



ISSUE BRIEF

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The Use Of Genetic Information In Disability Income And Long-Term Care Insurance

The use of genetic information affects all forms of life and health insurance. For individually purchased, voluntary insurance, such as most disability income and long-term care policies, the use or restriction of the use of genetic information in the underwriting process could have a significant impact on the cost and availability of insurance.

This issue brief describes the nature of disability income and long-term care insurance and discusses, from the perspectives of both consumers and insurers, the implications of the newly emerging genetic technologies for these products. Strategies to effectively address this emerging dilemma of how best to respond to public concerns about the possible misuse of genetic information, while preserving the viability of the voluntary, individual disability income and long-term care insurance markets are also explored.

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Background

Imagine for a moment the potential consequences of a blood test that could predict, with high certainty, the development of cancer later in life. How might it change consumer behavior, and how might insurers react? Imagine also the potential consequences of a drug treatment that could eradicate the vast majority of the cancerous cells. How and when would this affect the premiums of policies, both new ones and those currently in force? How might it alter consumers' need for, and purchase of, disability income (DI) and long-term care (LTC) insurance?

Ten years ago these scenarios might have been far-fetched, but they are much closer to reality today. Before 1990, about 200 genetic disorders were identified. Today, more than 1,500 disorders have been identified as genetic. Scientific advances from the Human Genome Project will facilitate earlier detection of diseases and accelerate the search for successful treatments.

Current underwriting and premium rating practices in voluntary, individual insurance markets have evolved to maintain a delicate balance between affordable premiums and meaningful coverage. If future developments in genetics alter the current equilibrium significantly, it will pose a serious challenge to the future viability of those markets.

Disability Income and Long-Term Care Insurance Coverage

In order to understand how the issues of genetic information are related to DI and LTC insurance, it is useful to review the nature of these insurance coverages. Both types of insurance offer protection from losses due to chronic and disabling conditions. DI insurance protects earned income against potential loss due to disabling injury or illness.¹ LTC insurance protects against the cost of needed LTC services, which may encompass a wide array of medical, social, and personal care services required by an individual with a chronic disability.² Both involve long-term commitments on the part of insurance companies to pay benefits to their policyholders if and when they suffer illnesses that either reduce or eliminate their ability to work, or require them to receive LTC services.

A DI or LTC insurance policy represents a significant promise that can extend for decades. To fulfill their promises to pay future claims, insurers offering these products must remain financially healthy over a long period of time. The financial health of an insurer depends on adequate pricing, administrative efficiency, sound investment strategy, and continued marketplace competitiveness.

There is a fundamental difference between employer-sponsored group coverage and voluntary, individually purchased policies. (Very small groups, such as those with two or three members, can exhibit many of the same characteristics as individual purchasers.) Individual insurance premiums usually are paid by the person insured, while employers typically pay at least part of the premium under group policies.³ Individual applicants can use far more discretion and control over which policy to buy, and when to buy it, than participants in group insurance plans. Usually, individual insurance contracts cannot be cancelled as long as premiums are paid, while group insurance often expires upon termination of employment or group membership.⁴

The Importance of Underwriting

Individual applicants may choose the timing and (within limits) the amount of their insurance purchase, as well as benefits and types of plans. If individuals purchase insurance on the basis of health information that is known to them but unknown to the insurer, adverse selection occurs. Adverse selection results in healthier people subsidizing the less healthy, and the resulting increase in premiums tends to drive healthier people from the insurance system. Ultimately, if enough healthy individuals leave the system, it may lead to insolvency.⁵

Individual DI insurance requires applicants to undergo a detailed medical underwriting evaluation. Group coverage offered to employee groups generally requires less underwriting than individual DI insurance. This is because employees are actively working and participation is relatively high if the employer subsidizes the premiums. Individual DI insurance can be issued on a non-cancelable basis where the initial premiums cannot be changed regardless of experience. Individual DI insurance can also be issued on a guaranteed renewable basis where premiums can be adjusted in the future based on the experience of

policies in the same risk classification. While guaranteed renewable policies are becoming more common, due to their lower price, most individual DI policies are still non-cancelable. "Accident-only" DI policies, which only cover losses due to accidents, are often sold with only minimal medical underwriting.

LTC insurance is almost exclusively issued on a guaranteed renewable basis. Applicants for individual LTC insurance are subject to detailed medical and functional underwriting evaluation. Most employer-sponsored LTC insurance is offered on a voluntary basis where the employer sponsors the program and provides the payroll deduction, but the employee decides whether to participate and pays the entire premium.

Coverage is typically offered to active employees, and sometimes their spouses, under a very limited form of underwriting known as "guaranteed issue." Eligibility for a minimum face amount of coverage is guaranteed to all active employees, some of who might not immediately be eligible for benefits. When group coverage is not offered on a guaranteed issue basis, streamlined underwriting known as "simplified issue" is generally provided. Coverage is often offered to the parents of employees also, but on a fully underwritten basis.

Underwriting is particularly important for both DI and LTC insurance. In contrast with health insurance, claims for both types of coverage are characterized by low frequencies and relatively large amounts. Fewer than 1 percent of those covered may file a claim in any year and the amount of the claim may range from \$20,000 to more than \$100,000. Moreover, the decision to file a claim is often more discretionary than for medical expense or life insurance claims. For LTC insurance, the market is less than 15 years old. Insurers have learned that the premium level that represents an attractive value to consumers cannot support a lax underwriting standard or an assessment spiral will occur as prices rise and healthier individuals leave the market.

Medical underwriting for DI and LTC insurance is generally similar to life insurance with some exceptions. Mental and nervous conditions are major causes of claims for DI insurance. Similarly, dementia is the leading cause for LTC insurance claims. Unlike claims for life insurance, these causes of DI and LTC claims have many gradations of severity, not all of which are insured.

It should be noted that a significant number of applications for DI and LTC insurance are classified as substandard risks that require higher premiums, or are declined insurance, based on conditions that are not directly medical (or genetic) in nature. For example, the risk inherent in a person's occupation is an important underwriting condition for DI. For LTC, the inability to perform one or more activities of daily living, such as bathing and dressing, or instrumental activities of daily living, such as shopping and taking medication, is grounds to decline coverage.

To evaluate applications for coverage, the following sources of underwriting information may be used: the insurance application, physicians' statements, medical records, information from MIB, Inc. (formerly the Medical Information Bureau),⁶ telephone interviews, and face-to-face functional and cognitive assessments. Use of this information has resulted in a decline rate of about 10 percent for DI and LTC. As a comparison, voluntary life insurance typically has a decline rate of less than 10 percent. One reason for the higher decline rate is that the use of substandard risk classes is less common in the DI and LTC markets. DI insurance, at times, can have exclusion riders that preclude claims from known conditions. The larger issue is that there are so many health-related conditions that do not necessarily affect mortality significantly, but have a large impact on an individual's ability to work and need for LTC services. When the decision to claim benefits is somewhat discretionary, an individual who would be classified as a substandard risk is two or three times more likely to make a claim than would an individual who is a standard risk.

Developments in Genetic Testing

The effectiveness of current genetic testing depends on the type of genetic disorder. Down's syndrome, leukemia, and lymphoma represent a category of diseases that result from chromosomal abnormalities. A second category of genetic diseases, such as cystic fibrosis and Huntington's disease, are due to single-gene defects. There are approximately 1,500 diseases for which a specific mutated gene has been identified.

Single-gene diseases manifest themselves in two stages. During the pre-symptomatic stage it is virtually certain that disease will develop if the individual lives long enough, but no symptoms are yet clinically apparent. The probability of advancing from the pre-symptomatic to the symptomatic stage is very high.

If a male age 30 has a positive DNA-based test for Huntington's disease, he may not yet be experiencing any symptoms. However, symptoms will appear and his condition will progressively deteriorate before age 50, since Huntington's has a late onset.

However, the vast majority of diseases fall into a third category, the multifactorial diseases, which result from the interaction of multiple gene mutations. There are more than 25,000 such disorders, including breast cancer, ovarian cancer, heart disease, diabetes, multiple sclerosis, and Alzheimer's disease.

For multifactorial diseases, there are also two stages — the predisposition or "at risk" stage and the symptomatic stage. However, predisposition does not necessarily mean that the disease will develop. Whether the disease actually develops may not be known for many years. Often, gene mutation is neither necessary nor sufficient to explain disease origination. Other factors, such as environment, life style, and preventive therapy are significant contributors to the future likelihood of the onset of these complex diseases. For example, change in diet and exercise habits has been shown to reduce plaque formation in the arteries, the cause of arteriosclerosis. The task to establish a risk profile of an individual for numerous late-onset diseases is not straightforward.

Furthermore, today's genetic tests suffer from specificity and availability problems. The test for Apolipoprotein E4 (ApoE4) has been touted as a predictor of Alzheimer's disease. While the presence of ApoE4 seems to indicate an increase in risk, the results are not conclusive. Early-onset familial forms of Alzheimer's disease are not associated with ApoE4.

A number of current tests are effective only for those who have a family history of the suspected disease. Examples of this class of tests are those for breast or ovarian cancer (BRCA1 & BRCA2 mutations) and for colon cancer (Hereditary Non-Polyposis Colon Carcinoma or HNPCC). Many genetic tests are quite expensive and are not currently covered by health insurance, which limits the availability of such tests. As more effective and less expensive genetic tests are developed, they may become as common as an x-ray is today.

Perhaps the most salient development regarding genetic testing is the rate of change. Genetic research is moving at an accelerated rate, and information is being disseminated at record speed. It is conceivable that in the not-too-distant future there will be one unified test that can screen all of the approximately 35,000 human genes for abnormalities. Many in the insurance industry feel an urgent need to prepare to cope with the rapid advancements in genetic science.

Genetic Regulation

Recent medical research advances, including the Human Genome Project, have brought the use of genetic information in insurance underwriting to the forefront of policy-makers' attention. More than half the states have enacted legislation restricting use of genetic information by insurers.

While most of the regulations in place today affect medical expense insurance, the distinction between employer-sponsored group medical coverage (or government-sponsored health programs) and voluntary life and disability insurance is generally not widely recognized and appreciated. Because the cost of providing DI and LTC benefits is related to the health status of the policyholders, and because of the voluntary nature of the coverage, there is a real danger that if voluntary DI and LTC insurance are treated in the same fashion as medical expense insurance for genetic regulatory purposes, they may become increasingly unaffordable.

Statutes in several states, including New Jersey and Arizona, apply to life and disability insurance, which includes DI and LTC insurance. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits employers from excluding or rating otherwise eligible employees from group health plans based on genetic information. Several federal bills proposed in recent years (for example, S. 422 – The Genetic Confidentiality and Nondiscrimination Act of 1997) would limit use of genetic information in life and disability insurance.

These activities suggest broad political support for restrictions on insurers' use of genetic information. But the current standing of various state regulations is evidence of the confusion as to the best approach. Among the states that have regulations specifically applying to DI and LTC insurance, some implicitly or explicitly allow testing and some prohibit testing. A few states appear to implicitly prohibit the use of genetic information.

In social policy terms, the need for basic health care is quite different from the need for income replacement and asset protection as provided by DI and LTC insurance. The former is increasingly viewed as necessary to ensure access to health care, and thus a basic right, while DI and LTC insurance are still viewed as discretionary. In addition, there are social safety-net programs in place that provide at least limited LTC and DI benefits to virtually all Americans (Medicare, Medicaid, and the Social Security Disability Insurance program). Moreover, since no one is forced to buy either DI or LTC insurance, there are limits to the extent to which regulations can restrict the natural workings of the market without resulting in adverse consequences. Regulators must carefully balance a variety of complex issues, including accessibility, affordability, financial equity and rate adequacy. These fundamental considerations are vital to any discussion of the use of genetic information.

Genetic Information Issues

Central to the complex genetic information debate is whether genetic information should be part of the underwriting information that is used by insurers to approve or decline applications for insurance. First, there is a definitional consideration of what constitutes a genetic test for the purpose of regulation. Then there is the associated question of how much information an insurer may require of an applicant for insurance. Requiring an applicant to take a genetic test for underwriting purposes raises concerns among individuals who may not want to know about conditions for which no treatment is available.

Prohibiting insurers from asking for the results of genetic tests that applicants have already taken may result in adverse selection. Estimating the impact of alternative regulatory policies is a significant actuarial challenge, particularly because we do not yet know how the new genetic technologies will ultimately develop. Concern about privacy is an important element for public policy decision-making. Finally, the impact of genetic regulations on the availability and cost of DI and LTC coverage should also be considered.

Definition of a Genetic Test

The emerging genetic testing technologies that are at the center of the current public policy debate are based on the analysis of DNA, RNA, and proteins to detect existence or susceptibility to inheritable diseases or defects. However, rather than focusing only on the new genetic tests that are becoming available, many advocates of genetic privacy legislation are looking at the much broader concept of “genetic information” — any information relating to a disease or health condition that is inheritable. In addition, it is becoming evident that many, if not most, diseases have a genetic component. Even our weight and blood pressure are partially genetic. Thus, the defining line between medical information obtained from a blood sample test or family history questionnaire and the results from a genetic test is becoming blurred. There is no clear boundary between genetic and non-genetic health information.

A broad definition of a genetic test would include virtually all routine chemical and blood tests, prohibiting their use in the underwriting process. A regulation based on the concept of “genetic information” would preclude virtually all health information, whether based on the new genetic technologies or not, and would have a significant impact on insurers’ current underwriting standards. On the other hand, consumer advocates are wary of arbitrary distinctions between genetic and non-genetic information, maintaining that if a narrow definition of genetic testing is used, legislation might allow the unchecked use of certain genetic tests.

Risk Classification

Risk classification, which groups together individuals with similar levels of risk and expected costs, is basic to the operation of the DI and LTC insurance markets. Risk classification permits insurers to charge an adequate premium, and it is fundamental to the operation of most markets for voluntary, individually purchased insurance. A primary goal of risk classification is to ensure that each individual purchasing coverage contributes an amount commensurate with the likelihood of receiving benefits and the expected amount of benefit payments that they will receive under the terms of the policy. This ensures that insurance premiums are comparable for individuals with similar risk status at the time the insurance is purchased — which is known as financial equity.

Because consumers tend to make financial decisions that are in their best interests, risk classification is essential to voluntary individual health insurance markets. The more information that is known by an applicant but unknown to the insurer, the less accurate the risk classification process will be.

Insurers need complete disclosure of all pertinent information in order to properly assess insurability. In this sense, insurers consider genetic information no different than any other underwriting information. Placing all applicants in their risk classes as accurately as possible means that consumers will pay fair prices based on their risk profiles. For insurers, this will provide narrower variation of experience.

Consumer advocates suggest that genetic information should be excluded from the underwriting process. They contend that genetic information is not necessary since the experience on which premiums are based already includes those who have genetic defects. Even though claims may be higher than anticipated due to the lack of genetic information for underwriting, premiums can be adjusted accordingly, they argue.

Because most diseases are treatable and because individual lifestyles can have significant influence on onset and outcome of diseases, causality cannot be established. To date, the predictive value of many genetic tests has not been established, and thus the proper interpretation of test results is often not clear.

Consumer advocates argue that an applicant who has been tested is being penalized over other applicants who have not been tested but have the identical predisposition to a certain genetic defect. Thus, they argue that meticulous risk classification is contrary to the pooling principle of insurance, and that the degree of refinement should be decided by society as a whole, rather than solely by insurers.

One fundamental public policy decision that appears unlikely to change is that the purchase of private DI and LTC insurance should be voluntary. Because consumers tend to make financial decisions that are in their own best interests, risk classification is essential to voluntary individual health insurance markets. However, the pursuit of accurate risk classification should be balanced with issues of accessibility, privacy, and equity.

Actuarial Implications

Underwriting for DI and LTC insurance is more concerned with the predisposition rather than with the diagnosis of diseases. An applicant who is outside the limits on the height and weight table but has no apparent illness is not deemed to be an acceptable risk. The probability of claim is too high for the properly calculated premium to be affordable. Results from genetic testing obviously can help immensely in establishing the risk profile of an individual. Genetic tests for certain specific diseases, such as Huntington's disease, are highly predictive. For other tests, the information provided is statistical in nature — those individuals who have at least one mutated gene from one parent will have a certain probability of developing the disease in midlife. Many other tests will take decades to validate. Even if the genes are mutated, individual actions to modify lifestyle habits can have a significant influence on the outcome. As a result, these tests are of limited value in predicting the future development of disease.

The very research that identifies the genetic factors in diseases may ultimately lead to treatments or even cures for those diseases. The Human Genome Project is providing a huge human genome database that can connect diseases to the associated genes. New techniques using DNA microarrays will shorten the time to develop new drugs.

Any modification of underwriting standards regarding genetic information should involve an assessment of the impact of underwriting on future claim costs. Estimates of future claim costs should take into consideration, among other things, the effect of early detection and the likelihood of new treatments.

Public Policy Concerns

Developments in regulations for genetic information have generally drawn a line between health insurance and life insurance. The HIPAA provisions that limit the use of genetic information apply to medical expense insurance only, as do most state restrictions. The principal argument against the use of genetic information in medical expense insurance is that basic health care should be accessible to everyone regardless of the genotype of the individual. The argument with respect to life insurance is that while it protects

against a financial loss, it is not viewed by society as a basic right, as is medical expense insurance. There is also an implicit recognition that underwriting has a significant impact for voluntarily purchased individual insurance. Any proposed restriction on underwriting deserves serious deliberation.

Where do DI and LTC insurance fit? Both types of coverage are voluntary and both protect against financial loss. Both types require a certain level of underwriting. DI insurance provides income replacement. A claimant typically receives a monthly indemnity (“stated dollar”) amount regardless of the medical needs. LTC benefit payments reimburse the cost of LTC services or a specified dollar amount benefit. In the absence of these payments, a substantial portion of the claimants’ assets will be depleted. As with health and life insurance, any public policy decisions need to consider the characteristics of the coverage.

Insurance exists for the social good. As such, certain practices are considered to be discriminatory and contrary to the interest of the public, therefore they are prohibited. Consumer advocates argue that an individual’s genetic makeup, like ethnicity, is not controllable. Thus they argue that use of genetic information for underwriting constitutes unfair discrimination and should be prohibited. In addition, they suggest that potential applicants may avoid genetic tests and treatments in order to obtain insurance. Consumer advocates also argue that it matters to society whether individuals are excluded from insurance without irrefutable evidence. Insurers in turn emphasize that the availability of affordable insurance is a matter of public interest. An unworkable regulation could destroy the voluntary insurance market.

Adverse Selection

Insurers maintain that the view of the consumer advocates conflicts with the economic realities of the voluntary insurance market. Insurers are concerned that if they were prohibited from obtaining genetic information from the medical records of applicants, then those applicants would know more about their genetic predisposition than the insurance company (asymmetric information), and more substandard and uninsurable individuals would qualify for insurance. Premiums could not be adjusted adequately to cover the deterioration of the insured population because the higher prices would drive out the healthy. As the insured population disproportionately became weighted toward those who were predisposed to certain genetic defects, experience would worsen and premiums would increase. The increase in premiums would further reduce the number of healthy policy-holders and could eventually cause the insurers to become insolvent.

The challenge is to quantify the impact of asymmetric information. Since only a relatively small number of genetic tests available today have high predictive power, one can probably estimate that the current cost impact on insurance costs is modest. A contrast can be made with the HIV/AIDS epidemic in the 1980s. The impact of AIDS claims was modest for the life insurance industry as a whole because the potential for widespread adverse selection was curtailed by the development of an effective AIDS blood test.

As with other forms of voluntary insurance, the cost of asymmetric information on DI and LTC insurance depends on:

- The extent of the information imbalance between the buyer and the seller.
- The relevance of the information to future claim costs.
- The willingness of consumers to condition their purchase of insurance on health information.

Key factors used in evaluating the impact of any restrictions include:

- The extent to which medical information is restricted.
- How predictive that information is.
- How willing consumers are to purchase insurance under the situation.

When compared to life insurance, the relatively higher percentage of declines and the higher claim rates in the DI and LTC insurance markets suggest that the cost may be higher than that for life insurance. On the other hand, claims that are not directly related to medical causes are more common for DI and LTC insurance. Another mitigating factor is the ability to increase premiums for some in-force DI policies and virtually all LTC policies. This ability is limited by regulations and by what the market will allow.

Predicting the future is a risky business. Currently, when we look at the new genetic technologies our situation is very similar to that of someone observing the Internet in 1985. As with the Internet then, the new genetic technologies now are developing rapidly. They have significant potential to change the way we live, but we cannot yet see how they will develop over time or what they're eventual capacity will be. Because we do not know what tests will be developed, when they will be developed, or what their predictive power will be, it is very difficult to model the potential future impact of regulations that might be enacted now.

Privacy

Insurers regard genetic information as no different from any other form of health information, and will treat it as any other underwriting information under current stringent privacy regulations. Furthermore, applying for voluntary insurance is a personal choice. No one is forced to divulge health information. While providing health information is voluntary, it is also a condition for issuance of the coverage in most individual insurance markets (much as disclosing financial information is voluntary, but a requirement for obtaining a mortgage loan).

Perhaps the most fundamental argument made by advocates of a complete prohibition on the use of genetic information is that it is personal and that any use of this information must be under the exclusive control of the individual. In other words, the privacy right of the individual supersedes any extenuating use. In this view, genetic information is not like other medical information, at least in part because genetic information regarding an individual can adversely affect the lives of family and relatives. Therefore, advocates in this camp believe that individuals should have the choice to disclose or not to disclose, to test or not to test. In the voluntary insurance setting, the exclusive use of genetic information by the individual may have an impact on other individuals by limiting their access to insurance or increasing their cost of insurance.

Genetic Testing for Underwriting

Emerging experience from DI and LTC insurance has already allowed insurance companies to refine their risk classification for the purpose of premium rating and evaluation of applications for insurance. Examples are ratings based on occupational classes for DI and ratings based on marital status for LTC. In turn, this has raised public concern that more people will be considered as substandard or uninsurable.

What would happen if a highly predictive genetic test could be devised for cancer? Since they are in a competitive market, some insurers might start requiring such a test as part of underwriting. Profits on new sales would rise since there would be lower future claims. Eventually, the whole market might move to lower premiums. For most consumers, premiums would become more affordable, but some would find private individual coverage more expensive or impossible to obtain.

How would consumers react? Consumers would argue that treatment and prevention can help to mitigate claim costs. They would insist that any actuarial demonstration include the probability of improvement in cancer treatment. Such a test should not be allowed until it has been thoroughly evaluated for sensitivity, value, and utility.

Furthermore, many consumers would see the requirement to undergo such a test as a clear case of invasion of privacy. They would insist that genetic testing should only be performed for medical purposes, and not to generate information for insurance. The public generally is mistrustful of insurers, and many fear that they will have no control over the information obtained from genetic tests.

As this debate plays out in the regulatory arena, it is not clear what the eventual outcome will be. Because the definition of genetic tests is ambiguous, insurers may well find themselves prohibited from continuing to use certain tests.

Future of the Market

It is unclear how the availability of genetic information will affect the market for DI and LTC insurance. The need for insurance to cover the unknown might be diminished if individuals were confident that they were free of certain diseases. This might reduce new sales as well as increase policy lapses.

If the same research that develops a genetic test also generates a treatment for the disease involved, claim experience will improve. The abatement of a major cause of claims will lower premiums and make the policies more affordable. Thus, it may spark more new sales. The lower premiums may also discourage lapses of existing policies.

Medical advances will affect DI and LTC insurance differently. There are more claims arising from primarily medical causes for LTC than for DI. Dementia and strokes are major causes of claims for LTC. Significant improvement in treatments for these impairments would have a correspondingly significant impact on claim experience. They would have a smaller impact on DI claims. However, medical advances can increase costs. When drug treatments for AIDS improved, the decline in mortality of AIDS claimants resulted in longer payments of DI benefits.

Exploring Alternatives

Currently, those on all sides of the policy debate appear to be reacting to fears about future scientific developments, with no agreement on the best general approach for regulating these new technologies. A wide range of policy responses is possible. Each has its own advantages and disadvantages, many of which cannot be predicted with certainty because we do not yet know how the technologies will develop or how powerful they will ultimately become. Legislation in this area could have wide-ranging impacts; thus it is important that any legislation be carefully considered and crafted.

At one end of the spectrum, any use of genetic information other than for directing medical care could be prohibited. While this would address certain privacy concerns, it does not reflect the privacy protections that are already in place, and it could have serious adverse consequences for those seeking private voluntary insurance coverage. At the other end of the spectrum, some would argue that no additional regulation is needed. This approach would have the advantage of not disrupting the current DI and LTC insurance markets. However, it would not provide any additional reassurance for those concerned about the potential misuse of genetic information.

Several intermediate approaches are also possible. For example, DI and LTC insurers could be prohibited from requiring applicants for insurance to undergo a genetic test, or from using genetic testing on blood or urine samples received from an applicant, but be granted access to genetic information collected prior to the application for insurance. This would keep individuals from being tested against their will while preventing biased selection that would undermine the market.

Another approach would be to establish an advisory board to assess the specificity, sensitivity, and predictability of each new genetic test. The board would make recommendations on the associated information as it relates to insurance.

A third approach might be to strengthen the safety nets provided by the Medicaid and Social Security Disability Insurance programs to ensure universal access to a minimum level of DI and LTC coverage, while allowing the continued use of information in the private market that supplements that safety net.

Still another approach would be to develop reinsurance pools for various genetic risk markets, much as is done today for high-risk drivers in the auto market or may be done for insurance against losses due to terrorism. Companies would have the right to reinsure genetic risk into a pool and would be required to participate in the pools in relationship to their market share. This would socialize the cost among all market participants and could be done with or without a public subsidy or backstop.

Whatever approach is ultimately chosen, it is important that policy-makers and the public understand the implications of new forms of health information for the voluntary individual DI and LTC markets, the legal protections already in place, and the limits of our knowledge as we consider an immature but rapidly developing technology.

The goal of genetic research is to improve health and to reduce morbidity and mortality. Insurance provides protection against the risk of financial loss due to health problems and other conditions. There is no inherent conflict between these goals. The purpose of this issue brief is to survey the complex issues facing policy-makers, consumers, and insurers as they consider the potential impact of the rapidly developing new genetic technologies on the DI and LTC insurance markets. To guard against unintended consequences it is vital that all of these parties engage in a constructive dialogue as any new regulatory framework governing genetic information is developed.

¹ The asset protected is the future earnings capacity of the insured individual. An insured event is the medical loss of the *capacity* to work, not the loss of the *opportunity* to work due to economic restructuring, family obligations, or lack of marketable skills. Benefits are typically expressed as a dollar amount of monthly or weekly income, or as a percentage of pre-disability income.

² There are a variety of approaches to designing LTC benefits. The most common test for benefit eligibility is based on the inability to perform a number of activities of daily living (ADLs), which are objective and correlate well with the need for care. LTC insurance policies also provide benefits for individuals who need care due to cognitive impairment. Perhaps the most important defining characteristic of LTC services is that they provide assistance with everyday activities in order to help an individual maintain as much independence as possible. Services may be provided at home, in the community, in an assisted living facility, or in a nursing home. Benefits are usually a fixed dollar amount per day, or a percentage reimbursement of actual charges up to a maximum dollar amount per day.

³ Employer-sponsored LTC insurance is an exception to this rule: It is often provided on a voluntary, employee-pay-all basis. These provisions, along with the fact that the individual insured bears the entire cost, gives voluntary LTC coverage some of the same characteristics as individual coverage.

⁴ Again, LTC insurance is unusual in that it provides for continuation of coverage or conversion to an individual policy. While federal law requires many employers to provide continuation of coverage for a limited period under their group health care plans, and many states require group health insurers to offer certain conversion rights, these rights are generally more limited than those available under employer-sponsored LTC plans or group life insurance plans.

⁵ For a more complete discussion of adverse selection and the role of risk selection in these markets, see the American Academy of Actuaries' issue brief titled "Risk Classification in Voluntary Individual Disability Income and Long-Term Care Insurance" (Winter 2001), which is available on the Academy's website at www.actuary.org.

⁶ MIB, Inc. is a not-for-profit organization established to deter, or detect, individuals who would commit insurance fraud by omitting or concealing relevant facts on applications for insurance. MIB maintains a list of impairments, not all of which are medical, that are relevant for underwriting. Member insurers submit to MIB information found during the underwriting process. MIB information indicates only whether an impairment is present – not the underwriting decision made by the submitting insurer. An insurer must have a signed authorization from an applicant before it can request information from MIB, and MIB rules prohibit participating insurers from using information received from MIB as a basis for issuing or denying coverage. MIB information does, however, provide a useful guide for an insurer's own information-gathering efforts.



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