes is that it enables researchers and scientists to study the structure and organization of our DNA in chromosomes and establish the blueprint of our individual biological make-up.¹³ To understand an individual’s genes is

8. See T. Shawn Taylor, *Job Gene Tests Raise Alarm, Many Predict Discrimination by Employers*, CHI. TRIB., Sept. 3, 2001, at 1 (noting the growing concern generated by the newly mapped human genome and reporting the plight of a railroad employee whose blood was tested without his knowledge).

9. See *id.* Taylor’s article recounts the story of Terri Seargent, a 45-year-old woman who discovered that she carried a gene that made her susceptible to a lung disease. See *id.* She began a \$4,000 per month treatment to protect her lungs from any further damage. *Id.* Seargent subsequently was fired from her job, despite a good performance review, and believed her employer fired her because her genetic disorder was affecting its bottom line. *Id.*

10. See Weiss & Gillis, *supra* note 5 (relating President Clinton’s remarks that “[w]ithout a doubt, this is the most important, most wondrous map ever produced by humankind”).

11. *Hearings on Genetic Information in the Workplace: Hearing Before the Senate Comm. on Health, Educ., Labor and Pensions*, 106th Cong. (July 20, 2000) [hereinafter 106th Congress, HELP Hearing] (testimony of Francis S. Collins, M.D., Ph.D., Director of National Human Genome Research Institute), available at http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/francis_72000_test.htm (last visited Aug. 18, 2002).

12. *Id.*

13. See Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL’Y 225, 227-28 (2000) (stating that “[g]enes

to have complete and unhindered access to the instructions that make that person who he or she is.¹⁴

Genetic advances revolutionize biological research and medical practice because they allow scientists to look beyond symptoms and sicknesses and see what kinds of predispositions each of us has embedded in our DNA.¹⁵ This, in turn, will lead to more effective therapies and preventive measures that will ensure that people with genetic flaws (i.e. almost all of us) live longer, healthier lives.¹⁶ The genetic tests that flow from these advances provide information about the likelihood of passing on genetic conditions to offspring and the increased risk of future disease or disability; they can even predict early death due to disease or disability.¹⁷

represent the blueprint for each individual's biological make-up" and that by identifying certain genes, "one can determine an individual's likelihood of manifesting certain traits, including disease and other disorders, or of passing along those traits to offspring"); see also Oak Ridge National Laboratory, *Frequently Asked Questions*, at <http://www.ornl.gov/hgmis/faq/faqs1.html> (last visited Aug. 8, 2002) (The Human Genome Project "will reap fantastic benefits for humankind, some that we can anticipate and others that will surprise us. Generations of biologists and researchers will be provided with detailed DNA information that will be key to understanding the structure, organization, and function of DNA in chromosomes."); see also Oak Ridge National Laboratory, *The Science Behind the Human Genome Project: Basic Genetics, Genome Draft Sequence, and Post-Genome Science*, at <http://www.ornl.gov/hgmis/project/info.html> (last visited Aug. 29, 2002) (explaining the complex science behind the human genome).

14. See Patrinos & Drell, *supra* note 4.

15. See Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, and Department of Justice, *Genetic Information and the Workplace*, Jan. 20, 1998 [hereinafter Interagency Report], at http://www.nhgri.nih.gov/HGP/Reports/genetics_workplace.html (last visited Aug. 23, 2002) (reporting that knowledge of genetics can help a person prevent or reduce the likelihood of illness and can even help reduce an individual's health care costs); see also 106th Congress, HELP Hearing, *supra* note 11 (testimony of Francis S. Collins) (stating that the HGP will enable society to better understand and more effectively treat diseases).

16. See 106th Congress, HELP Hearing, *supra* note 11 (testimony of Francis S. Collins). Collins testified:

These same discoveries about genetics likely will lead us to predict who will respond most effectively to a particular drug therapy, and who may suffer a side effect and ought to avoid that particular drug. Furthermore, these remarkable advances are expected to lead us to the next generation of designer drugs, focused in a much more precise way on the molecular basis of common illnesses, giving us a much more powerful set of targeted interventions to treat disease.

Id.

17. See Ilene V. Goldberg, *Genetic Information Privacy and Discrimination*, 20 HEALTH CARE MANAGER 19 (2001), available at 2001 WL 17480550 (citing the range of genetic tests that have become available in recent years).

These obvious medical advantages bring with them a distinct and severe set of legal repercussions.¹⁸ Issues of privacy, fair employment, and health insurance have arisen recently, as have the use of genomics in clinical trials, counseling, education and training, family relations, and social classification.¹⁹ Presently, as researchers continue their study of human genes and DNA, the majority of citizens are left to wonder how these medical and scientific advances will affect them.²⁰ Testifying before the Senate Committee on Health, Education, Labor and Pensions (HELP), Dr. Francis S. Collins, Director of the HGP and NHGRI, stated, "It is estimated that all of us carry dozens of glitches in our DNA – so establishing principles of fair use of this information is important for all of us."²¹ This conclusion – that misuse of a person's genetic information is a problem – is not without statistical support. A Harvard Medical School study published in 1996 documented over 200 cases of genetic discrimination.²² Increasingly, genetic privacy is becoming not

18. See Miller, *supra* note 13, at 226 (focusing on one of the results of the HGP, employment discrimination, as an emerging issue important to all workers as genetic testing becomes more common); see also 106th Congress, HELP Hearing, *supra* note 11 (testimony of Francis S. Collins) (testifying that despite the huge success that mapping the human genome represented, genetic information can also be used as the basis for discrimination in obtaining employment and health insurance).

19. See Drell, *supra* note 1. In 1990, the HGP ELSI group identified a list of issues it included in its research agenda: science policy issues (including intellectual property); clinical practice issues (including disclosure and counseling practices); health policy issues (including public health and allocation of resources); privacy issues (including definition of genetic privacy and databanking standards); civil rights issues (including employment, health, life and disability insurance, social discrimination, and race); and educational policy issues (including clinical education models and health professional training). *Id.*

20. See John A. MacDonald, *Congress Takes Up Genetic Privacy*, HARTFORD COURANT, Aug. 17, 2001, at A1. (citing the concerns of Dr. Francis S. Collins that potential misuse of genetic information could preclude many individuals from getting the care they need and reporting that one-third of those asked to participate in a recent genetic study refused because of the fear of misuse of their genetic information).

21. 106th Congress, HELP Hearing, *supra* note 11 (testimony of Francis S. Collins).

22. See *Dangerous Legacies: New Gene Tests Provide Fresh Grounds for Discrimination*, U.S. NEWS & WORLD REPORT, Nov. 10, 1997, available at 1997 WL 8332942; see also Interagency Report, *supra* note 15. Two of the 200 cases of discrimination chronicled in the study were those of Jamie Stephenson and Theresa Morelli. See Tim Friend, *Researchers Uncover Genetic Discrimination*, USA TODAY, Apr. 12, 1996, available at <http://www.usatoday.com/life/health/ins461.htm>. Stephenson's family health insurance coverage was canceled when the company found out that her son had a genetic disorder that causes mental retardation. Morelli, who tried to obtain a disability insurance policy in the event she was ever injured, was denied coverage because her medical records revealed that her father had Huntington's disease. *Id.* Cases of discrimination are not limited to insurance. One individual revealed to a potential employer that he was a carrier of a single mutation for Gaucher's disease. See Interagency Report, *supra* note 15. Even though he would not develop this disease himself, he had the

just a goal, but a mandate, as individuals are demanding legal protection and legislators are beginning to give the topic serious consideration.²³

Currently, there is very little legal protection available both on the federal and state level to combat genetic discrimination.²⁴ Various federal laws, such as the ADA,²⁵ and state laws offer questionable and inconsistent safeguards at best.²⁶ Because there has not yet been a leading case on genetic discrimination, we cannot know for sure whether the laws presently on the books are adequate.²⁷ Recent attempts to enact federal legislation have been limited to protection in health insurance and employment, but genetic-based discrimination reaches even further than those two areas.²⁸ Most state laws have also been limited to health insurance and employment, and only one is comprehensive enough to

ability to pass it on to his children. *Id.* Having no bearing on his own job ability, his genetic status caused him to be subsequently denied a job. *Id.* Similarly, a 53-year-old man "revealed that he had hemochromatosis but was asymptomatic." *Id.* He was first told by the employer that it was unable to provide him with health insurance because of his genetic condition. *Id.* The employer later informed him that it would not be able to hire him because of his genetic condition. *Id.*

23. See MacDonald, *supra* note 20 (noting that after five years of stalled action, Congress "is beginning to move legislation that would write the prohibition into federal law"). See generally Genetic Nondiscrimination in Health Insurance and Employment Act, S.318, 107th Cong. (2001); Genetic Nondiscrimination Insurance and Employment Act, H.R. 602, 107th Cong. (2001) available at <http://thomas.loc.gov>.

24. See Congressional Research Service, *Genetic Information: Legal Issues Relating to Discrimination and Privacy*, Report for Congress, RL30006, 4, at <http://www.cnle.org/nle/crsreports/science/st-55.pdf>.

25. 42 U.S.C. § 12101 (2000).

26. See Congressional Research Service, *supra* note 24, at 15 (noting that current state statutes vary in approach and substantive provisions and that most state statutes are limited by state insurance laws due to an ERISA preemption provision).

27. See *id.* at 10 (stating that so far there have been no reported cases addressing the issue of whether the ADA covers genetic discrimination).

28. See *id.* at 16 (noting that a number of bills have been introduced in Congress on genetic issues but that they do not receive congressional action); see also Patrinos & Drell, *supra* note 4 (stating that "the list of . . . issues is long and virtually all of them have legal ramifications"). This list includes:

[t]he fair use of genetic information; the impact on genetic counseling and medical practice; the effects on personal reproductive decisions; past uses and misuses of genetic information; privacy implications of personal genetic information in various settings, e.g., the work place, schools, or in the context of adoptions; issues of the commercialization and intellectual property protection of genome results, including DNA sequences; conceptual and philosophical implications; implications of personal genetic variation; and genetic literacy and the understanding of genetic information, particularly information related to complex conditions that involve multiple genes and genetic-environmental interactions.

Id.

provide for all types of genetic discrimination.²⁹ It is therefore imperative for Congress to take the initiative by enacting far-reaching legislation that will provide ample protection for any and all kinds of genetic discrimination.³⁰

This Comment examines the current debate concerning the use of an individual's genetic information and the scope of the legal protection currently available, as well as proposed legislation to safeguard against an invasion of this private information. Part I will survey the current legal protections available under federal and state law as they concern the legal and ethical repercussions of the Human Genome Project. Part I will also introduce the proposed federal legislation on genetic nondiscrimination. Part II will study and compare the proposed federal legislation and the enacted laws at the state and municipal levels, concluding that despite laws at the local, state, and federal level, significant gaps in coverage and severe loopholes linger. In Part III, this Comment proposes that a thorough overhaul of our country's civil rights laws, including the ADA, should be considered to ensure all genetic information is truly private and protected.

I. FEDERAL NONDISCRIMINATION LEGISLATION: FROM ENSURING THAT NO AMERICAN WOULD BE DISCRIMINATED AGAINST ON THE BASIS OF DISABILITY TO A LIMITED FORUM FOR PREDISPOSITIVE PROTECTION

A. *The Americans with Disabilities Act and the Supreme Court's Narrowing Interpretations of "Person with a Disability"*

There is little disagreement that "[t]here are no federal laws that directly and comprehensively protect against abuses in the gathering or use of genetic information. . . ."³¹ Still, it has been argued that the Americans with Disabilities Act (ADA)³² and its counterpart, the

29. See Genetic Privacy Act, N.J. STAT. ANN. §§ 10:5-43 – 10:5-49 (West Supp. 2002); see also Natalie Ann Stepanuk, Comment, *Genetic Information and Third Party Access to Information: New Jersey's Pioneering Legislation as a Model for Federal Privacy Protection of Genetic Information*, 47 CATH. U. L. REV. 1105, 1122-32 (1998) (analyzing the New Jersey legislation, which takes a privacy approach instead of an anti-discrimination approach).

30. See MacDonald, *supra* note 20 (citing Karen H. Rothenberg, a University of Maryland law professor who specializes in genetics issues, who stated that neither current state laws nor the limited federal laws provide enough protection against genetic discrimination).

31. Interagency Report, *supra* note 15.

32. 42 U.S.C. § 12101 et seq. (2000).

Rehabilitation Act of 1973,³³ would apply to genetic discrimination in employment and possibly health insurance.³⁴

The ADA prohibits discrimination against an individual with a disability in employment, public services, public accommodations, and communications.³⁵ To bring suit under the ADA, a plaintiff must be a "qualified individual with a disability" who "with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires."³⁶ An individual with a disability is further defined as someone who has "a physical or mental impairment that substantially limits one or more of the major life activities," has "a record of such an impairment," or is "regarded as having such an impairment."³⁷ Thus, to receive protection and to recover under the ADA, a plaintiff must prove he or she falls into one of the three definitions of disabled.³⁸

While the ADA does not specifically address genetic information, it does protect individuals with symptomatic genetic disabilities in the same way as individuals with other disabilities.³⁹ However, it does not expressly protect against discrimination based on "unexpressed genetic

33. 29 U.S.C. § 791 et seq. (2000).

34. See 106th Congress, HELP Hearing, *supra* note 11 (testimony of Paul Steven Miller, Commissioner of the Equal Employment Opportunity Commission), available at http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/miller_testimony.htm (last visited Apr. 20, 2002) (concluding that the ADA "can be interpreted to prohibit employment discrimination based on genetic information"). With regard to whether genetic discrimination in health insurance would be covered under the ADA, one scholar has noted:

Even if the ADA does apply to asymptomatic individuals with genetic defects . . . in the workplace . . . it most likely will not apply to cases of insurance discrimination. Title IV, section 501(c)(1) of the ADA makes clear that, as long as the underwriting policies of an insurance company are consistent with state law and based on sound actuarial data, they will not be subject to regulation under the ADA. This applies to both health insurance and life insurance. In this setting, the ADA does not prohibit discrimination, it only prohibits unfair or arbitrary discrimination.

Fedder, *supra* note 5, at 579-80 (footnotes omitted).

35. 42 U.S.C. §§ 12101 - 12213 (2000). The ADA is divided into four titles: Titles I and V cover employment; Title II covers public services; Title III covers public accommodations; and Title IV covers communications. *Id.*

36. *Id.* § 12111(8) (2000).

37. *Id.* § 12102(2) (2000).

38. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 478 (1999).

39. See Oak Ridge National Laboratory, *Genetics Privacy and Legislation*, at <http://www.ornl.gov/hgmis/elsi/legislat.html> (last visited Aug. 21, 2002). Symptomatic disabilities are, in essence, expressed genetic disorders or more simply, disabilities. See *id.*

conditions.”⁴⁰ In addition, the ADA allows employers to require an employee to provide medical information that is “job related and consistent with business necessity.”⁴¹

Because the language of the ADA does not plainly include genetic information and because no case of genetic discrimination has been brought under the ADA to court, it is unknown whether the law will be interpreted to include discrimination based on genetic make-up.⁴² In 1995, the Equal Employment Opportunity Commission (EEOC) issued an interpretation of the ADA that included its belief that discrimination based on genetic predispositions equates to regarding individuals as having a disability, and as such, those individuals fit within the third prong of the definition of disability.⁴³ However, EEOC interpretations and policy guidances are not binding in court and do not have the same legal effect as statutes or regulations.⁴⁴

In fact, the U.S. Supreme Court recently disregarded an EEOC interpretation of the term disabled in another context, leading many to wonder whether EEOC guidance on genetic discrimination would hold any weight.⁴⁵ In *Sutton v. United Air Lines, Inc.*,⁴⁶ the Court held that the petitioners, who had severe myopia, were not disabled because they used corrective lenses that brought their eyesight to 20/20 or better.⁴⁷ Conversely, the EEOC’s position was that, when evaluating ADA claims, individuals should be considered in their untreated state.⁴⁸ In

40. *Id.* An unexpressed genetic condition is an asymptomatic genetic disorder and occurs when an individual has a genetic marker for a condition but does not show any symptoms or signs of that condition. *See id.*

41. *Id.*

42. *See* Congressional Research Service, *supra* note 24, at 10.

43. *See id.* at 8; *see also* EEOC Compliance Manual, *Section 902, Definition of the Term Disability*, available at <http://www.eeoc.gov/docs/902cm.html> (last visited Apr. 20, 2002). The EEOC provided, “covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of ‘disability.’” *Id.*

44. *See* Oak Ridge National Laboratory, *supra* note 39 (citing the EEOC interpretation of the ADA that was issued in March 1995).

45. *See* *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 480 (1999); *see also* Miller, *supra* note 13, at 241 (acknowledging that even though the EEOC takes the position that the ADA protects individuals with unexpressed genetic conditions, the EEOC Interpretive Guidance can only be used as persuasive authority because it “does not have the same force of law as a federal statute or regulation” and that, as of yet, the EEOC position has not been tested in the courts).

46. 527 U.S. 471 (1999).

47. *Id.* at 475.

48. *Id.* at 480.

holding that “the determination of whether an individual is disabled should be made with reference to measures that mitigate the individual’s impairment,”⁴⁹ the Court effectively restricted the definition of who is an individual with a disability.⁵⁰ As to the petitioners’ claim that they were “regarded as” disabled, the Court answered:

There are two apparent ways in which individuals may fall within this statutory definition: (1) a covered entity mistakenly believes that a person has a physical impairment that substantially limits one or more major life activities, or (2) a covered entity mistakenly believes that an actual, nonlimiting impairment substantially limits one or more major life activities. In both cases, it is necessary that a covered entity entertain misperceptions about the individual — it must believe either that one has a substantially limiting impairment that one does not have or that one has a substantially limiting impairment when, in fact, the impairment is not so limiting.⁵¹

Thus, for a person with a genetic predisposition to bring suit successfully under the ADA, he must prove that he either presently has a substantial impairment or that he is mistaken to have a substantial impairment that presently limits a major life activity.⁵²

49. *Id.* at 475.

50. The Court’s opinion effectively restricted the definition of disability by requiring courts to evaluate plaintiffs after consideration of any mitigating or corrective measures. *See id.* For example, the plaintiffs in *Sutton* had severe myopia, but because they wore corrective lenses, the Court deemed them not disabled. *See id.* The Court stated:

For instance, under [EEOC Interpretive Guidance], courts would almost certainly find all diabetics to be disabled, because if they failed to monitor their blood sugar levels and administer insulin, they would almost certainly be substantially limited in one or more major life activities. A diabetic whose illness does not impair his or her daily activities would therefore be considered disabled simply because he or she has diabetes. Thus, the guidelines approach would create a system in which persons often must be treated as members of a group of people with similar impairments, rather than as individuals. This is contrary to both the letter and the spirit of the ADA.

Id. at 483-84.

51. *Id.* at 489.

52. 42 U.S.C. § 12102(2)(A),(C) (2000); *see also* *Murphy v. United Parcel Service, Inc.*, 527 U.S. 516 (1999). *Murphy* was one of three cases decided by the Supreme Court in 1999 that addressed the definition of disability. *Id.*; *see also* *Albertson’s Inc. v. Kirkingburg*, 527 U.S. 555 (1999); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999). In *Murphy*, the Court directly focused on the “regarded as” prong of disability and found that the plaintiff was not regarded as substantially limited in the major life activity of working. *Murphy*, 527 U.S. at 521-24. In short, *Murphy* illustrates that “making the case that one is regarded as substantially limited in a major life activity, particularly the major life activity of working, is likely to be difficult.” *See* Congressional Research Service, *supra* note 24, at 13.

The Court emphasized that the definition of “substantially limits” requires that a person “be presently – not potentially or hypothetically – substantially limited in order to demonstrate a disability.”⁵³ The *Sutton* Court, however, did not define what constituted a major life activity. It is clear that its restrictive definition of disabled and its narrow interpretation of being “regarded as” being disabled, as it relates to a major life activity, pose a hurdle for potential genetic discrimination plaintiffs.⁵⁴

Conversely, in another ADA case, *Bragdon v. Abbott*,⁵⁵ the Supreme Court held that the plaintiff’s HIV was a covered disability.⁵⁶ Specifically, the Court stated that asymptomatic HIV is a physical impairment “from the moment of infection” because of “the immediacy with which the virus begins to damage the infected person’s white blood cells and the severity of the disease.”⁵⁷ In support of the Court’s opinion, EEOC Commissioner Miller stated that “[t]he reasoning underlying the *Bragdon* decision supports the application of the ADA to individuals with asymptomatic genetic disorders and genetic predispositions.”⁵⁸ However, the Court found that Bragdon’s HIV substantially limited her ability to reproduce because of the fear of passing on the infection.⁵⁹ An asymptomatic genetic defect – even if it is found to be an impairment – presently does not adversely affect any major life activities the way asymptomatic HIV does.⁶⁰

53. *Sutton*, 527 U.S. at 482.

54. *See id.* at 492 (declining to determine the validity of the EEOC regulation classifying working as a major life activity but noting that “there may be some conceptual difficulty in defining ‘major life activities’ to include work”); *see also* Congressional Research Service, *supra* note 24, at 11 (concluding that the reasoning used by the Court in *Sutton* “appears to make it unlikely that an ADA claim based on genetic discrimination would be successful”).

55. 524 U.S. 624 (1998).

56. *Id.* at 630-47.

57. *Id.* at 637.

58. Miller, *supra* note 13, at 243.

59. 524 U.S. at 637-42 (describing the process by which HIV causes immediate abnormalities in a person’s blood and tissues, and concluding that persons infected with HIV are substantially limited in their ability to reproduce, considered by the Court to be a “major life activity,” because there is virtually no way to prevent the disease from being passed on to offspring).

60. An asymptomatic individual is described as one who has an increased risk for disease but no symptoms of that disease. *See* Michael S. Yesley, *Prohibitions of Genetic Discrimination Should Be Fine-Tuned*, Mar. 1, 2001, at http://www.geneletter.com/03-01-01/features/prn_discrimination.html. There is no guarantee that a person’s asymptomatic genetic defect will ever become symptomatic, whereas a person with asymptomatic HIV risks developing full-blown AIDS and passing on the disease through reproduction. Furthermore, not all genetic defects are inheritable. *See* Steve Lebau, *Genetic Testing*:

The holding of *Bragdon* should be taken with caution, however, because three dissenting Justices signaled how they may rule if the issue of genetic discrimination under the ADA were to arise.⁶¹ In asserting that reproduction is not a major life activity, Chief Justice Rehnquist stated in his dissent:

Asymptomatic HIV does not presently limit respondent's ability to perform any of the tasks necessary to bear or raise a child. Respondent's argument, taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease 'disabled' here and now because of some possible future effects.⁶²

The Court's reading of disabled in *Sutton* and the subtle glimpse provided by the dissent in *Bragdon* signal that the ADA is likely to provide little, if any, protection for cases of genetic discrimination and that therefore, potential plaintiffs must look elsewhere should they decide to bring a claim.⁶³

Balancing Benefits and Abuses, USA TODAY MAGAZINE, July, 2000 (noting that the dilemma lies with the fact that genetic tests only predict a probability that an individual will contract a disease in the future and that tests merely show a predisposition toward disability, not a guarantee that the person will develop that disability), available at http://www.findarticles.com/cf_dls/m1272/2662_129/63668117/print.jhtml (last visited July 26, 2001). EEOC Commissioner Miller articulated a similar view:

Carriers do not themselves have a particular disease or disorder and may never develop the disease or disorder, but they nevertheless possess recessive genes and pass them along to their children in whom the disease or disorder might occur. Possessing a faulty gene without more does not necessarily lead to the realization of the disease or disorder. A variety of factors influence the gene's penetrance and the chances one will actually develop symptoms.

Miller, *supra* note 13, at 229. Furthermore, while there are certain disorders for which genetic testing is highly accurate and predictive (Huntington's disease, for example), there are other diseases such as breast cancer, cystic fibrosis, and Alzheimer's for which the individual's chances of contracting the disease are largely dictated by family history. See *id.* at 230-31.

61. *Bragdon*, 524 U.S. at 661 (Rehnquist, C.J., dissenting, was joined by Justices Scalia and Thomas) (noting that "[a]symptomatic HIV does not presently limit respondent's ability to perform any of the tasks necessary to bear or raise a child"); see also 106th Congress, HELP Hearing, *supra* note 11 (testimony of Paul Steven Miller) (stating that "three members of the Supreme Court have already indicated their reluctance to find individuals with genetic markers for debilitating diseases covered under the ADA" and that Chief Justice Rehnquist's comments "raise the question whether the justices would reject outright the ADA's protection of individuals with genetic markers").

62. 524 U.S. at 661.

63. See Congressional Research Service, *supra* note 24, at 13 (noting that the Court's recent decisions "use reasoning that would make it unlikely that most ADA claims based on genetic discrimination would be successful").

B. One Step at a Time – The Health Insurance Portability and Accountability Act of 1996 and Executive Order No. 13,145 Prohibiting Discrimination in Federal Employment Based on Genetic Information

Currently, there are two federal statutes in existence that directly and indirectly address the issue of genetic discrimination.⁶⁴ In 1996, Congress enacted the Health Insurance Portability and Accountability Act (HIPAA),⁶⁵ which applies only to employer-based and commercially issued group health insurance.⁶⁶ At the time, HIPAA was “far reaching legislation designed to improve the portability of health coverage and to provide other protections to recipients of health coverage.”⁶⁷

This law bars the use of genetic information to deny health insurance to people who change jobs, but it does not regulate new insurance premiums.⁶⁸ HIPAA prohibits group health plans from using genetic information to deny or limit eligibility for coverage and from charging individuals more for coverage based on their genetic information.⁶⁹ The Act also defines and places limits on exclusions for pre-existing conditions.⁷⁰ However, the Act does not prohibit insurers from requiring or requesting genetic testing, nor does it require them to obtain

64. See *id.* at 4 (noting that there are no federal laws that “comprehensively address the issues raised by the use of genetic information” but that HIPAA and the executive order issued by President Clinton are the only federal laws that “directly addresses the issue of discrimination based on genetic information”); see also Interagency Report, *supra* note 15 (“A few protections exist incidentally under federal laws enacted to address other types of workplace discrimination. The incidental federal protections against workplace discrimination based on genetic information that do exist are narrow in scope and, in large measure, not well established.”).

65. 29 U.S.C. § 1181 (2000).

66. See, e.g., Oak Ridge National Laboratory, *supra* note 39 (noting that there is no parallel law applying to private individuals seeking health insurance coverage in the individual market).

67. *Genetic Non-Discrimination: Implications for Employer Provided Health Care Plans: Hearings on H.R. 602 Before the House Subcomm. on Employer-Employee Relations, Comm. on Educ. and the Workforce*, 107th Cong. 80 (Sept. 6, 2001) [hereinafter 107th Congress, Sept. House Hearing] (testimony of Mary K. Williams, Attorney for Alston & Bird), available at <http://edworkforce.house.gov/hearings/107th/eeer/eeerhearings.htm>.

68. See Oak Ridge National Laboratory, *DOE ELSI Program Emphasizes Education, Privacy – A Retrospective (1990-2001)*, at <http://www.ornl.gov/hgmis/resource/elsiprogram.html> (last visited Aug. 27, 2002) (noting that if a health insurance policy shows that an individual has a genetic condition, that person’s insurance premium may be prohibitively high).

69. See Oak Ridge National Laboratory, *supra* note 39 (identifying the major premises of the HIPAA provisions covering genetics).

70. *Id.* (stating that HIPAA explicitly asserts that “genetic information in the absence of a current diagnosis of illness shall not be considered a preexisting condition”).

authorization before disclosing this information.⁷¹ Furthermore, it does not prevent lifetime caps on all or specific benefits for certain conditions.⁷²

Pursuant to a provision in HIPAA that required supplemental comprehensive privacy regulations by the Department of Health and Human Services (HHS), in December 2000, HHS issued final regulations on issues of privacy within HIPAA (Privacy Regulations).⁷³ On July 6, 2001, HHS issued the first guidance on the Privacy Regulations in an effort to clarify certain aspects.⁷⁴

The Privacy Regulations apply to any use and disclosure of individual health information.⁷⁵ They give individuals a right to access their own medical records and to know who else has accessed them.⁷⁶ The regulations also impose strict requirements on health plan administrators to secure and control access to employee health information.⁷⁷ These requirements include an obligation to provide adequate firewalls so that employee health information is not shared with unauthorized personnel, as well as training measures to ensure that all employees are informed about "privacy protection policies and procedures, locking rooms that

71. See Congressional Research Service, *supra* note 24, at 5 (noting the exceptions in HIPAA).

72. *Id.*

73. See 107th Congress, Sept. House Hearing, *supra* note 67, at 81 (testimony of Mary K. Williams). HHS received and considered 52,000 comments after issuing proposed privacy regulations in 1999, and it solicited another 24,000 comments in March 2001 in an effort to understand the impact of the final regulations on employer-sponsored health plans. See *id.* The regulation was mandated by Congress when it failed to pass any comprehensive privacy legislation as required by HIPAA by 1999. See Oak Ridge National Laboratory, *supra* note 39. The regulations call for the HHS Office of Civil Rights to enforce their compliance. See U.S. Department of Health and Human Services, *HHS Announces Final Regulations Establishing First-Ever National Standards To Protect Patients' Personal Medical Records*, Dec. 20, 2000, at <http://www.hhs.gov/news/press/2000pres/20001220.html>.

74. See 107th Congress, Sept. House Hearing, *supra* note 67, at 81 (testimony of Mary K. Williams) (testifying that "[t]he changes to the Privacy Regulations over the last two years as well as the clarifications issued since the final regulations were issued demonstrate that. . . HHS has increased substantially [its] understanding of the administration of employer-sponsored health plans").

75. See *id.* at 81 (describing the regulations as they relate to employer-sponsored health plans).

76. See Oak Ridge National Laboratory, *supra* note 39 (describing patients' access to their own records as one of the new standards created by the Privacy Regulations).

77. See 107th Congress, Sept. House Hearing, *supra* note 67, at 81 (testimony of Mary K. Williams) (describing the administrative burdens that the Privacy Regulations imposed on group health plan administrators).

contain medical records, limiting access to computer files, and document retention and destruction policies.”⁷⁸

The Privacy Regulations are not specific to genetics but instead are sweeping regulations that govern all health information.⁷⁹ It has been noted that the HHS regulations impose “substantial administrative burdens” in the name of privacy.⁸⁰ Yet, in the two years since the regulations were issued, HHS has revised the regulations to allow health plans to obtain certain information without being burdened by the requirement of prior consent before disclosure.⁸¹ The revised regulations also allow for disclosure of health information in other, more administrative, tasks.⁸²

The HIPAA Privacy Regulations’ unfavorable relationship with the health care industry is not the only flaw associated with the 1996 legislation.⁸³ By far, the biggest downfall with HIPAA is that it is unmatched in the individual health insurance market.⁸⁴ According to the Congressional Research Service, HIPAA “has been hailed as taking ‘important steps toward banning genetic discrimination in health insurance’ but has also been criticized as not going far enough.”⁸⁵

One step toward preventing genetic discrimination, or at least providing a remedy for its occurrence, was taken on February 8, 2000 when President Clinton issued an Executive Order to prohibit genetic discrimination by federal employers and others receiving federal funding.⁸⁶ This order “[p]rohibits federal employers from requiring or requesting genetic tests as a condition of being hired or receiving benefits,” evaluating an employer’s ability to do his job, classifying

78. *Id.* (describing the measures taken by group health plans to ensure confidentiality of patient records).

79. See Oak Ridge National Laboratory, *supra* note 39 (noting that the new Privacy Regulation standards apply to all aspects of HIPAA, not just genetics issues).

80. See 107th Congress, Sept. House Hearing, *supra* note 67, at 80-82 (testimony of Mary K. Williams) (noting that the consent standard was the result of two years of HHS comments that ultimately resulted in the Privacy Regulations).

81. See *id.* at 82.

82. See *id.* These administrative tasks include “internal quality review, activities relating to creation, renewal, or replacement of a contract of health insurance or excess loss insurance, legal services, auditing functions and business planning.” *Id.*

83. See *id.* (summarizing some flaws in HIPAA’s Privacy Regulations).

84. See Oak Ridge National Laboratory, *supra* note 39 (emphasizing that HIPAA only applies to employer-based and commercially issued health insurance plans).

85. Congressional Research Service, *supra* note 24, at 5 (citing to the statement of Rep. Louise Slaughter Before the House Science Subcommittee on Technology, *Hearing on Technological Advance in Genetic Testing: Implications for the Future*, Sept. 17, 1996).

86. See Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 10, 2000).

employees based on genetic information, or denying any advancement or promotion because of an individual's genetic predisposition.⁸⁷ The order defines protected genetic information to include information about an individual's or his or her family members' genetic tests or other family medical history that reveals the occurrence of a medical condition, disease, or disorder in family members.⁸⁸

The order has several exceptions.⁸⁹ One allows employees who have been given a conditional offer of employment to be asked about any occurrence of disease or other medical condition consistent with other disability laws, namely the Rehabilitation Act.⁹⁰ Another exception allows employers to require genetic tests to monitor the effects of toxic substances in the workplace, and a third allows department or agency health offices to collect "protected genetic information" about employees who use employer-provided genetic or health care services.⁹¹ A fourth exception allows employers to request or require information if a current condition could prevent an "employee from performing the essential functions of the job, or where it is to be used exclusively to determine whether further medical evaluation is needed to diagnose a current disease."⁹² All four exceptions create gaps in a law that already only provides coverage to a select population, generating a need for more expansive legislation.⁹³

C. The Latest Federal Attempt: The Genetic Nondiscrimination in Health Insurance and Employment Act of 2001

The Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, proposed in the 107th Congress, is an effort to provide the

87. See Oak Ridge National Laboratory, *supra* note 39 (outlining the major provisions of the executive order).

88. See American Bar Association, Commission on Mental and Physical Disability Law, *Legislation & Regulations: A Selected Listing of Federal and State Actions Current as of March 1, 2000*, 24 MENTAL & PHYS. DIS. L. REP. 323 (2000).

89. See *id.* (listing the exemptions to include conditional offers of employment and requests for protected genetic information where the employee who uses the employer-provided health care plan authorizes the employer to collect the genetic information).

90. See *id.*

91. See Equal Employment Opportunity Commission, *Questions and Answers: EEOC Policy Guidance on Executive Order 13,145 Prohibiting Discrimination in Federal Employment Based on Genetic Information*, available at <http://www.eeoc.gov/docs/qanda-genetic.html> (last visited Aug. 20, 2002).

92. Congressional Research Service, *supra* note 24, at 7.

93. See Goldberg, *supra* note 17, at 23-24 (stating that the "obvious limitation" of the executive order is its scope of coverage, which leaves "millions" of workers without legal protection).

inclusive legal protection presently lacking in federal laws such as HIPAA, the Executive Order, and arguably, the ADA.⁹⁴ Introduced on the same day by Senator Tom Daschle and Representative Louise Slaughter, the proposed bill is the most recent attempt to enact federal legislation to protect against genetic discrimination.⁹⁵

Written to bar discrimination based on protected genetic information as it may apply to health insurance and employment, the bill both amends current law and creates new law.⁹⁶ There are many provisions detailing the obtaining, disclosure, and use of genetic information⁹⁷ as well as definitions of what this information includes.⁹⁸ There is also a provision for remedies in each of the health insurance and employment titles, should a violation occur.⁹⁹

Title I of the bill prohibits discrimination in health insurance. Its provisions amend current federal laws and will be discussed and analyzed here as a group, as the amendments are consistent within each section.¹⁰⁰ Similarly, the bill and this discussion cover the individual health insurance market – a sector not included within HIPAA – because the amendments to the Public Health Service Act include amendments to both the group and individual markets.¹⁰¹

94. See *id.* (stating that federal legislation is necessary to provide basic protection against genetic discrimination, while concluding that “despite numerous efforts over the course of the past decade, legal protection remains inadequate.”).

95. See Erin Heath, *Zippping Up Genes Discrimination*, NAT’L J., July 21, 2001, available at 2001 WL 7182492. Senator Tom Daschle introduced a similar bill in the 106th Congress, which failed by a 44-54 vote, and Representative Louise Slaughter has been proposing adaptations of genetic discrimination bills into the U.S. House of Representatives since 1995. *Id.*

96. See Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, S. 318, 107th Cong. (2001) available at <http://thomas.loc.gov> (last visited Aug. 20, 2002). Title I prohibits discrimination in health insurance on the basis of protected genetic information by amending the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act (PHSA), the Internal Revenue Code of 1986 (IRS Code), and the Social Security Act (SSA). *Id.* §§ 101-104. Title II prohibits discrimination in employment on the basis of protected genetic information, but it does not amend any federal laws. *Id.* §§ 201-210; see also Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 602, 107th Cong. (2001).

97. See, e.g., S. 318 § 203(a).

98. See, e.g., S. 318 § 201.

99. See S. 318 § 104(b)(1) (amending Title XVII of the Social Security Act); H.R. 602 § 104(b)(1) (amending Title XVIII of the Social Security Act); see also S. 318 § 207 (outlining the civil actions); H.R. 602 § 207 (outlining the civil actions).

100. See generally S.318 §§ 101-104 (relating to amendments to ERISA, PHSA, IRS Code, and SSA); H.R. 602 §§ 101-104 (same).

101. See S. 318 § 102 (amending provisions of the Public Service Act, 42 U.S.C. § 300 *et seq.*, concerning group health plans and individual health plans); H.R. 602 § 102 (same).

Generally, the bill prohibits insurers from denying eligibility or adjusting premiums based on a person's protected genetic information.¹⁰² An insurer is also prohibited from requiring an individual, or a family member of that individual, to undergo a genetic test; in addition, insurers are not allowed to request, require, collect, or purchase any protected genetic information.¹⁰³ Furthermore, insurers may not disclose any protected genetic information they have in their records.¹⁰⁴

Finally, a private right of action is created for violations of this bill, with legal remedies and equitable relief including attorneys' fees, the costs of expert witnesses, and civil penalties.¹⁰⁵ In addition, state laws

102. See S. 318 § 101(a)(2); H.R. 602 § 101(a)(2). There are definitions of what may be classified as genetic information, along with other specifying terms. See S.318 § 104(b)(1); H.R.602 § 104(b)(1) (defining genetic information to include "information about genes, gene products, or inherited characteristics that may derive from an individual or a family member of such individual (including information about a request for, or the receipt of, genetic services by such individual or family member of such individual). Protected genetic information means information about an individual's or a family member's genetic tests or information about the occurrence of a disease or disorder in such family members. See S. 318 § 104(b)(1); H.R. 602 § 104(b)(1). Information about the sex or age of the individual, about chemical, blood, or urine analyses (unless they are genetic tests), or about physical exams (or "any other information that indicates the current health status of the individual") are expressly excluded from the definition of protected genetic information. See S. 318 § 104(b)(1); H.R. 602 § 104(b)(1). Family members are limited to the spouse of an individual, the dependent children (including adopted children) of the individual, and any other individuals related by blood to the individual, his or her spouse, or dependent children. See S.318 § 104(b)(1); H.R.602 § 104(b)(1). Genetic services are defined as any health services that are used to "obtain, assess, or interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling." S. 318 § 104(b)(1); H.R. 602 § 104(b)(1). Finally, a genetic test is defined in the Act as "the analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detect genotypes, mutations, or chromosomal changes." S. 318 § 104(b)(1); H.R. 602 § 104(b)(1).

103. See S. 318 § 101(b) (outlining the prohibitions on the collection of genetic information by insurers); H.R. 602 § 101(b) (same).

104. See S. 318 § 101(b); H.R. 602 § 101(b). Disclosures are forbidden to other members of the same group health plan, other insurance agents, issuers or third party administrators, the Medical Information Bureau or "any other person that collects, compiles, publishes, or otherwise disseminates insurance information," an individual's employer, or any other person who may be specified by regulation. S. 318 § 101(b); H.R. 602 § 101(b). There is an exception, however, that allows insurers to request or collect this information if it is necessary to pay for genetic services. See S. 318 § 101(b); H.R. 602 § 101(b). The information is limited to evidence that genetic services were performed, but the results must not be disclosed. See S. 318 § 101(b); H.R. 602 § 101(b). An insurer may deny payment if such evidence is not provided. See S. 318 § 101(b); H.R. 602 § 101(b). Furthermore, disclosures between health care providers for the purpose of treating an individual are exempted from a requirement that prior consent be obtained before disclosure of any collected genetic information. See S. 318 § 101(b); H.R. 602 § 101(b).

105. See S. 318 § 104(b)(1) (describing the remedies available for violations); H.R. 602 § 104(b)(1) (same).

that offer more protection with respect to genetic information are not superseded by this bill.¹⁰⁶

Title II, relating to employment discrimination, is new and does not amend any existing federal employment laws.¹⁰⁷ The definitions included in Title I of each bill are identical to the definitions in Title II of each bill with respect to family member genetic services, genetic tests, and protected genetic information.¹⁰⁸ The bill makes it illegal for employers, employment agencies, and labor organizations to “fail or refuse to hire or to discharge any individual, or otherwise to discriminate against an individual with respect to the compensation, terms, conditions, or privileges of employment” based on that individual’s protected genetic information.¹⁰⁹

Similar to the provision for health insurance, an employer, employment agency, or labor organization may not request, require, collect or purchase any protected genetic information.¹¹⁰ However, an

106. See S. 318 § 104(b)(1) (stating that no state law will be superseded by the federal law); H.R. 602 § 104(b)(1) (same).

107. See S. 318 §§ 203-206 (applying to employer practices, employment agency practices, labor organization practices, and training programs); H.R. 602 §§ 202-205 (same).

108. See S. 318 §§ 201(2), (4)-(6); H.R. 602 §§ 201(2), (4)-(6); *see also supra* note 102 and accompanying text. Additionally, the terms “employee,” “employer,” “employment agency,” and “labor organization” are defined to have the meaning as such terms in Title VII of the Civil Rights Act of 1964. See S. 318 § 201(1); H.R. 602 § 201(1); *see also* Civil Rights Act of 1964, 42 U.S.C. § 2000e (2000). The terms “employee” and “employer” also include the meanings given under section 717 of the Civil Rights Act of 1964, 42 U.S.C. § 2000e-16 (2000). See S. 318 § 201(1); H.R. 602 § 201(1). In the context of employment, genetic monitoring is defined as:

the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.

S. 318 § 201(3); H.R. 602 § 201(3).

109. See S. 318 § 203(a)(1) (describing the employment processes prohibited); H.R. 602 § 203(a)(1) (same). This bill also makes it illegal to limit, segregate, or otherwise classify employees in any way that would deprive them of employment opportunities or would adversely affect their status as employees because of protected genetic material. See S. 318 § 203(a)(2); H.R. 602 § 203(a)(2).

110. See S. 318 § 203(a)(3) (describing the ban on collection or purchase of an employee’s genetic information); H.R. 602 § 203(a)(3) (same). There is an exception where the employee has provided prior consent or the information obtained from a test is used for genetic monitoring of biological effects of toxic substances in the workplace. See S. 318 § 203(a)(3)(A)(i); H.R. 602 § 202(a)(3)(A)(i). In that situation, the employee must receive the results only in a manner that ensures that the identity of specific employees is not disclosed. See S. 318 § 203(a)(3)(A)(iv); H.R. 602 § 202(a)(3)(A)(iv).

employer may request, require, collect, or purchase protected genetic information in cases where it has extended a conditional offer of employment to an employee.¹¹¹ Any request or requirement must be consistent with the provisions of the ADA and the Rehabilitation Act.¹¹² With the proposed legislation, when an employer has extended a conditional offer of employment, medical information may be used solely to assess whether the applicant is able to perform the “essential functions” for which the person applied.¹¹³

If an employer does possess any protected genetic information, there are provisions in the proposed legislation governing its maintenance.¹¹⁴ All information must be treated and preserved as a part of the

111. See S. 318 § 203(a)(3)(C) (describing the exemption from the rule against collection or purchase of genetic information for cases of conditional offers of employment).

112. See *id.* § 203(a)(3)(C)(i) (mandating compliance with the ADA and the Rehabilitation Act). The ADA has an absolute prohibition on any medical inquiries or examinations at the pre-offer stage of employment. 42 U.S.C. § 12112(d)(2)(A) (2000). Only after an employer has extended a conditional offer of employment – but before that individual has begun work – may the employer obtain extensive medical information about the individual, including genetic information. See *id.* § 12112(d)(3). In essence, the employer may condition employment on the individual’s successful completion of a medical exam. See *id.* An employer may only revoke a conditional offer of employment if the results reveal that the individual will not be able to perform the essential functions of the job, with or without reasonable accommodation. *Id.* Post-hiring rules differ, however, as employers are allowed to require employees to submit to medical exams if the employer can demonstrate that the information gained from such a test is “job-related and consistent with business necessity.” *Id.* § 12112(b)(4)(A). The EEOC has interpreted this standard to relate to employees’ present ability to perform the job. See *EEOC Enforcement Guidance: Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act (ADA)*, July 27, 2000, available at <http://www.eeoc.gov/docs/guidance-inquiries.html>. In 1998, a plaintiff brought suit against her employer, a government-funded research institution, to challenge the employer’s routine practice of testing for syphilis, pregnancy, and sickle cell traits. See generally *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1264 (9th Cir. 1998). Alleging that the testing was done during mandatory medical exams but without the plaintiff’s knowledge or consent, the Ninth Circuit found that the employer had no basis for performing these tests on employees like the plaintiff, who was employed in a clerical position. See *id.* at 1275. However, it is important to note that the suit was not won on the ADA claim because the court found that no adverse employment action was taken as a result of the tests. See *id.*

113. See S. 318 § 203(a)(3)(C)(ii)(II) (describing the type of information that may be requested after a conditional offer of employment has been extended).

114. See S. 318 § 207(a) (stating the requirements with which the employer must comply regarding any genetic information it has in its possession); H.R. 602 § 207(a) (same).

employee's confidential medical records.¹¹⁵ An employer shall not disclose this information to anyone except: the individual whose genetic information it has; occupational or health researchers conducting research; a federal court when ordered to comply with a legal proceeding; or government officials performing an investigation under the act.¹¹⁶

Title II of the proposed legislation also contains enforcement provisions and a private right of action.¹¹⁷ Individuals aggrieved by a violation of the bill may bring an action in either federal or state court.¹¹⁸ The bill specifies that the EEOC shall have the power and authority to enforce Title II and may promulgate regulations to execute these powers.¹¹⁹ However, there is no requirement in the Senate version of the legislation that individuals exhaust administrative remedies with the EEOC before commencing a suit in court, unless an individual has chosen to file charges of discrimination with the EEOC.¹²⁰ Courts may award "any appropriate legal or equitable relief," which may include attorneys' fees and the costs of obtaining expert witnesses.¹²¹ Similar to Title I on health insurance, Title II provides that the new law shall not supersede any state law that offers employees more protection.¹²²

Today, individuals who have been discriminated against on the basis of their genetic make-up have recourse in two federal laws, with a third bill pending in Congress. However, the group of people covered by the first two laws is limited to federal employees and participants in group health insurance plans. This leaves a large majority of the population without any legal protection from genetic discrimination. It is this group of individuals, along with those already covered, who should be most anxious for the pending legislation to be given serious consideration.

115. See S. 318 § 207(a) (stating that if an employer possesses genetic information about an employee, the information should be kept as part of the employee's confidential records); H.R. 602 § 206(a) (same).

116. See S. 318 § 207(b) (listing the exemptions to the rule of the maintenance of genetic information by the employer); H.R. 602 § 207(b)(3) (same).

117. See S. 318 § 208 (describing the remedies available); H.R. 602 § 207 (same).

118. See S. 318 § 208(a); H.R. 602 § 207(a).

119. See S. 318 § 208(b)(1) (stating the authority of the EEOC to regulate the legislation); H.R. 602 § 207(b)(1) (same).

120. S. 318 § 208(b)(2) (noting the absence of a requirement to file charges with the EEOC).

121. See S. 318 § 208(c) (describing the relief available for violations); H.R. 602 § 207(c) (same).

122. See S. 318 § 209(3) (reiterating that no state law shall be superseded by the federal legislation); H.R. 602 § 208(3) (same).

II. GENETIC NONDISCRIMINATION LEGISLATION – GOING TOO FAR OR NOT GOING FAR ENOUGH?

A. *Limitations of the Existing Federal Statutes and Case Law*

Should a case of genetic discrimination based on a predisposition be heard before the current Supreme Court, it is likely Chief Justice Rehnquist, along with Justices Scalia and Thomas (who joined the Rehnquist dissent in *Bragdon*), would hold that a genetic predisposition does not substantially limit any major life activities and thus is not a disability under the ADA.¹²³ In *Bragdon*, the Court held that reproduction was a major life activity and that plaintiff's HIV infection imposed a substantial limitation on that activity; thus, the plaintiff's HIV was labeled a disability.¹²⁴

It is possible to draw analogies between the plaintiff in *Bragdon* and a person with an asymptomatic genetic predisposition because reproduction may be impaired if the genetic disorder is inheritable.¹²⁵ The Court made it clear that "the disability definition does not turn on personal choice. When significant limitations result from the impairment, the definition is met even if the difficulties are not insurmountable."¹²⁶ One can infer from *Bragdon* that if individuals can prove to the Court that their genetic conditions impair their ability to reproduce, they would be deemed disabled and covered by the ADA.¹²⁷

123. See Miller, *supra* note 13, at 244-45 (noting that Chief Justice Rehnquist rejected the argument that "a person's ability to reproduce is limited because the fatal nature of HIV infection decreases the likelihood that the parent could survive to raise and nurture the child to adulthood"); see also *Bragdon v. Abbott*, 524 U.S. 624, 661 (1998) (Rehnquist, C.J., concurring in part and dissenting in part). Chief Justice Rehnquist argued:

Asymptomatic HIV does not presently limit respondent's ability to perform any of the tasks necessary to bear or raise a child. Respondent's argument, taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease "disabled" here and now because of some possible future effects.

Id.

124. *Bragdon*, 524 U.S. at 639.

125. See Miller, *supra* note 13, at 243-44 (concluding that *Bragdon* supports the argument that if a genetic condition is inheritable, the impairment would limit the individual's ability to reproduce the same way it did for *Bragdon*); see also Congressional Research Service, *supra* note 24, at 12 (noting that the definitional language in *Sutton* and *Bragdon* could be contrasted with circumstances in which genetic defects do not ever manifest).

126. *Bragdon*, 524 U.S. at 641.

127. See *id.* The Court in *Bragdon* held that conception and childbirth, while not impossible for an HIV-infected person, are "dangerous to the public health" and therefore meet the definition of a substantial limitation. *Id.*

However, potential plaintiffs may be required to prove to the Court that their genetic predispositions actually limit their ability to reproduce (by presenting the possibility of passing their disease to offspring) and that such genetic markers substantially limit other life activities besides reproduction.¹²⁸ Despite the holding in *Bragdon*, three dissenters expressed their view that reproduction is not a major life activity.¹²⁹ They also stated that each disability inquiry will be based on the particular individual before the Court.¹³⁰ Potentially, one person may be substantially limited in his or her reproductive ability and another person may be found not to be so limited. In *Sutton*, the Court made it clear that not just anyone will be considered disabled and afforded the protections of the ADA.¹³¹ As a result, individuals looking to the high court for redress for genetic discrimination are coming to the realization that winning under the ADA is becoming more difficult, if not impossible. Plaintiffs clearly need a more reliable legal shield with which to fight instances of genetic discrimination.¹³²

HIPAA and President Clinton's executive order, the two federal efforts that currently provide some protection in cases of genetic discrimination, are not adequate because they are limited in scope.¹³³ Thus, they do not eliminate the need for a wide-reaching federal nondiscrimination law addressing the specific concerns that genetics present.¹³⁴ Both HIPAA and the executive order have serious

128. See *id.* at 638. The Court confined its decision to the issue of whether reproduction was a major life activity, stating that "[i]t is our practice to decide cases on the grounds raised and considered in the Court of Appeals and included in the question on which we granted certiorari." *Id.*

129. *Id.* at 659 (Rehnquist, C.J., concurring in part and dissenting in part) (stating that aside from the particular facts of *Bragdon*, the Court was "simply wrong in concluding as a general matter that reproduction is a 'major life activity'").

130. *Id.* at 657 (Rehnquist, C.J., concurring in part and dissenting in part) (noting that the ADA could not be clearer on this point, stating that the disability determination must be made "with respect to an individual"); see also 42 U.S.C. § 12102(2) (2000).

131. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 482-83 (1999) (concluding that individuals must be evaluated in their mitigated state in order to be deemed disabled).

132. See Congressional Research Service, *supra* note 24, at 13 (theorizing that "[a]lthough an argument could be made that the ADA would cover individuals with genetic defects in certain cases, the Court's most recent decisions, particularly *Sutton* and *Murphy*, use reasoning that would make it unlikely that most ADA claims based on genetic discrimination would be successful").

133. See Miller, *supra* note 13, at 255 (stating that the major pitfall of HIPAA is that it does not cover the individual insurance market); Goldberg, *supra* note 17, at 23-24 (noting that the obvious limitation of the executive order is the class of people it covers).

134. See Goldberg, *supra* note 17, at 23-25 (concluding that federal legislation is necessary and surveying the pitfalls of existing federal law that could possibly cover genetics legislation).

deficiencies.¹³⁵ The reality of the executive order is that it only provides protection to a small percentage of the working population – federal workers.¹³⁶ While it provides protection for federal employees, it excludes the rest of working America, a large number of individuals who continue to be subjected to invidious discrimination based on their genes.¹³⁷ Additionally, executive orders may be revoked by succeeding presidents, leaving no guarantee that the legal protection offered by the order is permanent.¹³⁸ HIPAA, while it does much for health care generally, does little for cases of genetic discrimination because it does not apply to every individual.¹³⁹

While the ADA, HIPAA, and the executive order may act as deterrents to real cases of genetic discrimination, the reality remains that the coverage these laws provide is questionable at best during a time when medical science is rapidly evolving.¹⁴⁰ Furthermore, of the number of states that have enacted genetics legislation, most limit their coverage to health insurance and employment, or to one exclusively.¹⁴¹ Currently, adequate protection against genetic discrimination, which can be encountered in day-to-day activities, is lacking on both the federal and state levels.¹⁴²

B. Attempting To Fill in the Gaps: The Genetic Nondiscrimination in Health Insurance and Employment Act of 2001

In March 2001, two bills were introduced into Congress in an attempt to have the federal government finally legislate genetic discrimination, specifically when it occurs with regard to health insurance plans and

135. *See id.* at 23-24.

136. *See id.* (writing that this restriction leaves millions of workers who are not federal employees without protection).

137. *See* Oak Ridge National Laboratory, *supra* note 68 (noting that the executive order does not affect most of the private sector).

138. *See generally* WILLIAM F. FOX, JR., UNDERSTANDING ADMINISTRATIVE LAW 69-70 (4th ed. 2000) (noting that executive orders do not have the force and effect of law, but that they are “compelling documents that agencies ignore at their peril”).

139. *See* Goldberg, *supra* note 17, at 22-25 (listing the advantages of the Privacy Regulations to include recordkeeping improvement; stricter requirements for patient consent; and provisions allowing for both civil and criminal penalties for entities that misuse health information, but ultimately concluding that HIPAA is too limited in scope).

140. *See* Miller, *supra* note 13, at 259, 263 (stating that while there are laws on the state and federal levels that explicitly prohibit genetic discrimination in some circumstances, they do not provide workers with enough coverage).

141. *Id.* at 259-63 (surveying state legislation in twenty-four states with genetic anti-discrimination laws).

142. *See generally* Patrinos & Drell, *supra* note 4, at 8-10.

employment decisions.¹⁴³ While there are proponents and opponents of the legislation, both within Congress and among the various groups who would be affected by it, there is a general consensus that genetic discrimination is a potential problem and that some legislation may be needed.¹⁴⁴ What form it should take is the subject of great debate.¹⁴⁵

*1. Arguments Against Genetic Nondiscrimination Legislation:
Redundancy and Conflict With Current Federal Law*

Many believe that the proposed Genetic Nondiscrimination in Health Insurance and Employment Act is unnecessary and would create a conflict with existing federal laws.¹⁴⁶ The EEOC believes that the ADA covers people with genetic predispositions who are discriminated against on that basis in employment, but it supports the legislation given recent Supreme Court treatment of disability cases.¹⁴⁷ Some admit the clearest, though not the easiest, option would be to amend the ADA.¹⁴⁸

143. See generally Genetic Nondiscrimination in Health Insurance and Employment Act, S.318 and H.R. 612, 107th Cong. (2001) available at <http://thomas.loc.gov> (last visited Sept. 5, 2001).

144. See *Daschle Genetic Discrimination Bill Would Hurt ADA, Civil Rights*, 44 BLUE SHEET 7, available at 2001 WL 7811530 (quoting the testimony of Senator Michael Enzi of Wyoming and Washington, D.C.-based advocacy group LPA at the Senate Health Education, Labor and Pensions Committee hearing on July 25, 2001 regarding proposed federal genetic nondiscrimination legislation); see also Heath, *supra* note 95 (reporting the concerns of employers and the support federal legislation has received from members of the genetics community); *Genetic Discrimination Legislation May Move in Senate This Summer*, 44 BLUE SHEET 29, available at 2001 WL 7811487 (noting that although H.R. 602 has been met with strong support, the measure has also been delayed in the past by GOP leaders who oppose the bill); Goldberg, *supra* note 17, at 19 (reporting that “[m]any lawmakers believe that potential harm specifically resulting from the misuse of genetic information is so great that legal protection is required”).

145. See, e.g., *Genetic Discrimination Legislation May Move in Senate This Summer*, *supra* note 144 (commenting that Celera Genomics President and Chief Scientific Officer Craig Venter would support the legislation, but that he has concerns regarding insurance price controls).

146. See *Daschle Genetic Discrimination Bill Would Hurt ADA, Civil Rights*, *supra* note 144 (reporting the fear of some members of Congress that a new federal genetic nondiscrimination law would conflict with existing federal civil rights laws and the belief that this topic is already regulated).

147. See Goldberg, *supra* note 17, at 24 (illustrating the EEOC view that genetic disorders are covered by the ADA by discussing the hypothetical example of a case described in an EEOC guidance on the topic).

148. See *Genetic Nondiscrimination: Implications for Employers and Employees: Hearings on H.R. 602 Before the House Subcomm. On Employer-Employee Relations, Comm. On Educ. and the Workforce*, 107th Cong. (2001) [hereinafter 107th Congress, July House Hearing] (testimony of Harold P. Coxson, Esq. on behalf of the Genetic Information Nondiscrimination in Employment (GINE) Coalition), available at

Still others believe the ADA actually covers genetic testing under the provisions dealing with medical inquiries and examinations and that re-legislating the issue under the guise of genetics adds redundancy to the law.¹⁴⁹ Arguably, a genetic test is a medical exam because it is a tool that can be used to determine the ability of an employee to perform job-related functions.¹⁵⁰ The ADA has rules regarding when an employer may inquire about a disability or require that an individual submit to a medical examination, as noted above.¹⁵¹ These rules specify what is allowed at the pre-offer, pre-employment, and post-offer stages of employment.¹⁵² It is questionable whether a genetic test would comply

<http://edworkforce.house.gov/hearings/107th/eeer/eeerhearings.htm>. Coxson stated in his testimony:

[M]embers of this Committee certainly are aware of how difficult it can be to “open up” controversial labor and employment laws to amendment even decades after enactment, based on fears of the law’s original proponents that such amendments will be outside of their control. We are aware of the fact that proposals to amend the ADA may raise such fears, although a simple, straightforward ADA amendment would be the most direct way of addressing this issue. With reference to any genetic nondiscrimination legislation, we would suggest that one way to alleviate such fears, while avoiding “genetic exceptionalism,” would be to incorporate ADA principles in a free-standing genetic nondiscrimination bill; and, one way to avoid the risk of legislation which becomes out-dated “before the ink is dry” is to mandate Congressional review or study of the legislation within a few years of its enactment.

Id. at 75-76.

149. *See id.* at 80 (testimony of Harold Coxson) (arguing that an employer is already limited by the ADA from engaging in genetic testing and using the results to make employment decisions).

150. *See id.* (testimony of Harold Coxson). Coxson states that “[g]enetic testing is a medical examination and the ADA contains specific provisions limiting . . . medical examinations and inquiries.” *Id.* at 80. Permissible medical exams and inquiries during the employment stage are defined at 42 U.S.C. § 12112(d)(4)(B) (2000) to be “voluntary medical examinations, including voluntary medical histories, which are part of an employee health program available to employees at that work site. A covered entity may make inquiries into the ability of an employee to perform job-related functions.” Furthermore,

[a] covered entity shall not require a medical examination and shall not make inquiries of an employee as to whether such employee is an individual with a disability or as to the nature or severity of the disability, unless such examination or inquiry is shown to be job-related and consistent with business necessity.

42 U.S.C. § 12112(d)(4)(A) (2000).

151. *See supra* note 112 and accompanying text (describing what the ADA allows for medical inquiries and exams at the different stages of employment).

152. *See* 42 U.S.C. § 12112(d)(3) (2000) (allowing an employer to condition an offer upon the completion of a medical exam); *see also* 107th Congress, July House Hearing, *supra* note 148, at 81 (testimony of Harold Coxson) (noting that the conditional offer medical exam as provided in the ADA contains no limitations on the scope of the exam and concluding that the ADA would not bar an employer from engaging in genetic testing at that stage of the employment process); *cf.* 42 U.S.C. § 12112(d)(3)(A)-(C) (2000)

with the “job-related and consistent with business necessity” standard of the ADA because genetic markers may have no present impact on an individual’s ability to perform job-related functions.¹⁵³

Legislators have attempted to resolve this uncertainty with the proposed legislation.¹⁵⁴ The bill allows employers to request, require, collect, or purchase genetic information only if the request or requirement is consistent with the ADA.¹⁵⁵ This language, however, may not be a sufficient safeguard because employers may easily prove that the exam they administered *was* “job-related and consistent with business necessity,” and it remains to be determined how best to distinguish genetic from non-genetic information.¹⁵⁶ In addition, the provision

(listing the three requirements the employer must satisfy in order to give a medical exam: “all entering employees are subjected to such an examination regardless of disability; the information obtained regarding the medical condition or history of the applicant is collected and maintained in separate forms and files and is treated as a confidential medical record;” and the results of the exam are to be used only in accordance with the requirements of the statute). In addition, the ADA limits use of the information obtained through these exams and inquiries to deny employment only if it can be shown that they were “job-related and consistent with business necessity.” See *id.* § 12112(d)(4)(A); see also 29 C.F.R. § 1630.10 (stating that there should be a fit between job criteria and an individual’s ability to do the job); 106th Congress, HELP Hearing, *supra* note 11 (testimony of EEOC Commissioner Paul Steven Miller) (noting that during the conditional offer stage of employment, “the ADA may not prohibit an employer from, for example, obtaining genetic information of job applicants, requiring genetic screening as a condition of employment or purchasing genetic information about applicants from a genetic information data bank”).

153. See 107th Congress, July House Hearing, *supra* note 148 (testimony of Harold Coxson). Coxson stated:

The current trend of judicial decisions recognizes that non-disabled individuals may enforce the statute’s restrictions on medical inquiries. Hence, even if an individual with a genetic marker or defect is not deemed to be “disabled” within the definition of the ADA, the statute still protects the person from being required to undergo genetic testing unless the testing complies with the above requirements.

Id. at 82 (footnotes omitted). For a discussion of these requirements, see *supra* note 147.

154. See generally Genetic Nondiscrimination in Health Insurance and Employment Act, S. 318 and H.R. 602, 107th Cong. (2001) available at <http://thomas.loc.gov> (last visited Sept. 2, 2001).

155. See S. 318 § 203(a)(3)(C)(i) (describing the requirement that any request for genetic information must comply with the ADA provisions on medical exams and inquiries).

156. See generally Lainie Friedman Ross, *Genetic Exceptionalism vs. Paradigm Shift: Lessons From HIV*, 29 J. L. MED. & ETHICS 141, 142-44 (2001) (surveying the work of an ELSI task force that considered, and rejected, four arguments that would have classified genetic information as fundamentally different from other medical information); see also Fedder, *supra* note 5, at 577 (noting that anti-discrimination laws, while they impact on privacy concerns, do not adequately protect privacy because the main focus of anti-discrimination laws is to make sure genetic information is not used improperly, but the

stating that a request or requirement for the purpose of determining whether individuals have medical conditions or disorders that could prevent them from performing essential job functions does not include the critical language “with or without reasonable accommodation,” – which *is* included in the ADA provision.¹⁵⁷ This omission could be interpreted by a court to conflict with the ADA’s established provision regarding medical exams and conditional offers of employment.¹⁵⁸

Opponents also believe the bill is both redundant and would subject health insurance plans to conflicting federal laws.¹⁵⁹ Professionals in the health insurance industry vehemently oppose the legislation, stating that HIPAA already covers the issue.¹⁶⁰ They believe that HIPAA is “far-reaching legislation designed to improve the portability of health coverage and to provide other protections to recipients of health coverage.”¹⁶¹ It was believed that in enacting HIPAA, Congress had recognized the importance of clear, nationally uniform standards for health insurance.¹⁶² When HIPAA set out to ban genetic discrimination

laws do not usually prohibit the collection of genetic information in the first place); *cf.* 107th Congress, July House Hearing, *supra* note 148, at 39 (testimony of Cheye Calvo). Calvo looks at this distinction from a policy approach:

The central policy issue is whether genetic information is special and requires higher legal protections or whether it is simply another form of health information and should be treated the same. The answer to this question largely influences the policy approach. The ADA allows employers to condition job offers on the completion of medical exams and conduct medical examinations and inquiries on current employees that are “job-related and of business necessity.” Therefore, an inclusive approach to genetics employment policy, based on the ADA, permits some degree of genetic testing. Genetic-specific laws place greater restrictions on employers’ use of genetic information, and may include strict prohibitions on the use of genetic testing by employers.

Id. at 39.

157. *See* S. 318 § 203(a)(3)(C)(ii)(II) (noting the absence of reasonable accommodations in the definitional language). *But cf.* 42 U.S.C. § 12111(8) (2000) (noting that the definition of a qualified person with a disability is an “individual with a disability who, with or without reasonable accommodations, can perform the essential functions of the employment position that such individual holds or desires”).

158. *See* Interagency Report, *supra* note 15 (surveying the ADA provisions on medical inquiries and exams).

159. *See* 107th Congress, Sept. House Hearing, *supra* note 67, at 79-80, 82 (testimony of Mary K. Williams) (testifying that current federal law already protects group health plan participants from genetic discrimination).

160. *See id.* at 84 (testimony of Mary K. Williams) (testifying as to the current state of the law for the health care industry, and concluding that “[n]o additional regulation in this area of employee benefit law is needed to accomplish the objective of genetic non-discrimination”).

161. *Id.* at 80.

162. *See id.* at 79.

in health insurance, it was in essence ensuring uniformity for individuals across state lines.¹⁶³

Also, HIPAA's privacy rules protect the collection, use, and disclosure of health plan participants' medical information, which includes genetic information.¹⁶⁴ HIPAA also prohibits employers from using any health information that is received from a group health plan for any employment-related decisions.¹⁶⁵ Testifying before the House Subcommittee on Employer-Employee Relations, Attorney Mary Williams stated:

Because of the sweeping and comprehensive nature of HIPAA's Privacy Regulations, it would be virtually impossible to draft additional legislation governing health plans' use and disclosure of medical information without including issues already regulated by those Privacy Regulations. A multiplicity of federal laws governing the same subject matter leads to a complex and conflicting regulatory scheme creating confusion for both regulated entities and consumers alike.¹⁶⁶

By enacting the Genetic Nondiscrimination in Health Insurance and Employment Act, Congress would essentially be re-regulating an already regulated entity – group health plans.¹⁶⁷ However, because HIPAA only applies to group health plans, it may be necessary to revise HIPAA to include non-group health plans as well. Still, there remains the chance that the individuals seeking private health insurance may be at a greater risk for discrimination.¹⁶⁸ It has been suggested that provisions covering

163. *See id.* (noting that when Congress enacted HIPAA, it recognized that “the only way to establish clearly understood, workable and effective requirements for privacy and non-discrimination in a health plan was to establish a nationally uniform standard with a single enforcement scheme”).

164. *See id.* at 79-80 (explaining that “[a]ny use or disclosure of genetic information for purposes other than treatment, payment of a claim, or health care operations without written authorization of the plan participant, is illegal” under HIPAA).

165. *See id.* at 81-82 (further explaining how HIPAA makes employment decisions illegal if they are based on genetic information received from a health plan).

166. *Id.* at 82.

167. *See id.* (concluding that the health care industry is already regulated through HIPAA, and that further regulation will only add confusion and cost to the system).

168. *See id.* at 71 (testimony of Jane Massey Licata, J.D., Ph.D.) (stating that coverage should be expanded as fully as possible into the individual health insurance market). Licata also stated that imposing considerable penalties for any knowing violation of the Act may help protect potential victims of this type of discrimination. She stated:

Under the current scheme, the employee or insured, who may not have reasonable access to legal representation, may not be able to effectively protect their privacy interests. I would therefore suggest the Government take a more proactive role and that there be substantial civil penalties provided for in the event there is any violation.

individual policies be strengthened to prevent that inequality from occurring.¹⁶⁹

In addition, the insurance industry has concerns about the enforcement of these laws.¹⁷⁰ HIPAA's Privacy Regulations are enforced by the HHS Office of Civil Rights, while ERISA, which is amended under the new legislation, falls under the "enforcement jurisdiction of the Department of Labor."¹⁷¹ Accordingly, Williams testified that "not only would additional legislation subject health plans to conflicting federal laws, it would subject group health plans to multiple and conflicting penalties imposed by multiple regulatory agencies."¹⁷² Amending the current bill to provide for this situation may prevent future conflicts, but it would also likely make the business of offering health insurance that much more difficult, as administrators would be forced to be extremely familiar with all federal laws and the agencies enforcing them.¹⁷³

Williams foresaw another unintended consequence if Congress were to enact additional legislation with overly-broad language.¹⁷⁴ A law that is drafted "without a complete comprehension of the operations of a group health plan" will result in "burdensome requirements" that will drive employers to decide not to even offer health plans to their employees.¹⁷⁵

Id.

169. *See id.* (testifying that while the proposed legislation goes a long way toward protecting employees, one area that needs to be improved is the provisions relating to the individual health insurance market).

170. *See id.* at 82 (testimony of Mary K. Williams) (noting the confusion that will result if too many federal agencies are given the authority to enforce both HIPAA and genetic non-discrimination legislation).

171. *See id.* (describing which agency would be responsible for enforcement of the legislation).

172. *Id.*

173. *Id.* Williams further stated:

Allowing two regulatory agencies to enforce conflicting rules concerning the same subject matter will result in exactly the situation that ERISA was meant to correct. Employers that sponsor group health plans should have a single, uniform framework where the penalties for wrongful use or disclosure of any medical information, including genetic information, are clearly understood and fairly applied. The HIPAA Privacy Regulations attempt to serve this purpose.

Id.

174. *See id.* at 83 (stating that "[a]ny additional legislation in the medical information area, especially if it includes language directed at genetic non-discrimination, must be drafted very carefully to avoid unintended consequences that could negatively impact the broader (and non-discriminatory) use of information for purposes that benefit group health plan participants").

175. *See id.* Donald Young, Interim President of the Health Insurance Association of America has said that "[i]t is becoming increasingly costly for our members to sort through and comply with all these requirements, especially when an insurer does business in a

Clearly, it will be necessary for Congress to take another look at the exact language of the bill before moving forward, or it is sure to have the insurance industry fighting them in what could be a “reprise of the debate over the Patients’ Bill of Rights,” with no real support from labor management.¹⁷⁶

*2. Arguments Against Genetic Nondiscrimination Legislation:
Inconsistency With Other Federal Civil Rights Legislation*

Beyond those in the health insurance industry who oppose the Genetic Nondiscrimination in Health Insurance and Employment Act for its redundancy and potential conflict with existing laws, there are those who oppose it for its lack of consistency with existing federal civil rights and nondiscrimination laws.¹⁷⁷ In Congress, some members condition their support on the bill being amended to require exhaustion of administrative remedies.¹⁷⁸ Senator Michael Enzi (R-Wyo.) stated during a Senate HELP Committee meeting in July that “[i]t is difficult to see the justification for allowing claimants of genetic discrimination to file suit directly in court and thereby avoid the complaint process that claimants of other basis of employment discrimination must follow.”¹⁷⁹ The U.S.

large number of states. . . . This cost ultimately is borne by consumers in the form of higher premiums.” See MacDonald, *supra* note 20, at A1; see also *Genetic Discrimination Legislation May Move in Senate This Summer*, *supra* note 144 (reporting the written statement of House Energy and Commerce Chair Billy Tauzin (R-La.), who urged Congress to “take great care not to create an unnecessary bureaucracy that will chill the collection and use of genetic information on behalf of patients and for research”). Many believe regulating the use of genetic information is what is needed so that individuals do not avoid getting a genetic test that could identify serious diseases. See 107th Congress, HELP Hearing, *supra* note 7 (testimony of Kathleen Zeitz). Zeitz, a breast cancer survivor with a family history of breast cancer and a daughter who refuses to be tested for the identifiable BRCA1 or BRCA2 gene, testified that the potential for genetic discrimination leads individuals to be afraid to share information with their health care providers, to take advantage of genetic technologies, or to participate in genetic research. See *id.*

176. See MacDonald, *supra* note 20 (reporting that insurers have stalled action “as evidence has grown that the lack of federal rules on the use of genetic information is hurting workers”).

177. See *Daschle Genetic Discrimination Bill Would Hurt ADA, Civil Rights*, *supra* note 144 (noting that there has been opposition to the bill in Congress by members who believe its provisions are inconsistent with other nondiscrimination legislation).

178. See *id.* (reporting the views of Congressman Michael Enzi of Wyoming, who opposes the bill because its failure to comply with administrative procedures that are part of other federal laws puts it squarely in conflict with the federal civil rights laws).

179. *Id.*; see also 107th Congress, July House Hearing, *supra* note 148, at 41 (testimony of Cheye Calvo, Senior Policy Specialist for the National Conference of State Legislatures). Calvo testified that most state genetic discrimination laws provide the same enforcement provisions as other anti-discrimination laws, noting that “[t]he primary

Chamber of Commerce seems to agree that the proposed bill would disrupt the settled dispute resolution procedures set in place with the EEOC, stating that “[c]ontrary to every other employment discrimination law, the bill permits unlimited compensatory and punitive damages for discrimination based on genetic information. . . .”¹⁸⁰

Furthermore, the legislation permits victims of genetic discrimination who may be asymptomatic, and thus not currently disabled, to receive open-ended and uncapped damages beyond the damages available to plaintiffs who were discriminated against because of a current non-genetic-based disability.¹⁸¹ Some have labeled this possibility “genetic exceptionalism”¹⁸² because it gives genetics greater protection than other discrimination claims such as race, gender, religion, national origin, or age.¹⁸³

method of enforcement is through private rights of action, following an administrative review and fact finding by the state agency or the EEOC.” *Id.*

180. *See Daschle Genetic Discrimination Bill Would Hurt ADA, Civil Rights, supra* note 144.

181. *See* Goldberg, *supra* note 17, at 26 (noting that open-ended liability in the legislation permits victims of genetic discrimination to receive more damages than victims of other discrimination claims based on race, gender, religion, national origin, or age).

182. *See id.* Genetic exceptionalism is the concept that “genetic information is so fundamentally different from other health information that it must be given legal protection distinct from other forms of medical information.” *Id.*

183. *See id.*; *see also* 107th Congress, July House Hearing, *supra* note 148, at 39 (testimony of Cheye Calvo). Calvo testified that the central policy issue with genetic nondiscrimination legislation is whether genetic information “is special and requires higher legal protections or whether it is simply another form of health information and should be treated the same.” *Id.* Calvo went on to survey state law approaches, noting that twenty-six states have taken the “exceptional” approach, while other states have taken a more inclusive approach by incorporating genetics into current disability protections. *See id.* at 40. In an article comparing the approach that HIV health policy took to the one that genetics policy is currently debating, Lainie Friedman Ross considers and dismisses four arguments in support of policies of genetic exceptionalism. *See* Ross, *supra* note 156, at 141. The first argument supporting genetic exceptionalism is “that genetics, unlike HIV, reveals information that is fundamentally unique, such that exceptional policies will be necessary even after therapies are developed.” *Id.* at 142. Ross states such a policy has the potential to take on eugenic qualities but concludes that this argument is not compelling because “discrimination and stigmatization exist as long as there are differences” between individuals, regardless of whether those differences have a genetic basis. *Id.* at 141-42. The second argument is that genetic information has wider implications and can reveal more information than what HIV status can reveal. *Id.* Ross concludes that this argument fails as well, because the problem is not unique to genetics, and genetics only highlights the ethical, social, and legal issues that already exist. *Id.* at 142-43. Third, genetic information is immutable, meaning that “a genetic test only needs to be done once in order for one’s genetic status to be known forever,” whereas an HIV test and a person’s HIV status may change over time depending on exposure and susceptibility to infection. *Id.* at 143. Ross finds problems with this argument as well, stating that mutations do occur and even if genetics were immutable, the current

In addition, the bill is inconsistent with other anti-discrimination laws because it does not contain a statute of limitations provision.¹⁸⁴ Similarly, there is no “safe harbor” provision to protect employers from liability for unintentional violations, such as inadvertently receiving protected genetic information through insurance claims or through unsolicited conversations.¹⁸⁵ Ultimately, these shortcomings leave employers and labor organizations with no clear understanding of their obligations under federal labor and employment laws.¹⁸⁶ The bill loses credibility because it lacks a statute of limitations and an available safe harbor defense for employers.¹⁸⁷

knowledge of the human genome, despite the rapid advances, remains incomplete. *Id.* Finally, much genetic information is probabilistic, whereas HIV status is definitive. *Id.* Ross concludes that even though this is the strongest argument, genetic information is not always probabilistic, and HIV information is not always definitive. Problems of inaccuracy in test results occur with both classifications. *Id.* According to Ross, “[i]f what makes genetics exceptional is its probabilistic and ambiguous nature, this is a chronic problem in medicine and not unique to genetics. As such, a genetic diagnosis of disease predisposition is not so fundamentally different from a diagnosis of HIV seropositivity.” *Id.* (footnote omitted).

Ross further discusses the ELSI Task Force’s findings considering the same question about whether genetics should be treated as exceptional, and notes that the group ultimately rejected three justifications for such a policy. *Id.* Those justifications included: whether genetic information was sufficiently different from other health information because of its “prophetic potential;” whether genetic information was sufficiently different “because of its implications for other family members;” or whether genetic information was sufficiently different “because of its potential to stigmatize and victimize.” *Id.*

184. See 107th Congress, July House Hearing, *supra* note 148, at 86-87 (testimony of Harold Coxson) (testifying that by omitting a statute of limitations, the legislation both opens the door for excessive litigation and runs afoul of other federal nondiscrimination laws, which require that a plaintiff bring an action or file a complaint within a set period of time or be barred from bringing the claim at all).

185. See *id.* Coxson questions whether such an employer is “presumptively held strictly liable for any adverse employment action even for cause or based on performance.” *Id.* at 87. He concludes:

Certainly in the eyes of a jury, and without the filter of an agency such as the EEOC to screen non-meritorious charges, the employer will be hard pressed to demonstrate that the information was not an unlawful factor in the employment decision, especially a decision involving an individual with a life-threatening genetic marker who is likely to evoke the sympathy of a jury.

Id.

186. See *id.* 87-88 (stating that an absence of clear delineations of obligations under the proposed legislation, and other anti-discrimination laws, will lead to confusion and will impede the administration and enforcement of the laws).

187. But see 42 U.S.C. § 12113(a) (2000) (listing defenses available to employers in the ADA, which does not include a safe harbor defense). The ADA’s statute of limitations period is set by statute in 42 U.S.C. § 2000-5(e)(1) to be 180 days.

Additionally, the proposed Act does not limit its applicability to employers with fifteen or more employees, as the ADA does.¹⁸⁸ Small companies with fewer resources and different concerns will be subject to the same regulations as large companies that may have deeper pockets and diverse interests. As a result, the Act would be inconsistent with other federal anti-discrimination laws, such as the ADA, which apply only to employers with more than fifteen employees.¹⁸⁹

The numerous inconsistencies this legislation presents – lack of exhaustion of administrative remedies, uncapped damages, widespread applicability, and the lack of a statute of limitations – are potentially fatal flaws that could prevent it from ever passing a majority of Congress.¹⁹⁰ Because there is no cap on damages in the proposed bill and no requirement that a plaintiff file a complaint with the EEOC, this legislation opens the door to endless litigation with large money awards by sympathetic juries.¹⁹¹ One advocacy group in Washington, D.C. warns that the legislation will create even more litigation at a time when the judicial system is already at its limits.¹⁹² Clearly, more attention is needed if the proposed legislation is going to be consistent with – and ultimately amended into – existing federal civil rights laws.

188. See 42 U.S.C. § 12111(5)(A) (2000). The ADA defines an employer as: a person engaged in an industry affecting commerce who has 15 or more employees for each working day in each of 20 or more calendar weeks in the current or preceding calendar year, and any agent of such person, except that, for two years following the effective date of this subchapter, an employer means a person engaged in an industry affecting commerce who has 25 or more employees for each working day in each of 20 or more calendar weeks in the current or preceding year, and any agent of such person.

Id.

189. See 42 U.S.C. § 12111(5)(A) (2000); *supra* note 183 and accompanying text.

190. See *Daschle Genetic Discrimination Bill Would Hurt ADA, Civil Rights*, *supra* note 144 (stating that Representative Enzi and others in Congress are reluctant to support the legislation because of their belief that it upsets the balance of existing federal civil rights laws).

191. See 107th Congress, July House Hearing, *supra* note 148, at 87 (testimony of Harold Coxson). Coxson related the fears of those in the labor and employment industry by stating, “We are concerned that this legislation, with its overly broad definition of genetic information and open-ended liability for unlimited compensatory and punitive damages, may actually serve to foster litigation and workplace disputes.” *Id.*

192. See Goldberg, *supra* note 17, at 26 (reporting the opinions of LRA, an advocacy organization which represents human resources executives). By requiring claimants with discrimination cases to file a complaint with an administrative agency like the EEOC before filing an action in court, the rationale is that the agency will have the expertise to handle the claim, and the court’s docket will not unnecessarily be burdened. See FOX, *supra* note 138, at 317-20 (discussing the exhaustion doctrine).

3. *Arguments Against Genetic Nondiscrimination Legislation: Drafting Loopholes and Other Fatal Errors*

Beyond the criticism that the proposed legislation conflicts with current federal law, there are other more technical problems with the bill.¹⁹³ These drafting oversights range from the way genetic information is defined to a more serious drawback – the fact that this legislation *only* applies to employment and health insurance, leaving no protection for the numerous other areas where genetic discrimination can occur.¹⁹⁴

Recent congressional hearings have focused on many aspects of the bill, including the definitional language and, in particular, how this draft differs from past versions in the way it defines genetic information.¹⁹⁵ As drafted, the bill prohibits employers from “the mere receipt or possession of protected information.”¹⁹⁶ One witness recently testified before Congress:

A practical, real world concern among employers is whether such broad proscriptions would trigger litigation based on mere knowledge of an employee’s family disease or disorder, which may come to the employer’s attention through unsolicited genetic information in routine medical reports, leave requests, or even through on-the-job or off-the-job social conversations, newspaper obituaries, and the like, where family illnesses or causes of death may be discussed.¹⁹⁷

193. See, e.g., 107th Congress, July House Hearing, *supra* note 148, at 87-88 (testimony of Harold Coxson) (noting the definitional problems with the legislation).

194. See *id.* (testifying as to the definitional deficiencies); see also Patrinos & Drell, *supra* note 4 (listing other areas where new developments in genetics may pose legal issues).

195. See 107th Congress, July House Hearing, *supra* note 148, at 88 (testimony of Harold Coxson) (pointing to the difference in definitional language between the version of the legislation in the 106th Congress and the version before the 107th Congress).

196. See *id.* at 87-88 (testimony of Harold Coxson) (stating the GINE Coalition’s concern that the term “protected genetic information” is more inclusive than necessary and may leave employers with few legal defenses). In past years, drafts of the genetic nondiscrimination legislation used the term “predictive” genetic information, a term that is “commonly used and well understood” in the medical community. *Id.*

197. *Id.* (testifying that overly broad definitions such as “protected genetic information” could serve as the basis for litigation arising from any adverse employment decision and that if an employer is faced with unlimited damages, it may be forced to settle with employees in order to “avoid a potential run-away jury award”). Coxson continued to state that “[t]he law then becomes a ‘sword’ for trial lawyers rather than a ‘shield’ for employees. And under [the bill] as drafted, the litigation sword could potentially be wielded in multiple forums based on information received from normative human behavior – visiting the sick and consoling the bereaved – that our traditions, social mores, and laws should encourage.” *Id.* at 89.

Furthermore, defining genetic information to be “protected” rather than “predictive” undermines the significance of a subtle delineation between genetic information and other health information, a distinction with which scientists are still grappling.¹⁹⁸ There are well-established genetic markers and reliable diagnostic tests available today to help aid in this understanding, but a clearer definition may be necessary to avoid excessive litigation.¹⁹⁹ Additionally, eliminating the exclusion of “other information relevant to determining the current health status of the individual” from the definition of protected genetic information would lessen the chance that access to genetic information is inadvertently obtained.²⁰⁰

There are other provisions in the bill dealing with exceptions that may prove problematic.²⁰¹ One such exception, relating to Title I, allows health insurance companies to refuse to pay for a genetic services claim if the individual does not provide evidence that he or she actually had a genetic service performed.²⁰² In effect, this exception places the individual in the difficult position of choosing to pay for the service himself or risk disclosure by the company.²⁰³ This problem may be corrected with specific language inserted in Title I to clarify what would be sufficient evidence to satisfy such a claim.²⁰⁴

The other flaws in the legislation lay less with what is currently included and more with what is purposely excluded. Specifically, there is an absence of findings usually present in anti-discrimination or civil

198. See 107th Congress, July House Hearing, *supra* note 148, at 40 (testimony of Cheye Calvo) (concluding that as a result of this nuanced distinction, “laws must clearly define the realm of protections”).

199. See 107th Congress, Sept. House Hearing, *supra* note 67, at 70-71 (testimony of Jane Massey Licata) (stating that it would be “especially troublesome” if the information deemed “predictive genetic information” were used to make employment or insurance decisions).

200. See *id.* at 71 (testimony of Jane Massey Licata) (noting her concern that leaving out “other information relevant to determining the current health status of the individual” from the definition of protected genetic information could prove counterproductive to the goal of preventing misuse of private information).

201. Genetic Nondiscrimination in Health Insurance and Employment Act, S. 318, 107th Cong., § 102(a) (2001) (relating to the payment of claims for genetic services); Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 602, 107th Cong., § 102(a) (2001) (same).

202. See S. 318 § 102(a); H.R. 602 § 102(a).

203. See 107th Congress, Sept. House Hearing, *supra* note 67, at 71 (testimony of Jane Massey Licata) (discussing the exception for information needed for payment of a claim).

204. See *id.* (testimony of Jane Massey Licata) (suggesting that a receipt from a licensed laboratory or health professional would be sufficient to prove a genetic service was performed).

rights laws.²⁰⁵ This absence may be due to the shortage of known court cases charging genetic discrimination.²⁰⁶ Secondly, while there is a limited applicability to collective bargaining agreements, the bill does not include a provision regarding dispute resolution forums as an alternative

205. See, e.g., Americans with Disabilities Act of 1990, 42 U.S.C. § 12101-12213 (2000) (recording the findings of Congress at the time that it enacted the ADA). This section of the ADA includes findings that “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem” and that “unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination.” *Id.* at § 12101(a)(2), (4).

206. See Heath, *Zippping Up Genes Discrimination*, *supra* note 95, at 2346. Heath relates critics’ view that new federal legislation is unnecessary because “[f]or the most part, we’re not seeing any pattern of genetic discrimination.” *Id.* (quoting Mark Hall, professor of law and public health at Wake Forest University). Professor Hall further stated, “It’s difficult to craft legislation in advance of the problem arising, because you don’t fully know the dimensions of the problem.” *Id.* But see U.S. Equal Employment Opportunity Commission, *EEOC Petitions Court To Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans With Disabilities Act*, (Feb. 9, 2001) (detailing the case of an employee who sued his employer, Burlington Northern Santa Fe Railroad (BNSF), after the railroad required blood tests of employees who filed claims for work-related injuries) at <http://www.eeoc.gov/press/2-9-01-c.html> (last visited Aug. 28, 2002). The EEOC charged that BNSF employees were neither told of the genetic testing, nor asked to consent to the test, and that employees who refused to provide blood samples were threatened with losing their jobs. *Id.* The EEOC suit was the first lawsuit to challenge genetic testing under the ADA. *Id.* Two months after the EEOC suit commenced, BNSF admitted to testing certain employees for genetic markers and agreed to settle the case with the EEOC. See U.S. Equal Employment Opportunity Commission, *EEOC Settles ADA Suit Against BNSF for Genetic Bias*, (April 18, 2001), at <http://www.eeoc.gov/press/4-18-01.html> (last visited Aug. 28, 2002). Under the settlement, BNSF agreed not to directly or indirectly require its employees to submit to blood tests, analyze or evaluate any blood or gene test performed or obtained before the settlement, or retaliate or threaten employees who opposed testing or who otherwise participated in the EEOC suit. *Id.* Also, as a part of the agreement, the EEOC may seek compensatory and punitive damages up to \$300,000 for each BNSF employee who was subjected to a genetic test or who was retaliated against for a refusal to take a test. *Id.* Throughout the suit, the EEOC maintained that the genetic testing conducted by BNSF was a clear violation of the ADA’s provision on unlawful medical exams. *Id.* BNSF spokesperson Richard Russack said that the company requested its employees to undergo the tests because “‘there could be a predisposition within the body chemistry of the individual’ to develop the carpal tunnel syndrome ‘that had nothing to do with work.’” Scott Gottlieb, *U.S. Employer Agrees To Stop Genetic Testing*, *BRITISH MED. J.* (Feb. 24, 2001) at http://www.findarticles.com/ef_0/m0999/7284_322/71820699/print.jhtml (last visited Aug. 28, 2002). According to EEOC lawyers, BNSF became one of the first companies to admit using genetic tests on its employees. See *id.* Advocates of the new federal legislation are quick to point out that the BNSF case is not the only example of an employer misusing an individual’s genetic information, but rather that the EEOC/BNSF case’s high profile has “legitimized the cause.” See MacDonald, *Congress Takes Up Genetic Privacy*, *supra* note 20.

to court litigation.²⁰⁷ Third, there is no statute of limitations in either Title of the bill.²⁰⁸ Finally, and possibly most importantly, there is no sunset clause in the proposed federal genetic nondiscrimination bill.²⁰⁹ For legislation that may precede actual court cases claiming genetic discrimination, Congress should require a re-examination of this prophylactic legislation in a few years.²¹⁰

C. State and Local Attempts: Maryland's Genetic Nondiscrimination Law and Montgomery County's Amended Human Relations Code as Models for Federal Law

Perhaps a bigger problem than the technical aspects of the proposed bill is the reality that the federal government has severely fallen behind the states when it comes to protecting its citizens from genetic discrimination.²¹¹ In March of 2001, Maryland joined a long list of states

207. See S. 318 § 102(g)(2) (relating to the date on which collective bargaining agreements under the Public Health Service Act become enforceable); H.R. 602 § 102(g)(2) (same).

208. See, e.g., S. 318 § 208 (civil action); H.R. 602 § 207 (civil action).

209. See, e.g., S. 318 § 211 (effective date); H.R. 602 § 211 (effective date); see also *infra* note 210.

210. See 107th Congress, July House Hearing, *supra* note 148, at 75 (testimony of Harold Coxson). Coxson testified:

Today's genetic nondiscrimination legislation may quickly become outdated, and indeed counterproductive to its original purpose, unless it is drafted to avoid "unintended consequences" to the extent possible. The very information that is being censored today will very likely be the information that must be shared in a year or two to help someone delay the onset of disease or avoid it entirely. . . . [O]ne way to avoid the risk of legislation which becomes out-dated "before the ink is dry" is to mandate Congressional review or study of the legislation within a few years of its enactment.

Id.

211. See Heath, *Zippping Up Genes Discrimination*, *supra* note 95, at 2346-47 (noting that while Congress is still debating the pros and cons of federal nondiscrimination legislation, twenty-eight states have already passed laws banning genetic discrimination by employers). Overall, thirty-two states have laws providing some protection for health insurance, employment, or, like the proposed federal legislation, both health insurance and employment. See generally Goldberg, *supra* note 17, at 22-24. Some of the first state statutes to address genetic discrimination focused on particular genetic conditions. See Congressional Research Service, *supra* note 24, at 15. North Carolina was the first state to prohibit employment discrimination based on an identifiable sickle cell trait. *Id.* In 1991, Wisconsin was the first state to enact a comprehensive law, and it was signed by then-Governor Tommy Thompson, now the Health and Human Services Secretary. See Heath, *Zippping Up Genes Discrimination*, *supra* note 95, at 2347. President Bush signed a similar law in Texas in 1997 while he was governor of the state. *Id.* Nonetheless, commentators see the recent power shift in the U.S. Senate to be the impetus Congress needs to finally tackle the issue. See *id.* Some scholars have contemplated possible state common law actions in tort as a possible way to bring cases of genetic discrimination, but the state laws

that have enacted their own laws to combat genetic discrimination.²¹² The Maryland law bars employers from requiring job applicants to submit to genetic testing as a condition of employment.²¹³ The law also prohibits genetic information from being used as a factor in any employment decisions such as raises, wages, and bonuses.²¹⁴ Similar to the proposed federal law, the Maryland law makes unlawful any discrimination in employment simply because the individual has a genetic predisposition for a disease or disability.²¹⁵ Unlike the proposed federal legislation, but similar to other federal nondiscrimination laws such as the ADA, Maryland's new law only applies to employers with fifteen or more employees.²¹⁶

In August of 2001, Montgomery County, Maryland, home to both NIH's Human Genome Project and the privately funded Celera Genomics, amended its human relations code and became the first local jurisdiction to adopt a genetic discrimination law.²¹⁷ The law now includes employee protection against genetic bias and puts genetics on par with other human rights protections afforded to race, religion, national origin, age, disability, gender, and sexual orientation.²¹⁸ Unlike

vary widely and may not cover every instance of discrimination if there is no duty required by law. See Miller, *supra* note 13 at 257-60 (surveying extensively state legislation in this area as it relates to genetics). For a comprehensive survey of state statutes addressing genetic discrimination, see Congressional Research Service, *supra* note 24, at n.51, 52 (citing research by the National Conference of State Legislators). The National Conference of State Legislators can be accessed at <http://www.ncsl.org>.

212. See Michael Dresser, *Genetic Privacy Measure Gains: Legislature Approves Ban on Using Data in Hiring and Firing*, BALT. SUN, Mar. 23, 2001, at 1D; see also Miller, *supra* note 13, at 259-63 (surveying the states that have already enacted genetic nondiscrimination legislation and describing some of the features common to most state statutes).

213. See MD. ANN. CODE. § 16(a)(3) (Supp. 2001); see also Dresser, *supra* note 212 (noting that the "bill bars employers from requiring job applicants to submit to genetic testing as a condition of employment").

214. See MD. ANN. CODE. § 16(a)(1), (2) (Supp. 2001); see also Dresser, *supra* note 212 (stating the Maryland law makes it illegal to use genetic information in making decisions about wages and benefits).

215. See MD. ANN. CODE. § 16(a)(1), (2), (3) (Supp. 2001). At the time the Maryland law was enacted to cover employment practices, the state already had a law protecting people from genetic discrimination in health insurance practices. See Dresser, *supra* note 212.

216. See MD. ANN. CODE. § 15(b) (1998) (defining employer to be "a person engaged in an industry or business who has fifteen or more employees for each working day. . .").

217. See Stephen Manning, *Montgomery Human Rights Laws Expanded to Genetics*, ASSOCIATED PRESS, Aug. 13, 2001.

218. See MONTGOMERY COUNTY, MD., CODE § 27-1(a) (2001) (stating the policy of Montgomery County to eliminate discrimination, prejudice, intolerance, and bigotry on the account of genetic status).

Maryland's new law, the Montgomery County law only applies to county employees.²¹⁹ Also unlike Maryland's law, the Montgomery County law applies to all employers and eliminates the seven-employee minimum previously required in the original human rights law.²²⁰ Because Montgomery County's regulations are more stringent than the state law, it will take precedence over state law in situations where both county and state law apply.²²¹

III. THE DISABILITY PARADOX: WHO WILL NEW LAWS HELP AND WHO WILL THEY HURT?

As the name of the Genetic Nondiscrimination in Health Insurance and Employment Act of 2001 correctly implies, the proposed federal legislation would apply only to health insurance and employment genetic discrimination claims, just as the local and state laws currently do.²²² Beyond these contexts, where admittedly most cases of discrimination are likely to occur, there are other ways genetics can be the basis for discrimination, including adoption; prenatal diagnosis and reproduction practices (childbearing decisions); admissions decisions; financial assistance and credit approvals; and health, life, or disability insurance.²²³ Presently, neither the ADA nor the limited protections available through

219. See MONTGOMERY COUNTY, MD., CODE § 27-18 (2001) (defining employer).

220. See MONTGOMERY COUNTY, MD., CODE § 27-18(b) (2001) (deleting the original bill's six employee minimum); see also Manning, *supra* note 217 (noting that the original bill only covered employers with seven or more employees).

221. See Manning, *supra* note 217 (stating that Montgomery County's law will take precedence over the Maryland state law).

222. See The Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, S.318, 107th Cong. (2001), available at <http://thomas.loc.gov> (last visited Aug. 28, 2002); The Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 602, 107th Cong. (2001), available at <http://thomas.loc.gov> (last visited Aug. 28, 2002); see also Heath, *Zippping Up Genes Discrimination*, *supra* note 95, at 22 and accompanying text (noting the states that have coverage for employment discrimination); see also Goldberg, *supra* note 17 and accompanying text (detailing state law coverage). In a Report to Congress, it was noted:

It should be emphasized that legal issues relating to genetics may vary depending on whether insurance, employment or other types of discrimination, or medical research are involved. Approaches to addressing the issues raised in these contexts vary from taking no legislative action, addressing certain specific concerns (as was done in the Health Insurance Portability and Accountability Act), or more far reaching approaches such as comprehensive legislation on genetics or legislation focused on all medical records, including genetics.

See Congressional Research Service, *supra* note 24, at 4.

223. See Patrinos & Drell, *supra* note 4 (listing the issues ELSI identified to have potential legal ramifications).

HIPAA or the executive order will remedy this situation.²²⁴ Not even the proposed federal law will fully remedy the situation, because as the list above illustrates, the problem of genetic discrimination has the potential to extend far beyond health insurance and employment.²²⁵

Overall, the Genetic Nondiscrimination in Health Insurance and Employment Act of 2001 is an attempt to legislate an area that has already been partly legislated. However, the coverage is unpredictable and the focus of the existing laws uncertain.²²⁶ There are many gaps with the current version of the proposed federal legislation, including the reality that it may conflict with existing laws and that its provisions, as drafted, are severely inconsistent with similar anti-discrimination laws such that the proposed law loses credibility.²²⁷ Moreover, there are technical flaws with the legislation that both provide loopholes and create gaps in protection that, ultimately, defeat the purpose of enacting federal genetic nondiscrimination legislation in the first place.²²⁸ The federal government has a duty to provide legal protection to the citizenry. Before Congress enacts a piece of landmark legislation, it is necessary to first understand all of the issues involved – ethical, social, moral, and legal – and to balance these interests in a way that allows meaningful laws to be created and privacy to be protected.

Any new law must comply with existing federal anti-discrimination and civil rights laws, such as the ADA, the Civil Rights Act of 1964, the Age Discrimination in Employment Act (ADEA), and others.²²⁹ In order to accomplish that end, proposed legislation must not circumvent the

224. See Goldberg, *supra* note 17, at 22-25 (noting that HIPAA is limited in scope, the Executive Order's limitation is that it only applies to federal employees, and that the ADA's limited protection has not yet been tested by the courts and is thus uncertain).

225. See generally Patrinos & Drell, *supra* note 4; see also Kourtney L. Pickens, Comment, *Don't Judge Me By My Genes: A Survey of Federal Genetic Discrimination Legislation*, 34 TULSA L. J. 161, 180-81 (1998) (concluding that federal anti-discrimination legislation must not be limited to employment and health insurance, but must extend to life, automobile, disability and other forms of insurance; loan, mortgage, and credit card agencies; reproduction practices; adoption practices; and schools).

226. See Goldberg, *supra* note 17, at 25-28.

227. See *supra* notes 146-93 and accompanying text.

228. See *supra* notes 194-210 and accompanying text.

229. See *Daschle Genetic Discrimination Bill Would Hurt ADA, Civil Rights*, *supra* note 144 (reporting Senate Health, Education, Labor and Pensions Committee Member Michael Enzi's belief that a bill to prohibit genetics-based discrimination "would damage the Americans with Disabilities Act (ADA) and existing civil rights legislation"). Enzi said that he and others in Congress "believe the bill would 'upset the balance of interests created by existing employment nondiscrimination statutes' and would 'undermine the process for enforcing and redressing civil rights legislation.'" *Id.*

accepted processes established for dealing with violations.²³⁰ In addition, a new federal law must not conflict with existing law and, in essence, should not re-legislate an area already regulated.

To this end, the solution may entail amending existing civil rights laws to include genetics. The Americans with Disabilities Act was a lauded new law over a decade ago, but today, as a result of recent Supreme Court decisions narrowing its scope and questioning its constitutionality, there is no guarantee that it is a reliable sword to use in an action for genetic discrimination.²³¹ Amending the ADA would not be easy, but it would be a good idea.²³² Amending the Civil Rights Act of 1964 to include a ban against discrimination based on genetic predispositions is also a possibility. This option could avoid cries of genetic exceptionalism because it would put genetics on the same level as race, gender, national origin, and religion – in essence creating a new “right.”²³³ Genetics is the

230. *See id.* (detailing critics’ view that side-stepping the administrative procedures in place in other federal civil rights laws is unjustifiable).

231. *See* Congressional Research Service, *supra* note 24, at 11-13 (outlining the Court’s recent decisions in *Sutton* and *Bragdon* and the potential difficulty plaintiffs may have persuading a court to adopt the EEOC view that genetic discrimination is covered under the ADA). The constitutionality of the ADA has come under attack recently as well, and it could be argued that the proposed bill could be attacked on similar grounds, but that discussion will not be tackled here. *See* Board of Trustees of the Univ. of Ala. v. Garrett, 531 U.S. 356 (2001) (finding that Congress did not adequately abrogate states’ immunity when enacting the ADA using its authority under section 5 of the Fourteenth Amendment); *see also* Roger C. Hartley, *Enforcing Federal Civil Rights Against Public Entities After Garrett*, 28 J.C. & U.L. 41-44 (2001) (discussing the recent federalism revival in the Supreme Court and Congress’ power to abrogate states’ judicial immunity).

232. *See* 107th Congress, July House Hearings, *supra* note 148, at 75-76 (testimony of Harold Coxson) (noting the difficulty in amending controversial federal labor and employment laws such as the ADA). Furthermore, due to recent Supreme Court decisions unfavorable to the rights of the disabled, it is likely that the disability community would rather not test the ADA in a genetic discrimination case for fear that the Court would further restrict the reach of the civil rights law.

233. *See* Miller, *supra* note 13, at 264. Miller notes:

Employment civil rights laws are rooted in the principle that certain characteristics such as race, national origin, gender, religion, age, or disability may not be considered in making employment decisions because they are ultimately irrelevant to the person’s ability to perform the job in question. Discrimination based upon genetic information is no different.

Id. But *cf.* Ross, *supra* note 156, at 141 (analyzing the labeling of HIV health policy as a policy of exceptionalism, comparing genetic policy to HIV policy, and concluding that what is needed is a paradigm shift such as the one that transformed HIV policy). Ross argues:

[P]olicies and practices that promote genetic exceptionalism are not morally justifiable because genetic information is not qualitatively different from other medical information. As such, we should eliminate such practices now, before they become routine, and avoid writing policies, laws, and regulations that will

future, and it is important for the law to keep up with and stay consistent with science.²³⁴

IV. CONCLUSION

It is clear that genetic discrimination presents a serious problem. Over half the states have enacted new laws or amended existing ones to provide protection for this new kind of discrimination. This area is one where federal law can be a pioneer by covering all areas where genetic discrimination may occur and by ushering in a standard of genetic privacy. The Genetic Nondiscrimination in Health Insurance and Employment Act of 2001 is a step in the right direction, but it should not be the end. Changes are necessary, and more discussion is needed to ensure that any law Congress enacts is both consistent with existing federal discrimination and civil rights laws and that it does not create more hardship than benefits. Until it can be proven that the proposed law meets those goals, it should not be enacted.

V. ADDENDUM

Following the terrorist attacks on September 11, 2001, the Genetic Nondiscrimination in Health Insurance and Employment Act was pushed to the legislative back burner.²³⁵ While President Bush has endorsed a bill to protect against genetic discrimination, at the end of the 107th Congress, the Act was stalled in committee negotiations, particularly in the House of Representatives, where professional staffers stated that the bill was “unlikely to come to a floor vote in the House this

entrench these practices further. Instead, it may be instructive to consider how the issues raised by genetics can be transformative for our conceptions of health and disease.

[I]nstead of being treated as exceptional, genetics should serve to herald in a new era of clinical medicine — an era in which the concepts of health, disease, causality, and risk are incorporated into a new paradigm of health care that focuses on prevention. Even if genetics does not successfully catalyze clinical medicine, we must avoid the misunderstandings and misuses of genetics that foster the false need for policies that treat it as exceptional.

Id. at 145.

234. See Miller, *supra* note 13, at 265 (stating that “[w]hile advances in genetic research and technology portend tremendous benefits for humankind in medicine and science, adequate protections must be in place to insure that such technology will not be used for the wrong reasons”).

235. See *After Tuesday, Health Issues Become Lower Priority On Hill*, CONG. DAILY AM, (Sept. 13, 2001), available at 2001 WL 27552230 (noting that some matters may be put off until later while Congress focuses on the aftermath of the September 11th attacks).

session unless committee negotiations yield a consensus that the Republican leadership can support.”²³⁶

In the Senate, S. 318 has been competing with a second genetic nondiscrimination bill, S. 382,²³⁷ which was introduced by Senator Olympia Snowe (R-Maine) and supported by many GOP senators and independent moderates.²³⁸ Senator Snowe’s bill has also found support with the Bush administration, which does not want to “prohibit any information on current health status from being available to health plans.”²³⁹ The bill also seeks to address what GOP moderates see as problems in S. 318, namely that that bill has broad definitions.²⁴⁰ Furthermore, S. 382 specifies that predictive genetic information is limited to “tests that seek to assess disease risk in asymptomatic or undiagnosed persons” and distinguishes between protected genetic information and predictive genetic information.²⁴¹ However, unlike S. 318, S. 382 does not provide protection in the employment arena.²⁴²

Despite the presence of a competing bill in the Senate, the original sponsor, Senator Daschle, remains optimistic that the Genetic Nondiscrimination in Health Insurance and Employment Act will see Senate action soon.²⁴³ Even though the legislative session came to a close in December 2002 with no significant action on either H. 602 or S. 318, supporters of genetic discrimination legislation remain confident that the bill will be considered in the next term of Congress.²⁴⁴

236. See *House Health Leaders Confident in Position on Genetic Discrimination Bills*, 14 HEALTH NEWS DAILY 24 (2002) (noting House Republicans’ concerns and declaring that genetic nondiscrimination has only been a front-burner issue since President Bush mentioned the topic in a July 2001 radio address).

237. Genetic Information Nondiscrimination in Health Insurance Act of 2001, S. 382, 107th Cong. (1st sess. 2001).

238. *House Health Leaders Confident*, *supra* note 236, at 24 (noting that some Senators on the HELP Committee prefer the Snowe bill over Daschle’s bill).

239. See *Bush Preference for GOP Genetic Nondiscrimination Bill Hinted at by Official*, 45 BLUE SHEET 13 (2002) (noting that the Bush administration shares a policy goal with the sponsors of the Snowe bill).

240. *Id.*

241. *Id.*

242. See *id.* (noting Senator James Jeffords’ announcement during a committee hearing that S. 382 sponsors are “working on adding employment protections to their bill”).

243. See *House Health Leaders Confident in Position on Genetic Discrimination Bills*, *supra* note 236 (noting that Daschle “is passionate enough about the issue that he will bring his legislation directly to the floor if necessary”).

244. President Bush, a supporter of a genetic nondiscrimination bill in one form or another, renewed his support in the winter of 2002 by stating that “genetic information should be an opportunity to prevent and treat disease, not an excuse for discrimination; just as our nation addressed discrimination based on race, we must now prevent

Finally, though the disability community lost the “Father of the ADA” when long-time advocate Justin Dart died on June 22, 2002, the initial spirit of the ADA remains alive with many members of Congress, even though some members unsuccessfully attempted to amend the ADA to be more restrictive before the close of the legislative session.²⁴⁵ The ultimate fate of both the Genetic Nondiscrimination in Health Insurance and Employment Act and the ADA remains to be seen.

discrimination based on genetic information.” *Bush Preference for GOP Genetic Nondiscrimination Bill Hinted at by Official*, *supra* note 239.

245. See *Justin Dart, Jr. Dies; Activist Battled for Rights of Disabled*, WASH. POST, June 23, 2002, at C6; see also *Debate Over Proposed Changes in ADA*, 26 MONTANA LAWYER 34, Jan. 2001 (noting that “in the past year, a handful of other measures have been proposed to amend the act – and this fact has some disability advocates concerned”). But see ADA Notification Act, H.R. 914, 107th Cong. (2001), available at <http://thomas.loc.gov>. The ADA Notification Act is an attempt by some members of Congress to amend the ADA to require plaintiffs to give defendants thirty days notice of an alleged violation of Title III of the ADA. *Id.* Proponents contend such an amendment is necessary to put an end to frivolous litigation, while critics argue it is simply an attempt by legislators to further restrict the reach of the ADA. See generally Kristin Loiacono, *ADA Notification Act: Delaying Justice for People with Disabilities*, 36 TRIAL 10 (July 2000) (noting Florida Representative Mark Foley’s attempt to amend Title III of the ADA).

