

**Chapter 7**

# **Financing**

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Health care financing in the United States is not monolithic: There are several forms of private financing, as well as public financing. This chapter provides a general review of health care financing in the United States. It briefly discusses how each entity determines eligibility for coverage and describes how each is regulated. OTA has examined the U.S. health insurance industry in greater detail elsewhere (27).

This chapter also describes a 1991 OTA survey of U.S. commercial health insurers, Blue Cross and Blue Shield (BC/BS) plans, and the largest health maintenance organizations (HMOs). This chapter focuses on survey results of private sector insurers' general attitudes towards genetic tests and their reimbursement practices for genetic tests and genetic services. Chapter 8 reports on results from this survey that pertain to the potential impact of genetic information or genetic tests on access to health care coverage.

#### OVERVIEW OF U.S. HEALTH CARE FINANCING

Health care financing in the United States totaled more than \$800 billion in 1991 (15). Public funding includes Medicare and Medicaid programs, as well as the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), which insures military personnel and their dependents. Private funding mechanisms include self-funded plans (which generally are plans administered by large employers), commercial health insurance plans, BC/BS plans, and HMOs. Finally, membership in a State high-risk pool—in the 25 States that have them—is an option that is increasingly available to individuals who cannot obtain private health insurance (table 7-1).

#### *Public Financing*

Most public spending for health services covers six populations: low income individuals and others eligible for Medicaid, those over age 65, military personnel and their dependents, veterans, Federal civilian employees, and Native Americans. As with most workers in the United States, Federal civilian employees receive benefits through their employer,

the Federal Government, through plans similar to private sector plans. Native Americans are covered under the Indian Health Service.

#### Medicaid

Medicaid is a joint State and federally funded program for low income citizens and people with disabilities. Administered by the States, it provides medical assistance to an estimated 6 percent of the U.S. population (25). Operating within Federal guidelines, each State designs and administers its own Medicaid program. Thus, Medicaid eligibility requirements, services offered, and methods and levels of payment to providers vary widely among States, although a minimum Federal standard of services must be covered. The adequacy of Medicaid in ensuring access to health care in general, and genetic services specifically, depends on these State-specific features.

#### Medicare

For people over the age of 65 and some disability recipients under age 65, Medicare is the primary source of health insurance, covering about 12.6 percent of the U.S. population (32). People below age 65 who are totally and permanently disabled can become eligible for Medicare coverage after a minimum waiting period. In this way, some adults with cystic fibrosis (CF) (who have worked and contributed to the Social Security system for a period) can receive medical coverage through Medicare under the program's disability provisions.

**Table 7-1—Health Care Coverage in the United States**

U.S. population	245 million
Persons with health care coverage . . . . .	214 million
Persons with private coverage <sup>a</sup> . . . . .	189 million
Persons with public coverage <sup>b</sup> . . . . .	45 million
Number of uninsured persons. . . . .	31 million

<sup>a</sup>Persons with private coverage could be covered under commercial insurance plans, BC/BS plans, HMOs, or self-funded plans that offer these options. Of those covered by commercial plans, people can be covered under group plans, medically underwritten group plans, or individual plans.  
<sup>b</sup>Some persons with public coverage also have private coverage.

SOURCE: Office of Technology Assessment, 1992, based on Health Insurance Association of America, Source *Book of Health Insurance 1991* (Washington, DC: Health Insurance Association of America, 1991); and U.S. Department of Commerce, Bureau of the Census, Current Population Reports Series P-70, No. 17, 1990.

## CHAMPUS

Medical treatment is available for all active and retired military personnel and their dependents at Department of Defense (DOD) medical sites through the Military Health Services System (MHSS). CHAMPUS, a component of MHSS, provides health care for certain dependents of active duty personnel, military retirees, and their dependents. In 1989, expenditures for medical care comprised \$2.8 billion of the \$13 billion DOD budget (14).

### State Pools

In response to citizens' difficulties in obtaining health care coverage, several States have established health insurance pools for underinsured and uninsurable persons. As of December 1990, State legislation creating State high-risk pools for such individuals had been created in 25 States, but not all are operating (14). Several additional States are considering legislation.

State insurance pools provide an opportunity for many to purchase health insurance regardless of circumstance or physical condition, although generally at a rate considerably higher than most other individual plans. Although eligibility for the plans varies from State to State, the basic criterion for participation is denial of coverage by other insurers. To qualify for a State high-risk pool, an individual typically must have been rejected for health care coverage at least three times for reasons related to medical risk factors (17,20).

State pools vary greatly in the type and amount of coverage they provide. Premiums are paid by enrollees, but are capped at a certain level. Enrollee premiums help fund pools, with the balance of costs financed by State revenues and insurers. Insurance companies contribute funds to pools proportional to their market share in the State. Self-funded plans (described in a following section) are the largest payers of health care in the United States, but are not assessed premiums for State high-risk pools.

Because State pools insure individuals with the highest risks for medical needs and do not have broad-based financing, they have not been without problems. The high-risk insurance pool in Florida, for example, covers 7,600 people, but was closed for new enrollments in April 1991 because of budget problems (12). State high-risk pools often have large deductibles, high premiums, and maximum lifetime benefits.

## *Private Financing*

For the majority of Americans, access to health care—and the health insurance that makes such access possible—is provided through the private sector. Privately financed health insurance for medical expenses covers more than 189 million persons through self-funded companies, commercial insurance companies, BC/BS plans, and managed care programs (e.g., HMOS and preferred provider organizations (PPOS)) (14). Although the term health insurance broadly includes various types of insurance—e.g., disability income or accident—this chapter focuses on health insurance for medical expenses (also known as major medical expense policies).

Private health insurance exists in a variety of forms. The majority of Americans obtain health insurance coverage through employment—either directly as employees or as family members of the employed. The employer, in turn, contracts with a commercial insurer, a BC/BS plan, or an HMO. Such groups are both large, with no diagnostic tests or physical examinations required for entry (i.e., no medical underwriting) or small (i.e., require some diagnostic tests or physical examinations, on which the insurance contract's coverage and costs are based). An employer can also be self-funded, meaning it does not pay premiums to an outside insurer but instead pays its employees' medical claims out of its own resources—although self-funded companies can buy claims processing services from outside insurers (box 7-A). Finally, persons without group coverage can seek individual health insurance from commercial insurers, BC/BS plans, or HMOs.

BC/BS plans provide both individual and group coverage to more than 80 million Americans (16). Nationwide, 73 BC/BS plans operate on a regional basis—many enjoying significant shares of their local health care coverage market—and all offer some form of individual health coverage. Market share and regional focus can play a pivotal role in how a BC/BS plan underwrites its policies. That is, unlike commercial insurers, BC/BS plans are regional and do not sell coverage outside a particular State, metropolitan area, or region. The market share of many BC/BS plans—though decreasing in recent years—has historically overshadowed that of any individual commercial carrier, so that in some States as much as half the population are BC/BS subscribers. A secure market position can shape underwrit-

### **Box 7-A—Self-Funded Employee Health Benefit Plans**

*Since* enactment of the Employee Retirement Income Security Act of 1974 (ERISA) (29 U.S.C. 1131 et seq.), many companies have found it beneficial to self-fund their employee health insurance benefits. Under ERISA, a company is viewed as an employer providing benefits, not an insuring entity, and so escapes State insurance regulation. Self-funded plans, for example, need not comply with State laws that mandate health insurance contracts to include specified benefits (e.g., minimum maternity coverage or alcohol and drug addiction treatment), nor comply with certain antidiscrimination standards applicable to insured plans. Self-funded plans are also exempt from State insurance premium taxes and need not participate in insurance pools for high-risk individuals. Self-funding is particularly attractive to multi-State employers that do not want to tailor their benefit plans to each set of State laws. Today, the majority of the large group market is self-funded, leaving most of the group benefits marketplace virtually unregulated by the States (33).

Self-funding means benefits are provided by an employer, which directly assumes most or all of the financial risk for its employees' health care expenses. Self-funded employers can use and retain earnings on a pretax basis on money they must otherwise set aside in claims reserves. The actual value of these reserves varies from company to company, but can represent a sizable portion of the annual premium. Many employers prefer to have the use of their capital instead of holding it in reserve.

Although some self-funded companies administer their own plans, most use independent third-party administrators—often other commercial insurers, BC/BS plans, or independent claims processors. In addition to administrative services, some commercial insurers and BC/BS plans also provide stop-loss insurance, which allows employers to self-insure their plan up to a certain dollar amount. Should a company have employee health care claims exceeding this amount, the stop-loss plan becomes effective and the policy pays additional claims—i.e., stop-loss insurance protects an employer from a catastrophic claim (7).

SOURCE: Office of Technology Assessment, 1992.

ing policies allowing a plan, for example, to enroll high-risk applicants because the plan can spread risks over a broader base.

BC/BS plans often operate under considerably different regulatory conditions from commercial carriers. Currently, BC/BS plans in 12 States have an open enrollment period, during which all individuals who apply for coverage are accepted regardless of their health status (16) (box 7-B), although most contracts have waiting periods for preexisting conditions. Some open enrollment plans are continuous (accept all applicants throughout the year), whereas others limit open enrollment to a designated number of weeks.

One of the fastest growing areas of health insurance in the last decade has been managed care groups such as PPOs<sup>1</sup> and HMOs. HMOs are health care organizations that provide comprehensive services to enrolled members for a fixed, prepaid amount that is independent of the number of services actually used. The market share for these plans has increased at the expense of conventional health

insurance plans (14), although the net number of HMOs declined by 22 in 1990, reflecting industry consolidation. As of December 1990, there were 569 HMOs in the United States, with enrollment exceeding 36.5 million members (11).

As with other health insurers, HMOs are paid a fixed premium for each member. Unlike other insurers, however, an HMO is financially responsible for its members' medical costs only if the HMO's affiliated providers are used (except for emergencies) (24). By assuming not only the insurance risk but also the responsibility for providing their members' health care, HMOs operate under significantly different conditions from either BC/BS plans or commercial carriers. Another important distinction is that while commercial insurers and BC/BS plans are governed solely by State regulations, many HMOs voluntarily also adhere to Federal qualification standards. In order to become federally qualified, HMOs must meet certain financial, underwriting, and rate-setting standards and provide specified medically necessary health services (10). More than

<sup>1</sup>PPOs are similar to HMOs, but provide more flexibility in physician selection. They involve contractual arrangements with specific physicians or provider organizations.

**Box 7-B-Open Enrollment and Blue Cross and Blue Shield Associations**

When BC/BS plans were first offered in the 1930s, all applicants were accepted for coverage regardless of their health status-i. e., open enrollment. Today, plans in 12 States have an open enrollment period, although most contracts have waiting periods for preexisting conditions. The implications of such plans for the underwriting process are significant. Because no individual standards of insurability are applied to open enrollment applicants, adverse selection exists. Adverse selection occurs when applicants seek coverage because they are aware of medical problems (and hence medical expenses) that are not yet evident to the underwriter.

Most plans attempt to hold down premium rates for open enrollment subscribers by providing less comprehensive benefits than are offered in other plans. Other BC/BS plans require open enrollment subscribers to pay higher premiums than underwritten applicants for identical coverage. Finally, open enrollment coverage of high-risk applicants usually entails awaiting period before initial benefits are paid, and they often impose limitations on coverage of preexisting conditions.

Some applicants to BC/BS open enrollment plans must furnish evidence of their health status, even though the plans never deny an application. Individuals seeking health care coverage through an open enrollment program often have the option of undergoing medical underwriting, and even a physical exam, to determine whether they qualify for a more comprehensive benefit package at a lower rate. Additionally, health information may be required by the underwriter to develop benefit limits, exclusion riders, waiting periods for preexisting conditions, or premium rates.

SOURCE: Office of Technology Assessment, 1992.

half the Nation's HMOs are federally qualified, and 74 percent of HMO enrollment is in federally qualified plans (11). Federal qualification can be important to consumers: If an HMO accepts non-Medicare individual members, they must be either accepted at a community rate or rejected altogether. Exclusion riders and rated premiums are prohibited. Waiting periods as well as preexisting condition waivers are not allowed. However, medical screening of individual applicants is permitted.

**Individual Health Insurance**

Despite the fact that most people in the United States obtain health care through group plans, many have no access to an employer-sponsored plan because they are unemployed, self-employed, or employed by companies that do not provide health benefits. Thirty-six percent of companies with fewer than 25 employees offered their workers health insurance in 1990, compared to 87 to 99 percent of larger employers (13). An individual who is unable to obtain health care coverage through his or her employer must generally seek individual health insurance.

Persons who obtain health care through individual health insurance policies-from 10 to 15 percent of all persons with health insurance-usually have their health status evaluated by the insurer to determine whether they are insurable, and if so, at what price (a process called rating). This evaluation of the applicant's risk is commonly referred to as medical underwriting, and relies at a minimum on a medical history questionnaire, and less frequently, on other sources of information such as an attending physician's statement or medical tests. Applicants in groups of 10 or fewer employees are often individually medically underwritten as well (8,21). Medium to large groups with 10 to 25 or more members are seldom, if ever, medically underwritten. Risk classification is also generally not used in employer-sponsored/



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**Blue Cross  
Blue Shield**  
of the National Capital Area  
550 12th Street, S.W.  
Washington, D.C. 20005

**DO NOT WRITE IN THIS SPACE**

Identification Number		Group Number		Rep. Code	
Service Code		Effective Date			
Disp.	Trans. Date	Sub. By	Sp. By	Sex	M.S.

0406

## Application for Comprehensive Major Medical Non-Group Coverage

**PLEASE PRINT ALL INFORMATION**

**IMPORTANT - Please be sure to give complete information to your employer or other group.**

Name of employer or other group: \_\_\_\_\_

### HEALTH EVALUATION

Do you have any person named in this application had within the last seven years, or does such person have any of the following conditions?

YES	NO	(k)
<input type="checkbox"/>	<input type="checkbox"/>	Heart trouble, abnormal blood pressure (hypertension or hypotension), anemia, rheumatic fever, cardiovascular accident (stroke) (Female) irregular or excessive menstrual bleeding, reproductive system disorders, infertility, breast condition
<input type="checkbox"/>	<input type="checkbox"/>	(m) (Female) is currently pregnant; expected date of delivery _____
<input type="checkbox"/>	<input type="checkbox"/>	(n) (Male) Prostate trouble, reproductive system disorders, infertility
<input type="checkbox"/>	<input type="checkbox"/>	(o) Outpatient counseling, any psychiatric or psychological counseling, or any nervous or mental disorder
<input type="checkbox"/>	<input type="checkbox"/>	(p) Sexually transmitted diseases

**SECTION A -** To the best of your knowledge and belief, has any person named in this application had within the last seven years, or does such person now have any of the following?

YES	NO	
<input type="checkbox"/>	<input type="checkbox"/>	(a) Cancer, tumor or other growth
<input type="checkbox"/>	<input type="checkbox"/>	(b) Acquired Immune Deficiency Syndrome (AIDS), AIDS Related Complex (ARC), Human Immunodeficiency Virus Seropositivity (HIV test), positive HIV test
<input type="checkbox"/>	<input type="checkbox"/>	(c) Kidney trouble, diabetes, kidney stones, kidney or bladder trouble, urinary frequency or burning
<input type="checkbox"/>	<input type="checkbox"/>	(d) Gonorrhea, thyroid trouble, diabetes
<input type="checkbox"/>	<input type="checkbox"/>	(e) Seizure disorder, central nervous system abuse or substance abuse (drug or alcohol dependency, abuse or addiction)
<input type="checkbox"/>	<input type="checkbox"/>	(f) Gall bladder trouble, hernia, stomach or intestinal trouble, ulcers, hemorrhoids, liver disorder
<input type="checkbox"/>	<input type="checkbox"/>	(g) Trouble with other eye condition, asthma, bronchitis
<input type="checkbox"/>	<input type="checkbox"/>	(h) Cataract or other eye condition, external deformity
<input type="checkbox"/>	<input type="checkbox"/>	(i) Tuberculosis, lung condition, spinal deformity (amputation), back or spinal trouble, gout

**SECTION B -** In addition to the conditions listed in SECTION A, to the best of your knowledge and belief, within the past five years, has any person named in this application:

YES	NO	
<input type="checkbox"/>	<input type="checkbox"/>	(a) Had a physical examination?
<input type="checkbox"/>	<input type="checkbox"/>	(b) Excluding physical examinations, consulted a physician, health care provider, or other individual or facility for medical or surgical treatment, advice, screening for any condition, or reason for prescription medication not listed in SECTION A?
<input type="checkbox"/>	<input type="checkbox"/>	(c) Had any departure from good health not previously mentioned in any of the above questions for which treatment or advice may or may not have been sought?

**SECTION C -** If you have checked "YES" to any part of SECTION A or SECTION B, please provide complete information regarding diagnosis or condition of treatment, including all medications, hospitalizations, surgery, and diagnostic testing results and dates. If more space is needed, attach a separate sheet of paper.

Patient's First Name	Diagnosis or Condition	Duration Dates From To	Explain treatment including all medications, hospitalizations, surgery and diagnostic test results and physician's hospital name	Recovery Check only one box
				<input type="checkbox"/> Full <input type="checkbox"/> Partial
				<input type="checkbox"/> Full <input type="checkbox"/> Partial

### PLEASE READ CAREFULLY - THIS SECTION MUST BE DATED AND SIGNED

**IT IS UNDERSTOOD AND AGREED THAT:**

- The statements and answers made herein are complete and correct to the best of my knowledge and belief, and are made to cause the issuance of, and to become a part of, the contract for which I am applying. Should any statements or answers made herein change, or should the physical or health condition change of any person named in this application, before the contract becomes effective, I will notify Blue Cross and Blue Shield of the National Capital Area (hereafter "BCBSNCA").
- The contract will become effective the first of the month following approval of this application by BCBSNCA.
- Should any statements or answers contained in this application be untrue (if such statements are fraudulent or material to the acceptance of this application) or if any person named in this application, before the contract becomes effective, I will notify Blue Cross and Blue Shield of the National Capital Area (hereafter "BCBSNCA") and its obligation shall consist only of the return of any subscription charges actually paid, less the amount of any benefits paid under the contract.
- As a non-group Subscriber of BCBSNCA, no change to a higher level of coverage may be made by me except at such time as BCBSNCA may offer such change to non-group Subscribers having the coverage applied for herein.
- The Subscriber shall repay to BCBSNCA the amount of any payment made in error to the Subscriber on behalf of the Subscriber or any covered family member as the result of a claim.
- Any physician, nurse, hospital or other provider (hereafter "Provider") having treated or attended me or any of my family members listed on this application and having possession of any records or information with respect thereto, is authorized and directed to provide such information or records to BCBSNCA upon request for the purpose of evaluation of this application. This authorization is valid for 30 months.
- If this application is approved by BCBSNCA, I authorize any Provider to forward to BCBSNCA information concerning medical services or supplies provided to me or to any of my family members listed on this application for the purpose of review, investigation or payment of a claim. This authorization is valid for the duration of coverage.
- A copy of this application will be attached to the contract issued to the Subscriber.
- This contract includes a ten-month waiting period for the treatment of pre-existing conditions, tonsillectomies and adenoidectomies, sterilizations, infertility and complications resulting from any of these conditions or procedures unless credit toward the waiting period is granted by BCBSNCA.
- If this application is accepted by BCBSNCA, I will pay in advance, subscription charges applicable to the type of coverage selected directly to Blue Cross and Blue Shield of the National Capital Area.

Signature of Applicant

Signature of Applicant

Broker Name \_\_\_\_\_  
 Broker Soc. Security Number \_\_\_\_\_  
 Agency Tax ID \_\_\_\_\_  
 Broker Phone Number \_\_\_\_\_

**PLEASE ANSWER THE QUESTIONS ON THE REVERSE SIDE OF THIS FORM AND SIGN WHERE INDICATED.**

Photo credit: Office of Technology Assessment

A Blue Cross and Blue Shield Association application for individual health insurance.

group plans. Large group plans accept all eligible employees regardless of characteristics such as age, sex, or health. However, most individual, medically underwritten groups and large group plans have restrictions on preexisting conditions.

Individual insurance operates on the principle that the cost of insurance should be proportional to the risks involved. Most applicants for individual insurance receive standard rates (22). Individuals applying for insurance whose potential losses might be large, however, can expect to pay higher premiums—often called rated premiums—than those whose potential losses are expected to be less. Individuals might also be accepted at standard rates, but with certain waivers excluding health care coverage related to specific conditions. Some applicants might be accepted with both an exclusion waiver and at a rated premium. Applicants with significant disease can be denied insurance altogether.

Insurers are particularly concerned about applicants for individual insurance who seek to purchase coverage because they are aware of a medical problem that is not yet evident to the underwriter. Such applicants pose a financial threat to the insurer, and the situation is referred to as “adverse selection” or “antiselection” (of an insurer by high-risk applicants). It refers to the situation where, in the absence of any controls, persons who seek to obtain insurance will tend to be those who will use it most—that is, those with a greater than average probability of loss to the insurer. Insurers’ ability to accept applicants and their rating structure are influenced by the threat of adverse selection (16). The potential for adverse selection is most relevant for small group and individual insurance, because large groups tend to have an even distribution of low- and high-risk individuals.

#### The Medical Information Bureau and Individual Health Insurance

In 1902, a group of 15 life insurance companies established the Medical Information Bureau (MIB). Now located in Westwood, MA, MIB strives to discourage fraud when companies are called on to write insurance for applicants with conditions significant to longevity or insurability. MIB acts as a medical information clearinghouse where member companies can determine if an applicant for health or life insurance has previously been denied coverage for medical reasons. About 750 U.S. and Canadian life insurance companies at 1,150 loca-

tions belong to MIB (18). BC/BS companies are not members of MIB, and therefore do not use its data (4).

Although MIB was setup by and for life insurance companies, a member can also access MIB for health or disability insurance purposes if the member sells those products. Perhaps more importantly, information about persons applying for individual health insurance through an MIB member company can be entered into MIB.

Applications for individual insurance—health, life, or disability—carry an explanation about MIB. If the insurance company finds something in an applicant’s history that could affect longevity, the member company must file a report with MIB about the applicant’s insurability. The potential insurer also may request an MIB check to see if past reports about the applicant have been filed by other companies; MIB makes about 22 million such checks each year. MIB’s reports alert a potential insurer to omissions or misrepresentation of facts by an applicant. In principle, an applicant can refuse to allow his or her information to be communicated to MIB. The penalty to the applicant, however, typically means refusal by the insurance company to process the application.

MIB enters approximately 3 million coded records a year and has information on about 15 million persons in the United States (6). Information about applicants is encoded into a broad-based set of 210 medical categories and 5 nonmedical codes (e.g., aviation, hazardous sport) at the time an individual applies for medically underwritten life, health, or disability insurance from a member company. Not all information entered into MIB is negative information about an applicant, as normal results of tests are also submitted to MIB. For example, if an applicant has a previous record for high blood pressure, an entry might be made at a later date reflecting a normal blood pressure reading. Insurance claims made by individuals are not a source of records and codes for MIB.

MIB codes include a few for classifying genetic diseases. A specific category exists for CF and a broad category also exists for family histories of hereditary disease. Currently, MIB has no plans for expanding genetic disease categories to classify information that could become available from new genetic tests (6). Coded information on an applicant is released to authorized personnel at the member

company requesting the information through computer terminals dedicated exclusively to MIB activities.

Any individual can inquire whether MIB retains a record on him or her. Individuals can inspect and seek correction of their own records. On average, 19,000 people request disclosure annually, and about 400 make corrections to their records. MIB retains records on an individual for 7 years; if no additional applications or inquiries come to MIB on a person after that period of time, the record is purged.

MIB emphasizes that its reports are not used as the basis for a decision to reject an application or to increase the cost of insurance premiums ( 18). Actual underwriting decisions are based on information from the applicant and from medical professionals, hospital records, and laboratory results. In 12 States it is illegal under the National Association of Insurance Commissioners Insurance Information and Privacy Protection Model Act to make underwriting decisions solely on the content of an MIB record; the act also is adhered to by some insurers in States that have not enacted it. Another deterrent to using MIB codes to deny coverage: Insurers must disclose the basis for an adverse underwriting decision under the Federal Fair Credit Reporting Act (Public Law 101-50).

## REGULATION AND UNDERWRITING

Regulation of insurance in the United States is largely State-based, although some Federal laws apply. Within State laws, private insurers have some discretion in determining insurance coverage and how the costs will be distributed. For individual and medically underwritten groups, how much a policy costs, what type of coverage is available, and even whether insurance can be bought at all are determined, in large part, by how a group or individual is classified by insurers—i.e., rating, coverage, and underwriting decisions.

### *Regulation Of Insuring Entities*

The McCarran-Ferguson Act of 1945 (Public Law 79-15) accords States the principal regulatory responsibilities with regard to the business of insurance, although some Federal laws (e. g., the Employee Retirement Income Security Act, or ERISA)

affect health benefit plans, particularly group plans. Besides ERISA, the Federal tax code, through such things as the exclusion of employer contributions for health benefits from the taxable income of workers, has an important impact on health insurance.

All 50 States and the District of Columbia have insurance laws that require insurers to meet a variety of financial and other requirements in order to obtain a license to do business. These laws do not apply to self-funded plans. The exact requirements vary widely from State to State, but ordinarily stipulate certain amounts of financial resources needed to establish solvency as an insurer. BC/BS plans are treated somewhat differently. Although they do not have to adhere to State commercial insurance law, they are subject to a rate-making process that does not generally apply to commercial insurers.

### *Regulation of Insurance Contracts*

All States require that individual health insurance policy forms be filed with the appropriate regulatory authority before being used. Some States require filing and approval of premium rates for new business as well as for renewal rate changes for individual coverage. Most States also require similar filings of group insurance contracts. Insurance laws generally authorize a State insurance commissioner (or comparable authority) to disapprove policies if they contain unjust, unfair, inequitable, misleading, or deceptive provisions. Many States also permit their regulators to disapprove contracts on the grounds that the benefits provided are unreasonable in relation to the premium charged. Similar to the policies directed at commercial insurers, many BC/BS plans are required to obtain prior approval of individual subscriber rate schedules.

Certain types of practices in issuing, continuing, or canceling insurance policies are also prohibited and monitored by States. Certain factors can be barred from use in making underwriting decisions for individual coverages. Even though rating classification schemes must be submitted to State insurance authorities for review, insurers are not required (as they are with rating) to submit the criteria used in underwriting to regulatory authorities (35), and little empirical work on what State regulators actually do in reviewing rating classifications is available (26).

### ***Underwriting***

Underwriting is the process by which an insurer determines whether and on what basis it will accept an application for insurance. Evaluating whether an insurance applicant will be covered on a standard or substandard basis---or not at all---is called risk classification. Because of potentially large differences in the health status and potential risks presented of individual applicants, insurers evaluate individuals using criteria different from those for groups. Individuals generally are placed in classes with about the same expectation of loss. Those with higher than average risks might be accepted, but under special conditions. Seventy-three percent of applicants for individual policies from commercial insurers are classified as standard (26). Those with the highest expectation of loss are declined and deemed uninsurable, except in some States where BC/BS is required to accept all applicants (i.e., open enrollment periods are required).

## **OTA SURVEY OF HEALTH INSURERS**

Although genetic tests and information are important to companies that offer disability and life insurance (box 7-C), the 1991 OTA survey focused on health insurance. Specifically, OTA conducted a survey in 1991 of the commercial insurers, BC/BS plans, and largest HMOs that write individual health

insurance policies or medically underwritten groups to assess their practices and attitudes toward genetic tests. Complete data from the survey, as well as details about its methodology, are presented elsewhere (31). This section summarizes those findings most pertinent to carrier screening for CF.

### ***Demographics of the Survey Population***

OTA's survey population was derived from three sources: a Health Insurance Association of America (HIAA) database of member companies that offer individual health coverage, the BC/BS Association directory (3), and the Group Health Association of America 1991 National Directory of HMOs (11). Again, third-party payers' policies and attitudes for two particular populations were examined:

**Individuals** who seek insurance independently and without any association with an employer or membership group of any kind.

Medically underwritten groups---those groups whose members must be medically underwritten.

Members of these populations are required by insurers to undergo diagnostic tests or physical examination before a policy will be issued. Some large group policies might require tests or physical examinations for cases of late applicants (i.e., employees who are eligible for group health insurance but choose not to sign up until after the normal enrollment period when they know they will soon

### ***Box 7-C—Life Insurance and Cystic Fibrosis***

Life insurance does not provide access to health care, and the interaction of genetic tests with the life insurance industry could differ considerably from that with the health insurance industry. In the United States, about 156 million people are covered by some type of life insurance. For those covered under group plans as part of employee benefit packages, there is typically no medical testing or screening. For those who obtain individual life insurance, however, some medical screening invariably accompanies an application, and its thoroughness usually reflects the amount of coverage being sought. Companies reject about 3 percent of all applications for life insurance.

Life insurance generally is unavailable for individuals with cystic fibrosis (CF)---hence the current availability of DNA-based assays has no impact on life insurance for people with CF. Similarly, since CF carrier status does not affect life expectancy, being identified as a carrier should have no bearing on access to life insurance. Nevertheless, life insurance considerations in the context of CF carrier screening arise because of concerns about the effect other DNA tests could have, generally. Thus, while identifying CF carrier status represents a case with no risk of premature mortality related to that status (and having CF represents a case where an obvious risk of premature mortality would preclude life insurance), other genetic screening that could occur in the future---e.g., for breast or colon cancer---could influence the type and cost of life insurance coverage available to an affected individual.

SOURCE: Office of Technology Assessment, 1992, based on American Council of Life Insurance, *1990 Life Insurance FactBook* (Washington DC: American Council of Life Insurance, 1990); and R. Bier, American Council of Life Insurance, "Questions and Answers: Genetic Information and Insurance," June 1990.

**Table 7-2—Number of People Insured by OTA Survey Respondents**

		Commercial insurers	BC/BS plans	HMOs
Individual policies	Total:	2.0 million	1.7 million	306,861
	Individual respondent:	Range: 171 to 240,000	Range: 1,500 to 690,559	Range: 350 to 258,945
Medically underwritten group policies	Total:	2.3 million	2.4 million	4.0 million
	Individual respondent:	Range: 1,000 to 382,000	Range: 1,039 to 1,592,000	Range: 1,501 to 2 million

SOURCE: Office of Technology Assessment, 1992.

have expenses), but this survey does not encompass such cases. Thus, results from OTA's survey apply to the 12.7 million people who have individual or medically underwritten group coverage provided through survey respondents (table 7-2).<sup>2</sup>

### Commercial Health Insurers

In the United States, approximately 1,250 for-profit companies are in the business of writing health insurance policies (15). Increasingly, however, few commercial health insurers write policies for individuals or medically underwritten groups—the focus of OTA's survey. The OTA survey was sent to 225 health insurers that had recently offered individual coverage, as identified by the HIAA, and OTA received responses from 132 commercial health insurers (59 percent response rate). The list OTA obtained was 4 years old, and in that time period well over half of those companies had stopped offering individual coverage (22), which is confined by the 81 commercial insurance companies responding that they no longer wrote individual or medically underwritten group policies. Fifty-one commercial insurers responding to the OTA survey said they write individual or medically underwritten group contracts. Of these respondents, 29 companies offer individual coverage and 37 companies offer medically underwritten group policies. Fifteen companies offer both types of policies.

### Blue Cross/Blue Shield Plans

Both the chief underwriters and the chief medical directors for 72 of the 73 BC/BS plans were surveyed. (Puerto Rico's plan was excluded.) Twenty-nine chief underwriters completed a survey (40 percent response rate), as did 18 chief medical directors (25 percent response rate). Of the 29 BC/BS plans represented by the chief underwriters, 25 write individual policies; 21 of 29 write medically underwritten group contracts. To represent a

larger pool of plans and because a number of underwriters specified that their survey was a joint underwriter/medical director response, only data from the chief underwriters' survey are used in this chapter to describe BC/BS responses. Complete data are presented elsewhere (31).

### Health Maintenance Organizations

OTA sent surveys to the 50 largest local and national HMOs, as well as a sample of 28 plans that were the largest HMO within a State or the largest by HMO model type. (Four HMO model types exist: the staff model plan, group model plan, network model plan, and independent practice association model plan.) Forty-three surveys were returned (55 percent response rate); 20 of the responding HMOs offered policies neither to individuals nor medically underwritten groups. Of the 23 HMOs responding that do offer such coverage, 11 HMOs accept individuals and 20 medically underwrite groups.

### General Attitudes Towards Genetic Tests

OTA's survey findings indicate that insurers generally believe that it is fair for them to use genetic tests to identify those at increased risk of disease, and that they should decide how to use that information in risk classification (table 7-3). A majority of medical directors from commercial insurers (34 respondents, 67 percent) said they "agree strongly" or "agree somewhat" with the statement that "it's fair for insurers to use genetic tests to identify individuals with increased risk of disease" 15 disagree to some extent (30 percent). Similar responses were obtained from survey respondents from BC/BS plans and HMOs (table 7-3).

Survey respondents were also asked whether "an insurer should have the option of determining how to use genetic information in determining risks." Thirty-eight commercial respondents (74 percent)

<sup>2</sup> Throughout the discussion in this chapter, "no response" is not reported in the text, but the percentages presented account for them, as indicated in the tables.

Table 7-3-General Attitudes of Insurers Toward Genetic Tests

Statement	Respondent	Agree strongly	Agree somewhat	Disagree somewhat	Disagree strongly	No response <sup>a</sup>
It's fair for insurers to use genetic tests to identify individuals with increased risk of genetic disease.	<i>Commercials</i>	11 (22%)	23 (45%)	11 (22%)	4 (8%)	2 (4%)
	<i>HMOs</i>	3 (13%)	14 (61%)	2 (9%)	2 (9%)	2 (9%)
	<i>BC/BS plans</i>	4 (14%)	17 (59%)	4 (14%)	2 (7%)	2 (7%)
An insurer should have the option of determining how to use genetic information in determining risks.	<i>Commercials</i>	19 (37%)	19 (37%)	9 (22%)	3 (6%)	1 (2%)
	<i>HMOs</i>	2 (9%)	15 (65%)	4 (17%)	0 (0%)	2 (9%)
	<i>BC/BS plans</i>	9 (31%)	15 (52%)	4 (14%)	0 (0%)	1 (3%)

<sup>a</sup>Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

agreed strongly or somewhat with this statement; 12 respondents (28 percent) disagreed to some extent. Responses from HMOs indicated similar sentiments: 17 medical directors (74 percent) agreed strongly or somewhat compared to 4 (17 percent) who disagreed somewhat. For BC/BS plans, 24 respondents (83 percent) agreed with the statement to some extent, against 4 respondents (14 percent) who disagreed somewhat (table 7-3).

As genetic tests become widely available, under what conditions do insurers believe a negative financial impact would occur for their company? The majority of commercial insurers (30 respondents; 59 percent) said a negative financial impact would not occur if genetic tests were, in general, widely available to the medical/provider community. In contrast, 34 respondents from commercial insurers (67 percent) thought a negative financial impact would occur under such circumstances if constraints were placed on insurers' access to the results. Forty-seven respondents (92 percent)

thought a negative impact would occur if there were adverse claims or underwriting results due to adverse selection (table 7-4). Similar results were obtained from the BC/BS and HMO survey respondents (31).

OTA found that no commercial insurer had conducted an economic analysis of the costs and benefits of carrier tests as part of applicant screening or genetic tests as part of applicant screening. One commercial company reported it had done an analysis of the costs and benefits of carrier tests as part of prenatal coverage, but 48 companies had not. Similar data were found for both the BC/BS plans and for the HMOs (table 7-5). It is clear that few companies have considered genetic tests or services in terms of the costs and benefits of coverage. It is a particularly important finding that companies had not done such an analysis of the costs and benefits of using genetic tests for the purpose of applicant screening. For reimbursement purposes, it is also important to note that most insurers have not looked

Table 7-4-impact of Genetic Tests on Insurers

Question	Respondent	Yes	No	No n s e <sup>a</sup>
<b>Under what conditions would a negative financial impact be likely to occur for your company (check all that apply):</b>				
Widespread availability of genetic tests to the medical provider community.	<i>Commercials</i>	19 (37%)	30 (59%)	2 (4%)
	<i>HMOs</i>	10 (44%)	10 (44%)	3 (13%)
	<i>BC/BS plans</i>	7 (24%)	20 (69%)	2 (7%)
Widespread availability of genetic tests with constraints on insurers' access to results.	<i>Commercials</i>	34 (67%)	15 (29%)	2 (4%)
	<i>HMOs</i>	16 (70%)	4 (17%)	3 (13%)
	<i>BC/BS plans</i>	17 (59%)	10 (35%)	2 (7%)
Adverse claims or underwriting results from antiselection.	<i>Commercials</i>	47 (92%)	2 (4%)	2 (4%)
	<i>HMOs</i>	18 (78%)	2 (9%)	3 (13%)
	<i>BC/BS plans</i>	27 (93%)	0 (0%)	2 (7%)

<sup>a</sup>Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

**Table 7-5—Economic Analyses of Genetic Tests and Genetic Counseling by Insurers**

Question	Respondent	Yes	No	No response <sup>a</sup>
<b>Has your company ever conducted an economic analysis of:</b>				
<b>Carrier testing as part of applicant screening?</b>	<i>Commercials</i>	0 ( 0%)	50 (98%)	1 ( 2%)
	<i>HMOs</i>	0 ( 0%)	20 (87%)	3 (13%)
	<i>BC/BS plans</i>	0 ( 0%)	28 (94%)	1 ( 3%)
<b>Carrier testing as part of prenatal coverage?</b>	<i>Commercials</i>	1 ( 2%)	48 (94%)	2 ( 4%)
	<i>HMOs</i>	0 (10%)	20 (87%)	3 (13%)
	<i>BC/BS plans</i>	1 (13%)	27 (94%)	1 (13%)
<b>Genetic testing as part of applicant screening?</b>	<i>Commercials</i>	0 ( 0%)	49 (96%)	2 ( 4%)
	<i>HMOs</i>	0 ( 0%)	20 (87%)	3 (13%)
	<i>BC/BS plans</i>	0 ( 0%)	28 (97%)	1 ( 3%)
<b>Genetic counseling of carriers who are covered?</b>	<i>Commercials</i>	0 ( 0%)	49 (96%)	2 ( 4%)
	<i>HMOs</i>	1 ( 4%)	19 (83%)	3 (13%)
	<i>BC/BS plans</i>	1 ( 3%)	27 (94%)	1 ( 3%)

<sup>a</sup>Percentages may not add to 100 due to rounding.

SOURCE: Office of Technology Assessment, 1992.

into the costs and benefits of providing carrier screening or genetic counseling as part of a benefits package.

#### REIMBURSEMENT FOR GENETIC SERVICES—OTA SURVEY RESULTS

Will insurers pay for voluntary screening and followup counseling? And will insurance companies authorize payment for prenatal screening or testing of newborn children? Answers to these questions carry significant cost implications. They also will likely affect the degree to which carrier screening for CF becomes commonplace, since many people will be unwilling to pay out-of-pocket costs for the assays.

Insurance industry representatives assert that companies will not pay for most genetic tests unless they are “medically indicated.” Thus, many health insurance companies do not pay for what they consider to be “screening” tests (28). Currently, the trend is toward closer evaluation of tests’ medical necessity before insurance companies agree to pay for them. For example, a BC/BS task force evaluates 30 or 40 different procedures and devices each year and shares the results with the 73 independent BC/BS plans, each of which makes its own decisions about reimbursement (4).

More broadly, an increasing number of health insurance plans require that patients receive approval for procedures, including diagnostic tests,

before the company will reimburse the cost. As more people become aware of carrier screening for CF, insurance companies are likely to receive more requests for reimbursement. In addition to uncertainty about reimbursement for the test, uncertainty also exists as to who will pay for the genetic counseling that must accompany CF carrier screening. Third-party insurers often have a policy of not reimbursing for counseling unless performed by physicians, which means the costs are reimbursed as general medical consultation fees or absorbed as part of costs on research grants (28).

From the perspective of the commercial laboratory that provides genetic tests to medical providers and patients, the issue of reimbursement is crucial to the level of their potential business—current and future. Few efforts have been made to assess the degree that CF carrier screening is being reimbursed by insurers and self-funded companies, but some individuals have been successful in obtaining reimbursement even in the absence of family history.

One private genetic service provider surveyed 66 patients about this issue in February 1991, and 27 responded (40 percent). After CF carrier screening, each patient had been given a letter explaining the CF carrier assay to submit with their claim. Third-party payers covered all costs of CF carrier screening for 11 of the 27 patients who responded; costs for 5 patients were covered in part and 11 received no reimbursement. Three of the eleven patients who received no reimbursement did not submit the letter to their insurer (9). Two individuals who were

originally denied coverage appealed the decision and received full coverage. All patients who were partially covered had 80 percent coverage or had not yet met their deductible, which is compatible with CF carrier screening being treated as a compensable procedure. While the survey data represent a small sample size at one clinic, the information collected shows that some patients have obtained reimbursement when CF mutation analysis is done for screening purposes.

On balance, however, it appears that, for now, if no medical indication for the test exists, a third-party payor generally will not pay for the assay. However, an appeal can usually be made and is sometimes successful for CF carrier screening when the specifics of mutation frequencies are documented (2). Nevertheless, lack of reimbursement is likely to influence the number of individuals who opt to be screened. Thus, the concept of medical necessity is particularly important to CF carrier screening and revolves around the issue of standards of care (ch. 5); insurers are likely to continue refraining from reimbursement for tests not judged to be customary physician practice. If CF carrier screening becomes commonplace, especially in the context of obstetric/prenatal care, the current situation of third-party payment for CF mutation assay could change.

To analyze the extent to which genetic tests and services were being, or might be, reimbursed by third-party payers, OTA collected data from three populations: genetic counselors and nurses in genetics, health insurers, and State Medicaid directors.

### *Experiences of Genetic Counselors and Nurses*

In June 1991, members of the National Society of Genetic Counselors and the International Society of Nurses in Genetics who said they were currently in clinical practice were asked about the health care coverage of their patients (30). Approximately half of the respondents (198 respondents, 51 percent) reported that their patients have health care coverage very often or always (defined as between 75 and 100 percent of their patients). However, 43 respondents (11 percent) said that their patients sometimes or seldom if ever had coverage (between 0 and 50 percent of their patients).

Survey respondents were asked to recount their experience with reimbursement for various genetic services they performed. For general genetic coun-

seling services, 22 (5 percent) responded they seldom if ever were covered, 56 (13 percent) said they sometimes were covered, 53 (12 percent) said they often were covered, 42 (10 percent) said they very often were covered, and 67 (16 percent) said they almost always were covered.

Where there was a positive family history for CF, genetic counseling was reported to be seldom if ever covered by 17 respondents (4 percent), sometimes covered and often covered by 86 (20 percent), very often covered by 26 (6 percent), and almost always covered by 65 (15 percent) respondents. Where there was no family history for CF, genetic counseling was reported to be seldom if ever covered by 35 respondents (8 percent), sometimes or often covered by 69 respondents (16 percent), very often covered by 10 respondents (3 percent), and almost always covered by 16 respondents (4 percent).

When asked if they knew of a patient's insurance claims for DNA analysis being rejected, 96 respondents (27 percent) said that they knew of such denials. One respondent to OTA's 1991 survey of genetic counselors and nurse geneticists gave this reason for the denial of a client's claim:

In one family, the husband had an affected first cousin. This insurance would not pay for his screening because it is only a risk if the woman is a carrier and that the father's carrier status did not affect the pregnancy.

It is clear in this case that the insurance company falsely assumed that the father's carrier status was not relevant to the condition. At least two other surveys were conducted recently that also dealt with the issue of reimbursement for genetic screening services (1,19). One of these found a majority of respondents obtained full or partial reimbursement for CF mutation analysis. Reimbursement was more likely if a pregnancy was involved or when there was a family history of CF (1).

### *Health Insurers' Approaches*

OTA's survey of health insurers inquired whether certain genetic tests or services—again, for individual and medically underwritten groups—are covered “at patient request” (no family history, i.e., screening), “only if medically indicated” (family history), or “not covered.” No commercial company reimburses for CF carrier tests for screening purposes. The survey also found that carrier tests for CF—as well as Tay-Sachs and sickle cell (31)—are not

covered for any reason by 12 of 29 commercial insurers that offer individual coverage. Twelve respondents (41 percent) cover CF carrier assays if medically indicated. With respect to prenatal tests for CF, about 41 percent (12 respondents) that write individual policies reimburse for such tests when medically indicated (table 7-6).

For the 37 commercial companies offering medically underwritten group policies, carrier tests for CF (and, again, sickle cellorTay-Sachs(31)) are not covered by any company when done solely at patient request. CF mutation analysis is covered by 24 of 37 companies if medically indicated. Ten companies offering medically underwritten group coverage do not cover any of the carrier or prenatal tests in the OTA survey. Sixty-two percent of companies (23 respondents) that offer medically underwritten group policies cover prenatal tests for CF (table 7-6).

Two of 25 BC/BS plans offering individual coverage would reimburse CF carrier screening at patient request. Sixteen of these BC/BS plans (64 percent) cover them if they are medically indicated and seven do not cover them. For prenatal tests for CF, 3 of these companies cover them at a patient's request, 19 if medically indicated, and 3 not at all. Of

21 BC/BS plans offering coverage to medically underwritten groups, CF carrier screening is covered at patient request by 2 companies (10 percent), only if medically indicated by 11 companies (52 percent), and not at all by 8 companies (38 percent) (table 7-6). Data for reimbursement for prenatal CF tests by BC/BS companies that medically underwrite groups are also presented in table 7-6.

Of the 11 HMOs that offer health insurance under individual policies, 1 respondent (9 percent) covers CF carrier tests at patients' requests and 7 HMOs (64 percent) reimburse for them if medically indicated. For the 20 HMOs that offer medically underwritten group contracts, 1 HMO (5 percent) covers CF carrier tests at patients' request, 13 respondents (45 percent) reimburse for them if medically indicated, and 2 (10 percent) do not cover them at all. Table 7-6 presents these results as well as how HMOs cover prenatal tests for CF.

OTA's survey results reveal that carrier and prenatal tests often are not covered under individual and medically underwritten group policies unless they are medically necessary-i. e., a family history exists. Such lack of reimbursement could have a

**Table 7-6---Reimbursement for Cystic Fibrosis Carrier Tests and Genetic Counseling**

Question: Do your standard individual policies and medically undewritten policies provide coverage for:

	Respondent	At patient request	Medically indicated only	Not covered	No response.
<b>Individual policies</b>					
Carrier tests for CF?	<i>Commercials</i>	0 ( 0%)	12 (41%)	12 (41%)	5 (17%)
	<i>HMOs</i>	2 (18%)	7 (64%)	0 ( 0%)	2 (18%)
	<i>BC/BS plans<sup>b</sup></i>	2 ( 8%)	16 (64%)	7 (28%)	0 ( 0%)
Prenatal tests for CF?	<i>Commercials</i>	0 ( 0%)	12 (41%)	14 (48%)	3 (10%)
	<i>HMOs</i>	1 ( 9%)	7 (64%)	1 ( 9%)	2 (18%)
	<i>BC/BS plans</i>	3 (12%)	19 (76%)	3 (12%)	0 ( 0%)
Genetic counseling?	<i>Commercials</i>	2 ( 7%)	6 (21%)	18 (62%)	3 (10%)
	<i>HMOs</i>	1 ( 9%)	6 (55%)	1 ( 9%)	3 (27%)
	<i>BC/BS plans</i>	1 ( 4%)	9 (36%)	13 (52%)	2 ( 8%)
<b>Medically underwritten policies</b>					
Carrier tests for CF?	<i>Commercials</i>	0 ( 0%)	24 (65%)	10 (27%)	3 ( 8%)
	<i>HMOs</i>	1 ( 5%)	13 (65%)	2 (10%)	4 (20%)
	<i>BC/BS plans</i>	2 (10%)	11 (52%)	8 (38%)	0 ( 0%)
Prenatal tests for CF?	<i>Commercials</i>	1 ( 3%)	23 (62%)	10 (27%)	3 ( 8%)
	<i>HMOs</i>	2 (10%)	14 (70%)	0 ( 0%)	4 (20%)
	<i>BC/BS plans</i>	3 (14%)	14 (67%)	4 (19%)	0 ( 0%)
Genetic counseling?	<i>Commercials</i>	2 ( 5%)	16 (43%)	17 (46%)	2 ( 5%)
	<i>HMOs</i>	2 (10%)	12 (60%)	1 ( 5%)	5 (25%)
	<i>BC/BS plans</i>	1 ( 5%)	7 (33%)	12 (57%)	1 ( 5%)

<sup>a</sup>Percentages may not add to 100 due to rounding.

<sup>b</sup>OTA also inquired about reimbursement practices for BC/BS open enrollment nongroup policies and reports these data elsewhere (31).

SOURCE: Office of Technology Assessment, 1992.

significant impact on the ultimate utilization of CF mutation analysis.

OTA found that genetic counseling was not covered by 18 of 29 commercial companies offering individual coverage and 17 of 37 offering medically underwritten group coverage. Six insurance companies offering individual policies and 16 that medically underwrite groups cover genetic counseling only if it is medically indicated. Two companies offering each type of coverage will reimburse for genetic counseling at the patient's request (table 7-6). Similar results for BC/BS plans and HMOs are also presented in table 7-6.

Finally, respondents were asked to indicate whether they agreed or disagreed with the following scenario:

Through prior genetic testing, the husband is known to be a carrier for CF. Before having children, the wife seeks genetic testing for CF. The insurance company declines to pay for the testing, since there is no history of CF in her family.

For commercial insurers, 21 medical directors (41 percent) agreed strongly or somewhat. Twenty-nine respondents (47 percent) disagreed somewhat or strongly with this scenario. For respondents from BC/BS plans, 12 agreed strongly or somewhat (41 percent) and 15 disagreed strongly or somewhat (52 percent). Four respondents from HMOs (17 percent) agree somewhat compared to 17 who disagreed somewhat or strongly (74 percent). These results indicate that insurers are split in their attitudes (or in their understanding of genetics) towards financing CF carrier screening as a part of reproductive decisionmaking.

### ***Medicaid Reimbursement***

For some low income citizens, Medicaid provides access to genetic tests and genetic counseling. Medicaid reimbursement for genetics and pregnancy-related services has been reported to vary from State to State (34). To examine the current state of such reimbursement, OTA surveyed directors of State Medicaid programs in June 1991 to assess which of seven services—amniocentesis, ultrasound, chorionic villus sampling (CVS), maternal serum alpha-fetoprotein (MSAFP) tests, DNA analysis, chromosomal analysis, and genetic counseling—were cov-

ered. OTA also asked for information about reimbursement amounts for each service.

Respondents were asked to indicate if their State guidelines stipulated whether a procedure was “covered,” “not covered,” “coverage based on individual consideration,” or “unknown.” There was no attempt to determine how completely these guidelines were followed by each State, and there have been reports that people have experienced difficulties in getting any Medicaid reimbursement for the types of services OTA inquired about (29). In total, 47 States and the District of Columbia responded (94 percent response rate). Two States responded to OTA's survey, but are not included in this analysis. Arizona's program differs from all other States, and OTA could not obtain comparable data for it. Connecticut returned a survey, but said budget restraints precluded it from completing the survey.

State coverage of genetic procedures clearly varies (tables 7-7, 7-8). Of the 46 States<sup>3</sup> in the analysis, 45 cover amniocentesis, with an average reimbursement of \$59.32. Fetal ultrasound is covered in 44 of 46 States, with 2 States covering it only by individual consideration. The average reimbursement for fetal ultrasound is \$83.13. CVS is covered by 31 States (67 percent) and not covered in 10 States (22 percent), with 1 State reporting unknown coverage and 4 States reporting individual consideration only. The average reimbursement for CVS is \$145.90. MSAFP testing is covered in 44 States and by individual consideration in 2 States. Average reimbursement for MSAFP is \$21.76.

DNA analysis is covered by 26 States (57 percent) and not covered in 6 States (13 percent), with unknown coverage in 8 States (17 percent) and 6 States (13 percent) covering it based on individual consideration. Average reported reimbursement for DNA analysis is \$33.39. Chromosome analysis, from amniotic fluid or chorionic villus, is covered by 41 States (89 percent), not covered by 1 State, with 4 States (9 percent) reporting individual consideration only. Average reimbursement for chromosome analysis is \$235.68.

Whether the State covered genetic counseling clearly posed the most difficult question for Medicaid program directors. A substantial percentage indicated that if the service were coded as an office

<sup>3</sup> Hereinafter, “States” refers to the 45 States and the District of Columbia that completed a questionnaire used in OTA's analysis.

Table 7-7—Medicaid Reimbursement for Genetic Procedures By State

State	Amniocentesis	Ultrasound	Chorionic villus sampling	Maternal serum alpha-fetoprotein	DNA analysis	Chromosome analysis	Genetic counseling
Alabama . . . . .	\$ 45.00	\$ 58.50	Not covered	\$19.60	\$24.34	\$199.99	Not covered
Alaska . . . . .	220.00	126.00	\$100.00	24.00	31.00	270.00	Covered if part of office visit
Arizona . . . . .	Managed care plans offer different coverages. See text for explanation.						
Arkansas . . . . .	49.16	54.62	Covered <sup>a</sup>	34.00	29.50	275.21	Not covered
California . . . . .	46.94	80.98	Not covered	12.03	Not covered	273.18	\$200.56 complete 133.40 interim 100.28 followup
Colorado . . . . .	167.00	103.00	112.00	24.28	29.25	275.12	Not covered
Connecticut . . . . .	Questionnaire not completed due to budgetary constraints.						
Delaware . . . . .	Did not respond.						
District of Columbia . . . . .	41.00	100.71	44.65	15.87	?	80.00	Not covered
Florida . . . . .	23.00	137.00	23.00	24.50	14.50	243.50	Not covered
Georgia . . . . .	107.00	80.00	Covered <sup>a</sup>	6.85	Not covered	28.69	Not covered
Hawaii . . . . .	75.60	81.25	Covered <sup>a</sup>	23.52	?	164.5@	Covered if part of office visit
Idaho . . . . .	41.90	88.90	Covered <sup>a</sup>	26.55	Covered <sup>a</sup>	281.83	Not covered
Illinois . . . . .	59.95	70.65	105.00 <sup>b</sup>	24.41	14.40	87.10	Not covered
Indiana . . . . .	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	<sup>b</sup>	Not covered
Iowa . . . . .	<sup>5, 6, 5, 8</sup>	84.17	71.84	22.11	30.57	278.69	52.15/15 minutes
Kansas . . . . .	100.00	120.00	Not covered	20.25	Not covered	Not covered	Not covered
Kentucky . . . . .	75.00-100.00	97.50-130.00	375.00-500.00	24.41 <sup>b</sup>	29.50 <sup>b</sup>	268.94 <sup>c</sup>	100.00-300.00 <sup>b</sup>
Louisiana . . . . .	39.48	80.00	Not covered	15.70	?	275.21	?
Maine . . . . .	23.00	25.30-59.40	101.80	15.00	?	251.00	Covered as part of office visit
Maryland . . . . .	31.00	56.00	31.00	27.26	54.00	215.25	13.00-40.50
Massachusetts . . . . .	49.43	92.00	481.07	16.73	24.76	225.73	Covered if part of office visit
Michigan . . . . .	36.80	66.12	358.17	20.60	?	167.31	Covered as part of office visit; 11.00-54.00
Minnesota . . . . .	55.00	70.00	153.00	25.28	30.57	278.71	75% of office visit rates
Mississippi . . . . .	41.90	69.30	Not covered	6.15	Not covered	260.56	Not covered
Missouri . . . . .	25.00	65.00	Not covered	24.41	16.43	150.00	Not covered
Montana . . . . .	51.91	68.68	65.2% of charges	42.30	?	309.79	Covered if part of office visit
Nebraska . . . . .	Did not respond.						
Nevada . . . . .	69.70	152.36	Covered <sup>d</sup>	42.89-55.76	<sup>b</sup>	400-520	47.46-156.66
New Hampshire . . . . .	25.00	64.00	<sup>b</sup>	14.00	29.00	14.00	<sup>b</sup>
New Jersey . . . . .	37.00	55.00	Not covered	10.20	<sup>b</sup>	230.00	Covered <sup>a</sup>
New Mexico . . . . .	59.60	52.87	?	23.41	29.50 <sup>b</sup>	268.50 <sup>b</sup>	Not covered
New York . . . . .	20.00	55.00	Covered <sup>a</sup>	6.50	31.39	90.00	Covered <sup>a</sup>
North Carolina . . . . .	119.20	73.44 <sup>b</sup>	Not covered	20.80	Not covered	297.65	Not covered
North Dakota . . . . .	39.28	109.93	52.20	21.73	110.49	239.42	Not covered
Ohio . . . . .	75.00-98.00	95.77-102.65	250.00-402.00	24.41	<sup>b</sup>	268.94	16.88-20.00
Oklahoma . . . . .	59.50	92.70	Not covered	24.41	Covered <sup>a</sup>	268.93	Not covered
Oregon . . . . .	44.48	74.82	38.05	22.94	Covered <sup>a</sup>	268.93	Covered if part of office visit
Pennsylvania . . . . .	50.00	97.50	59.00	20.00	14.50-30.80	275.20	Covered if part of office visit; 30.00-49.00
Rhode Island . . . . .	Did not respond.						
South Carolina . . . . .	31.80	66.00	75.00	6.20	28.50	300.00	Not covered
South Dakota . . . . .	63.00	100.00	50% of usual and customary charges	24.41	29.50	275.21	?
Tennessee . . . . .	57.00-60.00	51.00-88.00	178.75	24.98	109.68	275.21	Covered <sup>a</sup>
Texas . . . . .	81.22	116.41	94.82	23.77	?	200.00	100.00 initial 25.00 followup
Utah . . . . .	46.45	47.29	111.60	20.87	11.86	Covered <sup>a</sup>	Covered if part of office visit
V e r m o n t . . . . .	22.00	75.00	Not covered	25.00	Not covered	400.00	Not covered
Virginia . . . . .	110.00	90.00	66.00	25.00	10.50	135.00	Covered if part of office visit
Washington . . . . .	31.54	61.10	Covered <sup>a</sup>	24.38	Covered <sup>a</sup>	251.91	Not covered
West Virginia . . . . .	43.00	36.00	<sup>b</sup>	24.98	20.97-31.39	275.20	Covered if part of office visit; 10.00
Wisconsin . . . . .	47.64	115.68	189.40	24.13	Covered <sup>a</sup>	281.47	Covered <sup>a</sup>
Wyoming . . . . .	50.00	127.95	Covered <sup>a</sup>	22.00	?	198.00	?

<sup>a</sup>No dollar amount reported to OTA.<sup>b</sup>Individual consideration.<sup>c</sup>Respondent did not indicate whether explicitly covered or not.

SOURCE: Office of Technology Assessment, 1992.

**Table 7-8—Average Medicaid Reimbursement for Genetic Procedures**

	Amniocentesis	Ultrasound	Chorionic villus sampling	Maternal serum alpha-fetoprotein	DNA analysis	Chromosome analysis	Genetic counseling
Number of States reporting dollar amounts of reimbursement. . . .	45	45	22	45	2	43	10
Average amount reimbursed. . . .	\$59.32	\$83.13	\$145.90	\$21.76	\$33.39	\$235.68	\$68.87

SOURCE: Office of Technology Assessment, 1992.

visit or consultation, it might be covered; in such cases, however, the service of genetic counseling is hidden in a general visit code. Eleven States (24 percent) reported covering genetic counseling; 11 (24 percent) reported covering it only if part of an office visit or consultation; 19 States (41 percent) do not cover genetic counseling, 2 States cover it by individual consideration, and 3 States (7 percent) reported unknown coverage. The average reimbursement amount, in large measure, reflects the range of reimbursements for different levels of office visits. As such, the average amount given (\$68.87) cannot be viewed as accurate for genetic counseling services only. It should also be noted that “family DNA testing” is covered in some States (e.g., New York).

In addition to finding that some States do not cover certain services, the survey indicates the amounts reimbursed by States that do pay fall well short of charges for the procedures (5,23) (ch. 9). Hence, genetic service providers that accept Medicaid patients must subsidize the costs.

## SUMMARY AND CONCLUSIONS

Because the U.S. insurance industry is not homogeneous in its composition and policies, interest in new technologies (e.g., CF carrier screening) will vary according to both the type of insuring entity and the specific company or plan involved. The majority of the insured U.S. population obtains health insurance through the workplace under group policies. Such policies do not require diagnostic tests or physical examinations. Some Americans, however, obtain health insurance through medically underwritten group policies or obtain it on an individual basis. These individuals typically undergo risk classification and might pay higher rates. Yet little data exist on how commercial insurers, Blue Cross and Blue Shield plans, and health maintenance organizations factor genetic tests in the risk classification process. Chapter 8 reports OTA survey data related to this issue.

How insurers view genetic tests, generically, might affect their utilization. OTA’s 1991 survey of commercial insurers, BC/BS plans, and HMOs that offer individual policies or medically underwrite groups sheds some light on how these populations view genetic tests, generally, and CF carrier tests, specifically. Clearly, they want the option of determining how to use genetic tests in determining risks. OTA’s survey also found that insurers generally agree that it is fair for them to use genetic tests to identify persons with increased risk of disease.

Finally, the issue of who pays for CF carrier tests, prenatal tests for CF, and genetic counseling is important to the frequency at which people will opt for CF carrier screening. OTA survey results indicate that the costs of carrier tests or prenatal tests for CF (as well as sickle cell anemia and Tay-Sachs) are rarely covered by an insurer when carried out at the patient’s request. Insurers either covered those costs when medically indicated (family history) or not at all. With respect to public financing for genetic tests, OTA surveyed State Medicaid directors to determine which services were covered and at what levels. Medicaid reimbursement for genetic services varies widely from State to State and does not approach full reimbursement of the actual amount charged for the service.

## CHAPTER 7 REFERENCES

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