Chapter 8

Discrimination Issues

Contents

Boxes

Figure

Tables

6. Day, N., Medical Information Bureau, Inc., Westwood, MA, personal communications, September 1991, December 1991.
7. DiCarlo, S., and Gabel, J., "Conventional Health Insurance: A Decade Later,' *Health Care Financing Review* 10(3):77-90, *1989.*
8. Gallagher, T., National Association of Insurance Commissioners, "Health Insurance Rating," testimony before the Subcommittee on Commerce, Consumer Protection and Competitiveness, Committee on Energy and Commerce, House of Representatives, U.S. Congress, Apr. 30, 1991.
9. Genetics & IVF Institute, Fairfax, VA, "Survey of Insurance Coverage of Cystic Fibrosis Testing, " personal communication, May 1991.
10. Group Health Association of America, *Employers, HMOs, and Dual Choice* (Washington, DC: Group Health Association of America, 1984).
11. Group Health Association of America, 1991 *National Directory* (Washington, DC: Group Health Association of America, 1991).
12. Halifax, J., ''Bill Would Close Health Insurance Pool to Newcomers," *Associated Press,* Apr. 16, 1991.
13. Hall, M., "The Purpose of Reforms in the Small-Group Market,' New *England Journal of Medicine* 326:565-570, *1992.*
14. Health Insurance Association of America, *Source Book of Health Insurance Data 1991* (Washington, DC: Health Insurance Association of America, 1991).
15. Iglehart, J.K., " The American Health Care System—Private Insurance," New *England Journal of Medicine 326: 1715-1720, 1992.*
16. Jest, D, C., Blue Cross and Blue Shield Association, ''Health Insurance Rating Practices, ' hearing before the Subcommittee on Commerce, Consumer Protection and Competitiveness, Committee on Energy and Commerce, House of Representatives, U.S. Congress, Apr. 30, 1991.
17. Kass, N. E., "The Ethical, Legal and Social Issues Concerning the Use of Genetic Tests by Insurers: Toward the Development of Appropriate Public Policy,' manuscript prepared for the NIH/DOE Ethical, Legal, and Social Issues Working Group, November 1990.
18. Medical Information Bureau, Inc., *A Consumer's Guide* (Westwood, MA: Medical Information Bureau, Inc., 1991).
19. O'Connor, K., letter to the editor, *Perspectives in Genetic Counseling* 13(2):10, *1991.*
20. Payne, J., Health Insurance Association of America, Washington, DC, personal communication, December 1991.
21. Pokorski, R., North American Reassurance Comp., Westport, CT, personal communication, February 1991.
22. Raymond, H., Health Insurance Association of America, Washington, DC, personal communication, December 1991.
23. Schulman, J. D., Genetics & IVF Institute, Fairfax, VA, personal communication, March 1992.
24. U.S. Congress, Congressional Research Service, *Health Care Financing and Health Insurance: A Glossary of Terms* (Washington, DC: Congressional Research Service, August 1988).
25. U.S. Congress, Congressional Research Service, *Health Insurance,* IB900005 *(Washington,* DC: Congressional Research Service, May 1991).
26. U.S. Congress, General Accounting Office, *Issues and Needed Improvements in State Regulation of the Insurance Business, GAO/FAD-79-72* (Gaithersburg, MD: U.S. General Accounting Office, October 1979).
27. U.S. Congress, Office of Technology Assessment, *Medical Testing and Health Insurance, OTA-H-384* (Washington, DC: U.S. Government Printing Office, August 1988).
28. U.S. Congress, Office of Technology Assessment, "Cystic Fibrosis, Genetic Screening, and Insurance, ' transcript of workshop proceedings, Feb. 1, 1991.
29. U.S. Congress, Office of Technology Assessment, "Cystic Fibrosis, Genetic Screening, and ERISA,'' transcript of workshop proceedings, Aug. 6, 1991.
30. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and Genetic Screening: Policies, Practices, and Attitudes of Genetic Counselors-Results of a Survey,* OTA-BP-BA-97 (Washington, DC: U.S. Government Printing Office, forthcoming 1992).
31. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and Genetic Screening: Policies, Practices, and Attitudes of Health Insurers—Results of a Survey,* OTA-BP-BA-98 (Washington, DC: U.S. Government Printing Office, forthcoming 1992).
32. U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, *Characteristics of Persons With and Without Health Care Coverage: United States, 1989, No. 201,* June 1991.
33. Vranka, L. A., "Defining the Contours of ERISA Preemption of State Insurance Regulation: Making Employee Benefit Plan Regulation an Exclusively Federal Concern, ' *Vanderbilt Law Review 42(579):607-638, 1989.*
34. Weiner, J., and Bernhardt, B. A., "A Survey of State Medicaid Policies for Coverage of Abortion and Prenatal Diagnostic Procedures, ' *American Journal of Public Health* 90:717-720, *1990.*
35. Wortham, L., "Insurance Classification: Too Important To Be Left to the Actuaries,'' *University of Michigan Journal of Law Reform* 19:349-423,1986.

Chapter 8
Discrimination Issues

dis•crim•i•na•tion/dis-krim-a-niã-shan/ n differential treatment or favor with a prejudiced outlook or action.

stigŽmaŽtiŽzaŽtion/stig-ma-to-zã-shan/ *n* branding, marking, or discrediting because of a particular characteristic.

Stigmatization of, or discrimination against, persons with certain diseases is not unique to genetic conditions. Persons with certain infectious diseases (e.g., leprosy, tuberculosis, or AIDS) have often borne the brunt of social ostracism, as have people with conditions such as cancer or schizophrenia (for which genetic components are now known to exist). As technologies for predicting genetic disorders expand, so do concerns about behavior toward people who have such conditions, or who are carriers for them.

The primary effect of any screening is to provide information (18), but how will the information be used? What is ''genetic discrimination, ' and will it increase (27,33,48)? Will the new knowledge elucidated through the Human Genome Project positively or negatively affect how Americans obtain or retain health care coverage?

This chapter examines aspects of discrimination from several perspectives: societal stigmatization, access to health care coverage, insurers' views toward genetic information, and genetics and new Federal antidiscrimination law (i.e., the Americans With Disabilities Act of 1990 (ADA); Public Law 101-336; 42 U.S.C. 12101 et seq.).[1] For some areas, the discussion is limited to carrier status. In others, the analysis encompasses the broader issue of the role genetic information and tests—whether to reveal carrier status or diagnose illness-play in discrimination issues.

STIGMATIZATION AND CARRIER STATUS

Increased knowledge about human genetics challenges existing public perceptions of "genetic normalcy. In his or her genome, each person harbors stretches of DNA that silently code for recessive, lethal, or debilitating genetic disorders or that predispose-with or without certain environmental factors—future illness. As the Human Genome Project progresses, the capacity to reveal these silent genes will increase. What will the social and psychological effect of knowing such information be to an individual? Will carriers be viewed as flawed-by themselves or others-or as blameworthy for having children despite identified genetic risks? Because genetic diseases sometimes cluster in ethnic or racial groups, will the potential for discrirnination and stigmatization be compounded (27,38)? Public misinformation, for example, can lead to a ''courtesy stigma' applied to those afffiated only by common ancestry to the stigmatized individuals (25,38).

Some express concern that routine carrier screening for cystic fibrosis (CF) (or other disorders) might be viewed as a tacit acknowledgment that the birth of children with genetic conditions should be avoided. They express concern that if emphasis is placed on preventing the births, less effort will be made, or fewer funds allocated, to create a climate of greater tolerance and social inclusion of people with disabilities (3,63). Similarly, concern is raised that a focus on prenatal CF carrier screening raises questions about further stigmatization of pregnant women (41); one 1992 survey found 70 percent of respondents viewed all pregnant women as "people who are acutely sick' (44,52).

While some relationship exists between a characteristic's visibility and the amount of stigma it arouses (29,57), nonvisible characteristics (e.g., carrier status) are also stigmatized (25). Individuals who reveal hidden differences often encounter hostility, aversion, or discomfort (25). People with epilepsy, for example, have been ostracized---even in the absence of a visible seizure-when others have found out about their condition (60, 1983). Thus, because CF carrier status is not observable, the condition could be less stigmatized than some

[1] The use of genetic monitoring and screening assays specifically in the workplace, and the broad array of legal implications arising from such use, were discussed in an earlier OTA report (68). This chapter expands on developments since publication of that report. It focuses on the ADA and its implications for employability of carriers or persons with genetic disease.

Photo credit: American Philosophical Society

Eugenics Building, Kansas Free Fair, 1929.

attributes, but some negative reactions might well result from carrier idenitification.

In fact, stigmatization of carriers is likely to focus on beliefs that it is irresponsible and immoral for people who could transmit disability to their children to reproduce (box 8-A) (23,54). Embodied in this notion is the view expressed by one philosopher that: "If reproductive partners are informed they both carry a dread disease such as Tay-Sachs or CF, and even so conceive with the intention of bringing every conceptus to birth, their supposed right to reproduce becomes ethically invalid" (23).

While this sentiment represents one pole in the gradient of views on reproductive decisionrnaking and genetic information, it is not inconsistent with the views of many Americans. A 1990 general population survey found 39 percent said "every woman who is pregnant *should be* tested to determine if the baby has any serious genetic defects. ' Twenty-two percent responded that regardless of what they would want for themselves, ''a woman *should* have an abortion if the baby has a serious genetic defect," with nearly 10 percent believing a woman should be required by law **to have an** abortion rather than have the government help pay for the child's care if the parents are poor (64).

How CF is viewed by the American populace obviously will affect perceptions and potential reproductive stigma associated with CF carriers. Increased public awareness and education as screening becomes more common could reduce problems of stigmatization of carriers, generally, with CF

Box 8-A—Bree Walker Lampley and Preventing Versus Allowing Genetic Disability

In July 1991, Los Angeles radio talk show host Jane Norris launched a fiestorm of controversy when she solicited listener comments on Los Angeles television anchorwoman Bree Walker Lampley's pregnancy. Making her disapproval clear, Norris said:

> We're going to talk about a woman in the news and I mean that literally. She's a very beautiful, very pregnant *news* anchor, and Bree Walker also has a very disfiguring disease. It's called syndactyly [sic] and the disease is very possibly going to be passed along to the child that she's about to have. And our discussion this evening will be, is that a fair thing to do? Is it fair to pass along a genetically disfiguring disease to your child?

Bree Walker Lampley has ectrodactyly, a genetic condition manifest as the absence of one or more fingers or toes. It is an autosomal dominant disorder; hence her potential offspring have a 50-50 chance of inheriting ectrodactyly. Norris' show highlighted the public tension that exists over attitudes toward preventing genetic disability, illness, and disease.

Some listeners agreed with Norris' opinion against knowingly conceiving a child who would be at 1 in 2 risk of "this deformity-webbed hands, . . ." One caller stated she would "rather not be alive than have a disease like that when it's a *50-50* chance. " Other callers compared her comments to racism and eugenic genocide: ". . this tone of yours that just kind of smacks of eugenics and selective breeding. . . . Are you going to talk in the next hour about whether poor women should have kids?"

The opinions offered illustrate the concern over the potential for discrimination or stigmatization as personal knowledge of one's genetic makeup increases. Shortly after the program aired, one disability rights activist pointed out that the radio show reminded her of her discomfort with the Human Genome Project.

On August 28, 1991, Bree Walker Lampley delivered a healthy baby boy, who has ectrodactyly. In October 1991, arguing that a biased presentation with erroneous information was broadcast, Walker Lampley was joined by her husband, several groups, and other individuals in filing a complaint with the Federal Communications Commission (FCC), Norris and the radio station stand by their right to raise the issue and "have no regrets." The FCC rejected Walker Lampley's complaint in February 1992, and no appal is planned.

SOURCE: Office of Technology Assessment **1992, based** on Associated *Press, ''KC* Rejects Anchorwoman's Complaint Over Call-In Radio Show, " Feb. 14, 1992; J. Mathews, "The Debate Over Her Baby: Bree Walker Lampley Has a Deformity. Some People Think She Shouldn't Have Kids," *Washington Post,* Oct. 20, 1991; and J. Seligmann "Whose Baby Is It Anyway?, ''Newsweek, Oct. 28, 1991.

carrier screening serving as a model. Such awareness and education might avert a case such as one described by a respondent to OTA's 1991 survey of genetic counselors and nurses in genetics:

> Carrier screening can be a loaded gun; just this week one of our patients learned he was a carrier of the DF508 mutation and his fiancee broke off their engagement. Now not only has he been dealt the bad news of being a carrier, his personal life is in a shambles and we have spent a great deal of time addressing his feelings of guilt, anger, and betrayal.

Empirical Studies

A few empirical studies addressing stigmatization and carrier status have been conducted in the United States, most in conjunction with Tay-Sachs screening during the 1970s (12-15,35; app. B). Data indicate that the majority of carriers felt they were not stigmatized, but one program found that 10 percent of noncarriers reported they would not marry a carrier (14,15). A small percentage of noncarriers expressed attitudes of superiority (11). One survey, conducted about 2 years after carriers were identified through Tay-Sachs screening, reported they and their spouses were initially "upset" when they learned the results, but that only a small minority considered themselves adversely affected (1 1).

Little current data on stigmatization and genetics exist; few are specific to CF. Research funded by the National Center for Human Genome Research, National Institutes of Health (NIH), however, is under way (47). One pilot study on attitudes toward CF carriers was recently conducted among high school students in Montreal, Canada who had been screened for DF508. In general, carriers expressed positive views about their new awareness of carrier status. Most (68 percent) would want their partner tested, and 60 percent said if the partner were a carrier, it would not affect the relationship. Sixty-three percent of persons negative for DF508 believed there would be no harm to their self-image should subsequent screening reveal they were actually

carriers of a non-DF508 CF mutation. The study is only preliminary, however, with a small sample size. Further, some speculate that social values and the structure of Canada's health care system might render these data nontransferable to attitudes in the United States (36), although others believe the Canadian experience can be applied here (62).

Screening Without Increasing Stigma

Concern about stigmatization arising from widespread CF carrier screening does not necessarily translate to unequivocal opposition by advocates for individuals with disabilities. A coherent effort that includes successful education and counseling could offer CF carrier screening without stigmatizing people with CF mutations as being disabled. Achieving this requires a commitment by health professionals and government that only those wanting to be screened will be screened; that all who want screening can have access to it; that results will remain confidential; and that individuals will not be coerced-overtly or covertly-into making any particular reproductive decision following screening (3,39).

Reducing perceived biases-so individuals can autonomously access the data needed to make informed choices about bearing children with CF—is of paramount concern if widespread CF carrier screening is to be viewed acceptable to those concerned about disability rights and the potential for stigmatization (3,13,55). Despite the commitment to nondirective genetic counseling, biases can sometimes emerge in the choice of words used to describe conditions, the questions asked, and the information provided (3,19,55,73).

Finally, as mentioned earlier, public education appears to resolve some potential stigmatization associated with carrier screening. Experience with massive public education efforts for ß-thalassemia, for example, demonstrates that such outreach can reduce stigmatization (2,10). On the other hand, when public education is insufficient (e.g., targeted only to the screened population and not to all individuals), stigmatization can be exacerbated, as witnessed by sickle cell carrier screening (38).

HEALTH CARE COVERAGE

Many view good health care-and access to it—as a moral right, not a privilege (box 8-B) (46). Perhaps the most widely raised social question stemming from the Human Genome Project is what effect genetic tests have had (and will have) on health care access in the United States. Because for most citizens health care access involves private health insurance, concern focuses on this "market.

Consumers fear exclusion from health care coverage due to genetic or other factors. Such fears are not unfounded. Health insurance in the United States is largely employment-based: 147 million Americans secure health insurance as part of a benefits package from their or another family member's employer (31). A nationwide survey revealed 3 in 10 Americans say they or someone in their household have stayed in a job they wanted to leave mainly to preserve health care coverage (17). This so-called "job lock" freezes an employee with medical problems (or one with a dependent with medical problems) in place, because a change in employment (and health insurance) would likely result in preexisting medical conditions being excluded from health care coveragetotally or for some period of time. Job lock also occurs when an individual cannot secure a new job because of a potential employer's fear of increased health care costs. This is particularly true in small businesses, where a single employee with costly health care needs can result in cancellation of the company's policy or premium increases that become unmanageable for the remaining employees.

A 1989 OTA survey of Fortune 500 companies and a random sample of 1,000 businesses with at least 1,000 employees found 11 percent of respondents assess the health insurance risk of job applicants on a routine basis; another 25 percent assess health risks sometimes. Of these, 9 percent of employers surveyed also take into account dependents' potential expenses when considering an individual's employment application. Forty-two percent of respondents said the health insurance risk of a job applicant reduced the likelihood of an otherwise healthy, able job applicant being hired. Whether the company was self-funded, used a private carrier, or some combination of both was not predictive of response (69). Consternation about restricted health care for a nongenetic factor has already been voiced in COUrt (bOX 8-C).

Box 8-B—Ethics, Genetics, and Health Insurance

As with many issues involving public policy, discussions about the use of genetic information or tests and health insurance do not center solely on legal considerations. While ethical and legal analyses can share common ground, the overlap between law and ethics is limited. The law does not reflect a ll moral values held by members of society, nor can it necessarily be used to resolve ethical dilemmas. Ethical arguments about health care access and health insurance, for example, often address obligations, rights, or values not explicitly covered by law, and are used to express incumbency the law does not acknowledge.

In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concluded that health care is a need, and that:

> . . .society has an ethical obligation to ensure equitable access to health care for all. This obligation rests on the special importance of health care, which derives from its role in relieving suffering, preventing premature death, restoring functioning, increasing opportunity, providing information about an individual's condition, and giving evidence of mutual empathy and compassion *(53).*

The Commission also pointed out that determining that health care access is a need does not determine the mechanism for distributing it, only that the system or combination of systems (i.e., public and private) should meet the need.

In philosophy, justice concerns the distribution of social goods (e.g., health care access) and ills-basically, that similar cases should be treated alike and unlike cases should be treated differently. If a particular case of just or unjust treatment arises, the philosophical question becomes, ''What makes these cases like or unlike in a morally relevant way?' Failing to state a morally relevant reason for treating the case (or people) differently lays way to the charge that action is arbitrary, capricious, or unjust.

Human genetics can be viewed as a science of inequality-a study of human particularity and difference. Genetic factors can be used as answers to the question: What makes these individuals alike or different? For some cases, the genetic difference provides a morally persuasive answer. Height, for example, is largely determined by genetics and an important factor in some jobs (e.g., playing professional basketball) but not in other jobs (e.g., computer programming). It would not be unjust to use a particular genetic difference-height-in selecting basketball players, but it would be unjust to use it in hiring computer programmers.

Thus, genetic differences are sometimes good moral reasons for treating different people differently, but in some cases they are not. Are genetic differences in propensity toward disease, for example, good moral reasons for treating people differently with respect to their access to health care? To the extent that health insurance is a mechanism for obtaining access to health care, then arguments about justice and access to health care hold equally for justice and access to health insurance. If the President's Commission was correct in concluding that there is a social obligation to provide equitable access to health care for all, then an obligation exists to ensure that people who need health care can obtain health insurance, or get access by some other means. If genetic characteristics like cystic fibrosis make it difficult for people to get the health care they need, then using genetic characteristics to disqualify individuals for health care coverage would be morally unjust.

SOURCE: Office of Technology Assessment 1992, based on T.H. Murray, "Genetics, Ethics, and Health Insurance," **contract document** prepared for the U.S. Congress, Office of Technology Assessment, July 1991.

Insurers' Attitudes Toward Genetic Risk Factors: OTA Survey Results

Risk classification and the world of insurance underwriting are arcane to most people. Persons without insurance, especially those who recently lost coverage, are puzzled (and, indeed often panicked) by interactions with the insurance industry. Any obstacles—real or perceived-encountered as they attempt to obtain individual coverage can lead to a situation of misunderstanding and mistrust. In many respects, citizens' generic concerns about health care access (49) increase concern about health insurers' use of genetic information.

As detailed in chapter 7, organizations offering health care coverage medically underwrite some policies-i. e., they classify risks of an individual or goup based on actuarial data. Currently, about 10 to 15 percent of individuals with health care coverage are medically underwritten. This selection process—i.e., differentiation based on medical characteristics—is an integral part of the insurance mechanism. Risk classification is the foundation, in fact, for the concept of private insurance.

Box 8-C—McGann v. H & H Music Co.

In August 1988, H & H Music Co. in Houston, TX, faced with rising health insurance premiums, decided it would switch from purchasing coverage from a commercial plan and become self-funded. At the same time, the company eliminated drug and alcohol treatment benefits and lowered the benefits cap for AIDS to $5,000, compared to a $1 million cap that was available for other catastrophic problems.

John McGann, who had worked for H & H Music for 5 years, learned he had AIDS in December 1987. In a suit filed in U.S. District Court, McGann held that the change in coverage was differential treatment aimed at him. He contended that dropping the coverage was discriminatory because the plan capped the AIDS benefit after he was stricken and after he informed his employer he had AIDS-the latter claim disputed by H & H Music.

Although Texas insurance law prohibits the denial of health insurance coverage for AIDS and AIDS-related illnesses, self-funded plans (like that of H & H Music) are exempt from State law because their regulation falls under Federal jurisdiction defined by the Employee Retirement Income Security Act of 1974 (ERISA; 29 U.S.C. S 1131 et seq.). Thus, McGann could not use State law to support his case. EFUSA does provide that a company cannot discriminate against people for the purposes of keeping them from attaining their benefits. McGann argued that H & H Music's capon AIDS-related benefits violated ERISA because it constituted discrimination motivated by his prior filing of AIDS-related claims, or was discrumination designed to prevent him from using health benefits to which he would have been entitled.

The district court ruled against McGann, finding that it was permissible for a self-funded plan to cover any disease it wanted, and to deny benefits for diseases for which it did not want to offer benefits; McGann died in June 1991. In November 1991, the U.S. Court of Appeals for the 5th Circuit upheld the district court opinion. The decision has clear implications for cystic fibrosis or other genetic conditions. Under current law, any self-funded company can cap, modify, or eliminate employees' health care benefits for a particular condition at any time, as long as the company complies with the notice requirements in the plan agreement. The Americans With Disabilities Act of 1990 does not address this issue. In March 1992, the U.S. Supreme Court agreed to hear the case.

SOURCE: Office of Technology Assessment 1992, W on*Associated Press*, *"AIDS* Victim's Case May Define Health Plan Caps on Expensive Illnesses," Houston, TX, June 24, 1991; M.A. Bobinski, University of Houston Health Law and Policy Institute, Houston TX, personal communication August 1991,

Over the last decade, health insurers have exhibited a tendency to avoid risks, rather than to find ways to spread risks over a broader base (40). Some commentators speculate that, overall, genetic analyses will mean fewer people will have access to health insurance because tests identify or refine risks. They argue genetic tests will provide the best reason yet for a nationalized health care system (4,32,65). Others contend, however, that genetic assays could detect noncarriers or rule out an individual's risk for a disorder and hence increase access to health care coverage (5 1). That is, making use of genetic information allows insurers to better assess risks, such that individuals at elevated risk will pay more (or be denied access), but people with low risk will pay less (30). Still others point out that as the number of genes identified increases, so will the number of potentially adverse conditions that apply to the general population, which could spread risk (45). All positions depend on the practices and attitudes insurance carriers actually have toward tests for genetic disorders, as well as the morbidity and mortality of a particular condition.

OTA found no data on how third-party payers view genetic information, generally, and the use of genetic assays for testing and screening specifically. To this this void, OTA undertook a survey[2] in 1991 to determine how third-party payers might use genetic information in risk classification, how they would view presymptomatic, carrier, and prenatal testing, and what impact insurers project genetic tests could have on their future practices. This section uses results from the OTA survey to report how medical directors at commercial insurance companies, Blue Cross/Blue Shield (BC/BS) plans,[3]

2 Complete data from OTA's **surve**, of commercial insurers, HMOS, and BC/BS plans are published separately (71).

[3] OTA surveyed both chief underwriters and medical directors of BC/BS plans to see whether responses would differ. Eighteen medical directors responded and 29 chief underwriters responded. To represent a larger pool of plans, only data from the chief underwriters' survey are used in this chapter to describe BC/BS responses. Small sample size and a poor response rate from the BC/BS medical directors makes analyzing statistically significant differences in responses between the two BC/BS populations impossible. A separate report addresses this issue and presents relevant medical director responses (71).

Table 8-I—Genetic Information as Medical Information or Preexisting Conditions

Question	Respondent	Agree strongly	Agree somewhat	Disagree somewhat	Disagree strongly	No response[a]
Genetic information is no different than other types of medical information	*Commercials*	17 (33%)	10 (20%)	12 (23%)	10 (20%)	2 (4%)
	HMOs	7 (30%)	6 (26%)	5 (22%)	3 (13%)	2 (9%)
	BC/BS plans	6 (21%)	14 (48%)	6 (21%)	1 (3%)	2 (7%)
Genetic conditions such as cystic fibrosis or Huntington disease are preexisting conditions	*Commercials*	14 (28%)	9 (18%)	17 (33%)	8 (16%)	3 (6%)
	HMOs	12 (52%)	8 (35%)	1 (4%)	0 (0%)	2 (9%)
	BC/BS plans	8 (28%)	7 (24%)	8 (28%)	5 (17%)	1 (3%)
Carrier status for genetic conditions such as cystic fibrosis or Tay-Sachs are preexisting conditions	*Commercials*	8 (16%)	12 (24%)	16 (31%)	13 (25%)	2 (4%)
	HMOs	5 (22%)	12 (52%)	0 (0%)	4 (17%)	2 (9%)
	BC/BS plans	4 (14%)	6 (21%)	7 (24%)	9 (31%)	3 (10%)

[a]percentages may not add to 100 due to rounding.

SOURCE: Off Ice of Technology Assessment, 1992,

and health maintenance organizations (HMOs) view genetic risk factors. As with survey results in chapter 7, these results represent attitudes and practices for insurers that write individual and medically underwritten group policies only.

The information presented in the following sections should not be construed to represent either numbers or percentages of commercial entities, BC/BS plans, or HMOs that have dealt with the issues presented. Respondents were asked how they *would* treat certain conditions or scenarios presented (currently or in the future, depending on the question), not whether they, in fact, *had* made such decisions.

Medical Information Versus Genetic Information

Do insurers view genetic information as just another type of medical information? At first glance it would appear they do. In OTA's survey, 27 medical directors (53 percent) from commercial insurers said they ''agree strongly' or ''agree somewhat' with the statement that ''genetic information is no different than other types of medical information; 22 (43 percent) disagreed to some extent. For medical directors of HMOs, 13 respondents (57 percent) generally agreed, compared to 8 (35 percent) who generally disagreed. Chief underwriters for BC/BS plans responded similarly: OTA found 20 respondents (69 percent) who agreed against 7 (24 percent) who did not. Similarly, OTA found that, collectively, the majority of respondents ''agree strongly' or ''somewhat' that genetic conditions (e.g., CF or Huntington disease) are preexisting conditions, but carrier status (e.g., for CF or Tay-Sachs) is not (table 8-1).[4]

Yet these general views are not wholly consistent with what factors insurers view as important to insurability (not rating). Personal and family medical histories were the most important factors in determining insurability whether the respondent was from a commercial insurer, HMO, or BC/BS plan, and personal history appears to outweigh family medical history. All 29 commercial vendors (100 percent) offering individual policies in OTA's survey said personal medical history of significant conditions was ' 'very important,' and 36 (97 percent) who sell medically underwritten group policies answered similarly. The large majority of HMOs and BC/BS plans also take personal medical history into account (table 8-2).

In contrast, OTA found medical directors and underwriters felt less strongly about "genetic predisposition to significant conditions" as a facet of insurability than they did about medical history. Genetic predisposition was a "very important" criterion to 4 medical directors (14 percent) from commercial insurers of individual policies, ' 'important' ' to 6 (21 percent), unimportant to 3 (10 percent), and never used by 16 (55 percent). No commercial-based respondent whose company offers coverage to medically underwritten groups considered genetic predisposition to significant conditions an important factor for insurability-18 (49 percent) never used it, 6 (16 percent) considered

[4]Throughout this chapter, survey results might not add to 100 percent because of rounding and because 'no response' is not included in the text (but is included in the tables).

Table 8-2—Medical History, Genetic Factors, and Insurability

Question: For each category of coverage, please indicate the importance of each of the following factors in determining insurability (not in rating):

	Respondent	Very important	Important	Unimportant	Never used	No response[a]
individual policies						
Personal medical history of significant conditions	*Commercials*	29(100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
	HMOs	9(82%)	0 (0%)	0 (0%)	1 (9%)	1 (9%)
	BC/BS plans	22(88%)	1 (4%)	0 (0%)	1 (4%)	1 (4%)
Family medical history of significant conditions	*Commercials*	5 (17%)	11 (38%)	9 (31%)	4 (14%)	0 (0%)
	HMOs	1 (9%)	0 (0%)	2 (18%)	7 (64%)	1 (9%)
	BC/BS plans	0 (0%)	6 (24%)	4 (16%)	14 (56%)	1 (4%)
Genetic predisposition to significant conditions	*Commercials*	4 (14%)	6 (21%)	3 (10%)	16 (55%)	0 (0%)
	HMOs	0 (0%)	3 (27%)	1 (18%)	6 (55%)	1 (9%)
	BC/BS plans	1 (4%)	2 (8%)	5 (20%)	16 (64%)	1 (4%)
Carrier risk for genetic disease	*Commercials*	2 (7%)	5 (17%)	6 (21%)	16 (55%)	0 (0%)
	HMOs	0 (0%)	2 (18%)	1 (18%)	7 (64%)	1 (9%)
	BC/BS plans	0 (0%)	2 (8%)	5 (20%)	17 (68%)	1 (4%)
Medically underwritten groups						
Personal medical history of significant conditions	*Commercials*	36 (97%)	1 (3%)	0 (0%)	0 (0%)	0 (0%)
	HMOs	15 (75%)	1 (5%)	0 (0%)	3 (15%)	1 (5%)
	BC/BS plans	18 (86%)	1 (5%)	0 (0%)	2 (10%)	0 (0%)
Family medical history of significant conditions	*Commercials*	3 (8%)	14 (38%)	10 (27%)	9 (24%)	1 (3%)
	HMOs	4 (20%)	3 (15%)	2 (10%)	10 (50%)	1 (5%)
	BC/BS plans	1 (5%)	3 (14%)	4 (19%)	13 (62%)	0 (0%)
Genetic predisposition to significant conditions	*Commercials*	0 (0%)	12 (32%)	6 (16%)	18 (49%)	1 (3%)
	HMOs	0 (0%)	3 (15%)	2 (10%)	13 (65%)	2 (10%)
	BC/BS plans	1 (5%)	1 (5%)	4 (19%)	15 (71%)	0 (0%)
Carrier risk for genetic disease	*Commercials*	1 (3%)	9 (24%)	9 (24%)	17 (46%)	1 (3%)
	HMOs	0 (0%)	3 (15%)	2 (10%)	13 (65%)	2 (10%)
	BC/BS plans	1 (5%)	0 (0%)	5 (24%)	15 (71%)	0 (0%)

a percentages may **not add** to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

it unimportant, and 12 (32 percent) considered it important.

With respect to CF carrier screening, OTA found that "carrier risk for genetic disease' '—where the individual has no symptoms of the disease—was ''very important" (2 respondents; 7 percent) or "important' (5 respondents; 17 percent) in individual policy insurability by commercial insurers. For medically underwritten groups, carrier risk was viewed as ''very important' or ''important" by 10 commercial respondents (27 percent). Response for HMOs and BC/BS plans are also presented in table 8-2.

On the other hand, when specifically asked how an individual's application would be treated if the applicant were asymptomatic but had a family history of CF, 27 medical directors (93 percent) from commercial insurers would accept the person with standard rates; 1 respondent would accept the applicant at standard rates, but with an exclusion waiver; and 1 would decline coverage. All 11 HMOs (100 percent) offering individual coverage would accept CF carriers at standard rates. But for BC/BS plans, 16 chief underwriters (55 percent) would accept at standard rates, while 6 (21 percent) would accept at the standard rate with a waiting period, and 2(7 percent) would decline to cover the carrier(71).[5] Thus, the mere fact that a medical director or underwriter considers carrier status important to insurability does not appear to translate into difficulties in obtaining health care coverage (rating). For

[5] The fact that the underwriters' responses are used here to report BC/BS data versus the medical directors' responses is not relevant. For the 18 BC/BS medical directors who responded, 9 (50 percent) would accept at standard rates, 3 (17 percent) would accept at standard rates but require a waiting period, and 2 (11 percent) would decline to cover.

those who responded they would accept with a waiting period or decline to cover, reluctance to offer standard insurance might stem from not wanting to pay for possible children or from a misunderstanding of the meaning of carrier status.

Given these results, do commercial insurers, HMOs, and BC/BS plans view genetic information differently than medical information? In response to the direct question comparing the two, apparently not. On the other hand, ''genetic predisposition to significant conditions' is clearly part of 'personal/family medical history of significant conditions. " So if genetic information is viewed as a subset of personal and family medical history, why was it accorded less weight than medical history in deciding insurability? A few explanations seem plausible.

Medical directors of insurance companies, HMOs, and BC/BS might have accounted for the probabilistic nature of genetics, and therefore viewed genetics as ' ' important,' ' but not "very important. " They also might have weighted the importance of genetic information to determining insurability as less important than personal and family medical history, although OTA did not ask them to do so. It also might be that no single risk---e.g., genetic risk-is as important as general medical risk and so entire family history was weighted more heavily. In any case, OTA's survey reveals, not surprisingly, that genetic history is used in assessing risk for individual policies and medically underwritten groups. In making decisions on insurability and rating based on genetic history, what seems important is the particular condition and its health care costs-e. g., CF, diabetes, sickle cell anemia (ch. 7), not that the consequence is genetically based.

Genetics and Coverage Decisions: One Scenario

Because information derived from CF carrier screening is primarily useful for reproductive decisionmaking, OTA sought the reactions of commercial insurers, HMOs, and BC/BS plans to a hypothetical situation based on a real-life case (described in a following section). One alteration from the actual incident was made in this hypothetical case: Rather than refusing to pay for all health care of the child, the scenario was constructed so the insurer refused to pay for CF-related costs of the child. This change was made because, as described later, OTA was aware that insurers in all States and the District of Columbia must cover (or offer the option to include, with or without conditions) a newborn child if a valid insurance contract for the parent exists, and felt it unethical to ask respondents about breaking the law, even unknowingly. Specifically, respondents were asked to indicate whether they 'agree strongly,' ''agree somewhat, " "disagree somewhat,' or 'disagree strongly,' with:

> Prenatal diagnosis indicates the fetus is affected with cystic fibrosis; the couple decides to continue the pregnancy. The health insurance carrier, which paid for the tests, informs the couple they will have no financial responsibility for the CF-related costs for the child.

For commercial vendors, three medical directors (6 percent) who responded to the OTA question agreed strongly or somewhat. Thirteen individuals (25 percent) in this population disagreed somewhat and 34 (67 percent) disagreed strongly. Among medical directors at HMOs, 3 respondents (13 percent) agreed to some extent with the decision in the hypothetical case, but 18 medical directors (78 percent) disagreed, 15 (65 percent) of them strongly. For chief underwriters of BC/BS plans, 6 respondents agreed (21 percent), either strongly or somewhat, with the decision in the scenario. OTA's survey revealed 8 chief underwriters (28 percent) indicated they disagreed somewhat, and 14 (48 percent) disagreed strongly.

Perspectives on the Future of Genetic Tests

Third-party payors already use genetic information in making decisions about individual policies or medically underwritten groups. Applicants for such coverage reveal genetic information when responding to the battery of questions in personal and family histories. OTA is unaware of any insurer who underwrites individual or medically underwritten groups and requires carrier or presymptomatic tests (e.g., for Huntington or adult polycystic kidney diseases). Preliminary data from a 1991 Health Insurance Association of America survey also reveal no health insurer requires genetic tests in underwriting (56), and ordering tests to review an application appears remote at this time (l). What will be the practice in the next 5 or 10 years?

Even a decade from now, OTA's survey found that the majority of respondents do not expect to require genetic tests of applicants who have a family history of serious genetic conditions, nor do they anticipate requiring carrier assays (table 8-3). OTA finds that a minority of commercial insurers who

Table 8-3—Projected Use of Genetic Tests by Insurers in 5 and 10 Years

	Respondent	Very likely	Somewhat likely	Somewhat unlikely	Very unlikely	No response[a]
How likely do you think it is that your company/HMO will in the next 5 years:						
Require genetic testing for applicants with family histories of serious conditions?	*Commercials*	1 (2%)	3 (6%)	16 (31%)	31 (61%)	0 (0%)
	HMOs	1 (4%)	4 (17%)	7 (39%)	9 (39%)	2 (9%)
	BC/BS plans	0 (0%)	1 (3%)	11 (38%)	15 (52%)	2 (7%)
Require carrier tests for applicants at risk of transmitting serious genetic disease to offspring?	*Commercials*	2 (4%)	13 (25%)	35 (69%)	1 (2%)	0 (0%)
	HMOs	2 (9%)	3 (13%)	5 (22%)	11 (48%)	2 (9%)
	BC/BS plans	0 (0%)	1 (3%)	12 (41%)	14 (48%)	2 (7%)
Require genetic testing for applicants with no known risk of genetic disease?	*Commercials*	0 (0%)	0 (0%)	4 (8%)	47 (92%)	0 (0%)
	HMOs	1 (4%)	0 (0%)	2 (9%)	18 (78%)	2 (9%)
	BC/BS plans	0 (0%)	1 (3%)	6 (21%)	20 (69%)	2 (7%)
Offer optional genetic testing and carrier testing?	*Commercials*	0 (0%)	3 (6%)	18 (35%)	30 (59%)	0 (0%)
	HMOs	4 (17%)	6 (26%)	6 (26%)	5 (22%)	2 (9%)
	BC/BS plans	1 (3%)	5 (17%)	9 (31%)	12 (41%)	2 (9%)
How likely do you think it is that your company/HMO will in the next 10 years:						
Require genetic testing for applicants with family histories of serious conditions?	*Commercials*	2 (4%)	17 (33%)	14 (28%)	18 (35%)	0 (0%)
	HMOs	3 (13%)	5 (22%)	9 (39%)	3 (13%)	3 (13%)
	BC/BS plans	0 (0%)	10 (34%)	8 (28%)	9 (31%)	2 (7%)
Require carrier tests for applicants at risk of transmitting serious genetic disease to offspring?	*Commercials*	1 (2%)	13 (25%)	16 (31%)	21 (41%)	0 (0%)
	HMOs	3 (13%)	4 (17%)	9 (39%)	4 (17%)	3 (13%)
	BCIBS plans	0 (0%)	9 (31%)	9 (31%)	9 (31%)	2 (7%)
Require genetic testing for applicants with no known risk Of genetic disease?	*Commercials*	0 (0%)	4 (8%)	8 (16%)	39 (76%)	0 (0%)
	HMOs	1 (4%)	0 (0%)	6 (26%)	13 (57%)	3 (13%)
	BC/BS plans	0 (0%)	3 (10%)	9 (31%)	15 (52%)	2 (7%)
Offer optional genetic testing and carrier testing?	*Commercials*	0 (0%)	12 (24%)	17 (33%)	22 (43%)	0 (0%)
	HMOs	5 (22%)	7 (30%)	6 (26%)	2 (9%)	3 (13%)
	BC/BS *plans*	3 (10%)	10 (34%)	5 (17%)	9 (31%)	2 (7%)

a Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

responded believe it will be “very likely” (2 respondents; 4 percent) or “somewhat likely” (17 respondents; 33 percent) that they will, in 10 years, require genetic testing for applicants who have a family history of serious conditions. Over the next decade, no BC/BS chief underwriter considered it ‘‘very likely’ that his or her company would require genetic testing for applicants who had family histories of serious disorders; 10 (34percent)replied they viewed it as ‘‘somewhat likely. ’ Of medical directors at HMOsS, 3 (13 percent) thought their HMO would require applicants to have a genetic test if a family history of a serious disorder existed, and 5 (22 percent) said they considered it “somewhat likely” tests would be required in this manner—again, in the next 10 years. A similar distribution of responses was revealed when respondents were queried about requiring carrier tests for applicants at risk of passing on serious genetic conditions to their offspring (table 8-3). Requiring carrier screening as a condition of consideration for insurance appears even more remote than using genetic assays on those who have family histories of serious disorders (table 8-3).

Few respondents believe their companies will require genetic tests in either 5 or 10 years, but what about optional testing? Commercial health insurers and BC/BS plans do not anticipate that optional testing or screening will be part of their company’s policy in 5 or 10 years. It is interesting to note that a majority of HMO-based medical directors who responded to OTA’s survey said they considered it “very likely’ or ‘‘somewhat” likely that their

Table 8-4—Projected Use of Genetic Information by Insurers in 5 and 10 Years

	Respondent	Very likely	Somewhat likely	Somewhat unlikely	Very unlikely	No response[a]
How likely do you think it is that your company/HMO will in the next 5 years:						
Use information derived from genetic tests for underwriting?	*Commercials*	7 (14%)	12 (24%)	16 (31%)	16 (31%)	0 (0%)
	HMOs	1 (4%)	5 (22%)	9 (26%)	6 (26%)	2 (9%)
	BC/BS plans	3 (10%)	8 (28%)	10 (34%)	6 (21%)	2 (7%)
In the next 10 years:						
Use information derived from genetic tests for underwriting?	*Commercials*	12 (24%)	20 (39%)	11 (22%)	7 (14%)	1 (2%)
	HMOs	3 (13%)	6 (26%)	8 (35%)	3 (13%)	3 (13%)
	BC/BS plans	5 (17%)	13 (45%)	3 (10%)	6 (21%)	2 (7%)

a $p_{ermn}t_{age}$s may **not add to** 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

HMO would offer optional genetic testing and carrier testing in 10 years (12 respondents; 52 percent) (table 8-3), The difference in response between the HMO population versus the commercial insurers and BC/BS plans could reflect HMOs' longer history with and emphasis on managed and preventive care.

Health insurers do not need genetic tests to find out genetic information. It is less expensive to ask a question or request medical records. Thus, whether or not genetic information is available to health insurers hinges on whether individuals who seek personal policies, or are part of medically underwritten groups, become aware of their genetic status because of general family history, because they have sought a genetic test because of family history, or because they have been screened in some other context. Even then, a majority of respondents to OTA's survey reported they thought it "somewhat unlikely' or "very unlikely" that they would be using information derived from genetic tests for underwriting (table 8-4).

Access to Health Insurance After Genetic Tests: OTA Survey Results

Existing information about how genetic test results affect individuals' health care coverage is largely anecdotal (7). Quantifying such information has proved difficult, and verifying it, impossible. Reported insurance rejections on genetic bases sometimes fail to distinguish among insurance product lines--+. g., health, life, or disability. Some cases reflect insurers' longstanding risk classification practices to decline coverage (or reduce coverage or offer it at increased rates) to individuals in ill health, regardless of whether it has a genetic basis. One case from the Baylor College of Medicine, Houston, TX, however, illustrates why concern is continually expressed about health-insurer uses of genetic tests.

> A couple in their 30s has a 6-year-old son with CF. Prenatal diagnostic studies of the current pregnancy indicate the fetus is affected. The couple decides to continue the pregnancy. The HMO indicated it should have no financial responsibility for the prenatal testing and that the family could be dropped from coverage if the mother did not terminate the pregnancy. The HMO felt this to be appropriate since the parents had requested and utilized prenatal diagnosis ostensibly to avoid a second affected child. After a social worker for the family spoke with the local director of the HMO, the company rapidly reversed its position (22).

Industry representatives acknowledge that an individual company could exercise poor judgment, but contend the problem is not widespread: If the problem were prevalent, ample court cases could be cited because patients and their attorneys would not be passive recipients of ill-based judgments such as occurred in the case just described ***(56).*** Clients and patient advocates argue to the contrary ***(6,43)*** and maintain that cases like those just mentioned represent the tip of an iceberg.

Do individuals who avail themselves of genetic tests subsequently have difficulty obtaining or retaining health insurance? To explore this issue, OTA decided not to survey either party with a direct stake in the answer, but chose instead to ask third parties-genetic counselors and nurses in genetics—for their firsthand experiences ***(70), In*** contrast to the survey of health insurers, which asked respondents to speculate about accepting applicants with certain conditions, this survey attempted to measure actual

occurrence. Specifically, in June 1991, OTA surveyed 794 members of the National Society of Genetic Counselors and the International Society of Nurses in Genetics and asked:

> Have any of your patients experienced difficulties in obtaining or retaining health insurance coverage as a result of genetic testing? If yes, please provide details.

Four-fifths (347) of the431 respondents to OTA's inquiry currently perform genetic counseling. Fifty respondents (14 percent) reported they had clients who had experienced difficulties obtaining or retaining health care coverage as a result of genetic testing (table 8-5). Because some respondents described more than one case, the number of affirmative answers understates the actual number of cases. Examination of the qualitative responses, some of which are presented in table 8-6, reveals affirmative responses represent, at minimum, 68 individual cases. (Where the term ''patients was used with specifics not described, a single event was recorded.)

Test results for some conditions where positive results led to reported difficulties-such as for Huntington disease, adult polycystic kidney disease, and Marfan syndrome-were cited by more than one respondent. Since genetic tests for conditions such as Huntington disease or Marfan syndrome are available at a limited number of sites, OTA attempted to ascertain whether surveys reporting patient insurance difficulties were geographically consistent with known test sites. With few exceptions, the respondent resided in a State where the test was available. In exceptions, the counselor resided in a neighboring State.

In addition to affrmative answers, several respondents reported that although they had no direct experience with a patient's difficulty in obtaining or retaining health care coverage, they had clients who

Table 8-5-Difficulties in Obtaining or Retaining Health Insurance After Genetic Tests

Question*: Have any of your patients experienced difficulties in obtaining or retaining health insurance coverage as a result of genetic testing?

	Number	Percent
No.	281	81.0
Yes.	50	14.4
No answer.	16	4.6

[a]1991 OTA survey of genetic counselors and nurses in genetics. Sample base of 347 represents individuals currently in clinical practice.

SOURCE: Office of Technology Assessment, 1992.

Table 8-6-Case Descriptions of Genetic Testing and Health Insurance Problems[a]

Positive test for adult polycystic kidney disease resulted in canceled policy or increased rate for company of newly diagnosed individual.
Positive test for Huntington disease resulted in canceled policy or being denied coverage through a health maintenance organization.
Positive test for neurofibromatosis resulted in canceled policy.
Positive test for Marfan syndrome resulted in canceled policy.
Positive test for Down syndrome resulted in canceled policy or increased rate.
Positive test for alpha-1 -antitrypsin defined as preexisting condition; therapy related to condition not covered.
Positive test for Fabry disease resulted in canceled policy.
Woman with balanced translocation excluded from future maternity coverage.
Positive Fragile X carrier status and subsequent job change resulted in no coverage.
After prenatal diagnosis of hemophilia-affected fetus, coverage denied due to preexisting condition clause.
Denied coverage or encountered difficulty retaining coverage after birth of infant with phenylketonuria.
Woman diagnosed with Turner's syndrome denied coverage for cardiac status based on karyotype. Normal electrocardiogram failed to satisfy company.
Family with previous Meckel-Gruberfetus denied coverage in subsequent applications despite using prenatal diagnosis and therapeutic abortion.
Mother tested positive as carrier for severe hemophilia. Prenatal diagnosis revealed affected boy; not covered as preexisting condition when pregnancy carried to term.
After a test revealed that a woman was a balanced translocation carrier, she was initially denied coverage under spouse's Insurance because of risk of unbalanced conception. Subsequently overturned.
Woman without prior knowledge that she was an obligate carrier for X-linked adrenoleukodystrophy found out she was a carrier. She had two sons, both of whom were healthy, but each at 50 percent risk. Testing was done so they could be put on an experimental diet to prevent problems that can arise f rom mid- to late childhood or early adulthood. One boy tested positive. The family's private pay policy (Blue Cross/Blue Shield) is attempting to disqualify the family for failing to report the family history under preexisting renditions.
After birth of child with CF, unable to insure unaffected siblings or themselves.

[a]1991 OTA survey of genetic counselors and nurses in genetics. Not all cases, or multiple cases involving same disorder, listed.

SOURCE: Office of Technology Assessment, 1992.

feared their coverage would be dropped if they requested payment for tests from insurers. One respondent commented that greater than 80 percent of her clients who have tests for Huntington disease self-pay. Similarly, others with no direct experience said they often advise patients not to request reimbursement for a test so that an insurer would not learn that testing had occurred. One counselor offered the information that a patient had refused testing for adult polycystic kidney disease because of concern over health insurance. Another respondent reported that a patient with a CF-affected child had been dropped by one insurance company and would not consider prenatal testing in the future for fear her current insurer would not cover the child should she decide to continue the pregnancy.

Such fears persist despite the fact that most contracts for individual health insurance coverage preclude blanket nonrenewal (37,56). Similarly, an insurer cannot raise rates for an individual who has been continuously covered if the person develops a new condition (37). On the other hand, it is legal for an insurer not to renew a group contract based on the results of one individual's genetic or other medical test. Group policies are rarely guaranteed renewable (37). In lieu of not offering to renew, an insurer might opt to levy a steep premium increase at renewal time.

OTA's survey reports-conservatively-consumer difficulties in obtaining or retaining health care coverage after genetic tests. OTA has no basis for evaluating whether the nonrespondents would be more or less familiar with patients' insurance difficulties and potentially know of additional cases. The data permit neither extrapolation about the total number of cases that have occurred in the United States, nor speculation about any trends.

OTA did not attempt to ascertain whether or not patients had challenged-or were challenging—insurers' rulings. Thus, OTA cannot determine whether some of the disputes reported in table 8-6 were resolved fully in favor of the consumer because the initial judgment was deemed improper or illegal. Some cases, for example, reported a fetus or newborn had tested positive and coverage had been denied. In all 50 States and the District of Columbia, insurers must cover (or offer the option to include) a newborn child if a valid insurance contract for the parent exists. However, whether the insurance company can deny certain benefits for the newborn by evoking the preexisting condition clause generally contained in all insurance contracts is unclear.

In presenting table 8-6, OTA does not judge the validity-positively or negatively-of the claim. Some cases might have been settled in favor of the individual. Others might have been cases where an applicant attempted to select against an insurer by misrepresenting his or her health history, which would have been resolved against the individual.

In 1991, at least 50 genetic counselors or nurses in clinical practice knew of at least 68 actual incidents where their own patients reported difficulties with health insurance due to genetic tests. OTA estimates, based on the average number of patients directly counseled, that genetic counselors and nurses responding to the survey collectively saw about 110,600 individuals in 1990. However, OTA did not advise respondents to limit descriptions of clients' insurance difficulty to 1990. Thus, it is unlikely that all reported cases occurred in 1990; assuming all reported cases occurred in 1990, the 68 cases represent 0.06 percent of patients seen by survey respondents.

Critics, however, question whether the data—especially the qualitative descriptions-merely represent more anecdotal stories that unfairly present one side of the story and for which no response can be developed (56). Skeptics point out that some of the cases might fall into the gray area of whether exclusion or increased rates resulted because an adverse medical condition was revealed through a diagnostic test that just happened to be genetic. The border between what conditions are genetic or not is blurred, however, and will become increasingly diffuse. Because genetic-based predictive tests promise to have a profound impact on clinical medicine (28)-and because access to medical care is inextricably linked to private health insurance in this country-these cases underscore certain policy dilemmas arising from the increased availability of genetic assays. For genetic testing or screening to detect genetic illness (or the potential for illness), the possibilities for problems are not remote, but real indeed.

Finally, it is important to note that most of the cases revealed through the OTA survey do not involve recessive disorders and carrier screening for conditions like CF. And while one assumption might have been that health care coverage for CF carriers would not be an issue because the individuals are

asymptomatic, OTA's survey of health insurers reveals that a few insurers would require a waiting period or deny coverage for these individuals.

GENETICS, DISCRIMINATION, AND U.S. LAW

Federal, State, and local laws provide only incomplete protection against invidious genetic discrumination (48). Overall, explicit safeguards have not been enacted in most jurisdictions to protect against discrimination, or to allow favoritism, specifically on the basis of genetic characteristics. This section examines how State statutes and the Americans With Disabilities Act of 1990 (Public Law 101-336; 42 U.S.C. 12101 et seq.) apply-or could apply—to discrimination with a genetic basis.

Is genetic discrirnination a form of racial or gender discrirnination? Or is it best classified as a form of disability differentiation? Some argue that CF carrier screening, specifically, is unlikely to raise issues under Title VII of the Civil Rights Act (42 U.S.C. 2000e), or its 1991 amendments (Public Law 102-166). That legislation focuses primarily on protecting groups historically the subject of discrimination. Thus, some argue that only if it can be shown that CF carrier screening has a disparate impact on women (67) would the Civil Rights Act and other protections be pertinent, and that since CF mutation analysis is done on both men and women, it does not have such an impact. Others disagree, asserting that if discriminatory consequences arise from CF carrier screening, a case could be made that the Civil Rights Act applies.

State Statutes and Hereditary Conditions

Several States—Arizona, California, Florida, Illinois, Iowa, Kentucky, Louisiana, Maryland, Missouri, New Jersey, New York, Oregon, Virginia, and Wisconsin-have statutes that specifically mention testing, counseling, or employment of persons with hereditary conditions.[6] The California (box 8-D), Maryland, and New Jersey laws recognize that disease-specific language could prove too rigid and instead have broad application to "any hereditary disorder." California also draws the distinction between carriers and those who experience manifestations of the disease. A handful of statutes narrowly target specific conditions or traits, such as sickle cell (Florida, Louisiana, New York), hemophilia (Florida, Missouri), CF (Missouri), Tay-Sachs (New York), or Cooley's anemia (ß-thalassemia; New York).

Statutes in at least seven States-Florida, Oregon, Louisiana, New Jersey, New York, North Carolina, and Wisconsin-prohibit employment discrimination against persons with any atypical hereditary or blood trait or with named genetic conditions or traits. New York law, for example, says that persons with sickle cell trait and carriers of Tay-Sachs disease or Cooley's anemia may not be denied opportunities for employment unless their disorder would prevent them from performing the job. Some State statutes address issues beyond employment discrimination. Wisconsin and Arizona, for example, prohibit certain forms of insurance discrimination. Genetic-related State laws also prohibit certain types of screening (Florida), provide funding for research or treatment (Florida, Iowa), or require information on or testing of genetic disorders be given to marriage applicants (California, Illinois, Kentucky, New Jersey, Virginia). Other State laws are concerned with genetic counseling and confidentiality (Missouri).

The Americans With Disabilities Act of 1990

In 1990, Congress enacted the ADA, a comprehensive civil rights bill to prohibit discrimination on the basis of disability.[7] Unlike the Rehabilitation Act of 1973, which is still in force, the ADA extends antidiserimin ation protection of persons with disabilities to private sector employment, public services, public accommodations, and telecommunications.

State and local antidiscrirnination legislation supplement Federal law and are not preempted by the ADA. All 50 States have disability statutes, 48 of

6 Arizona Rev, Stat. Sec. 20-448 (1991); California Health and Safety Code, Sec. 150, 151, 155,309,341 (West 1990); Florida Statute, Sm. 385.206 (1989); Illinois 1990 Public Act 86-1028; Iowa Code Sec. 136A.2 (1989); Kentucky Rev. Stat. Ann. Sec. 402.320 (Banks-Baldwin 1991); Louisiana Rev. Stat. Ann. Sec. 46.2254 (West 1982); Maryland Health-Gen. Code Ann. Sec. 13-101; Missouri Rev. Stat. Sec. 191 (1989); New Jersey Rev. Stat. Sec. 26:5 B-3 (1987); New York Laws 900 (1990); Virginia Code Ann. Sec. 32.1-68. (1990); 1991 Wise. Act 177 (signed Mar. 5, 1992).

7 Two Federal disability laws other than the ADA have potential application to broad considerations of genetic discrimination but are not discussed in this report-the Education for All Handicapped Children Act of 1975 (Public Law 94-142, 89 Stat. 773; renamed the Individuals With Disabilities Education Act of 1990, Public Law 101-476, 104 Stat. 1142) giving all school-aged children with disabilities the right to a free public education in the least restrictive environment appropriate to their needs and the Fair Housing Amendments Act of 1988 (Public Law 1OO-43Q 102 Stat. 1619).

Box 8-D—The California Hereditary Disorders Act of 1990

California law is the most comprehensive of State statutes specifically addressing discrimination and hereditary conditions. It touches on access to health care services, professional and public education about genetic disorders, confidentiality of genetic information, voluntariness of genetic screening, and continued reproductive freedom for those at risk of passing on a disabling genetic trait. The 1990 Hereditary Disorders Act finds that "In order to minimize the possibility for the reoccurrence of abuse of genetic intervention in hereditary disorders programs . . . [t]he Legislature finds it necessary to establish a uniform statewide policy for screening for hereditary disorders.

The statute mandates that:

. The public . . . should be consulted before any rules, regulations, and standards are adopted by the State Department of Health Sexvices.
. Clinical testing procedures established for use in programs, facilities, and projects be accurate and provide maximum information, and that the testing procedures produce results that are subject to minimum misinterpretation.
. No test(s) shall be performed on any minor over the objection of the minor's parents or guardian, nor may any tests be performed unless such parent or guardian is fully informed of the purposes of testing and is given reasonable opportunity to object to such testing.
. No testing, except initial screening for phenylketonuria and *other* diseases that maybe added to the newborn screening program, shall require mandatory participation. No testing programs shall require restriction of childbearing, and participation in a testing program shall not be a prerequisite to eligibility for, or receipt of, any other service or assistance from, or to participate in, any other program, except where necessary to determine eligibility for further programs of diagnoses of or therapy for hereditary conditions.
. Counseling services for hereditary disorders shall be available through the program or a referral source for all persons determined to be or who believe themselves to be at risk for a hereditary disorder as a result of screening programs. Such counseling shall be nondirective, emphasize informing the client, and not require restriction of childbearing.
. All participants in programs on hereditary disorders shall be protected from undue physical and mental harm, Those determined to be affected shall be informed of the nature, and where possible, the cost of available therapies or maintenance programs, and be informed of the possible benefits and risks associated with such therapies and programs.
. All testing results and personal information generated from hereditary disorders programs shall be made available to an individual over 18 years of age, or to the individual's parent or guardian.
. All testing results and personal information from hereditary disorders programs obtained from any individual, or from specimens from any individual, shall be held confidential. An individual whose confidentiality has been breached may recover compensatory damages. In addition, he or she may recover civil damages not to exceed $10,000, reasonable attorney's fees, and the costs of litigation.

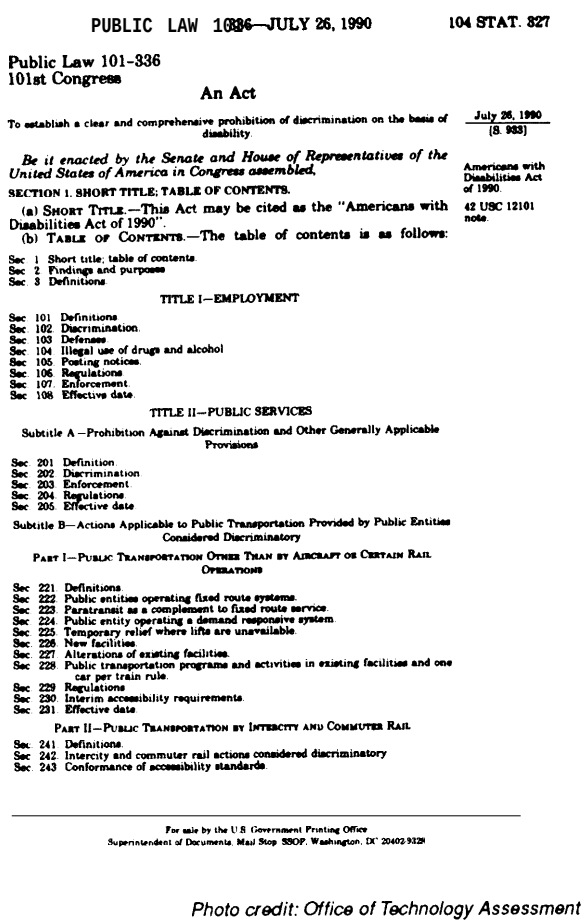
California's law, any violation of which is a misdemeanor, authorizes the State Department of Health Services to administer a statewide prenatal screening program for genetic disorders. The Department shall also develop an education program designed to educate physicians and the public concerning the uses of prenatal testing, as well as to set quality control standards for clinics offering prenatal screening. Funding is to be assured for screening services for low income women. To emphasize the noneugenic purposes of the program, special attention is paid to voluntary participation. In addition, repeated mention is made that screening and counseling should emphasize information delivery, and should not be directed toward persuading or coercing individuals to forego childbearing or conception.

Although Maryland has a law with similar goals, the California legislation has not been widely adopted, nor have its broad goals been fully realized due to funding constraints. It could serve as a model for State efforts to ensure that genetic tests take their place beside other, voluntary health services, while simultaneously discouraging third parties from discriminating against those who suffer from or carry traits for genetic disorders. Conversely, it can also be viewed as a poor model that represents unnecessary government intervention and control of medical and laboratory genetics.

SOURCE: Office of Technology Assessment, 1992, based on California Health and Safety Code, Sec. 150, 151, 155,309,341 (West 1990); 1990 California Senate Bill 1008 (ch. 26).

them prohibiting discrimination in the private, as well as public, sector; Alabama's and Mississippi's laws extend to the public sector only (58). State and local disability laws are enforced by human rights organizations that are often successful at both public education and at alternative dispute resolution, resulting in settlement of over four-fifths of their cases (27). Thus, such laws might remain important protections against genetically based discrimination, although only a few State cases directly involve genetic discrimination (58).

The following sections examine how genetic illness, predisposition to genetic conditions, or carrier status appear to be treated under provisions of the ADA and Equal Employment Opportunity Commission (EEOC) regulations that define disability and impairment.



PUBLIC LAW 101-336—JULY 26, 1990 104 STAT. 327

Public Law 101-336
101st Congress

An Act

To establish a clear and comprehensive prohibition of discrimination on the basis of disability.

July 26, 1990
[S. 933]

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

Americans with Disabilities Act of 1990.

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the "Americans with Disabilities Act of 1990".

42 USC 12101 note.

(b) TABLE OF CONTENTS.—The table of contents is as follows:

Sec. 1. Short title; table of contents.
Sec. 2. Findings and purposes.
Sec. 3. Definitions.

TITLE I—EMPLOYMENT

Sec. 101. Definitions.
Sec. 102. Discrimination.
Sec. 103. Defenses.
Sec. 104. Illegal use of drugs and alcohol.
Sec. 105. Posting notices.
Sec. 106. Regulations.
Sec. 107. Enforcement.
Sec. 108. Effective date.

TITLE II—PUBLIC SERVICES

Subtitle A—Prohibition Against Discrimination and Other Generally Applicable Provisions

Sec. 201. Definition.
Sec. 202. Discrimination.
Sec. 203. Enforcement.
Sec. 204. Regulations.
Sec. 205. Effective date.

Subtitle B—Actions Applicable to Public Transportation Provided by Public Entities Considered Discriminatory

PART I—PUBLIC TRANSPORTATION OTHER THAN BY AIRCRAFT OR CERTAIN RAIL OPERATIONS

Sec. 221. Definitions.
Sec. 222. Public entities operating fixed route systems.
Sec. 223. Paratransit as a complement to fixed route service.
Sec. 224. Public entity operating a demand responsive system.
Sec. 225. Temporary relief where lifts are unavailable.
Sec. 226. New facilities.
Sec. 227. Alterations of existing facilities.
Sec. 228. Public transportation programs and activities in existing facilities and one car per train rule.
Sec. 229. Regulations.
Sec. 230. Interim accessibility requirements.
Sec. 231. Effective date.

PART II—PUBLIC TRANSPORTATION BY INTERCITY AND COMMUTER RAIL

Sec. 241. Definitions.
Sec. 242. Intercity and commuter rail actions considered discriminatory.
Sec. 243. Conformance of accessibility standards.

For sale by the U.S. Government Printing Office
Superintendent of Documents, Mail Stop: SSOP, Washington, DC 20402-9328

Photo credit: Office of Technology Assessment

The Americans With Disabilities Act (Public Law 101 -336).

What Is Disability?

Disability is defined broadly in the ADA to mean:

> (A) a physical or mental impairment that substantially limits one or more of the major life activities. . . . (B) a record of such impairment, or (C) being regarded as having such an impairment (42 U. S.C.A. Sec. 12102(2)).

This definition is based on the term "handicap" in the Rehabilitation Act of 1973 (29 U.S.C. Sec. 706(7)(B) (1988)) and Fair Housing Amendments Act of 1988 (45 U.S.C. Sec. 3602(h) (Supp. 1990)). Congress intended that regulations implementing the Rehabilitation Act and the Fair Housing Amendments Act apply in interpreting the term ' 'disability" in the ADA (21).

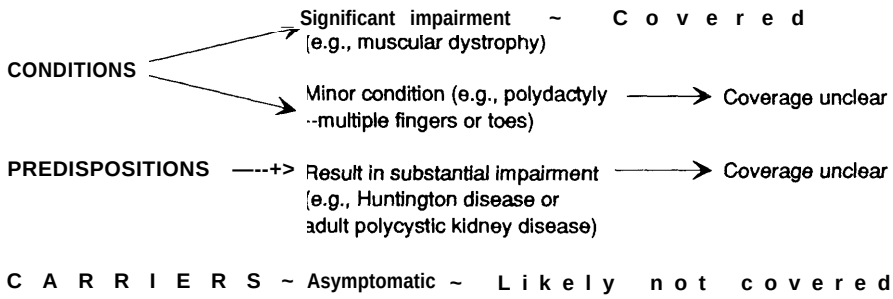
In spelling out the meaning of subsection (A), the Senate Report states:

> "Physical or mental impairment" includes the following: any physiological disorder or condition, disfigurement, or anatomical loss affecting any of the major bodily systems, or any mental or psychological disorder such as mental retardation, mental illness or dementia. . . . The term physical or mental impairment does not include simple physical characteristics, such as blue eyes or black hair. . . [nor does it include] environmental, cultural, and economic disadvantages [in and of themselves] (72).

A person with a disability includes someone who has a "record" of or is ''regarded' as having a disability, even if there is no actual incapacity. Further, a "record" of disability means that the person has a history of impairment, or has been misclassified as having an impairment (72). This provision protects those who have recovered from a disability that previously impaired their life activities. In this manner, Congress recognized that people who have recovered from diseases such as cancer—or have diseases under control such as diabetes---can face discrimination based on misunderstanding, prejudice, or irrational fear (21,42,50), and so still merit protection.

Additionally, individuals regarded as having disabilities include those who have an impairment, but do not have limitations in their major life functions and yet are treated as if they did have such limitations. Thus, the ADA encompasses people who are discriminated against based on a false belief that they have disabilities (61). This provision is particularly important for individuals who are per-

Figure 8-l-Genetics and the Americans With Disabilities Act of 1990



SOURCE: Office of Technology Assessment, 1992.

ceived to have stigmatic conditions. That is, society's reaction, rather than the disability itself, deprives the person of equal enjoyment of rights and services (27).

The ADA and Genetics

Given the dearth of State legislation specific to genetic characteristics, if the ADA addressed this issue it would create a nationwide standard of protection. The ADA is silent with respect to genetics, per se, however, as are the EEOC's regulations implementing it (29 CFR part 1630; 56 FR 35726) (58,59). Furthermore, the legislative history of the ADA indicates that little attention was given to the role of genetics in discrimination. During debate on the ADA, the Congressional Biomedical Ethics Advisory Committee was informed that genetic discrumination was "not raised or discussed, ' and so could not be addressed by the conference committee-although several Representatives supported the argument that the ADA will also benefit individuals who are identtiled through genetic tests as being carriers of a disease-associated gene (27). The following sections examine the apparent coverage--or lack of coverage—for different genetic statuses under the ADA (figure 8-l).

Genetic Conditions. Disability under the ADA is defined only according to the degree of impairment, with no distinction between disabilities with genetic origins and those without. Congress and the courts have long recognized disabilities of primarily or partial genetic origin, including Down syndrome, CF, muscular dystrophy, multiple sclerosis, heart disease, schizophrenia, epilepsy, diabetes, and arthritis (8,24,34,72). In fact, the legislative history of the ADA cites muscular dystrophy as an example of a condition covered by the ADA.

That the condition is genetic, then, is not the defining event. At issue is how severely the disability interferes with life activities, not its origins. In defining disability, the courts require a ' 'substantial" limitation of one or more major life activities. A genetic condition that does not cause substantial impairment might not constitute a disability, unless others treat the person as disabled. Thus, significant cosmetic disfigurements from burns or neurofibromatosis could be classified as disabilities if public prejudices act to limit the life opportunities of those with the cosmetic problem (72).

Genetic Predisposition. The ADA expressly protects not only individuals who actually have disabilities, but also those who are ''regarded' or perceived as having them. It judges disability not by an objective measure of inability to perform tasks, but also subjectively by the degree to which the public makes the condition disabling through misunderstanding or prejudice (21,50). This definition might then apply to individuals who are asymptomatic but predicted to develop disease in the future-i.e., persons who are sometimes referred to as the "healthy ill" or "at risk" (16,27).

One commentator argues that the ADA's legislative history indicates that genetic predisposition might be encompassed (27). For example, one Congressman stated during the 1990 debate over the conference report that persons who are theoretically at risk ''may not be discriminated against simply because they may not be qualified for a job sometime in the future. Several Representatives agreed, arguing that those at risk for future disabilities are to be ''regarded" as having disabilities (136 Congressional Record H4614, H4623, H4624, H4626). On the other hand, no further substantive discussion on the issue occurred (58), and as

described later, the EEOC rejects the premise that genetic predisposition is covered.

Carrier Status. The ADA's prohibition of discrimination and case law generally hold that employment decisions must be based on reasonable medical judgments showing that the disability prevents the individual from meeting legitimate performance criteria (9,26,61,66). For asymptomatic carriers of recessive genetic conditions such as CF, sickle cell anemia, the thalassemias, and Tay-Sachs, there is no disability per se. Carriers appear not to be covered by the ADA. Such individuals are, however, at risk of having an affected child if their partners also carry the trait, and are often themselves misunderstood to be affected by the disease. Discrimination against asymptomatic carriers, therefore, arguably can constitute discrimination based on a perception of disability.

The Equal Employment Opportunity Commission Regulations

Although the ADA does not provide explicit guidance about how genetic information should be viewed, the lack of this type of specificity in the literal reading of a law is not unusual. Instead, the executive branch (the EEOC in this case), relying on the bill's legislative history and congressional intent, interprets the legislation and issues regulations for executing the law. Thus, speculation about any perceived vagueness of the law could be addressed through public comment on EEOC's proposed rules.

In February 1991, EEOC proposed regulations for implementing the ADA (56 FR 8578). EEOC's proposed regulations did not specifically prohibit discrimination against carriers or persons who are identified presymptomatically for a late-onset genetic condition (e.g., adult polycystic kidney disease or Huntington disease). This perceived void led the Joint Working Group on Ethical, Legal, and Social Issues (ELSI) of the NIH and Department of Energy (DOE) to urge that the EEOC revise its proposed rule to explicitly include such individuals (74). Similarly, the members of the NIH/DOE Joint Subcommittee on the Human Genome endorsed the ELSI Working Group's action, and recommended that EEOC make explicit the protection of carriers or those diagnosed presymptomatically (i.e., that no individual shall be discriminated against on the basis of genetic makeup) (5).

In July 1991, EEOC published the final rule addressing the definitions of disability and impairment under the ADA (56 FR 35726). The final rules did not reflect the suggestions of either the ELSI Working Group or the Joint Subcommittee on the Human Genome. In fact, EEOC specifically amended its interpretive guidance "to note that the definition of the term 'impairment' does not include characteristic predisposition to illness or disease' (56 FR 35727).

Additionally, in correspondence to the Joint Subcommittee on the Human Genome, EEOC stated that ''the ADA does not protect individuals, who are not otherwise impaired, from discrimination based on genotype alone' (20). Thus, from EEOC's perspective, asymptomatic carriers are not encompassed by the ADA's provisions. With respect to individuals diagnosed presymptomatically, EEOC has concluded that "such individuals are protected, either when they develop a genetic disease that substantially limits one or more of their major life activities, or when an employer regards them as having a genetic disease that substantially limits one or more of their major life activities' (20). Again, as with carriers, EEOC's interpretation is that individuals who are identified as at risk for a late-onset adult disorder are not protected by the ADA until the condition is manifest. Some argue that the ADA might need amending if carriers or presymptomatic individuals come to be widely perceived as having a disability, thus invoking the law's broader definition.

The ADA and Health Insurance

An employer's fear of future disability in an applicant's family that would affect the individual's usage of health insurance and leave time would also appear to be a prohibited basis for discrimination under the ADA. Nevertheless, the ADA does not speak to this point directly, and so leaves open for future interpretation whether employers may discriminate against carriers who are perceived as more likely to incur extra costs due to illnesses likely to occur in their future children. The ADA specifically states that it does not restrict insurers, health care providers, or other benefit plan administrators horn carrying out existing underwriting practices based on risk classification (27,59). Nor does the ADA make it clear whether such employers may question individuals about their marital or reproductive plans prior to offering employment or enrollment in an

insurance plan, (As discussed earlier and described in box 8-C, however, after a person is hired, self-funded insurance plans can alter benefits to exclude or limit coverage for specific conditions.)

SUMMARY AND CONCLUSIONS

Among the many issues raised by prospects of both routine carrier screening for CF and increased availability of DNA-based diagnostic or predictive tests are stigmatization and discrimination. For CF carrier screening, stigmatization might focus on the notion that it is irresponsible for people who are at risk of having offspring who might have a genetic condition to have affected children, With respect to discrimination, CF carrier screening raises questions about access to health care coverage and Federal discrimination law.

Few empirical studies have examined stigmatization of CF carriers directly, but several projects are underway. Existing research on stigmatization and carriers for Tay-Sachs or sickle cell anemia have a bearing on carrier screening for CF, but only in a limited manner. These studies can guide efforts to help clients avoid feelings of guilt or shame that could be associated with being identified as a CF carrier, but provide less concrete approaches that must be taken to educate the public. Historical perspectives can assist health care professionals in counseling clients identified as carriers, but the greatest barrier-public perception of genetic status—will require new initiatives in large numbers. Public education for Tay-Sachs carrier screening worked because the target population was both defined and inclined to seek screening. In contrast, the potential target population for CF carrier screening is larger and more diffuse, with unknown attitudes toward carrier identification.

With respect to accessing health care coverage and CF carrier screening, OTA's survey found that the majority of third-party payers offering mdividual or medically underwritten group policies view genetic information as no different from other types of medical information. Genetic information is used in decisions determining risk classification and underwriting, but no blanket statement can be made as to the weight placed on it. Not surprisingly, respondents rank genetic information as relatively more important to individual policies than for medically underwritten groups. Medical directors and chief underwriters view personal and family medical histories as the most important determinants in classfying and rating candidates for individual or medically underwritten insurance. Whether a condition is genetically based or not is of less import. The increased availability of genetic information, however, adds to the amount of medical information that insurers can use for underwriting. Concern is expressed this additional information will lead to risk assessments that are so accurate on an individual level that they undermine the risk spreading function of insurance.

OTA's survey of health insurers illustrates why some claims of inappropriate or illegal health care coverage decisions based on genetic test results have occurred. These decisions might continue to arise, or they could disappear with time if such insurers become familiar with and educated about the significance of CF carrier screening. OTA's survey of genetic counselors and nurses reveals more than 14 percent of respondents have clients who reported difficulties in obtaining or retaining health insurance due to results from genetic tests.

Finally, Federal antidiscrimination law, particularly the Americans With Disabilities Act, clearly encompasses individuals who have a genetic condition that substantially limits one or more major life activities. According to regulations promulgated by the Equal Employment Opportunity Commission, however, ADA does not include predisposition to illness or disease if the individual is asymptomatic. Similarly, carriers of genetic disorders per se are not covered by ADA's provisions according to EEOC; genetic status is not a defining factor in determining disability or impairment under the ADA. Nor does the ADA restrict insurers from carrying out existing underwriting practices based on risk classification. Thus, if any health care reform is viewed as necessary because of the future of widespread carrier screening for CF, predictive testing for other disorders, or increased knowledge stemming from the Human Genome Project, it will necessarily, and probably appropriately, be done under the umbrella of general health care reform currently being debated in the United States.

CHAPTER 8 REFERENCES

1. American Council of Life Insurance and Health Insurance Association of America, *Report of the ACLI-HIAA Task Force on Genetic Testing, 1991* (Washington, DC: American Council of Life Insur-

ance or Health Insurance Association of America, 1992).
2. Angastiniotis, M., Cyprus Thalassaemia Centre, Archbishop Makarios III Hospital, Nicosia, Cyprus, "Development of Genetics Services From Disease Oriented National Genetics Programs,' presentation at the 8th International Congress of Human Genetics, Washington, DC, October 1991.
3. Asch, A., 'Ethical Implications of Population Screening for Cystic Fibrosis: Disability and Stigmatization, " contract document prepared for the U.S. Congress, Office of Technology Assessment, May 1991.
4. Beckwith, J., Harvard University, in N. Touchette, "Genes In Good Hands With Insurers?,' *Journal of NIH Research* 2:37, *1990.*
5. Berg, P., and Wolff, S., National Institutes of Health/Department of Energy Joint Subcommittee on the Human Genome, letter to Evan J. Kemp, Chairman, Equal Employment Opportunity Commission, July 10, 1991.
6. Billings, P. R., "Genetics and Insurance Discrimination," presentation before the U.S. Congress, Office of Technology Assessment advisory panel on *Genetic Monitoring and Screening in the Workplace,* March 1989.
7. Billings, P. R., Kohn, M. A., de Cuevas, M., et al., "Discrimination as a Consequence of Genetic Testing," *American Journal of Human Genetics 50:476-482, 1992.*
8. *Bowen v. American Hospital Association, 476* U.S. 610 (1986).
9. Burris, S., "Rationality Review and the Politics of Public Health," *Villanova Law Review* 34:933-993, *1989.*
10. Cao, A., Istituto di Clinica e Biologia dell'Età Evolutiva, University Studi, Calgliari, Italy, "A Disease Oriented National Health Service,' presentation at the 8th International Congress of Human Genetics, Washington, DC, October 1991.
11. Childs, B., "The Personal Impact of Tay-Sachs Carrier Screening," *Tay-Sachs Disease: Screening and Prevention,* M.M. Kaback (ed.) (New York, NY: Alan R. Liss, Inc., 1977).
12. Childs, B., Gordis, L., Kaback, M. M., et al., "Tay-Sachs Screening: Social and Psychological Impact," *American Journal of Human Genetics* 28:550-558, *1976.*
13. Clarke, A., "Is Non-Directive Genetic Counseling Possible?," *Lancet* 338:998-1991.
14. Clew, C.L., and Scriver, C.R., "Knowledge and Attitudes Toward Genetic Screening Among High-School Students: The Tay-Sachs Experience," *Pediatrics* 59:86-91, *1977.*
15. Clew, C.L., and Scriver, C.R., "The Adolescent Copes With Genetic Screening: A Study of Tay-Sachs Screening Among High-School Students," *Tay-Sachs Disease: Screening and Prevention,* M.M. Kaback (cd.) (New York, NY: Alan R. Liss, Inc., 1977).
16. Council for Responsible Genetics, Human Genetics Committee, "Position Paper on Genetic Discrimination," *Genewatch,* May 1990, p. 3.
17. Eckholm, E., "Health Benefits Found to Deter Job Switching," New *York Times, Sept. 26,1991,* p. A1.
18. Eddy, D.M., "How To Think About Screening," *Common Screening Tests,* D.M. Eddy (cd.) (Philadelphia, PA: American College of Physicians, 1991).
19. Elias, S., and Annas, G.J. (eds.), *Reproductive Genetics and the Law* (Chicago, IL: Year Book, 1987).
20. Equal Employment Opportunity Commission, Washington, DC, letter to P. Berg and S. Wolff, Aug. 2, 1991.
21. Feldblum, C.R., "The Americans With Disabilities Act Definition of Disability," *The Labor Lawyer* 7:11-26, 1991.
22. Fernbach, S. D., Baylor College of Medicine, Houston, TX, personal communication, November 1991.
23. Fletcher, J. F., "Knowledge, Risk, and the Right to Reproduce: A Limiting Principle,' *Genetics and the Law II,* A. Milunsky and G.J. Annas (eds.) (New York, NY: Plenum, 1980).
24. *Gerben v. Holsclaw, 692* F. Supp. 557 (E.D. Pa. 1988).
25. Goffman, E., Stigma: *Notes on the Management of Spoiled Identity* (Englewood Cliffs, NJ: Prentice-Hall, 1963).
26. Gostin, L., "The Future of Public Health Law," *American Journal of Law and Medicine* 12:461-490, *1986.*
27. Gostin, L., "Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers," *American Journal of Law and Medicine* 17(1&2):109-144, 1991.
28. Green, E.D., and Waterston, R.H., "The Human Genome Project: Prospects and Implications for Clinical Medicine," *Journal of the American Medical Association* 266:1966-1975,1991.
29. Hahn, H., "The Politics of Physical Differences: Disability and Discrimination," *Journal of Social Issues* 44:39-47, *1988.*
30. Havighurst, C. C., Duke University School of Law, Durham, NC, personal communication, September 1991.
31. Health Insurance Association of America, *Source Book of Health Insurance Data, 1989* (Washington, DC: Health Insurance Association of America, 1989).
32. Holtzman, N. A., Johns Hopkins University, in N. Touchette, "Genes In Good Hands With Insurers?," *Journal of NIH Research* 2:37, 1990.

33, Holtzman, N. A., and Rothstein, M. A., "Invited Editorial: Eugenics and Genetic Discrimination," *American Journal of Human Genetics* 50:457-459, *1992.*
34. *Jane Doe v. Region 13 Mental Health-Mental Retardation Commission, 704* F.2d 1402 (5th Cir. 1983).
35. Kaback, M. M., Becker, M., and Ruth, V. M., "Sociologic Studies in Human Genetics: I. Compliance Factors in a Voluntary Heterozygote Screening Program," *Ethical, Social and Legal Dimensions of Screening for Human Genetic Disease,* D. Bergsma (cd.) (New York, NY: Stratton Intercontinental Medical Book Corp., 1974).
36. Kaplan, F., Clew, C., and Scriver, C. R., "Cystic Fibrosis Carrier Screening by DNA Analysis: A Pilot Study of Attitudes Among Participants," *American Journal of Human Genetics* 49:240-243, 1991.
37. Kass, N. E., Johns Hopkins University, personal communication, December 1991.
38. Kenen, R. H., and Schmidt, R. M., ''Stigmatization of Carrier Status: Social Implications of Heterozygote Genetic Screening Programs,' *American Journal of Public Health* 68:116-1120, *1978,*
39. Kimura, R., "Genetic Screening and Testing: Report of a Working Group,' *Genetics, Ethics, and Human Values: Human Genome Mapping, Genetic Screening, and Gene Therapy-Proceedings of the XXIVth CIOMS Round Table Conference, Z.* Bankowski and A.M. Capron (eds.) (Geneva, Switzerland: Council for International Organizations of Medical Sciences, 1991).
40. Kosterlitz, J., ''Unrisky Business, " *National Journal,* Apr. 6, 1991, pp. 794-797.
41. Lippman, A., "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities, " *American Journal of Law and Medicine* 17(1&2):15-50, *1991.*
42. Mayerson, A., "The Americans With Disabilities Act-An Historic Overview, " *The Labor Lawyer* 7:1-9, *1991.*
43. Meyers, A. S., National Organization for Rare Disorders, "The Rising Cost of Health Insurance," testimony, U.S. House of Representatives, Committee on Energy and Commerce, Subcommittee on Commerce, Consumer Protection, and Competitiveness, Apr. 30, 1991.
44. Myers, S. T., and Grasmick, H. G., 'The Social Rights and Responsibilities of Pregnant Women: An Application of Parson's Sick Role Model,' *The Journal of Applied Behavioral Science* 26:157-172, *1990.*
45. Murray, R. F., Jr., Howard University College of Medicine, Washington, DC, personal communication, March 1992.
46. Murray, T. H., "Genetics, Ethics, and Health Insurance, ' contract document prepared for the U.S. Congress, Office of Technology Assessment, July 1991.
47. National Center for Human Genome Research, National Institutes of Health, 'Ethical, Legal and Social Issues Program, National Center for Human Genome Research: Grant-Making Status Report," August 1991.
48. Natowicz, M. R., Alper, J. K., and Alper, J. S., "Genetic Discrimination and the Law, ' *American Journal of Human Genetics* 50:465-475, *1992.*
49. Northwestern National Life Insurance Co., "Americans Speak Out on Health Care Rationing" (Minneapolis, MN: Northwestern Life Insurance Co., 1990).
50. Parmet, W., ''Discrimination and Disability: The Challenges of the ADA, ' *Law, Medicine, and Health Care* 18:331-344, *1990.*
51. Pauly, M.V., Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia, PA, personal communication, September 1991.
52. Peterson, K. S., ''Pregnancy Often Seen As Illness," *USA Today,* Mar. 12, 1992.
53. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Securing Access to Health Care* (Washington, DC: U.S. Government Printing Office, 1983).
54. Purdy, L. M., "Genetic Diseases: Can Having Children Be Immoral?," *Ethical Issues in Modern Medicine,* 3rd cd., J.D. Arras and N.K. Rhoden (eds.) (Mountain View, CA: Mayfield, 1989).
55. Rapp, R., ''Chromosomes and Communication: The Discourse of Genetic Counseling,' *Medical Anthropology Quarterly* 2:143-157, 1988.
56. Raymond, H. E., Health Insurance Association of America, Washington, DC, personal communication, December 1991.
57. Richardson, S. A., "Attitudes and Behavior Toward the Physically Handicapped," *Birth Defects: Original Article Series* 12:15-34, *1976.*
58. Rothstein, M. A., University of Houston Health Law and Policy Institute, Houston, TX, remarks at U.S. Congress, Office of Technology Assessment workshop, "Cystic Fibrosis, Genetic Testing, and Self-Insurance Under ERISA," Aug. 6, 1991.
59. Rothstein, M. A., "Genetic Discrimination in Employment and the Americans With Disabilities Act,' *Houston Law Review,* vol. 29, in press, 1992.
60. Schneider, J., and Conrad, P., *Having Epilepsy: The Experience and Control of Illness* (Philadelphia, PA: Temple University Press, 1983).
61. *School Board of Nassau County, Florida v. Arline, 480* U.S. *273 (1987).*
62. Schulman, J. D., Genetics & IVF Institute, Fairfax, VA, personal communication, December 1991.
63. Seligmann, J., "Whose Baby Is It, Anyway ?," *Newsweek,* Oct. *28,* 1991.

64. Singer, E., "Public Attitudes Toward Genetic Testing,'' *Population Research and Policy Review,* 10:235-255, *1991.*
65. Stone, D., Brandeis University, in S. Brownlee and J. Silberner, ''The Assurances of Genes," U.S. News& *World Report,* July 23, 1990.
66. Susser, P., "The ADA: Dramatically Expanded Federal Rights for Disabled Americans," *Employee Relations Law Journal* 16(2):157-176, 1990.
67. *United Auto Workers v. Johnson Controls, Inc.,* 111 *S.* Ct. 1196 (1991).
68. U.S. Congress, Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace,* OTA-BA-455 (Washington, DC: U.S. Government Printing Office, October 1990).
69. U.S. Congress, Office of Technology Assessment, *Medical Monitoring and Screening in the Workplace: Results of a Survey-3a ckground Paper,* OTA-BP-BA-67 (Washington, DC: U.S. Government Printing Office, October 1991).
70. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Policies, Practices, and Attitudes of Genetic Counselors—Results of a Survey,* OTA-BP-BA-97 (Washington, DC: U.S. Government Printing Office, forthcoming 1992).
71. U.S. Congress, Office of Technology Assessment, *Cystic Fibrosis and Genetic Screening; Policies, Practices, and Attitudes of Health Insurers-Results of a Survey,* OTA-BP-BA-98 (Washington, DC: U.S. Government Printing Office, forthcoming 1992).
72. U.S. Congress, Senate, Committee on Labor and Human Resources, *Americans With Disabilities Act of 1990,* report to accompany S. 933, S. Rpt. 101-116 (Washington, DC: U.S. Government Printing Office, 1989).
73. Wertz, D. C., and Fletcher, J. C., "An International Survey of Attitudes of Medical Geneticists Toward Mass Screening and Access to Results," *Public Health Reports* 104:35-44, *1989.*
74. Wexler, N. S., Beckwith, J., Cook-Deegan, R. M., et al., "Statement of Recommendations by the Joint Working Group on Ethical, Legal, and Social Issues (ELSI) Concerning Genetic Discrimination and ADA Implementation, Apr. 29, 1991," *Human Genome News,* September 1991.