

## **Position Paper on Genetic Discrimination Legislation**

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### **Introduction**

The National Council on Disability (NCD) is an independent federal agency that advises the President and Congress on issues affecting 54 million Americans with physical and mental disabilities. NCD's fundamental purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, inclusion, and integration into all aspects of society.

For a number of years, NCD has recognized the harmful effects of discrimination based on individuals' genetic information and supported the need for federal legislation prohibiting genetic discrimination as well as the enforcement of existing legislation that may prohibit certain types of genetic discrimination. It has addressed the issue of genetic discrimination in several reports, including the following:

- ***Achieving Independence: The Challenge for the 21st Century. July 26, 1996*** (expressing serious concern about the quandaries and implications of obtaining and using genetic information; calling for further examination of the interface of genetic testing practices with antidiscrimination law and access to health insurance for people with disabilities).
- ***National Disability Policy: A Progress Report. July 26, 1996–Oct. 31, 1997*** (noting the potential for discrimination based on genetic information in employment, health care and other areas, and urging the President to work with Congress to enact legislation outlawing genetic discrimination and restricting access to genetic information by employers, insurance carriers and others).

- ***National Disability Policy: A Progress Report. Nov. 1999–Nov. 2000*** (applauding the Clinton Administration for issuing an executive order prohibiting certain types of genetic discrimination by federal employers, and urging the prompt reintroduction of legislation prohibiting genetic discrimination by employers and health insurers).
- ***Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act. June 27, 2000*** (supporting the U.S. Equal Employment Opportunity Commission’s (EEOC) position on genetic discrimination in its guidance on the definition of disability, which considered an individual discriminated against based on a genetic predisposition to disease or disability to be a person with a disability protected by the Americans with Disabilities Act (ADA) by virtue of being “regarded as” substantially limited in a major life activity; calling for technical assistance from federal agencies in emerging areas of ADA policy and enforcement such as genetic discrimination).

NCD’s interest in genetic discrimination legislation stems partly from the fact that the need for this legislation arises due to narrow judicial interpretations of ADA, and these same interpretations also create the need for legislation to restore protections for individuals who have actually developed health conditions. NCD believes that the concerns of individuals with actual health conditions have not been fully addressed in the dialogue about legislative proposals to address genetic discrimination.

### **The Need for Federal Legislation Prohibiting Genetic Discrimination**

#### **Recent Advances in Genetic Research Have Brought Increasing Potential for Genetic Discrimination**

Recent years have brought dramatic scientific advances in the study of human genetics. Scientists have mapped out DNA sequences in the human body and have identified many genes that cause disease. Consequently, they have been able to use genetic testing to identify individuals who may be susceptible to many diseases that are genetically linked.<sup>1</sup> Tests now exist that are able to detect genetic predispositions for many diseases and illnesses, such as Huntington’s disease, breast cancer, cystic fibrosis, Alzheimer’s disease, colon cancer, and Parkinson’s disease.<sup>2</sup> The number of conditions that may be detected by genetic tests is rapidly growing.<sup>3</sup> While these genetic advances hold tremendous potential for early identification, prevention and treatment of disease,

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<sup>1</sup> Deborah Gridley, Note, *Genetic Testing Under ADA: A Case for Protection from Employment Discrimination*, 89 Georgetown Law Journal 973, 976 (2001).

<sup>2</sup> *Id.* at 975; Testimony of Mary Davidson, Executive Director of Genetic Alliance, before U.S. House of Representatives Subcommittee on Commerce, Trade and Consumer Protection of the Committee on Energy and Commerce (July 11, 2001).

<sup>3</sup> Testimony of Mary Davidson, *supra* note 2.

they also create opportunities for discrimination against individuals based on their genetic information, even where individuals have no symptoms of disease.

In recent testimony before Congress, Dr. Francis Collins, Director of the National Human Genome Research Institute at the National Institutes of Health, observed:

while genetic information and genetic technology hold great promise for improving human health, they can also be used in ways that are fundamentally unjust. Genetic information can be used as the basis for insidious discrimination. . . . The misuse of genetic information has the potential to be a very serious problem, both in terms of people's access to employment and health insurance and the continued ability to undertake important genetic research.<sup>4</sup>

### **Genetic Discrimination is a Historical and Current Reality**

Discrimination based on genetic information is not a new phenomenon. During the early 1970s, employers used genetic screening to identify and exclude African Americans carrying a gene mutation for sickle cell anemia.<sup>5</sup> These individuals were denied jobs despite the fact that many of them were healthy and never developed the disease.<sup>6</sup> During the same time period, individuals who were carriers of sickle cell anemia were also discriminated against by several insurance companies despite the fact that they were asymptomatic.<sup>7</sup>

Genetic discrimination by employers and insurers has continued to be a systemic problem. According to a 1989 survey conducted by Northwestern National Life Insurance Company, 15 percent of the companies surveyed indicated that by the year 2000, they planned to check the genetic status of prospective employees and their dependents before making employment offers.<sup>8</sup>

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<sup>4</sup> Congressional Research Service, *Genetic Information: Legal Issues Relating to Discrimination and Privacy*, Report No. RL30006 (July 19, 2001) (hereafter "Congressional Research Service Report"), at 2.

<sup>5</sup> Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, Department of Justice, *Genetic Information and the Workplace* (Jan. 20, 1998) (hereafter "Joint Government Report"), at 3.

<sup>6</sup> *Id.*

<sup>7</sup> E. Virginia Lapham et al., *Genetic Discrimination: Perspectives of Consumers*, 274 *Science* 621 (1996).

<sup>8</sup> Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 *American Journal of Law & Medicine* 109, 116 (1991).

A 1996 survey of individuals at risk of developing a genetic condition and parents of children with specific genetic conditions indicated more than 200 instances of genetic discrimination reported by the 917 respondents. The discrimination was practiced by employers, insurers, and other organizations.<sup>9</sup> Another survey of genetic counselors, primary care physicians, and patients identified 550 individuals who were denied employment or insurance based on genetic information.<sup>10</sup> A study on genetic discrimination, published in 1996, found that health and life insurance companies, health care providers, blood banks, adoption agencies, the military, and schools engaged in genetic discrimination against asymptomatic individuals.<sup>11</sup>

*Science* magazine reported that in a study of 332 individuals with one or more family members with a genetic disorder who are affiliated with genetic support groups, 40 percent of the respondents recalled being specifically asked about genetic diseases or disabilities on their applications for health insurance.<sup>12</sup> Twenty-two percent of the respondents said they or a family member were refused health insurance as a result of the genetic condition in the family.<sup>13</sup> Fifteen percent of the respondents reported that they or affected family members had been asked questions about genetic diseases or disabilities on employment applications.<sup>14</sup> Thirteen percent reported that they or a family member had been denied a job or fired from a job because of a genetic condition in the family, and 21 percent reported being denied a job or fired due to their own genetic disorder.<sup>15</sup>

In addition to these and other studies, numerous anecdotal examples of genetic discrimination by employers and insurers have been detailed in testimony before Congress in hearings about genetic discrimination.

### **Genetic Discrimination Undermines the Purposes of Genetic Research and Testing**

The misuse of genetic information not only excludes qualified individuals from employment and denies insurance coverage to individuals without justification, but also undercuts the fundamental purposes of genetic research. Such research has been undertaken with the goals of early identification, prevention and effective treatment of disease. These goals will be undermined if fear of discrimination deters people from genetic diagnosis and prognosis, makes them fearful of

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<sup>9</sup> Joint Government Report, *supra* note 5, at 2.

<sup>10</sup> *Id.*

<sup>11</sup> Congressional Research Service Report, *supra* note 4, at 3.

<sup>12</sup> Lapham et al., *supra* note 7, at 622.

<sup>13</sup> *Id.* at 624.

<sup>14</sup> *Id.* at 626.

<sup>15</sup> *Id.*

confiding in physicians and genetic counselors, and makes them more concerned with loss of a job or insurance than with care and treatment.<sup>16</sup>

The fears engendered by genetic discrimination—fears of disclosure of genetic information to physicians and of participation in genetic testing and research—have been well documented in numerous studies. In one study, 83 percent of the participants indicated that they would not want their insurers to know if they were tested and found to be at high risk for a genetic disorder.<sup>17</sup> In a 1997 survey of more than 1,000 individuals, 63 percent of the participants reported that they would not take genetic tests for diseases if health insurers or employers could get access to the results.<sup>18</sup> Additionally, researchers conducting a Pennsylvania study to determine how to keep women with breast cancer gene mutations healthy reported that nearly one third of the women invited to participate in the study declined out of fear of discrimination or loss of privacy.<sup>19</sup> The results of a national survey released by the California HealthCare Foundation in 1999 indicate that 15 percent of adults surveyed took steps to keep genetic information private, such as paying for testing out of pocket rather than using their insurance coverage, constantly switching doctors to avoid the compilation of a comprehensive medical history, refusing to seek needed medical care, and/or providing false or incomplete information to physicians.<sup>20</sup> Another study showed that 57 percent of surveyed individuals at risk for breast or ovarian cancer had chosen not to take a needed genetic test, and 84 percent of those individuals who had decided to forego the test cited fear of genetic discrimination as a major reason for their decision.<sup>21</sup>

These fears eliminate people's opportunities to learn that they are not at increased risk for the genetic disorder in the family or to make lifestyle changes to reduce risks.<sup>22</sup> They may also affect the number of people willing to participate in scientific research.<sup>23</sup>

### **Genetic Test Information Has Little Value for Purposes of Making Employment Decisions and Insurance Decisions**

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<sup>16</sup> Gostin, *supra* note 8, at 113.

<sup>17</sup> Lapham et al., *supra* note 7, at 622.

<sup>18</sup> Joint Government Report, *supra* note 5, at 2.

<sup>19</sup> *Id.*

<sup>20</sup> Genetic Alliance, *The Insured, the Underinsured, and the Uninsurable: the Role of Genetics in Health Care Coverage* (Oct. 2001) (unpublished), at 2-3.

<sup>21</sup> Caryn Lerman et al., *BRCAl testing in families with hereditary breast-ovarian cancer. A prospective study of patient decision making and outcomes*, 275 *Journal of American Medical Ass'n* 1885 (1996). In another study, concern about health insurability was the leading reason for individuals' decisions to decline cancer genetic counseling services. Katherine P. Geer et al., *Factors Influencing Patients' Decisions to Decline Cancer Genetic Counseling Services*, 10 *Journal of Genetic Counseling* 25 (2001).

<sup>22</sup> Lapham et al., *supra* note 7, at 622.

<sup>23</sup> *Id.*

There is no consensus on the scientific validity of genetic tests or their usefulness for predicting an individual's susceptibility to exposure.<sup>24</sup> The results of genetic-based diagnosis and prognosis are uncertain for many reasons. First, the sensitivity of genetic testing is limited by the known mutations in a target population. Many individuals with a genetic predisposition for a particular disease will not be identified because these markers are not among the known genetic mutations.<sup>25</sup> Secondly, many individuals are falsely labeled "at risk" due to the genetic screening of family members.<sup>26</sup> Thirdly, genetic markers are generally not valid predictors of the nature, severity and course of disease. For most genetic disease, the onset date, severity of symptoms, and efficacy of treatment and management are highly variable, with some people identified by screening remaining symptom-free and others progressing to disabling illness.<sup>27</sup> Genetic tests alone cannot predict with certainty whether an individual with a particular genetic error will actually develop a disease.<sup>28</sup> These tests evaluate people according to stereotypes of future ability to function and the probability that disease will occur, rather than evidence of actual disease and ability.<sup>29</sup>

### **Existing Laws Are Insufficient to Protect Individuals from Genetic Discrimination**

There are existing laws that may prohibit genetic discrimination in some contexts. However, these laws do not reach much of the discrimination that occurs and, in some cases, may be interpreted not to apply to genetic discrimination at all.

### **The Americans with Disabilities Act**<sup>30</sup>

The Americans with Disabilities Act (ADA), an anti-discrimination law, protects individuals who have an impairment that substantially limits them in a major life activity, who have a record of such an impairment, or who are regarded as having such an impairment.<sup>31</sup> Congress intended ADA to cover individuals with a broad range of diseases, and some members of Congress

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<sup>24</sup> Joint Government Report, *supra* note 5, at 3.

<sup>25</sup> Gostin, *supra* note 8, at 113.

<sup>26</sup> *Id.* at 114.

<sup>27</sup> *Id.*

<sup>28</sup> Joint Government Report, *supra* note 5, at 1; Elaine Draper, *The Screening of America: The Social and Legal Framework of Employers' Use of Genetic Information*, 20 Berkeley Journal of Employment & Labor Law 286, 290-91 (1999).

<sup>29</sup> Draper, *supra* note 28, at 290.

<sup>30</sup> The analysis of ADA's application to genetic discrimination in employment also applies to Section 504 of the Rehabilitation Act, which applies to federal employers and entities receiving federal funds. Section 504 has the same definition of disability as that contained in ADA.

<sup>31</sup> 42 U.S.C. § 12102(2).

explained at the time of ADA's passage that it would protect people who experience discrimination on the basis of predictive genetic information where those individuals were regarded as having a disability.<sup>32</sup> ADA has also been interpreted by EEOC to prohibit some forms of genetic discrimination. In 1995, the EEOC issued enforcement guidance advising that an employer who takes adverse action against an individual on the basis of genetic information may regard the individual as having a disability and, therefore, may be violating ADA.<sup>33</sup> EEOC recently settled its first court action challenging an employer's use of genetic testing<sup>34</sup> and also issued a finding of cause in an administrative complaint filed by a woman who was terminated based on a genetic test result.<sup>35</sup>

Nonetheless, ADA is a highly problematic vehicle for fully addressing genetic discrimination. At recent Senate hearings, EEOC Commissioner Paul Steven Miller testified that while ADA could be interpreted to prohibit employment discrimination based on genetic information, it "does not explicitly address the issue and its protections are limited and uncertain."<sup>36</sup>

ADA could be interpreted to protect individuals with genetic markers for disease in two ways. First, as described above, such individuals may be protected if they are regarded as substantially limited in a major life activity B for example, if they are regarded as substantially limited in working due to their genetic predisposition. However, recent Supreme Court cases discussing what it means to be regarded as substantially limited in working suggest that such claims are extremely unlikely to succeed. In *Sutton v. United Airlines, Inc.*<sup>37</sup> and *Murphy v. United Parcel Service, Inc.*,<sup>38</sup> the Court stated that a job requirement excluding individuals based on their impairments does not necessarily establish that the employer regards individuals excluded by this requirement as substantially limited in working. To be covered under the "regarded as" prong, the plaintiffs would have to prove that they were regarded as substantially limited in performing a broad class of jobs, not merely their own jobs. It may prove extremely difficult for plaintiffs with genetic markers who are denied employment due to an employer's concern about health

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<sup>32</sup> 136 Cong. Rec. H4627 (statement of Rep. Waxman).

<sup>33</sup> Joint Government Report, *supra* note 5, at 6; EEOC Compliance Manual § 902, Order 915.002, 902-45 (1995).

<sup>34</sup> *EEOC v. Burlington Northern Santa Fe Railroad*, Civ. No. 01-4013 MWB (N.D. Iowa Apr. 23, 2001) (Agreed Order). The Railroad, which had tested for carpal tunnel syndrome propensity, agreed to stop requiring genetic tests, using genetic information relating to its employees, and disclosing such information to the public.

<sup>35</sup> Congressional Research Service Report, *supra* note 4, at 9 (describing complaint filed by Terri Sergeant alleging a violation of ADA based on her termination after being diagnosed with Alpha 1 Antitrypsin Deficiency).

<sup>36</sup> *Id.*

<sup>37</sup> 527 U.S. 471, 473-74 (1999).

<sup>38</sup> 527 U.S. 516, 516-17 (1999).

insurance premiums or productivity losses to show that the employer regarded them as substantially limited in performing not only the job in question but a broad class of other jobs as well.

Individuals who experience genetic discrimination may also be covered under ADA if they are regarded as substantially limited in other major life activities besides working. It is unlikely that most plaintiffs will be able to establish the requisite proof to prevail on such claims. Most courts have interpreted “substantially limited” so restrictively that an individual must be extremely debilitated.<sup>39</sup> Moreover, the courts have interpreted ADA to require consideration of any measures that an individual takes to control the effects of her limitations.<sup>40</sup> Thus, it is unlikely that an individual with a genetic predisposition for a disease, but who has not actually developed the disease, will be able to show that he was regarded as substantially limited in any major life activity.

An individual who experiences genetic discrimination may also be covered by ADA under the first prong of the definition of disability—that is, by showing that she has an actual impairment that substantially limits her in a major life activity. In *Bragdon v. Abbott*,<sup>41</sup> the Supreme Court held that an individual with asymptomatic HIV was covered under the first prong because she was substantially limited in reproduction due to the risk of transmitting HIV to a fetus. The Court found that the asymptomatic HIV was a physical impairment based on the physiological effects of the infection. It is unclear, however, whether courts would find a genetic marker to constitute an actual impairment.

Even assuming ADA did apply, in many situations it might not prevent employers from accessing genetic information. While ADA does bar medical inquiries before a conditional offer of employment is made, it would permit employers to request genetic information if they could establish that the information was job-related and consistent with business necessity.<sup>42</sup>

### **The Health Insurance Portability and Accountability Act**

The Health Insurance Portability and Accountability Act (HIPAA) prohibits genetic discrimination by insurers in very limited circumstances. It prohibits group health plans from

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<sup>39</sup> For a discussion of how the courts have interpreted ADA far more restrictively than Congress intended, see Chai Feldblum, *Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?*, 21 Berkeley Journal of Labor & Employment 91 (2000).

<sup>40</sup> *Sutton v. United Airlines, Inc.*, 527 U.S. at 481-88; *Murphy v. United Parcel Service*, 527 U.S. at 521.

<sup>41</sup> 524 U.S. 624 (1998).

<sup>42</sup> 42 U.S.C. § 12112(c); Congressional Research Service Report, *supra* note 4, at 13.

using any health status-related factor, including genetic information, as a basis for denying or limiting coverage or for charging an individual more for coverage.<sup>43</sup> However, a plan may still establish limitations on the amount, level, extent or nature of benefits or coverage provided to similarly situated individuals.<sup>44</sup> Thus, plans may still provide substantially fewer services even though they may not charge more for coverage. In addition, privacy regulations issued pursuant to HIPAA require patient consent for most sharing of personal health information by health insurers, providers, and health care clearinghouses. Companies that sponsor health plans are prohibited from accessing personal health information for employment purposes unless the patient consents. These provisions do little to prevent genetic discrimination in the workplace and, while they do prohibit some forms of genetic discrimination by insurers, that protection is extremely limited.

### **Title VII**

Race and gender discrimination laws may apply to certain forms of genetic discrimination as well.<sup>45</sup> For example, Title VII of the Civil Rights Act of 1964, which prohibits employment discrimination based on race or gender, may prohibit employers from denying employment based on genetic markers linked to race, such as that for sickle cell anemia, or linked to gender, such as those for breast or ovarian cancer. Some courts have said in dicta that employment classifications based on sickle cell anemia would create a disparate impact on African Americans, but no lawsuit has successfully been brought challenging such classifications under Title VII.<sup>46</sup> At least one court has rejected such a claim.<sup>47</sup>

### **State Laws**

A number of states have passed state laws that prohibit certain forms of genetic discrimination. These laws, however, vary widely in the scope of their protection.<sup>48</sup> Many are narrowly targeted to particular genetic conditions, some prohibit only certain types of screening but do not prohibit adverse employment actions based on genetic information, and some only address genetic counseling and confidentiality.<sup>49</sup> These laws have been described as “a patchwork of provisions

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<sup>43</sup> 29 U.S.C. § 1182(a)(1), 1182(b)(1).

<sup>44</sup> *Id.* § 1182(a)(2)(B).

<sup>45</sup> See Gostin, *supra* note 8, at 109; Congressional Research Service Report, *supra* note 4, at 30 n.8.

<sup>46</sup> Gostin, *supra* note 8, at 138.

<sup>47</sup> *Id.* at 138-39.

<sup>48</sup> Joint Government Report, *supra* note 5, at 8.

<sup>49</sup> Gridley, *supra* note 1, at 980-81.

which are incomplete, even inconsistent, and which fail to follow a coherent vision for genetic screening, counseling, treatment and prevention of discrimination.”<sup>50</sup>

In light of the inadequacies of federal and state law to address genetic discrimination issues, comprehensive federal legislation that specifically addresses these issues is necessary.

### **Principles for Genetic Discrimination Legislation**

NCD believes that it is crucial for any proposed legislation addressing genetic discrimination to reflect the following principles:

#### **Workplace Discrimination:**

Any proposed legislation must provide effective prohibitions against discrimination by employers based on genetic information. Employers must not be permitted to use predictive genetic information as a basis for hiring, firing, or taking any other employment action, or as a term or condition of employment. Nor should an employer be permitted to use this information, or be permitted to limit, segregate or classify employees or job applicants. This information should not be permitted to play a role in an employment agency’s referral of individuals for employment; in decisions by a labor organization about admission to its membership; or in admission to or employment by a training program.

#### **Collection and Disclosure of Genetic Information by Employers:**

Any proposed legislation must contain strict limits on the collection and disclosure of genetic information by employers so as to prevent that information from being used for discriminatory purposes. Employers must not be permitted to collect genetic information except under very limited circumstances that will be used only to benefit employees and only on a voluntary basis.

Specifically, employers should be permitted to request predictive genetic information only: (1) for the purpose of monitoring effects of toxic substances in the workplace, and only if an employee has provided written consent to such monitoring, the employee is informed of the results, the monitoring conforms to national standards, and the employer does not receive results for particular individuals but rather receives only aggregate results for all individuals monitored; and (2) for the purpose of providing genetic services to employees, but only if such services are provided with the employee’s written consent and only the employee receives the results.

Additionally, employers must maintain strict confidentiality of genetic information of applicants or employees that is in the employers’ possession. Genetic information should be kept

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<sup>50</sup> Gostin, *supra* note 8, at 142.

confidential and maintained separately from personnel files and other non-confidential information. It should be disclosed only to the employee, to officials enforcing this legislation, or as required by other federal laws.

### **Insurance Discrimination:**

Any proposed legislation should contain comprehensive protection against genetic discrimination by providers of health, life, disability, and other types of insurance. Legislation must bar insurers from making decisions about enrollment based on genetic information. It must also prohibit insurers from using genetic information in determining premium or contribution rates, or other terms or conditions of coverage. Finally, it must bar insurers from requesting or requiring an individual to undergo genetic testing.

### **Collection and Disclosure of Genetic Information by Insurers:**

Any proposed legislation must prohibit insurers from requiring, requesting, collecting, or buying genetic information about individuals who are covered or seeking coverage.

Insurers should be permitted, however, to obtain this information only for the limited purpose of paying for claims for genetic testing or other genetic services. Strict protections must be in place to ensure that when such information is requested, it is not used to affect an individual's enrollment, premiums, or terms or benefits of coverage.

Insurers must also be prohibited from disclosing genetic information to health plans or issuers of health insurance (except in the limited circumstances described above where the information is used for purposes of payment of claims), employers, and entities that collect and disseminate insurance information.

### **Health Care Provider Discrimination:**

Any proposed legislation should protect against genetic discrimination by health care providers. Health care providers must not be permitted to refuse treatment to individuals, or treat them differently, based on genetic information. For example, "futile care" policies, under which medically indicated treatments may be denied based on determinations that such treatments would be "futile" in light of an individual's expected quality of life, should be prohibited to the extent that they result in denials of treatment based on genetic information.

### **Collection and Disclosure of Genetic Information by Health Care Providers:**

Any proposed legislation must prohibit health care providers from requiring, requesting, or collecting genetic information about individuals who are seeking treatment. Providers may only collect this information for the purpose of providing genetic testing or other genetic services.

Health care providers must not be permitted to disclose genetic information except to the patient, to insurers only for the limited purpose of seeking payment for genetic testing or genetic services rendered, to officials enforcing this legislation, or as required by other federal laws.

**Education and Technical Assistance:**

Any proposed legislation should include funding to permit education and technical assistance to be provided by appropriate organizations in order to ensure that individuals affected by the legislation are aware of its requirements. Such assistance is important to ensure effective enforcement of the legislation.

**Effective Enforcement Mechanisms:**

Any proposed legislation must contain a private right of action for individuals to enforce its provisions. Additionally, EEOC should have the authority to investigate and resolve complaints of violations of the employment provisions of the law. In order to be effective, the legislation must provide for the full panoply of legal remedies, including attorney's fees.

**Relationship to Other Laws:**

Any proposed legislation must serve as a set of minimum standards that do not preempt more stringent standards that may exist in other laws. Thus, the legislation must not preempt stronger state laws. Similarly, it must not preempt other federal laws that may be applicable where those laws provide stronger protection against genetic discrimination.

**Addressing Protections for Individuals with Actual Health Conditions:**

As discussed above, courts have interpreted ADA in a number of ways that severely restrict the number of people protected.<sup>51</sup> They have interpreted ADA to protect only individuals who are so limited in major life activities that they are extremely debilitated, and to exclude protection for many individuals who take mitigating measures to control the effects of their impairments. They have made it extraordinarily difficult for individuals to establish that an employer regards them as substantially limited in working. These interpretations of ADA have resulted in far more limited protection than Congress envisioned when it passed ADA.

The same interpretations that make ADA difficult to enforce by individuals with genetic markers make it difficult to enforce by individuals with a range of health conditions. When Congress considers protections for individuals who experience discrimination based on genetic

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<sup>51</sup> See Feldblum, *supra* note at 39.

information, it should also ensure that if these individuals are eventually diagnosed with medical conditions, they will be protected against discrimination.