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Genetic Discrimination and the Public Entities and Public Accommodations Titles of the Americans with Disabilities Act

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Summary

The introduction of newly developed medical genetic diagnostic tests has been accompanied by social problems involving privacy issues and genetic discrimination. Previous studies of genetic discrimination have focused on the areas of employment and insurance. In this paper, we provide six hypothetical illustrative cases of genetic discrimination involving access to public entities and to private entities considered to be public accommodations. We argue that many of these forms of genetic discrimination that arise in both the public and private sectors should be prohibited by Titles II and III, respectively, of the Americans with Disabilities Act of 1990.

Introduction

Numerous recent advances in medical genetics have led to dramatic improvements in the diagnosis and, in some instances, treatment of genetic diseases (Childs et al. 1988; Antonarakis 1989; Scriver et al. 1989). However, as has been the case with other new technologies, the advances in medical genetics have been accompanied by potential social problems. For the particular case of genetic diagnostic tests, these problems include privacy issues involving the disclosure of test results to relatives and unrelated third parties and ethical issues involving prenatal screening and alternative reproductive procedures. Of increasing importance are issues involving genetic discrimination.

Genetic discrimination is discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the typical ("normal") genome in the genetic constitution of that individual (Billings et al. 1992*b*; Natowicz et al. 1992*b*). These articles distinguished genetic discrimination from discrimination based on disabilities (including disabilities caused by altered genes), by excluding from the former category discrimination against an individual who at the time of the discriminatory act is affected by the disease. We would extend the above definition, however, to include individuals who are affected by a genetic disease, if the cause of the discrimination is their genotype rather than the phenotypic manifestations of their genotype. Thus, in addition to those individuals who are asymptomatic or presymptomatic and who experience discrimination because of a genetic diagnosis in themselves or in a family member, we would include people with genetic conditions whose symptoms are sufficiently mild so that they are not actually disabled but who are regarded as being disabled simply because their condition is a genetic one. In addition, we would include people who are more seriously disabled but who experience discrimination not because of their own disability but because of their genetic diagnosis per se or because their children might inherit their condition.

At least one commentator (an anonymous reviewer of an earlier version of this paper) has questioned the need for a separate category of genetic discrimination, since some forms of genetic discrimination cannot always be easily distinguished from other forms of disability discrimination. For example, some persons with abnormal genotypes may experience discrimination not because of their genotype but because of the abnormal phenotype that might result from that genotype. This type of discrimination is closely related to the case of

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discrimination against a person who is currently asymptomatic but HIV positive.

We would argue, however, that one should not dismiss the category of genetic discrimination simply because it cannot always be easily distinguished from other forms of disability discrimination. Most types of genetic discrimination are clearly distinguishable from other forms of discrimination based on disability. Two examples are discrimination directed against a relative of an individual with a genetic diagnosis and discrimination directed against an asymptomatic heterozygote for an autosomal recessive condition.

In addition, discrimination on the basis of genotype should be considered as a separate category because, in the political and social arena, it has already been regarded as separate (Blumenthal 1991; Thornton 1991). In fact, some students in the field believe that the Americans with Disabilities Act of 1990 (ADA) may, in fact, not cover some forms of genetic discrimination (Holtzman and Rothstein 1992). In addition, and further emphasizing the importance of the notion of genetic discrimination, is the fact that a number of states (e.g., California, Wisconsin, and Ohio) have enacted or considered legislation specifically addressing the issue of genetic discrimination (McEwen and Reilly 1992).

The ADA is the most important civil rights legislation ever enacted on behalf of people with disabilities. Its primary purpose is "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" (Sec. 2[b][1]). Disability, as defined by the ADA, includes "a physical or mental impairment that substantially limits one or more of the major life activities . . . ; a record of such an impairment; or being regarded as having such an impairment" (Sec. 3[2][A–C]). The ADA provides protection in the areas of employment, state and local government services, public accommodations, and telecommunications.

Several recent articles have discussed the potential role of the ADA in proscribing genetic discrimination. These articles have focused primarily on discrimination in the areas of employment and insurance because it is anticipated that most cases of genetic discrimination will occur in these areas (Rothstein 1990; Gostin 1991). As we have discussed in a previous paper (Natowicz et al. 1992*b*), we believe that Title I of the ADA should prohibit most forms of genetic discrimination in employment, because the ADA prohibits discrimination against people who are perceived as having a disabling impairment, even though these people may in fact be asymptomatic. It is important to note, however, that the issue of whether Title I of the ADA prohibits discrimination against people who are asymptomatic is not universally agreed on and will require clarification in the courts (Thornton 1991; Holtzman and Rothstein 1992; Natowicz et al. 1992*a*). With regard to discrimination by insurance companies, it is clear that the ADA allows insurance companies to discriminate against individuals in underwriting both health and life insurance policies if the underwriting policies are consistent with state law (Title V, Sec. 501[c][1]) and "are based on sound actuarial data" (56 Fed. Reg. 35563 [July 26, 1991]). However, the provisions of the ADA that exempt insurers cannot be used as a subterfuge to evade the intent of the employment and public accommodations sections of the law (42 U.S.C Sec. 12201[c]).

To date, there has been almost no published work regarding genetic discrimination outside the areas of employment and health and life insurance. It is clear, however, that genetic discrimination can arise in a large number and variety of situations (Billings et al. 1992*b;* M. R. Natowicz, unpublished data). The principal aim of the present paper is to alert clinicians and allied health professionals to previously unrecognized aspects of discrimination associated with genetic disorders and to the possible remedies provided by the ADA. Specifically, we discuss the potential protection against genetic discrimination provided by Titles II and III of the ADA. As is the case with Title I, these titles of the ADA cover asymptomatic individuals who are regarded by others as having a disability, as well as individuals who are symptomatic or have a record of being disabled.

Title II of the ADA prohibits discrimination by public entities: "Subject to the provisions of this title, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity" (Sec. 202). Public entities include any state or local government and any agency of a state or local government. (Executive agencies of the federal government are prohibited from discriminating by Secs. 501 and 504 of the Rehabilitation Act of 1973.)

Title III prohibits discrimination in public accommodations and services provided by private entities: "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a

place of public accommodation" (Sec. 302[a]). The varieties of private entities that are considered public accommodations by the ADA are listed in Section 301(7) of the act. Of particular relevance to genetic discrimination are the entities listed in subsections "(F) bank, . . . , insurance office, professional office of a health care provider, hospital, or other service establishment"; "(J) a nursery, elementary, secondary, undergraduate, or postgraduate private school or other place of education"; "(K) day care center, senior citizen center, homeless shelter, food bank, adoption agency, or other social service center establishment" and "(L) a gymnasium, health spa, bowling alley, golf course, or other place of exercise or recreation." It is important to note that although the categories are exhaustive (e.g., service establishments [F], places of education [J], social service center establishments [K], and places of exercise or recreation [L]), the examples provided in the statute are only representative (56 Fed. Reg. 35551 [July 26, 1991]).

Hypothetical Cases of Genetic Discrimination

In this section, we discuss six hypothetical cases illustrating a wide variety of examples of genetic discrimination. The first two are based on actual cases described earlier (Billings et al. 1992*b*). Of the six cases, one (case 3) involves genetic discrimination by a state government agency; the others involve private entities considered to be public accommodations.

Case 1

A man with Charcot-Marie-Tooth disease, a nonfatal and clinically variable neuromuscular condition, was denied automobile insurance even though he had no significant symptoms and had had no accidents or traffic violations in 20 years of driving. The insurance company had never refused to issue an automobile insurance policy to an individual who had mild symptoms due to a nongenetic condition. The analysis of the regulations enacted by the U.S. Department of Justice interpreting the insurance provisions of the ADA quoted above requires that there be an actuarial basis for discrimination in all types of insurance underwritten on an individual basis (56 Fed. Reg. 35562–35563 [July 26, 1991]). There is no actuarial basis for this incident of discrimination, however. The individual had no prior history of motor vehicle accidents. It is also unlikely that his denial was based on the actual driving experiences of persons affected with Charcot-Marie-Tooth syndrome, as we are unaware of any published data regarding this issue. Thus, since there was no actuarial basis for the denial of automobile insurance, we believe that the insurance company would be in violation of Title III of the ADA.

Case 2

A woman who was at risk for Huntington disease desired to have a baby. Rather than risk passing the Huntington gene to her own children, she and her husband decided to adopt a child. The adoption agency rejected their application because she had a 50% chance of developing this invariably fatal disease.

Section 302(b)(2)(A)(i) of Title III of the ADA states that discrimination includes the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability—or any class of individuals with disabilities—from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations, unless such criteria can be shown to be necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered.

Denying a couple the opportunity to adopt a child because of the risk for a genetic or nongenetic disabling condition is certainly a form of discrimination that involves criteria described in the quoted section of the ADA. We would argue that the condition of being at risk for Huntington disease should not be a sufficient condition for being excluded from the privilege of adopting a child. We believe that legitimate criteria for adopting a child should be based on the current or short-term ability of the prospective parents to support and nurture the child, rather than on their long-term health or longevity. In Massachusetts, for example, adoption agencies may not discriminate on the basis of age (Standards for Licensure or Approval of Placement Agencies Offering Adoption Services, Reg. 102 CMR 5.00 and 5.079). In addition, many people in the population are at increased risk for such potentially fatal diseases as cancer and heart disease. It is unlikely that these people would be denied the right to adopt a child. Moreover, even if the woman did develop Huntington disease, the child's father or other caregivers could assume the entire parenting role. In contemporary society in which a significant proportion of marriages end in divorce leaving the children with one parent in the home, it seems an unreasonable and certainly unnecessary criterion to deny a couple a child because of the probability that the child will lose one parent (Billings

et al. 1992*a*). Our analysis is both equitable for the prospective parents and in keeping with a "best interests of the child" standard.

Case 3

A graduate of dental school has a late-onset form of Tay-Sachs disease. The disease was unexpectedly ascertained during an assessment for her Tay-Sachs disease carrier status. She is presently physically and mentally competent but is at increased risk of developing muscle weakness, movement disorders, and, possibly, early-onset dementia (Navon et al. 1986). She was denied a license to practice dentistry by her state, because of the fear that, if she did develop significant neuromuscular involvement or dementia, she would pose a serious risk to her patients.

It should be noted that the ADA would permit the license to be denied if the dentist posed a "direct threat to the health and safety of others" (ADA Sec. 302[b][3], 56 Fed. Reg. 35701). However, according to the interpretation of the regulations implementing the ADA, these concerns for the health and safety of others must be balanced against the "goal of protecting disabled individuals from discrimination" (56 Fed. Reg. 35701). The interpretation further provides that "objective evidence" be used to determine "the probability that the potential injury will actually occur, and whether reasonable modifications of policies, practices, or procedures will mitigate the risk." We would argue that the state is required to grant the license insofar as her genetic diagnosis is not relevant to the current performance of her job and to the health and safety of others (Natowicz et al. 1992*c*). However, the state could require the dentist to provide the licensing board with the results of periodic medical evaluations to insure that she remains fit to practice dentistry. We would further argue that this standard should apply to all dentists and not just to those at risk for genetic conditions.

Case 4

A healthy 30-year-old internist was recently diagnosed as being presymptomatic for Friedreich ataxia (FA), an autosomal recessive neurodegenerative condition. He has a positive family history for FA; two older siblings are symptomatic. The diagnosis of the condition in his case was achieved by DNA linkage analysis (Fujita et al. 1990). The loan officer of his bank learned of the diagnosis in the course of conversation with the internist. As a result of the diagnosis, the internist's application for a mortgage to finance the purchase of a house was rejected. The bank said that, although he is presently healthy, he is at risk for a disabling condition that could, at some future time, prevent him from pursuing his medical career and, thus, maintaining his current level of income. In our opinion, this type of discrimination is illegal. Irrespective of whether the individual will actually become disabled, on the basis of Section 302(b)(2)(A)(i) of Title III quoted above, we believe that banks (Sec. 301[7][F]) will not be able to deny mortgages or other long-term loans to qualified people who may develop a genetic disease later in life, just as federal law prohibits the denial of a mortgage to an elderly person whose life expectancy is less than the term of the mortgage (Equal Credit Opportunity Act 15 U.S.C. §1691 [a][1]; Reg. B, 12 CFR 202.2[v]). Qualifications for a mortgage include only *present* financial status.

Case 5

An asymptomatic, academically gifted 22-year-old woman applied for admission to a private medical school. The woman, who had a family history of autosomal dominant polycystic kidney disease, sought testing and was found to carry the altered gene. She mentioned her condition during the interview for admission and shortly thereafter received a letter of rejection. She was subsequently told by the admissions office that her rejection was based on the high likelihood that she would be able to practice medicine for a significantly shorter period of time than would the average medical school graduate. Thus, despite her excellent academic and personal qualifications, the admission's committee felt that she would not represent a "good investment" of the school's resources.

According to the ADA, a medical school will not be able to use genetic or nongenetic medical information about an applicant when deciding whether to admit that applicant to the school. Discrimination against either a person with a serious disease or an asymptomatic individual who has a genotype that will (or might) result in a serious disease later in life would most probably be barred by Title III of the ADA (or by Title II, if the medical school is a public institution). Also, insofar as the central issue in this example is the diminished number of years of professional service, it should be noted that federal law prohibits educational institutions that receive federal funds from discriminating on the basis of age (Age Discrimination in Federally Assisted Programs, Chap. 76, §6102, §6107[B][i]).

Case 6

A 30-year-old African-American man applied for membership in a health club. To ensure that its members are free from medical conditions that might be exacerbated by exercise, the health club requires the submission of a medical history form. On discovering that the applicant in this case is a heterozygote for sickle cell disease, the club rejected his application. Even though he was asymptomatic and would remain so, the club believed that strenuous exercise might result in the manifestations of a sickling crisis. Since the medical evidence supporting this belief is limited and controversial (Kark et al. 1987; Weatherall et al. 1989; U.S. Congress Office of Technology Assessment 1990, pp. 41–52), we believe this rejection to be illegal according to the ADA. This hypothetical example is by no means improbable. At one time, the U.S. Air Force forbade carriers of sickle cell disease from becoming pilots, because of the belief that carriers would encounter difficulties resulting from the decreased oxygen level at high altitudes (U.S. Congress Office of Technology Assessment 1990, pp. 41–52).

Limitations of Titles II and III of the ADA

Health maintenance organizations and hospitals, as well as insurance companies, are not, as mentioned above, prohibited or restricted by the ADA in their activities involving "underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law" and based on sound actuarial data. This legal qualification could serve as the basis for denying life or disability insurance to an individual with a genetic diagnosis. Similarly, health maintenance organizations or health insurance companies could deny a policy to an individual with a genetic diagnosis, even if the individual were presymptomatic, provided that a sound actuarial basis for the denial could be established. In fact, it is quite likely that a health maintenance organization would not be prevented by the ADA from requiring a pregnant woman to undergo prenatal screening and to abort the fetus if it were affected by a serious genetic disease, as a condition for covering the pregnancy and the child under a family health plan.

Conclusions

In this paper, we have given hypothetical examples of genetic discrimination in areas other than employment and have argued that the ADA should provide protection against these forms of discrimination. Although at the present time there have been few published cases of genetic discrimination involving areas outside of employment and insurance, we expect the incidence of these and other forms of genetic discrimination to increase markedly in the near future, as a result of several factors. First, the number and predictive value of genetic tests for a wide variety of genetic conditions are increasing with remarkable rapidity. Second, as medical records become more computerized and centralized, it will become an increasingly common practice for governments, corporations, and social service agencies to obtain copies of these records (Andrews 1987, pp. 187–220, 1991; Norton 1989; Cunningham 1990; DeGorgey 1990; Andrews and Jaeger 1991; Natowicz and Alper 1991; Miller 1992). The dissemination of medical information will most likely become as widespread as the dissemination of economic information in the form of credit histories of individuals. We might note that insurance companies already have access to a centralized depository of medical information, the Medical Information Bureau, that contains detailed medical records of many of the people who have ever applied for insurance (Norton 1989).

At the present time, we do not know the number of people who have experienced genetic discrimination. The empirical reports published to date involve case studies focusing on the significance and variety of genetic discrimination (Billings et al. 1992*b*). However, the case-study approach does not provide quantitative information about the frequency of genetic discrimination. In addition, it is too soon after the passage of the ADA to estimate the number of cases of genetic discrimination on the basis of numbers of lawsuits filed. Even state insurance commissions may not be aware of the magnitude of the problem, since neither they nor the people experiencing such discrimination may be aware of this newly described form of discrimination.

Despite this lack of documentation about the frequency of genetic discrimination, we believe that there can be no doubt about its significance. Given the wide variety of circumstances in which such discrimination can occur, we believe that the reported cases represent only a small fraction of the number of actual cases. But even if there are fewer cases of genetic discrimination than we believe, the importance of the problem must not be underestimated. The hardship and suffering associated with genetic discrimination, like that associated with other types of discrimination, cannot and

should not be measured by the number of people subjected to unfair treatment.

Previous case studies (Billings et al. 1992*b*), as well as our work in progress, provide evidence that genetic discrimination exists and often results in severe and unnecessary hardships. Although most of the cases evaluated to date occurred in the areas of employment and health and life insurance underwriting, the cases presented in the present paper show that genetic discrimination can arise in many aspects of daily life. We have given examples involving automobile insurance, adoption, acquisition of a professional license, qualification for a mortgage, and admission to a medical school and to a health club. These examples are by no means exhaustive; they merely illustrate the potential scope of the problems raised by genetic discrimination. They are intended to show, first, that the potential exists for genetic discrimination outside the areas of employment and insurance and, second, that, in our opinion, regulatory agencies and the judiciary will rule that Titles II and III of the ADA provide a significant degree of protection against genetic discrimination.

Despite the strengths of the ADA and other related legislation protecting people with disabilities, these laws will not be sufficient to eliminate discrimination. As noted above, insurance companies are exempt from most provisions of the ADA. In addition, the mere existence of strong legislation such as the ADA does not ensure that it will be used. Financial inability to secure legal assistance, fear of retribution from an employer, and difficulties with understanding English are but some of the barriers that may limit utilization of antidiscrimination laws. These barriers can only be removed by addressing the root causes of the various forms of discrimination. Toward this end, further studies of cases of genetic discrimination will be helpful for developing proactive approaches to remedying this form of discrimination.

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