
Genetic Testing and the Future of Disability Insurance: Ethics, Law, and Policy

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I. Introduction

Genetic testing poses fundamental questions for insurance. Testing can predict the probability of future illness and disability, which can help promote the insurability of individuals with a family history of genetic risk, but it can also invite insurers to reject applicants, increase premiums, exclude people with certain illnesses and disabilities, and otherwise adjust the underwriting processes for individuals with certain genotypes. In the workplace, these issues may cause employers who offer or pay for insurance to alter their hiring behavior, either by selecting those with desirable genetic makeup or rejecting, dismissing, or reassigning those who carry an unwanted risk, ultimately threatening employability and the safety net that insurance is intended to provide.

Many prior analyses have examined the problem of genetic testing in the context of health insurance. A National Institutes of Health (NIH) Department of Energy (DOE) Task Force, for example, concluded that health insurance is so fundamental to individual well-being and genetic testing so potentially disruptive that health insurance in the United States should be restructured to guarantee coverage for all.¹ Less radically, most states have now enacted statutes that limit health insurers' use of genetic tests, albeit imperfectly.²

Some analyses have looked at life insurance.³ However, those states enacting statutes on life insurers' use of genetic tests have allowed them considerably

more leeway than health insurers,⁴ suggesting that life insurance, while important, may be considered less critical than health or disability insurance.⁵

Of all the analyses of genetic testing in the context of insurance, few focus on disability insurance.⁶ Arguably, disability insurance is more vital than life insurance and perhaps as essential as health insurance. A recent survey showed that the public is equally concerned with health and disability coverage and less concerned with life insurance in the event of a serious illness. When asked which type of insurance they would purchase if a test indicated an increased risk of cancer or heart disease, 70.3 percent said they were likely to purchase, or purchase more, disability insurance, and 70.6 percent would purchase health insurance, as compared to 61.1 percent who would purchase life insurance.⁷ As discussed below, the federal government, and to some extent the states, already provide some disability income insurance as a social safety net, though the coverage offered is in many ways inadequate. Existing public programs suggest the societal importance of disability insurance. Indeed, some scholars have ranked the need for disability insurance in the United States as a problem whose urgency is second only to the unsatisfied need for health insurance.⁸

Clearly, loss of income due to disability can threaten individuals' ability to provide for themselves and their dependents' basic needs, including housing, food, and medical care. The purpose of disability insurance is to protect individuals and their dependents from such

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loss. Disability insurance allows disabled workers to continue functioning. It also may allow temporarily disabled individuals to ultimately return to the workforce. Disability insurance further provides a financial buffer for individuals from the stigma often associated with disability.

Disability insurance is a double-edged sword, however, with risks as well as rewards. Qualifying as “disabled” may provide income replacement, but also invites the stigma and discrimination so often placed upon the disabled in our society. Further, availability of disability insurance in its various forms may encourage employers to declare certain workers “disabled” and remove them from employment, rather than finding ways to continue their employment or improve workplace safety. The cost of offering and maintaining disability insurance may also encourage employers not to hire some workers who are at risk of becoming disabled in the future.

Indeed, who is considered “disabled” and who sees themselves as “disabled” may change over time and in response to the economy. Unlike the objective decision to pay life insurance benefits at death, determining when to pay disability insurance benefits is often subjective. The very concept of disability is at least in part a social construct and often says more about the flexibility of a work environment than an individual’s ability to work. Further, in slow economies, employers may reduce payrolls by regarding more employees as disabled, while more employees may seek disability benefits as a form of unemployment compensation. Indeed, the stress of a slow economy may actually reduce some individuals’ ability to work.⁹ Disability insurance is intrinsically more subjective than life insurance, as it depends on determining not only “disability,” but also how total and how permanent the individual’s inability to work is. Individuals vary in their subjective “will to work,” some returning to work with disabilities that others experience as total and permanent.¹⁰

How, then, does genetics affect the meaning of disability and the purpose of disability insurance? Deciding genetic testing’s proper role in disability insurance forces consideration of what “disability” should mean in this era of genetic testing. Should the prediction of future illness or future loss of function in a currently asymptomatic individual be considered? Should mere genetic vulnerability to future health problems be included as well? Are we entering an era of “molecular impairment” (to use Anita Silvers’s phrase)¹¹ or molecular disability? Analyses of whether the Americans with Disabilities Act (ADA) and related legislation protect against disadvantage based on genetic tests¹² have debated some of these issues, but many questions remain.

Disability insurance is complex, too, because of its diverse forms, each with its own details. Indeed, a leading treatise lists 42 types of disability income programs.¹³ The most important forms of private insurance are group disability insurance (usually obtained through an employer) and individual disability insurance, both of which are intended to replace income for disabled workers. We focus our recommendations below on private insurance, as most public insurance applies to limited circumstances (such as total inability to work at any job) and typically offers limited compensation; we see little intent to widen these public programs. There are, however, three major forms of public insurance: Workers’ Compensation, a state mechanism to compensate for workplace illness or injury; Social Security Disability Insurance (SSDI), a federal system that awards benefits to former workers now unable to work due to a medical condition; and Supplemental Security Income (SSI), a different federal program awarding benefits to those who are unable to work and cannot draw on SSDI because of a limited work history. Each of these is part of a larger social safety net to provide part of the basic welfare needs of individuals unable to work. A disabled worker may receive benefits from a number of these public and private sources over time, and the various forms of disability insurance may be coordinated to offset each other and avoid duplicative recovery.

In addition to the lack of ethical and policy analyses of the role of genetic testing in disability insurance, few laws exist to regulate it, and a limited number of state statutes on genetic discrimination in insurance address disability insurance.¹⁴ On the federal level, although the Health Insurance Portability and Accountability Act (HIPAA) addresses genetic testing in group health insurance,¹⁵ and Executive Order 13,145 addresses genetic testing in federal employment,¹⁶ no statute or executive order addresses disability insurance. In addition, the Genetic Information Nondiscrimination Act of 2005,¹⁷ passed unanimously in the Senate in February 2005, addresses health insurance and employment discrimination, but does not address disability insurance. However, because the House failed to take any action on the bill, it died with the closing of the 109th Congress.¹⁸ As we discuss below, it is not clear if the federal ADA limits any insurer’s use of genetic tests.

Because of this ethical, policy, and legal vacuum, we convened a national Working Group comprised of diverse experts to produce the first in-depth analysis of the role of genetic testing in disability insurance. We met over the course of two years, reviewed the literature in depth, analyzed disability insurance policies, and sponsored a day-long symposium with

invited speakers. This paper reports the conclusions and policy recommendations of the authors, informed by input from the Working Group. While the complex and contentious issues we address here prevented group consensus, this paper is schooled by the insights and positions of group members. As noted above, not all Working Group members agree with the conclusions and recommendations below. We found that disability insurance may be more controversial than health insurance. There is broad agreement on the social importance of health insurance, even if how to make it more accessible remains controversial. However, far less agreement exists on the social importance of disability insurance.

II. Definitions and the Focus on Genetics

One preliminary question is pivotal to this discussion of the role genetic testing plays in insurance: What does “genetic testing” mean, especially in the context of disability insurance?

Genetic tests attempt to determine whether an individual has a genetic mutation or variation that poses health risks to that individual or potential offspring. Included in our definition of genetic tests are tests that actually examine genetic material (e.g., molecular examination of DNA or analysis of chromosomes) and other tests commonly used for genetic testing that can directly reveal a genetically-based disorder without actually studying the genetic material (e.g., by assessing protein levels).¹⁹ The genetic variation at issue may be at the level of the nucleotide sequence comprising a gene or of interactions among genes or of chromosomal variation. A range of tests is used, sometimes in combination. These include direct molecular examination of nucleotide sequence, examination of chromosomes, and determination of the level of proteins or other metabolic products of an individual’s genotype. While family history examination may suggest the existence of a genetic variation or mutation of concern, it usually lacks the definitiveness of scientific genetic testing. Nonetheless, genetic pedigree analysis or examination of patterns in family history, disability, or mortality that draw genetic conclusions about an individual are included in our definition of genetic testing.

Genetic testing is undertaken in a range of contexts: diagnostic, reproductive, and predictive. Increasingly, genetic testing may also be done to predict response to certain drugs or treatments, a focus of the relatively new field of pharmacogenomics. For our purposes, we focus on employer and insurer use of genetic test results to determine, predict, or consider the probability of inability to work for health reasons.

Beyond the testing of a genetic sample, protein products, and consideration of family inheritance pat-

terns, antidiscrimination law, and literature on genetic testing conclude that an employer or insurer might consider additional information in speculating on an individual’s genetics. This could include the mere fact that an individual or genetically related family member took or refused such a test. The fact that an individual participated in research relating to a certain genetic condition may also suggest that he or she is affected.

Genetic testing can produce a range of information. It can predict to a certainty that an individual will develop a disorder such as Huntington’s disease, which is inherited in an autosomal dominant fashion and will manifest in each individual with the mutation, ultimately proving fatal. More commonly, however, genetic testing generates a non-certain probability that an individual will develop a disorder.²⁰ The degree to which that disorder will be disabling and when it will be disabling may be uncertain too. Thus genetic testing can generate probabilities of future risks, but often cannot determine whether an individual will actually manifest a serious disease. In fact, identifying genetic risks through testing may lead individuals to alter their diet or avoid exposure to certain chemicals in an attempt to avoid future disease.

The case of *EEOC v. Burlington Northern Railway* is an example of an employer’s consideration of genetic test results.²¹ The railway conducted genetic testing without consent after employees complained of carpal tunnel syndrome, looking for an indication of genetic predisposition to the syndrome. The Equal Employment Opportunity Commission’s (EEOC) first case challenging genetic testing by employers led to a \$2.2 million settlement. Although few systematic data on employer and insurer use of such tests exist, they suggest that most insurers and employers do not yet participate in genetic tests.²² However, the proliferation of genetic tests will predictably increase the potential applications of genetic testing, including insurance. The number of possible genetic tests will increase as we better understand the human genome, and technology makes testing more efficient and affordable. Unfortunately, at the same time there is little regulation and quality control for new genetic tests,²³ and data suggest that genetic tests are commonly misunderstood by both the lay public and health professionals.²⁴ The *Burlington Northern* case, for example, involved a genetic test that had only a tenuous connection to the relevant condition of carpal tunnel syndrome.

Many commentators agree on the need to protect the privacy of genetic information, to protect individuals against being disadvantaged due to genetic information, and to improve genetic understanding, but they agree less on how to accomplish these goals.

Problems of genetic privacy, for example, are clearly part of the larger problem of how to secure the privacy of all medical information. Some commentators argue that solutions aimed specifically at protecting genetic information – examples of what some call “genetic exceptionalism” – are too narrow and may be futile, as genetic information increasingly suffuses individuals’ medical records.²⁵ In addition to the practical and empirical difficulties of segregating genetic information from other medical data, opponents of genetic exceptionalism maintain that

“arguments based on fairness cannot support policies that protect health care or income access for those with genetic risks, but not for those with health problems of less clear etiology,” as there is no rational basis for making such a moral distinction, though “precedent exists for insurers...to be regulated when there are overarching social or public policy concerns.”²⁶

Other commentators maintain that two levels of protection are necessary, one for securing the privacy of medical information generally and a second for responding to abuses of genetic information that wrongly stigmatize and penalize individuals.²⁷ We recognize that the debate over genetic exceptionalism is a substantial one. A number of the dangers associated with predictive genetic information also apply to other predictive medical information. We nonetheless focus here on the challenge of genetic testing in disability insurance because the problems are significant and largely unanalyzed. Further, as a practical matter, state legislatures and many other policymakers have focused on the problem of genetic discrimination and of genetic disadvantage in debating and crafting insurance legislation. Health policy gains often proceed incrementally. Even if misuse of genetic testing in disability insurance is part of the larger problem of needed insurance reform, progress on the narrower question of genetic testing may be more achievable in the short term than progress on the larger insurance reform problem.

Beyond this, it is important to note that our focus in this article is not to distinguish between genetic and non-genetic illnesses. Instead, our concern is with genetic prediction of disability and specifically with genetic prediction in the absence of any symptoms or manifestation of the disability. We do not claim that discrimination and disadvantage based on non-genetic health information and non-genetic prediction of disability should go unaddressed. In fact, the ADA is one statute that already tries to avert wrongful disadvantage based on health status. We join, how-

ever, a number of analysts who recognize the dangers of genetic exceptionalism but see an important role for carefully crafted measures addressing the misuse of genetic information.²⁸ While underwriters should be careful with all predictive information, actuarial reliance on genetic prediction warrants concern. Unlike much information that could serve as a basis for non-genetic prediction (e.g., diet), genetics are beyond individual control and immutable. Further, genetic vulnerability is universal. Once discovered, it has the potential to affect many biological family members through time, rendering them vulnerable to the same genetic prediction. Finally, many have long misunderstood and abused genetic information. What do we mean, then, in saying we focus here on genetic testing in the context of disability insurance? In analyzing disability insurance, we consider the use of genetic information to specifically determine or predict current or future inability to work at the occupation for which an individual is trained or the inability to work entirely. We focus on these because the traditional aim of disability insurance has not been to compensate all individuals in the event of disability, whether or not the disability affects the ability to work, but to provide income replacement specifically for those who cannot work due to disability.

One might conclude from this that our question is narrow: When do genetic test results genuinely diagnose or forecast inability to work? But genetic testing typically generates probabilities rather than certainties. In addition it is usually unclear when inability to work will set in, if ever. Further, genetic testing clearly expands the universe of those who may be considered unable to work. All of us have genetic variations associated with potentially disabling conditions. As the capacity for genetic testing expands, more of us will come to appreciate the genetic component of current or potential conditions interfering with our ability to work. And as genetic information increasingly determines who will become disabled and when, the “disabled” category might easily evolve from including only those with physical manifestations of disability to those with merely a genetic predisposition to disability.

Genetics thus reinforces the reality that all workers need to insure against future loss of the ability to work. But it also suggests the need for care and analysis to decide how “disability” should be used in this context. After all, one could foresee a future in which we *all* know of our genetic vulnerability to a condition potentially interfering with job functions. This forces all of us to face difficult policy questions. Should those whose genetics makes them more vulnerable to future inability to work be excluded from the social safety

net of insurance and thus cast out of the risk-sharing community once they can no longer work? Should they be excluded even earlier, once their genetic “flaw” is known, by being denied insurance or even employment? Should the work world be stratified by the accident of genetics, so that those with known genetic vulnerabilities are the most marginal and burdened workers?

Our analysis proceeds by examining first the two main types of private disability insurance: individual and group insurance. Then we place those private insurance mechanisms in context by examining the three major public programs: Workers’ Compensation (which is really a mixed public-private program), SSDI, and SSI. In each instance, we describe how the insurance works and then analyze the issues posed by genetic testing. Finally, we offer our recommendations for the future.

Our core recommendation is that workers should not be excluded from access to disability insurance based merely on predictive genetics. Private individual disability insurers should at least be required to treat genetic risks like actuarially similar non-genetic risks, and fair trade practice laws currently provide this protection through requirements that underwriting be actuarially justified. In reality there are problems with enforcement, remedies, and deference to insurers’ definitions of what is actuarially justified. Legislators and regulators should consider going further and ruling that such insurers may not reject or rate an application on the basis of genetic information, at least in the absence of manifestation and diagnosis of the predicted phenotypic condition. Group disability insurers, who typically do not use individual underwriting anyway, should not require genetic testing, consider individuals’ genotypes, or exclude conditions based on genetic predisposition. Disability insurers should be required to protect the confidentiality of genetic information, should ensure that their rules and decision-making processes reflect genetic sophistication and understanding, and should educate their personnel.

III. Private Disability Insurance

Private disability insurance refers to any privately purchased policy that provides periodic payments to an insured person if he or she is unable to work due to injury or illness.²⁹ Disability insurance provides income protection to the individual who becomes too sick to work, though businesses may also purchase disability insurance to protect the business in case key individuals become disabled. “Disability” for the purposes of private insurance refers to an insured’s loss of the ability to perform his or her “own occupation” or sometimes “any occupation.”³⁰ This loss usually

must be due to sickness or injury for which the insured needs medical care.

Private disability insurance is sold in two primary ways: to individuals and to groups (primarily employers), with the great majority of policies in the United States sold on a group basis.³¹ For example, in 2000, there were over 4.5 million individual disability insurance policies in force, generating net premiums of more than \$4.1 billion. But there were over 42 million individuals covered by group disability insurance, generating net premiums of over \$9.7 billion.³² Though group disability insurance thus accounts for more of the private disability insurance market, we start our analysis with individual insurance as the role for genetic testing is more obvious there.

A. Individual Disability Insurance

HOW IT WORKS

Individual insurance allows the insurer to probe the medical history of the applicant, and often the applicant’s family, in order to classify the individual by risk. This process is called medical underwriting. Premium rates and waiting periods are set accordingly, and various exclusions may be written into the policy based on the risks discovered. For instance, a policy may exclude a specified disease from coverage if there is too great a risk that the applicant will suffer from it. For this reason, there is less of a role for a pre-existing condition exclusion clause than exists in a group policy. We address the issues raised by pre-existing condition exclusions in the discussion of group insurance below.³³ These exclusions help protect the insurer from the risks of adverse selection, that is, the risk that those individuals who know they are most at risk will purchase the most insurance.³⁴

Individual contracts offer two basic types of coverage: short-term disability coverage (STD) and long-term disability coverage (LTD). Both STD and LTD pay only a portion (usually between 50 and 70 percent, with the actual benefit amount determined at the time of underwriting) of a disabled worker’s lost wages and both have a waiting period (ranging from three days to a full year) before benefits may be collected. Paying less than the full amount of a worker’s lost wages is a way for insurers to reduce moral hazard, that is, the risk that the insurance will provide an incentive to avoid work or avoid returning to work. The percentage of income provided by disability insurance generally decreases as income rises.³⁵ STD provides benefits for a specified maximum time (usually 13 or 26 weeks, but up to two years). LTD extends benefits for a longer period (e.g., five years, 10 years, until age 65 or retirement, or even for life). STD and LTD differ by pricing, underwriting, and breadth of coverage.

Policies differ in what losses they cover and whether benefits are reduced by coverage from other sources. Some policies cover the loss of income caused by accident only, while others cover loss from either accident or sickness.³⁶ Some policies cover both occupational and non-occupational disabilities;³⁷ others cover only non-occupational disabilities to exclude losses covered by Workers' Compensation.³⁸ If the disabled individual receives SSDI, the disability insurance contract may be written to reduce benefits accordingly.³⁹

GENETIC TESTING

Because private disability insurers typically require a medical examination and access to the applicant's medical records in order to underwrite policies individually, genetic testing and information can play a large role in the process. We have found no empirical studies to date analyzing that role.⁴⁰ However, studies do document public concern over genetic discrimination and some people's experience with it.⁴¹

Consumer advocates argue that use of genetic information for underwriting purposes constitutes unfair discrimination since an individual's genetic makeup is an immutable characteristic beyond one's control.⁴² Advocates contend that genetic information is markedly different and more stigmatizing than other types of medical information due to its potential to have a subsequent, adverse impact on the ability of one's family and relatives to access and afford the cost of insurance.⁴³

This fear of discrimination is important, as individuals may decide to forego genetic testing (even when it might prove medically useful) in order to protect themselves against insurance discrimination. Genetic testing and information will likely play an increasing role in health care over time as tests proliferate, become less expensive, and are integrated into medical practice.

Genetics may play a larger role in private disability insurance than private health insurance or life insurance. State and federal statutes place some limits on health insurers' use of genetic information, fewer limits on life insurers' use of such information, and very few limits on disability insurers.⁴⁴ Further, in the realm of private individual life insurance, individual underwriting is less stringent than in disability insurance, as life insurers cover a single event – death. Because an individual may be disabled early in life precluding decades of income, disability insurers are exposed for longer periods of time than life insurers and for potentially much larger amounts of money. This exposure creates an incentive for disability insurers to use predictive medical information including genetic information, since genetics may help predict whether a disability

precluding work will manifest at all, when, how, and for what duration.

To underwrite individual disability insurance, the insurer must carefully review the medical history of the applicant. On the basis of that information, the insurer may issue the coverage as applied for, charge additional premiums for the coverage, exclude specific conditions from coverage, change the benefit or elimination periods, or refuse to issue the coverage. As noted above, disability insurers providing individual policies generally rely less than group insurers on pre-existing conditions exclusions. The insurer is thus motivated to perform careful health research on an applicant. The insurer is also motivated by the requirement in most states that the policy include an incontestability clause.⁴⁵ The incontestability clause provides that after two years, the insurer cannot deny benefits or cancel a policy if it discovers error in the information supplied by the applicant, so long as the insured did not intentionally defraud the insurer. Once this period has expired, the insurer thus loses the option to deny or cancel a contract due to pre-existing conditions that it failed to uncover.⁴⁶ Incontestability clauses add to the insurer's incentives to discover as much as possible about an applicant's medical history – including genetic susceptibility to future disability – at the time of application, or at least within two years of it.

Thus far we have addressed the insurer's use of genetic information. However, insured individuals sometimes seek and use genetic information themselves. An insured person may use a genetic test to prove that he or she is *not* at risk for a particular condition at issue, such as Huntington's disease. Insured individuals have also sometimes used genetics in claims disputes to characterize an illness as physical rather than mental.⁴⁷ Many disability policies offer only limited benefits for "mental disorders."⁴⁸ (These policies have been challenged as violations of the ADA. The courts usually reason that the ADA prohibits discrimination on the basis of disability but does not make it illegal to discriminate "between" disabilities.)⁴⁹ An insured may claim that the genetic basis of his or her disease is physical rather than mental.⁵⁰ For example, in one case concerning a health insurance policy, a jury found that the insured, suffering from bipolar disorder, was entitled to "benefits provided for a physical condition rather than those provided for a mental one."⁵¹ In another case, however, the court rejected this argument and heard testimony for the insurer that "the present state of...knowledge in the field is that Bipolar Disorder is a mental disorder."⁵² Most mental illnesses do not yet have an identified genetic basis, but if this changes, the physical/mental dichotomy will face increasing challenge. Some insurers have anti-

pated this problem by defining “mental disorder” in their policies as those diseases that are listed in the current *Diagnostic and Statistical Manual (DSM)* and treated by mental health professionals.⁵³ Because such definitions are treatment-based rather than cause-based, they may help avoid litigation over the physical/mental issue.

Given the incentives described above, the crucial questions that arise about genetic testing in private individual disability insurance are whether an insurer may ask an applicant for genetic information known to them; perform or require a genetic test; and use genetic information (however acquired) in underwriting, whether to exclude certain conditions, alter pricing, or deny coverage. A number of state statutes forbid health insurers from engaging in any of these practices, while permitting life insurers to engage in them as long as the insurer seeks informed consent for performing a genetic test and pays for it.⁵⁴ The question is where should private disability insurance fit along this spectrum.

We suggest that the social importance of disability insurance is close to that of health insurance. Like health insurance, disability insurance provides coverage when individuals become sick or injured, protects the individual as well as the individual’s dependents (in contrast to life insurance, which focuses on dependents), and provides for the basic needs of the covered individual. This view of the importance of disability insurance meets resistance in some quarters. A report from the American Academy of Actuaries argues that while health insurance may be essential to securing health care and may thus be a right, disability income insurance remains discretionary.⁵⁵ However, lack of disability insurance could cause catastrophic loss of assets (including one’s home) and threatens the most fundamental needs of the individual and dependents. Uninsured disability is likely to trigger a cascade of losses including one’s employment, home, and health insurance. Consideration must thus be given to extending legal protections that already restrict access to and use of genetic information in health insurance to disability insurance as well.

Those legal protections could take several forms. First, a statute may forbid an insurer from accessing genetic information in the first place by prohibiting an insurer from asking the applicant for such information or prohibiting required genetic testing. An intrinsic problem with this approach is that genetic information increasingly suffuses medical records, so that preventing access entirely is increasingly difficult. Indeed, even a family history will at least suggest genetic information. Thus statutory prohibitions on access at best decrease access to genetic information rather than

stop it. Insurers’ primary argument against restricting access to genetic information in the context of private individual disability insurance is that private individual disability insurance is more vulnerable to adverse selection than any other of the major forms of disability insurance. Adverse selection occurs when the applicant has knowledge of a medical condition that increases the risk of disability but withholds this knowledge from the insurance company. This knowledge can motivate an individual to apply for insurance as someone who is more likely to have a claim in the future is more likely to buy insurance.

Adverse selection negatively affects the insurance company because the underwriter will underestimate the risk of claim. Insurers argue that when this happens, premiums for all disability insurance policy holders must rise in order to cover the cost, and that such an increase in premiums may “drive out the healthy,” leading to a reduced number of healthy disability insurance policy-holders and a downward financial spiral.⁵⁶ While adverse selection can occur whenever an individual chooses to apply for insurance, the impact of adverse selection is arguably greater on disability insurers than health insurers. The former may make an insurance promise that lasts for decades and provides a big and extended pay-out in case of qualifying disability.⁵⁷

Thus, even if one agrees that the need for disability insurance is akin to the need for health insurance, it is not clear that the need should be met by making private individual disability insurance more available. Making group insurance or the public programs more available might make more sense.

Clearly there is an interactive effect here. If private individual disability insurance is aggressively underwritten using genetic information, that places an enormous potential burden onto the other programs, as all of us have genetic variations that indicate vulnerability to certain disabilities, whether we know it now or not. Further, not all workers have access to group disability policies; some are forced to rely on individual policies.

Thus, arguments that have widely prevailed in the health insurance context – that broad risk-sharing should be the norm and underwriting by genetics should be restricted – should be considered in the disability context as well. Twenty-six states prohibit health insurers from requiring genetic tests or information.⁵⁸ Forty-three states prohibit health insurers from basing eligibility decisions on genetic information. Forty-one states forbid health insurers from using genetic information for risk classification in underwriting. States have imposed these restrictions on health insurers’ use of genetic information even though health insurance is

subject to adverse selection. A strong argument exists for imposing such restrictions on disability insurers as well.

A number of states have already begun to address the use of genetic information in disability insurance. Thus, we see statutory provisions stating that disability insurers should not refuse to consider an applicant because of a genetic condition (as in Arizona and Montana); should not engage in unfair discrimination by treating genetic risks differently from actuarially similar non-genetic risks (as in Arizona, California, Kansas, Maine, Montana, New Jersey, New Mexico, and Wisconsin); should not engage in unfair discrimination by rejecting or rating an application on the basis of a genetic test in the absence of the diagnosis or manifestation of the relevant condition (as in Arizona and California); should obtain informed consent for any genetic test (as in New Jersey, New York, Oregon, and Vermont); and should notify an applicant when the applicant is rejected for genetic reasons (as in New York).⁵⁹ Yet no state has restricted disability insurers' access to genetic information, as many states have restricted health insurers.

Given the importance of disability insurance, ideally legislators and regulators would impose the same restrictions on disability insurers as they do on health insurers. Norman Daniels analyzes the implications of setting up a disability insurance social safety net by eliminating medical underwriting (including consideration of genetics) while requiring that everyone have a minimum amount of disability insurance.⁶⁰ Daniels does not go so far as to advocate this, but he recognizes it as an option to preserve equality of opportunity in the face of disability disrupting employment and income. For many individuals, this goal might be met through group insurance and public disability programs. When an individual can obtain the minimum amount of disability insurance needed through these other mechanisms, then individuals with a higher level of income can buy additional private individual insurance for additional income protection. Yet there will be some individuals without access to group insurance and unable to qualify for public programs who need access to a minimum safety net of individual disability insurance.

Despite the importance of disability insurance, stringently restricting insurers' access to genetic information may be problematic, as this information increasingly pervades medical records and may be difficult to segregate. However, if private individual disability insurers are permitted to obtain genetic information, the next question is how they may use it. May insurers deny insurance, charge higher premiums, or exclude certain conditions predicted or diagnosed by genetic

tests? Using genetic information to treat some individuals differently raises a basic question of fairness. It is only a function of the pace of scientific discovery that some genes are discovered and tests for them developed before others. If current tests are conducted, they will single out the individuals unfortunate enough to have the genes discovered early. This does not mean that those who test positive using available genetic tests will be at greater genetic risk than those who do not, but only that they have the misfortune of possessing the particular genes for which tests have already been developed. Eventually, a full panoply of genetic tests will be available, and we will find that we each should some genetic risks. This argues for treating the population as a pool to share risk rather than trying to single out and quantify what will be a dizzying array of genetic variation and risk.

The state restrictions emerging on disability insurers' use of genetic information are instructive. At a minimum, the procedural safeguards currently embraced by the states should be considered. But they may not go far enough. Requiring actuarial fairness that genetic risks be treated like other medical risks does not address the reality that some applicants will benefit simply because their genetic vulnerability is not yet known. Further, assuring actuarial fairness requires a rigorous understanding of underwriting and how genetic information may be misused and misinterpreted by both insurers and applicants.

We recommend below that legislators and regulators consider prohibiting individual disability insurers from rejecting or rating an application simply on the basis of genetics, absent the manifestation and diagnosis of the predicted phenotypic condition. Further, restrictions on pre-existing condition exclusions are important. Exclusion of a condition merely on the basis of genetic information in the absence of phenotypic manifestation and diagnosis of the predicted condition should be disallowed. Permitting exclusion of all such conditions simply on the basis of genetics would gut the social utility and risk-sharing function of these policies, as the genetic substrate of more and more conditions is discovered. However, it may be necessary to permit insurers to adjust premiums (not deny coverage altogether) for genetic information alone, as long as that information reliably predicts a high likelihood of the applicant developing a significantly disabling condition that will qualify for benefits payment. For highly disabling diseases whose onset and severity is reliably predicted by genetics (mainly rare monogenetic diseases such as Huntington's disease), this latitude in premiums may make sense. Such allowed adjustments will have to be limited so that the premiums charged are not so inflated as to make

insurance unaffordable and effectively constitute an exclusion. The American Academy of Actuaries outlines some options that could be used to pursue this policy direction, including reinsurance pools for high-risk genetics markets and use of an advisory board to evaluate the value and significance of specific genetic tests.⁶¹

B. Group Disability Insurance

HOW IT WORKS

Group disability insurance policies, mostly available through an employer, involve three entities rather than the two involved in individual contracts. Group contracts typically run between the employer and insurer, with the employee receiving proof of insurance. The employee has no individual bargaining power. If the employee is represented by a union or other collective that can bargain over the disability policy, then this may introduce a fourth entity.

The architecture of group disability insurance, especially in the employment context, thus raises questions about the employer's as well as the insurer's coverage and claims practices. If the employer elects to self-insure, thereby acting as the disability insurer as well as employer, the employer plays an even bigger role. Employers might take on this role to avoid state regulation, as self-funded plans enjoy broader preemption of state law under the federal Employee Retirement Income Security Act (ERISA). Group policies often include a buy-up provision allowing some employees to purchase additional disability coverage. Typically, the employee seeking additional coverage must undergo a medical examination and provide access to medical records to permit medical underwriting. Underwriting for buy-ups introduces the issues discussed above relevant to individual policies since they are effectively additional individual policies. However, these buy-up options are not underwritten as stringently as individual policies. They thus represent a kind of policy intermediate between group and individual. We focus in this section and in our recommendations below on group policies themselves.

Group policies are sold based on the experience rating of the group or the demographics of the population being insured or both. They are not individually underwritten, so information about any individual's medical history and risks is not available to the insurer until the insured files a claim. Unlike individual policies, group policies commonly include an exclusion for pre-existing conditions. Once an individual files a claim, a claim based on a pre-existing condition can be denied.

GENETIC TESTING

Group disability insurance, especially when employment-based, raises many of the same genetics issues as individual insurance, yet the context is fundamentally different. Group disability insurance covers many more people than individual insurance.⁶² It is typically offered as a benefit of employment and is easier to qualify for than individual insurance because it is not individually underwritten. This means that insurers do not require individual employees to meet medical criteria to qualify for coverage and so do not demand medical exams or scrutinize individual medical records to determine insurability or premium levels. Because of these factors, group disability insurance is more likely than individual insurance to provide a basic package of disability income insurance. In addition, adverse selection is not as acute an issue when insurance is a benefit of employment instead of an entirely individual choice. Thus, there may be more latitude in the group insurance, context to limit employer and insurer use of genetic information, without the risk of employees taking advantage of genetic information.

Indeed, in the context of group health insurance, Congress has spoken directly to the use of genetic information to determine eligibility. HIPAA forbids using an individual's or a dependent's genetic information to determine eligibility for group health insurance.⁶³ Though HIPAA does not go further to assure affordability by limiting the impact of genetics on premiums, that impact should be limited by the very fact that group insurance is not individually underwritten. Further, the 109th Senate passed a bill prohibiting discrimination in group and individual health insurance on the basis of genetic information and generally limiting the use of that information.⁶⁴ If one considers the importance of group disability insurance, HIPAA and the recently proposed legislation thus set powerful precedent for ruling genetics off-limits for determining eligibility for disability insurance.

There are gaps in group disability insurance coverage; it is not universal.⁶⁵ Group disability insurance is not offered by all employers. Part-time workers also have less access than full-time workers. In addition, a larger percentage of the workforce is covered by short-term disability insurance than by long-term disability insurance. Yet if one were to argue for access to a basic disability insurance package for all workers regardless of genetics, group disability insurance would be a logical place to start.

Because group disability insurance is not individually underwritten, genetic information and disputes will not arise when an employee first enrolls. Instead, most genetics issues arising between the insurer and insured will occur in the claims process. Yet the

employer/insurer relationship or the fact that the employer is self-insuring will create incentives for the employer to pay attention to applicants' and workers' vulnerability to disability. The employer's aggregate disability claims experience for the group over time may lead the insurer to adjust policies and premiums. Thus, an employer's premiums may depend on the health of its workforce. *Burlington Northern* provides some evidence that employers may be interested in using genetic testing to identify workers with a genetic propensity to certain disabilities.⁶⁶ Genetic information is thus important in group disability insurance in two major ways. First, either the insurer or insured may point to such information in disputes over claims; second, the employer may seek genetic information to secure a healthy workforce and bring down insurance premiums and disability insurance costs.

The most obvious way in which a disability insurer may use genetic information in a claim dispute is to exclude a pre-existing condition. The effect of the pre-existing condition clause is to exclude from coverage those conditions that are manifested during some defined period of time before the policy becomes effective and that cause a loss of work capacity within a limited period of time at the start of employment. Group disability policies routinely include provisions excluding conditions that begin before the policy is in force.⁶⁷ Clearly, this is a complicated issue when genetic information is involved, raising the question of whether a disease "existed" simply by virtue of the individual's genetics before the disease manifested in symptoms and before it was amenable to diagnosis.

A typical policy might define a pre-existing condition as

a sickness or physical condition for which prior to the effective date: 1) symptoms existed that would cause an ordinarily prudent person to seek advice or treatment from a physician, or 2) advice or treatment was recommended by or received from a physician.⁶⁸

Another policy defines pre-existing condition as:

a condition for which you received medical treatment, consultation, care or services including diagnostic measure, or took prescribed drugs or medicines for your condition during the given period of time as stated in the plan; or you had symptoms for which an ordinarily prudent person would have consulted a health care provider during the given period of time as stated in the plan.⁶⁹

Both definitions require symptoms or physician consultation, not just genetic information.

Yet the courts have suggested that even indistinct symptoms leading to physician consultation may constitute a pre-existing condition if ultimately attributable to a genetic condition diagnosed after the effective date of coverage.⁷⁰ In the *Fath* case, the plaintiff had consulted physicians and chiropractors over decades for neck and back pain, and a variety of diagnoses were offered. A physician finally diagnosed the plaintiff with Ehlers-Danlos Syndrome Type III (EDS), a painful genetic condition that eventually causes the joints to become lax and dislocate. All previous symptoms were attributed to the disease. When the plaintiff could no longer work, she applied for disability benefits, only to have her claim denied based on the pre-existing conditions exclusion, maintaining that the disease "existed" before the policy was in force despite the fact that no medical professional could diagnose it properly. The *Fath* case is not unique; the court cited other cases that had reached identical results.⁷¹ *Fath* confirms the fear that genetic testing can "reach back," making sense of earlier symptoms and thus making the individual "disabled" long before the start of the policy in the eyes of disability insurers. Such cases, by allowing the insurer to argue that a claimant's indistinct symptoms predating a policy constitute a pre-existing genetic disease, threaten to make such individuals uninsurable.

Pre-existing conditions exclusions in the context of genetics cause further problems by creating incentives for individuals to avoid discussing with their doctor symptoms and diagnostic options, including genetic tests. In another case, a disabled plaintiff argued that he had visited his physician merely for prescription refills.⁷² However, because he had at the same appointment complained of symptoms related to the disease that ultimately disabled him, the court denied his disability claim under the pre-existing conditions clause. Thus, discussion of symptoms, diagnostic options, or available treatments, when conducted before a policy is in effect, may trigger a pre-existing conditions exclusion for the purposes of disability insurance.

In a related vein, group disability policies also usually require that disability be due to "sickness."⁷³ "Sickness," in turn, is defined as an illness or disease that "begins," "first manifests," or "first appears" while the contract is in force.⁷⁴ This definition is another reminder that a condition may not predate the policy and thus raises similar problems as pre-existing conditions exclusions. It raises concerns over a genetic test revealing a disease that arguably began, first manifested, or first appeared before the policy went into effect.

Given the societal importance of disability insurance and especially the basic group benefits offered

by many employers, there is a strong argument that such policies should not exclude conditions merely because genetics and even vague symptoms predate the policy. Nor should recognition of the underlying genetics through a genetic test predating the policy lead to exclusion. To permit such exclusions would vitiate coverage for any condition with a recognized genetic component. Yet over time, we are likely to recognize a genetic component of the majority of illnesses and disorders. Disability insurance would then be useless. A more reasonable application of pre-existing conditions exclusions would follow the lead of state statutes requiring clear manifestation or diagnosis of the actual disabling condition predating the policy, not just recognition of the genetic vulnerability and even vague symptoms, as discussed above.⁷⁵ Indeed, Congress similarly confined group health insurance plans in HIPAA by prohibiting plans from treating genetic information as a pre-existing condition “in the absence of a diagnosis of the condition related to such information.”⁷⁶

Further issues arise because the cost of group disability insurance provides an incentive for the employer, either as a self-insurer or purchaser of insurance, to determine the health status of its employees. Employer concerns about health care costs, health insurance premiums, missed work, Workers’ Compensation costs, and exposure to liability for work-related injury or illness are added incentives for employers to try to predict employees’ disability.

A complex body of state and federal law confines the latitude of employers to consider health and disability in hiring, firing, and related decisions such as promotion. The federal ADA restricts employers to considering health and disability only after making a conditional offer of employment.⁷⁷ The employer may then require a medical examination and gain access to the prospective employee’s medical records. Even though the employer may not withdraw the job offer if the employee can perform the essential functions of the job with reasonable accommodation, many commentators have argued that the proverbial cat is already out of the bag since the employer has the employee’s medical and perhaps genetic information and can use that information even if that is illicit under the ADA.⁷⁸

Furthermore, ADA protection against discrimination based on asymptomatic genetic conditions remains unclear.⁷⁹ The ADA by its terms fails to address genetics. Its three-pronged definition of “disability” includes having a history of a health condition interfering with life functions and “being regarded as” disabled, but not having a predicted future of such a condition.⁸⁰ Genetic testing thus suggests a missing fourth prong to the definition of “disability.” And

although the EEOC, the agency charged with enforcing the ADA, stated in 1995 that the Act should be construed to cover asymptomatic genetic conditions predicted to cause future health problems,⁸¹ the courts have not yet ruled on whether this interpretation of the ADA is good law. Congress has also failed to provide statutory clarification. A bill proposed in the Senate would have prohibited employers from requiring employees to provide genetic information and from making discriminatory employment decisions based on such information, but the House’s inaction on the bill regrettably resulted in its death at the close of the 109th Congress.⁸²

An Executive Order issued by President Clinton in 2000 confined federal employers’ use of genetic testing and information.⁸³ The Order combats “genetic discrimination” in federal employment by creating a category of “protected genetic information” and then prohibiting federal employers from requesting the information and refusing to hire, fire, or deprive employees of opportunities based on the information. However, the “exceptions” are broad, permitting an employer to request or require the information if, among other things, the disorder at issue could prevent performance of essential functions of the position (apparently at any unspecified time and to any degree of probability), the employee uses genetic or health care services provided by the employer, or the employer is engaged in genetic monitoring of biological effects of toxins in the workplace.

A number of state statutes offers protection or addresses genetic testing in employment explicitly.⁸⁴ Mark Rothstein and colleagues have praised a Minnesota statute that confines prospective employers from access to medical information relevant to job functions.⁸⁵ This means that employers do not gain the access to health and genetic information that the ADA would allow in the hiring process. But even the Minnesota statute would seem to allow access to genetic information if the employer deemed it relevant to present or future job function.

Numerous states have enacted more specific statutes prohibiting employer access to and use of genetic information when hiring.⁸⁶ However, some of these statutes permit genetic testing once an employee has brought a Workers’ Compensation claim in order to determine, for example, whether the employee had a genetic susceptibility to workplace toxins.⁸⁷ Oklahoma law is even broader, allowing an employer to use genetic testing to determine insurance coverage or benefits.⁸⁸

In like vein, states have also enacted statutes on genetic testing to determine eligibility for disability and other forms of insurance in an employee benefit

plan.⁸⁹ New Hampshire, for example, while prohibiting genetic testing in hiring, allows “genetic testing for evidence of insurability with respect to life, disability income, or long-term care insurance under the terms of an employee benefit plan.”⁹⁰ Such a law suggests that an employee may be hired without requiring genetic tests, but may then face genetic testing to qualify for employee insurance benefits.

Federal and state law thus provide uneven and incomplete protection from employment discrimination based on genetics. Indeed, state law varies widely. Numerous federal proposals to remedy the problem have yet to be enacted.⁹¹

We suggest that at the time of hiring, promotion, or job reassignment, employers should be able to consider genetics only if it helps diagnose and establish current inability to perform the job. Employers should not be able to use genetics to predict inability in the future.

As noted above, most private disability insurance is group insurance and acquired largely through employment. Thus group disability insurance is pivotal in securing a financial safety net in the event of disability interfering with income. Employers already have the latitude under state and federal law to refuse to hire applicants with a disability that precludes performing essential functions of the job, despite reasonable accommodation. Though one can certainly debate whether employers are accurately making this judgment and offering adequate accommodation, the core idea that employers have no duty to hire those who genuinely cannot perform the job with reasonable accommodation makes sense. This would apply even if the disabling condition happened to stem in part or entirely from genetics.

More problematic are individuals currently able to perform the job but whose genetics predict a future disability interfering with job function. The individual may have a mutation predicting such future disability to a certainty (as in the case of Huntington’s disease) or merely creating a probability. Moreover, due to limitations in our current understanding of the interaction between genetic predisposition and environmental triggers, the degree and timing of future impairment may be easy or difficult to predict.

Given this range, we suggest that it is unfair to exclude from the workplace those currently able to perform the job, but who may at some uncertain future date no longer be able to do so. Any employee may at any time develop an illness or suffer an injury rendering him or her unable to do the job. In this sense, the employer always takes the risk of future employee disability. Indeed, disability insurance limits employer liability for supporting disabled employees, Workers’ Compensa-

tion protects employers from tort liability for workplace injury or illness, and employers themselves can insure their workforce or key employees to protect the business from loss in the event of employee disability. Thus, disability insurance in its various forms should actually serve to mitigate any risk employers assume in hiring those who may become unable to perform job functions in the future.

Employers may counter that they have an economic imperative to seek a less expensive workforce whose workers will require fewer accommodations, will have fewer absences, and will produce less disability-related cost, including premiums for disability insurance. However, the ADA already embodies the societal determination that employers should share in the cost of accommodating the disabled who can work. Because most people will eventually develop a disability with some genetic component, the argument is even stronger that employers should not escape societal participation in bearing the cost. To decide otherwise would allow employers to create a massive class of people who are unemployable or subject to inferior job conditions on the basis of a genetic prediction of future disability.

We turn then from employers’ use of genetic testing conducted outside the workplace to genetic testing by employers in the workplace. Employers use two types of genetic testing in the workplace: genetic screening and genetic monitoring. Genetic screening involves an initial genetic test used by employers at the time of hiring as a means of identifying and excluding individuals who are at high-risk of ill effects from toxins used in that workplace.⁹² Genetic monitoring involves the repeated genetic testing and screening of workers exposed to toxic substances in the workplace in compliance with federal Occupational Safety and Health Act (OSHA) requirements and ensuring that workers do not suffer substantial chromosomal damage as a result of their presence in the workplace.⁹³ Genetic screening is gaining increasing favor with employers seeking to reduce operational costs.⁹⁴

Employers may cite two circumstances for screening or monitoring. First, employers using toxins (or other materials or conditions) with differential effects on those individuals with certain genetic vulnerabilities may seek testing or screening to avoid hiring these persons or to transfer those more likely to suffer harm from exposure. This pits employers’ desire to save money and employers’ paternalistic interest in protecting the safety of employees against employees’ freedom of choice. After all, employers always can (and should) inform employees of the risk of exposure to harmful substances and the role genetics plays in exposure risk; employers can even offer genetic testing

to determine risk at the employee's election.⁹⁵ If test results were confidential, it would then be entirely up to the employee whether to go forward with the job.

In *Chevron U.S.A. v. Echazabal*, however, the Supreme Court upheld an EEOC regulation permitting employers to refuse to hire individuals because the job would endanger their health.⁹⁶ In this case, the employer refused to hire the applicant for an oil refinery job because the employer's doctors indicated that exposure to toxins would aggravate liver damage the applicant had sustained from Hepatitis C. *Echazabal* raises the question of whether prospective employers can legitimately use genetic tests to exclude applicants because of genetic susceptibility to damage from workplace exposures or conditions.

Echazabal suggests that under the ADA a prospective employer would be able to exclude a symptomatic applicant or employee only if medical evidence pointed to a direct threat of significant harm.⁹⁷ This indicates that exclusion would require a scientifically supported and direct connection between a genetic vulnerability and a predicted significant harm.⁹⁸ Further, the Court unanimously upheld the importance of "individualized medical determinations of risk" requiring medical evidence of a connection to a current health risk.⁹⁹ This gives the medical community and occupational health providers who conduct these pre-employment medical exams much control over what genetic information employers can collect and access.¹⁰⁰ Given employers' economic incentive to amass as much information as possible about employees' and the absence of legislation regulating the collection of genetic information, the medical community will now play a critical role in protecting workers.¹⁰¹

While *Echazabal* grants employers only the right to exclude symptomatic applicants whose condition would be threatened by the work environment, the case will undoubtedly lead to litigation over the application of this to an array of genetic conditions.¹⁰² *Echazabal* may thus open the door to applicant and employee genetic screening, though some states do have statutes imposing limits.

The prospect of widespread genetic screening in the workplace, purportedly to avoid harm to employees themselves, is troublesome. Many jobs, including mining, construction, and farming, involve heightened risk; genetics is only one of a number of factors that can make a job riskier for some than others. Other factors include pregnancy, high blood pressure, and cardiac illness, depending on the nature of the workplace risk. This problem has been much debated outside the genetics context.¹⁰³ Some writers are now addressing the genetic risks.¹⁰⁴ The prevalent recommendation, which we endorse, is that employers should be

required to make the workplace safer for all, a stated goal of OSHA.¹⁰⁵ Once an employer offers a safe workplace, asymptomatic workers should generally be able to elect their own risks – including genetic risks – with informed consent. Clearly, genetic monitoring may in some cases be part of maintaining a safe workplace. But the most preferable solution would be to minimize chemicals and exposures that suggest a need for monitoring in the first place, making the workplace safe for all, requiring strong evidence that monitoring will confer employee benefit, and creating systems allowing employees voluntary access to confidential testing.

The other claim employers may make is that they need genetic testing to determine a worker's qualification for disability income, whether through the employee benefit of group disability insurance or Workers' Compensation. Determining whether a worker qualifies under the group policy again raises the questions addressed above in discussing acceptable limitations in individual policies. In the group context the argument against allowing the policies to exclude and limit on the basis of genetic tests is even stronger, as group insurance is more essential to the disability insurance safety net than individual. If individual policies should not be able to differentiate on this basis, then the employer claim fails. We consider the Workers' Compensation argument below.

IV. The Public Insurance Context

Though we focus our analysis and recommendations on private insurance, we need to place the private insurance system in context. As previously mentioned, the primary forms of public insurance are Workers' Compensation, SSDI, and SSI. Workers' Compensation is actually a mixed public-private program; it is typically state mandated, but may be financed by both employers and government. While these public programs together pay out a substantial amount in benefits per year, each is more specialized than private insurance. Workers' Compensation compensates for workplace injury or illness up to a certain cap. SSDI and SSI each pay only for total disability expected to last a year or longer. The compensation levels for each insured are relatively limited in each program. We describe each of the three public or mixed programs below, considering the role that genetic testing may play.

A. Workers' Compensation

HOW IT WORKS

As originally conceived, Workers' Compensation was a compensatory system to guarantee some minimum benefit to a worker who suffered a work-related injury

or illness, regardless of who was at fault. The employer, in turn, was given immunity from liability in tort for the injury.¹⁰⁶ This trade-off is often expressed in the literature as a contract or bargain between workers and employers to avoid the costly tort system, which created tension in the workplace and yielded unpredictable results.¹⁰⁷

Workers' Compensation provides benefits for injuries, illnesses, or death caused by a worker's job.¹⁰⁸ It also covers those illnesses that worsen due to work or the work environment.¹⁰⁹ The usual coverage includes medical treatment for the injury, partial coverage of lost wages, benefits for permanent partial damage, benefits for permanent total damage or death, and rehabilitation for a new job if necessary.¹¹⁰ State law requires employers to purchase insurance or to self-insure in order to cover Workers' Compensation claims.¹¹¹ A state agency usually adjudicates contested claims, with appeals to the state courts.

Some states have separate statutes for injuries and diseases, allowing for different levels of compensation or different time limits for making claims.¹¹² It is often difficult to assign a given condition to one or the other of these categories, though. Paradigmatic occupational diseases are "coal miners' pneumoconiosis or 'black lung' disease, radiation illness, silicosis, and the asbestos-related diseases."¹¹³ However, a common condition that is cumulative such as carpal tunnel syndrome could be seen as either an injury or an occupational disease; this distinction may affect the level or duration of benefits.¹¹⁴

For a time, Workers' Compensation statutes may have accomplished their original goals of softening the effects of the tort system and promoting workplace peace. Eventually, however, Workers' Compensation insurance became more costly for employers, and the courts began to allow employees to sue their employers under judicially created exceptions to Workers' Compensation law and under anti-discrimination law.¹¹⁵ Because the cost of Workers' Compensation is high and the threat of litigation is once again a part of the employment relationship, the original advantages to the bargain between workers and employers have proven somewhat illusory. Employers now have several types of tort liability exposure, and workers often have to fight to get their Workers' Compensation benefits.

The late 1960s and 1970s saw significant increases in Workers' Compensation benefits.¹¹⁶ Programs now provide up to two-thirds of a worker's pre-disability income, but place a cap on benefit payments.¹¹⁷ This means that the system better covers the needs of low- and middle-income workers than others.¹¹⁸ Because Workers' Compensation is a short-term solution, con-

tinued support must come from other sources, most likely SSDI and SSI, which are the federal disability programs discussed below.¹¹⁹

Workers' Compensation law differs by state. In addition, federal Workers' Compensation statutes govern certain workplaces.¹²⁰ However, the essential question under all statutes is whether work or disease caused the injury.¹²¹ Doctors' testimony is usually necessary to determine its cause; thus, the system is dependent upon medical experts' view of the cause of injury or illness.

Inevitably, the causation requirement raises questions about pre-existing conditions or susceptibilities. The long-standing rule governing compensation for workplace injury or illness is that employers take workers as they find them, including the workers' vulnerability.¹²² Thus, even if a worker has a pre-existing condition or susceptibility aggravating the effects of an injury or illness caused by the workplace, the worker will be entitled to full compensation.¹²³ This rule, although it seems worker-friendly on its face, has made both firing and refusing to hire disabled workers the most efficient solution for employers.¹²⁴

To correct the effects of the "take the worker as you find him or her" rule, state legislatures have passed statutes reducing employer risk of hiring workers with pre-existing conditions.¹²⁵ One solution has been to allow apportionment of the responsibility to the previous employer, a previous insurance company, or a state fund (usually called a "second injury fund" or a "special fund") if the disabled employee's current work did not cause all of the harm.¹²⁶ Thus, the employer or insurer can share the cost of compensation.

Another solution has been to require that the worker's injury be substantially or predominantly caused by current employment for the worker to collect benefits from the current employer.¹²⁷ A finding of causation greater than 50 percent from a disabled employee's current work may be required before a claimant may be awarded benefits.¹²⁸ This heightened causation requirement attempts to relieve for the employer or insurer of the duty to compensate the worker when the current work is not the primary cause.

GENETIC TESTING

The Workers' Compensation causation requirement, as well as the apportionment and 50 percent causation laws, encourage the employer or insurer to argue that genetic factors are either totally or partially responsible for the harm done to the worker. At one end of the spectrum, a Workers' Compensation adjudicator could find genetic factors completely responsible for the claimant's injury, illness, or death. In such a case, the claimant would receive no benefits because the

current work did not cause the injury or illness. At the other end, the adjudicator could find that the workplace caused underlying genetics to manifest symptoms, in which case the claimant would receive benefits, with the possibility that another entity such as a second injury fund or a previous employer might pay a portion. In those states where the claimant has to prove greater than 50 percent causation by the workplace, an adjudicator could find that both genetic factors and the workplace combined caused the illness or injury, but that one cause predominated. If genetic factors were found to predominate, the claimant would be out of luck; if work factors were found to predominate, the claimant would win compensation.

These complexities create incentives for employers to screen applicants and workers for their genetic susceptibilities and pre-existing conditions and to eliminate such individuals from the workforce before the workplace causes harm. The employer also has an incentive to collect medical and genetic information concerning pre-existing ailments or susceptibilities to defend against eventual Workers' Compensation claims. Because the central question in Workers' Compensation is whether the injury or illness was caused by the work, any alternative explanation for the claimant's condition may benefit the employer. Insurers may also pressure the employer to test and discharge risky employees; one Wisconsin case even refers to workers who were tested and then fired at the insistence of the Workers' Compensation insurer.¹²⁹

Employers' interest in workers' genetics is evidenced in Workers' Compensation disputes. Employers have often opposed Workers' Compensation claimants by citing genetic predisposition.¹³⁰ The success of a Workers' Compensation claim commonly depends on expert testimony by physicians as to whether the illness or injury was caused by the work. Often such testimony includes speculation that a claimant is genetically predisposed to a particular illness or injury, suggesting that the condition would have developed on its own or that genetics is largely responsible for the condition.¹³¹ Yet frequently such expert testimony relies on nothing more than a generalized suspicion that a disease such as a mental illness is inherited because it is observed in multiple family members.¹³² Occasionally, a physician may actually have conducted a genetic test. For instance, a positive test for HLA B-27 has been invoked to argue that a claimant's arthritis would progress naturally without the contribution of the workplace.¹³³

Genetic arguments have thus been made in many Workers' Compensation proceedings. In two cases, questions were raised as to whether a noisy workplace caused hearing damage in claimants or alterna-

tively a genetic predisposition to deafness was entirely responsible.¹³⁴ Another dispute involving possible genetic impact arose when a worker was hurt on the job and suffered depression as a result.¹³⁵ In that case, arguments that genetic factors were responsible for the "mental" portion of the damage were successful.¹³⁶ In one case a worker's genetic predisposition (as indicated by family history) was put at issue when he developed ulcerative colitis after taking nonsteroidal anti-inflammatories and antibiotics for a workplace injury.¹³⁷ In another case the adjudicator found that hallux abductor valgus (a bunion) was not caused by requiring the worker to stand all day, because a physician stated that the condition was "hereditary."¹³⁸ The view that various immunologic diseases are "genetic," such as arthritis and ankylosing spondylitis, has also raised the question whether injuries are solely work related.¹³⁹

A number of state statutes explicitly permit employers' use of genetic testing in response to a Workers' Compensation claim.¹⁴⁰ Other states have enacted laws protecting employees' rights to genetic privacy and allowing genetic testing only at the employee's request and with the employee's consent.¹⁴¹ Some employees developing an occupational disease that takes time to manifest may want genetic testing. If a worker can show genetic susceptibility to a disease, that may help support a claim that otherwise may be rejected if much time has elapsed since workplace exposure. Indeed, in the future, genetic testing documenting exposure to certain toxins may help a worker establish workplace exposure to those toxins well before he or she showed symptoms.

While Workers' Compensation law may create incentives for employers to conduct genetic testing on applicants and employees in order to gain knowledge of vulnerabilities and pre-existing conditions, the ADA limits this practice, as noted above.¹⁴² The employer is, however, allowed to make a conditional offer of employment subject to the results of a medical examination. Although results of such examinations are confidential, EEOC Interpretive Guidance states that the employer "may submit information to State workers' compensation offices or second injury funds in accordance with State workers' compensation laws."¹⁴³

Thus the Workers' Compensation system again raises questions of employer and insurer access to and use of genetic information. It also raises the question of when, if ever, asymptomatic genetic susceptibility or predisposition should eliminate or reduce employer responsibility for Workers' Compensation benefits. Finally, because Workers' Compensation agencies and adjudicators already face employee claims and

employer defenses raising genetic issues, the question remains how to educate adjudicators, expert witnesses, and lawyers to approach these genetic issues competently.

B. Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)

HOW THEY WORK

SSDI and SSI are related but distinct programs administered by the Social Security Administration (SSA). They share the same definition of disability, but have different histories, financing, and purposes. Essentially, SSDI is an insurance program for totally disabled workers who have worked long enough to qualify for benefits. SSI, however, is a welfare program for those who are totally disabled and poor and who do not meet SSDI eligibility requirements.

Although the Federal Social Security Act was passed in 1935, it was not until 1956 that the Title II program known as SSDI was established by amendments to the Act.¹⁴⁴ These amendments created the Disability Insurance Trust Fund funded by payroll taxes and provided insurance benefit payments to those workers over 50 unable “to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or to be of long-continued and indefinite duration.”¹⁴⁵ Over time, several changes were made to the program. Benefits for the dependents of disabled workers were included,¹⁴⁶ and the age requirement was removed.¹⁴⁷ The definition of durational requirement disability was revised to read:

inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.¹⁴⁸

In 1967 Congress added new provisions designed to target what it saw as overly liberal interpretations of the existing statute by the SSA.¹⁴⁹ Congress imposed a new severity requirement, a new insistence on medical or clinical evidence, and language stating, “An individual shall not be considered to be under a disability unless he furnishes such medical and other evidence of the existence thereof as the Secretary may require.”¹⁵⁰ More recent changes to the Social Security Act have included the elimination of alcoholism and drug addiction as qualifying disabilities¹⁵¹ and a somewhat heightened standard for disability in children.¹⁵²

SSDI is thus a program for people who become disabled after working in jobs covered by Social Security.

The premise is that workers who have paid the Social Security tax deserve access to that money if they are no longer able to work. Benefits are determined by the lifetime average earnings of the beneficiary and are paid out monthly. SSDI is also available to disabled children if a parent has the requisite work history.¹⁵³ The child must meet the criteria established for disability by the SSA.

SSI was established more recently in 1972.¹⁵⁴ UNTil 1972, Aid to the Permanently and Totally Disabled (APTD) provided public assistance to the blind, elderly, and disabled poor. Administered by the states and financed with federal matching funds, APTD varied in implementation by state. In 1972 Congress assigned the new SSI program to the SSA, which took over the responsibility of supplying benefits to the blind, elderly, and disabled poor.

States retain some involvement in both SSI and SSDI. State agencies (Disability Determination Services or DDS), which contract with SSA, make the initial decision as to whether an individual is disabled.¹⁵⁵ State agencies apply the regulations somewhat differently, yielding variation in the percentage of claimants determined to be disabled.¹⁵⁶

SSI, unlike SSDI, is funded by general taxes rather than payroll taxes and is in the nature of a welfare plan rather than insurance.¹⁵⁷ Although SSI requires that the applicant establish need, the definitions of disability are identical in the SSI and SSDI programs.¹⁵⁸ Also, recipients of SSDI whose payments are too small to live on due to a short work history can receive SSI.¹⁵⁹ Indeed, many individuals qualify for SSDI and SSI in the same proceedings. Disabled children may also receive SSI.¹⁶⁰ SSI benefits, unlike SSDI, may be contingent on accepting vocational rehabilitation services.¹⁶¹ The essential difference between the two programs is that SSDI is seen as an entitlement, whereas SSI is seen as a form of public assistance.

The first step under either program is filing an application with an SSA District Office, which makes a threshold determination of the claimant’s status. In the case of SSDI, this is a question of the claimant’s earnings record and whether he or she has accumulated enough credits to collect benefits. In the case of SSI, the initial determination focuses on the claimant’s need. The application will also ask for names of doctors and treatment facilities. This information is then forwarded to the state DDS. The state agency is responsible for putting together complete medical records from the information supplied by the claimant. The state agency may request medical records or call treating physicians. At this point the applicant is required to sign medical releases. State DDS offices are staffed mainly by lay persons, assisted by a physi-

cian or a psychologist. If benefits are denied at this point, a claimant can request review, usually a hearing conducted by an Administrative Law Judge (ALJ). If the ALJ denies benefits after a hearing, the claimant may appeal to an Appeals Council; claimants may then appeal to the federal courts.

To meet the SSA definition of disabled under both programs a person must be unable to work in any job because of a disability expected to last a year or to result in death.¹⁶² There is an extensive Listing of Impairments;¹⁶³ if the disability is not listed, then the SSA will compare it with those listed.¹⁶⁴ A five-step process governs disability determinations under both SSI and SSDI.¹⁶⁵ The first step asks if the claimant is working at substantial gainful activity. The second step asks whether the claimant has a severe impairment. Medical documentation must show that the limitations claimed actually interfere with the claimant's ability to perform gainful activity. The third step determines whether the claimant "meets" or "equals" one of the impairments in the Listing of Impairments. A diagnosis usually does not suffice. The claimant must show that he or she has the disease at the level of severity suggested under the disease headings. The fourth step determines whether the claimant can perform his or her past relevant work; the claimant's residual functional capacity is evaluated with input from physicians. If the claimant cannot return to the past work, the fifth step is for the Commissioner to show that the claimant can perform some other kind of work.

Claims for benefits must rest on objective medical information. The impairment or combination of impairments must be proven to result from anatomical, physiological, or psychological abnormalities that can be shown by medically acceptable clinical and laboratory diagnostic techniques, including medical evidence of symptoms, signs, and laboratory findings.¹⁶⁶ Although Social Security cases follow a treating doctor rule (the treating physician's opinion is accorded more weight than that of a physician who has not treated the patient),¹⁶⁷ the doctor's statement of disability must be supported by tests or signs.

Disability under the Social Security Act is an all-or-nothing proposition. There is no option to find partial disability, as there may be under Workers' Compensation. The standard for disability under the Social Security Act is quite restrictive as well. Whereas a worker who is insured under a private disability policy may only have to prove that he or she is disabled from performing his or her own occupation or an occupation for which he or she is reasonably fitted by education, training, or experience, the Social Security claimant has to show that he or she cannot work at all in any

job in the national economy. Thus a surgeon with a hand problem, who is disabled for private disability purposes, will most likely not be disabled under the Social Security Act.

The process of adjudicating Social Security cases emphasizes function rather than diagnosis. The Listing of Impairments describes the point at which diseases are severe enough to be considered disabling. An individual who does not have a specifically listed disease or condition can still prove disability by showing that the effect of his or her condition is as severe as those conditions in the listings.

Most diseases are not considered severe enough based on diagnosis alone.¹⁶⁸ For example, to qualify for disability for Multiple Sclerosis (MS), an individual must not only be diagnosed with the disease, but also must manifest "visual or mental impairment..., significant, reproducible fatigue of motor function with substantial muscle weakness on repetitive activity..., or "disorganization of motor function."¹⁶⁹ In contrast, diagnosis of Amyotrophic Lateral Sclerosis (ALS) will suffice when "established by clinical and laboratory findings."¹⁷⁰

When a medication or treatment can correct a condition, the claimant will not be found disabled.¹⁷¹ An individual must follow any reasonable, prescribed treatment that can restore the ability to work, or in the case of a child, restore functional limitations so that they are no longer marked or severe.

GENETIC TESTING

Applicants for SSDI and SSI are required to disclose all tests and medical records.¹⁷² This raises obvious questions of genetic privacy, as those records will often contain genetic test results or genetically suggestive information such as family medical history. In the process of applying for SSI or SSDI benefits, medical information may be studied by a great number of people, some of whom are lay people with no apparent duty of confidentiality toward the claimant.

Genetic testing may be required for claimants trying to prove that they meet certain listings in the Listing of Impairments. These listings include Down syndrome (chromosomal analysis), cystic fibrosis (gene mutation or sweat test), and gonadal dysgenesis ("chromosomally proven").¹⁷³ The diagnosis of a number of other diseases listed will surely depend on a genetic test or another test that confirms a genetic disease, but the listings do not explicitly mention such tests.

There is somewhat special treatment for Down syndrome. A child or adult with Down syndrome applying for disability benefits will qualify if there is evidence of the chromosomal abnormality and if the "characteristic physical features" are present.¹⁷⁴ This determina-

tion is made without regard to the claimant's ability to work. The SSA, in its explanation of these rules, has stated that the "current [listing] represents what we have known for some time: that when we obtain appropriate evidence, virtually all individuals who have non-mosaic Down syndrome will be found disabled under our rules."¹⁷⁵ An applicant with Mosaic Down syndrome will be evaluated according to the severity of the disease, which the SSA notes is highly variable.¹⁷⁶ The Administration concedes that it may sometimes be difficult to find a chromosomal analysis performed on an individual if some time has passed.¹⁷⁷ In this case, the Administration will pay for a test;¹⁷⁸ this is the only instance in which the SSA has gone on record saying that it will pay for a genetic test.

As discussed above, nearly all diseases enumerated in the listings are evaluated based on the severity criteria. For instance, a cystic fibrosis diagnosis will not be enough to meet the definition of disability.¹⁷⁹ However, as a practical matter, it is likely that few claimants with cystic fibrosis are denied Social Security benefits, as we have found no court cases reviewing adverse determinations of cystic fibrosis sufferers. Claimants with sickle-cell disease are apparently treated differently, as there are quite a few cases involving this disease.¹⁸⁰

The SSA defends its emphasis on function rather than diagnosis based on treatment and rehabilitation progress.

In the past, it may have been reasonable to assume that individuals with particular diagnoses were disabled once the diagnoses were objectively established. However, with state-of-the-art medicine,... [i]t is more important now to determine how an individual is functioning with treatment and use of technological advances....¹⁸¹

This raises the question of whether the state agency determining disability or the SSA may require genetic testing to establish the nature and seriousness of a disability as well as its effect on employment. The SSA is permitted to order examinations and tests and is even required to do so in some cases if they might shed light on the claimant's situation.¹⁸² A genetic test could be performed as part of a consultative exam. A physician suspecting a certain condition such as cystic fibrosis may well do a genetic test as a part of a competent exam. In addition, the claimant may request a genetic test, asking the Administration to bear the cost.¹⁸³ Many people who would qualify for SSI may not have the means to pay for genetic testing to determine disability. Access to the doctors and testing required to prove disability may be difficult for applicants of limited income.

If the SSA can order testing or claimants can request such testing or submit genetic information, then issues of data handling, the privacy of genetic test results, and access to medical records by employers and others come to the fore. To permit testing, especially when it may benefit the applicant, it is important that the privacy of the information be protected and that the genetic testing be put to use only by those equipped to understand it. Applicants are presumably more likely to opt for genetic testing if they are assured of the privacy of test results.

Genetic issues are already arising in SSDI and SSI proceedings. Often the date of a condition's onset is at issue and a genetic test may lend credibility to the claimant's contention that the disease dates back to a crucial point in time.¹⁸⁴ For example, if disability can be established from up to a year before the date of application, SSDI benefits are payable retrospectively for that period.¹⁸⁵ It may also be necessary to prove that the disease dates to a period in which the individual was covered by SSDI because of his or her work history.¹⁸⁶ For SSI claimants, benefits are payable only from the date of application, but it is important to establish the disease's presence and severity at that time since years can elapse between an initial application and the receipt of benefits. Also, both SSDI and SSI claimants need to establish that a disease will last at least twelve months; a genetic test may be germane to that prediction.

Because children may qualify for SSI and SSDI, debate about the propriety of subjecting children to genetic testing becomes relevant. Either a caregiver seeking SSI on behalf of the child or the government may seek such testing to document disability. Much of the literature on genetic testing in minors questions its propriety when there is no direct therapeutic benefit to the child.¹⁸⁷ SSI and SSDI raise the question of whether financial benefits should suffice. However, there are substantial risks of inflicting unwanted medical information on a child, which could stigmatize him or her and render the child vulnerable to future job and insurance discrimination. This again raises concerns over data handling and sharing the test results, including whether and under what conditions a child can have access to his or her own test results.

There may be cases in which genetics is used to challenge the alcoholism exclusion. In one case, an alcoholic argued that the exclusion of alcoholics from Social Security benefits was a violation of equal protection and due process.¹⁸⁸ The plaintiff argued that no rational basis existed for treating alcoholics differently, because their disease was genetically caused. The court held that

Congress was well within its discretion to determine that no other severe, potentially disabling impairment has such a volitional component, which in some part makes a person responsible for the onset of the diseases and, more importantly, for its perseverance.¹⁸⁹

This logic, of course, raises the question of whether Congress could exclude other conditions in the future because genetic testing warned an individual of a vulnerability and the person then failed to take necessary steps to avoid developing the disability condition.

Finally, state disability evaluators, SSA, attorneys, and ultimately the courts have to know how to handle genetic claims. This is true for both SSDI and SSI, but is especially important for SSI. SSI applicants have limited means and access to the health professionals, who would alert them to genetic issues and provide testing and counseling.

Recommendations

Our recommendations are based on two factors. First, some kind of disability insurance is important. Without it, one's home, health, and family are at risk. This makes its importance closer to health insurance than life insurance, as the latter is widely seen as optional and discretionary, rather than a key part of the social safety net.¹⁹⁰ Given the importance of disability insurance, consideration must be given to extending the sort of legal protection already in place in the context of health insurance, restricting access to and use of genetic information in disability insurance as well.

Based on our analysis, we offer the following recommendations:

A. Individual Private Disability Insurance

1. Legislators and regulators should consider imposing the same restrictions concerning access to and use of genetic testing information on disability insurers that they impose on health insurers.
2. Legislators and regulators should determine that disability insurers may not refuse to consider an applicant merely because of the applicant's genetics.
3. Legislators and regulators should insist at the minimum that disability insurers treat genetic risks as they would actuarially similar non-genetic risks.
4. Legislators and regulators should consider going further in deciding that disability insurers may not reject or rate an application on the basis of genetic information or an applicant's genotype,

- at least in the absence of the manifestation and diagnosis of the predicted phenotypic condition.
5. Legislators and regulators should disallow exclusions (including pre-existing conditions exclusions) based on genetic information absent manifestation of the predicted phenotypic condition.
 6. Disability insurers should obtain informed consent from individuals for any genetic test.
 7. Insurers should rigorously protect the confidentiality of genetic information including through adherence to HIPAA, all federal and state regulations, and professional guidelines.
 8. Disability insurers should notify an applicant of the reasons for rejection or for charging a higher than standard premium rate, as well as of his or her right to appeal this determination.
 9. Because actuarial fairness and the appropriate handling of genetic information require rigorous understanding of the use and potential misuse of genetic information in underwriting, disability insurers should educate their personnel on the proper interpretation of genetic information. Establishing an advisory board on genetic testing may be recommended.

B. Group Private Disability Insurance

1. Given the societal importance of a basic package of group disability insurance, legislators and regulators should determine that group disability insurers may not require genetic testing or consider individuals' genotypes.¹⁹¹
2. Legislators and regulators should rule that group disability policies may not exclude conditions based on genetic predisposition.
3. Legislators and regulators should disallow exclusions (including pre-existing conditions exclusions) based on genetic information, absent manifestation of the predicted phenotypic condition.
4. Legislators and regulators should require that insurers setting group rates for group disability insurance treat genetic risks as they would actuarially similar non-genetic risks.
5. Disability insurers and employers should obtain informed consent from individuals for any genetic test.
6. Group disability insurers and employers should rigorously protect the confidentiality of any genetic information they acquire, including through adherence to HIPAA, all federal and state regulations, and professional guidelines.
7. Group disability insurers and employers should educate their personnel to properly interpret

genetic information. Establishing an advisory board on genetic testing may be recommended.

8. Legislators and regulators should rule that at the time of hiring, job assignment, or promotion, employers should be able to consider genetic information only if it helps diagnose and establish current inability to perform the job, and not to predict inability in the future. To provide guidance to employers, legislators or regulators should set forth a predetermined list of when considering genetic information is permissible, as well as a mechanism for adding to this list based on scientific findings linking a disease to particular genes.

Taken together, these two sets of recommendations mean that group disability insurers cannot exclude individuals based on their genetics, parallel to HIPAA's rule that group health insurers cannot do the same.¹⁹² Under the approach we envision, group insurers would be expected to shoulder most of the burden of providing a basic package of disability insurance. Individual disability insurers, who will mostly be offering supplemental packages to those individuals able to pay for more income replacement, may be given more freedom to consider genetics. However, at a minimum they must still treat genetic risks as they would actuarially similar non-genetic risks. We recommend that legislators and regulators consider prohibiting private individual disability insurers from rejecting or rating applicants based on genetics, at least absent phenotypic manifestation of the predicted condition.

C. Public Insurance

The public insurance programs provide the background and context for all private disability insurance. We have demonstrated that genetics already plays a role in those public programs, whether through Workers' Compensation, SSDI, or SSI. Making disability claims, evaluating those claims, and adjudicating claims disputes involve genetics now and will continue to do so in the future. Yet there are troubling signs that those involved in these processes may not be adequately trained to understand what genetic information does and does not mean. There is a pressing need to educate all involved in the claims process, including judges, lawyers, and physicians.

Conclusion

We have tried to show that disability insurance occupies a special place in public policy owing to its mission: income replacement and protecting basics, such as housing, food, and the like. Due to this special status, access to disability insurance should not be limited by predictive genetics. There are important implications

of this position for the use of genetic testing and the information it yields, the understanding and definition of pre-existing conditions, and the definition and use of the concept of disability.

As indicated earlier in the report, our Working Group found many of the issues addressed in this report to be difficult and contentious; not all members agree with the conclusions and recommendations offered here. We propose, with some disagreement among our Working Group members, that individuals should not be excluded from disability insurance coverage based on their genetics, at least in the absence of the manifestation and diagnosis of the predicted phenotypic condition. Our hope is that the Working Group's efforts and this document have significantly advanced the discussion regarding the ethics, law, and policy of using genetic information in disability insurance.

Acknowledgements

Work on this article was supported by the National Institutes of Health, National Human Genome Research Institute grant #1-R01-HG02089 to the Center for Bioethics and Joint Degree Program in Law, Health and the Life Sciences at the University of Minnesota. Members of the Working Group were the following: Dianne M. Bartels, R.N., Ph.D. (University of Minnesota); David Christianson (Thrivent Financial for Lutherans); John H. Dodge, M.D. (UnumProvident Corporation); Roger Feldman, Ph.D. (University of Minnesota); Robert H. Jerry, II, J.D. (University of Florida); Eric T. Juengst, Ph.D. (Case Western Reserve University); Nancy Kass, Sc.D. (Johns Hopkins School of Public Health); Bonnie LeRoy, M.S. (University of Minnesota); Mark A. Rothstein, J.D. (University of Louisville School of Medicine); Kathryn J. Sedo, J.D. (University of Minnesota); and Anita Silvers, Ph.D. (San Francisco State University). Members of the Working Group offered input to guide development of this paper, but do not necessarily subscribe to its recommendations. The contents of this article do not necessarily represent the official views of NHGRI or NIH.

Thanks to Larina Brown, Aaron Chapin, Jenna Hannigan, Sally Mermelstein, Susan Parry, Lesli Rawles, Benjamin Schneider, and Ashley Wenger for their research assistance. Thanks also to Steve Befort and faculty at Vanderbilt University School of Law for helpful comments.

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 15. 42 U.S.C. §§ 300gg, 300gg-1 (2003).
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 17. S. 306, 109th Cong. (2005).
 18. H.R. 1227, 109th Cong. (2005). Since the House took no action with respect to the Genetic Information Nondiscrimination Act before the end of its two-year congressional term in December of 2006, this bill lost its active status and would have to be reintroduced in order to be considered by the 110th Congress. In 2003 the House also failed to pass an earlier version of the Senate bill, S. 1053, 108th Cong. (2003), as well as the House's own Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 1910, 108th Cong. 1st Sess. (2003), possibly due to concerns of overlap with the ADA and HIPAA. See W. R. Corbett, "The Need for Revitalized Common Law of the Workplace," *Brooklyn Law Review* 69 (2003): 91-162. Legislative efforts continue. See H.R. 493, S. 358, 110th Cong. (2007).
 19. Dodge and Christianson significantly over-read our definition of genetic testing. See J. H. Dodge and D. Christianson, "Genetic Testing and Disability Insurance: An Alternative Opinion," *Journal of Law, Medicine & Ethics* 35, no. 2, Supplement (2007): 33-35. Many genetic tests, such as the test most commonly used for Tay-Sachs, evaluate protein levels but directly reveal a genetic disorder. Thus, our definition does not threaten to include all health tests.
 20. L. Andrews and E. S. Zuiker, "Ethical, Legal, and Social Issues in Genetic Testing for Complex Genetic Disease," *Valparaiso University Law Review* 37 (2003): 793-829.
 21. *EEOC v. Burlington Northern Santa Fe Ry. Co.*, No. 02-C-0456 (E. D. Wisc. 2002); M. McDonough, "EEOC Reaches \$2.2 Million Settlement with Railroad," *ABA Journal E-Report* 1, no. 21 (May 31, 2002).
 22. See Hall and Rich, *supra* note 1; Office of Technology Assessment, *supra* note 1. For contrasting views see, for example, N. E. Kass et al., "Medical Privacy and the Disclosure of Personal Medical Information: The Beliefs and Experiences of Those with Genetic and Other Clinical Conditions," *American Journal of Medical Genetics* 128A (2004): 261-270; NCD Position Paper, *supra* note 12.
 23. See N. A. Holtzman, "Are Genetic Tests Adequately Regulated?" *Science* 286 (1999): 409; A. Huang, "FDA Regulation of Genetic Testing: Institutional Reluctance and Public Guardianship," *Food and Drug Law Journal* 53 (1998): 555-591.
 24. See generally M. A. Rothstein and S. Hoffman, "Genetic Testing, Genetic Medicine, and Managed Care," *Wake Forest Law Review* 34 (1999): 849-888.
 25. See generally M. A. Rothstein, "Genetic Privacy and Confidentiality: Why They Are So Hard to Protect," *Journal of Law, Medicine & Ethics* 26, no. 3 (1998): 198-203; Rothstein and Hoffman, *supra* note 24, at 857; see M. A. Rothstein, "Why Treating Genetic Information Separately Is a Bad Idea," *Texas Review of Law and Politics* 4 (1999): 33-37; T. Lemmens, "Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws?" *McGill Law Journal* 45 (2000): 347-412; L. O. Gostin and J. G. Hodge, Jr., "Genetic Privacy and the Law: An End to Genetics Exceptionalism," *Jurimetrics* 40 (1999): 21-32; M. A. Rothstein, "Genetic Exceptionalism and Legislative Pragmatism," *Journal of Law, Medicine & Ethics* 35, no. 2, Supplement (2007): 59-65. Rothstein maintains that genetic exceptionalism is poor public policy since genetics-specific laws can work to reinforce the stigma of genetic disorders by treating them differently from other conditions. Further, he argues that the social stigma associated with genetic information stems in large part from unfamiliarity with its widespread use, and thus he conjectures that the public's unique fear of genetic information will dissipate over time as it becomes more common on the medical charts of all patients.
 26. N. Kass and A. Medley, "Genetic Screening and Disability Insurance: What Can We Learn From The Health Insurance Experience?" *Journal of Law, Medicine & Ethics* 35, no. 2, Supplement (2007): 65-72. State legislatures and regulators as well as insurance companies themselves have often considered restricting underwriting and actuarial practice to pursue public policy goals. See, e.g., Soule, *supra* note 9, at 251-52.
 27. E. M. Holmes, "Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project," *Kentucky Law Journal* 85 (1996-97): 503-663; E. Draper, "The Screening of America: The Social and Legal Framework of Employers' Use of Genetic Information," *Berkeley Journal of Employment and Labor Law* 20 (1999): 298-324; P. S. Miller, "Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace," *Journal of Health Care Law and Policy* 3 (2000): 226-265; H. R. Watterson, "Genetic Discrimination in the Workplace and the Need for Federal Legislation," *DePaul Journal of Health Care Law* 4 (2001): 423-448.
 28. See, e.g., D. Hellman, "What Makes Genetic Discrimination Exceptional?" *American Journal of Law & Medicine* 29 (2003): 77-116; H. T. Greely, "Genotype Discrimination: The Complex Case for Some Legislative Protection," *University of Pennsylvania Law Review* 149 (2001): 1483-1505; M. A. Rothstein, "Predictive Genetic Testing for Alzheimer's Disease in Long-Term

- Care Insurance," *Georgia Law Review* 35 (2001): 707-733; see Rothstein, "Genetic Exceptionalism and Legislative Pragmatism," *supra* note 25. Despite Rothstein's overarching criticisms of genetic exceptionalism, at the conclusion of his article in this symposium, Rothstein admits that enacting genetics-specific laws may be necessary and appropriate under certain limited conditions. He says that genetics-specific laws may have some pragmatic value, so long as: (1) there is some true value to the law, in that there is a demonstrated need for the legislation and it can be shown that the proposed legislation will resolve one or more aspects of the problem; (2) the law is carefully drafted to avoid any negative, unintended consequences to third parties, such as employers and insurers; (3) enactment of the genetics-specific law does not delay the enactment of legislation better designed to promote broader public policies, such as the role of predictive health information in society; and (4) there is recognition among legislators and the public that the law is not ideal, but rather the best that can be achieved at the moment.
29. E. J. Vaughan and T. M. Vaughan, *Fundamentals of Risk and Insurance, Health Insurance: Disability Insurance*, 8th ed. (New York: John Wiley, 1999): at 356.
 30. *Id.*; see also Unum, "Specimen Insurance Policy: Lifelong Disability Protection (New Jersey) No. LA R000000," issued to John A. Doe, July 1, 1995, effective July 1, 1995, at 8 (on file with authors) [hereinafter cited as Unum, Lifelong Disability Protection]; Unum, "Specimen Insurance Policy: Income Series; Individual Income Protection Insurance (Form 600 & 601) No. 123456789," issued to John A. Doe, effective January 1, 2000, at 10 (on file with authors) [hereinafter cited as Unum, Individual Income Protection]; Unum, "Specimen Contract: Group Short Term Disability and Group Long Term Disability Income Protection Plans, No. 123456," issued to ABC Company, effective March 1, 2000: at STD-BEN-1, LTD-BEN-1 (on file with authors) [hereinafter cited as Unum, Group Short and Long Term Disability Income Protection]; "Provident Life and Accident: Specimen Insurance Policy: Accident Disability Income Policy, No. 66-475-999999," issued to John Provident, December 28, 1997, effective January 1, 1998, at 5 (on file with authors) [hereinafter cited as Provident, Accident Disability Income]; Lutheran Brotherhood, "Sample Insurance Policy: Business Overhead Expense, No. H0012345," issued to John Doe, June 1, 1996; at 5 (on file with authors) [hereinafter cited as Lutheran Brotherhood, Business Overhead Expense]; Lutheran Brotherhood, "Sample Insurance Policy: Disability Income, No. H0012345," issued to John Doe, June 1, 1996, at 5 (on file with authors) [hereinafter cited as Lutheran Brotherhood, Disability Income].
 31. See Vaughan and Vaughan, *supra* note 29.
 32. American Council of Life Insurers, *Life Insurers Fact Book, 2001* (Washington, D.C.: ACLI, 2000): 137. "In 1995, disability insurers paid over \$5 billion in claims to group policy holders and over \$3 billion in claims to individual policy holders." Health Insurance Institute, *Sourcebook of Health Insurance Data 1999-2000* (New York: Health Insurance Institute): at 159.
 33. See Soule, *supra* note 9, at 60-61, 94.
 34. For a discussion of adverse selection, see generally S. J. Chandler, "Visualizing Adverse Selection: An Economic Approach to the Law of Insurance Underwriting," *Connecticut Insurance Law Journal* 8 (2001-2002): 435-503; T. Baker, "Containing the Promise of Insurance: Adverse Selection and Risk Classification," *Connecticut Insurance Law Journal* 9 (2002-2003): 371-396; A. Stark, "The Double Irony of Health-Insurance Regulation," *Society* 40, no. 5 (2003): 28-35; P. Siegelman, "Adverse Selection in Insurance Markets: An Exaggerated Threat," *Yale Law Journal* 113 (2004): 1223-1280.
 35. See Abraham and Liebman, *supra* note 5, at 84.
 36. See Provident, Accident Disability Income, *supra* note 30, at 1.
 37. See, e.g., Lutheran Brotherhood, Disability Income, *supra* note 30, at 10 (occupational sickness or injury not included in "exceptions and limitations").
 38. See, e.g., Group Short and Long Term Disability Income Protection, *supra* note 30, at STD-BEN-4 ("Your plan does not cover any disabilities caused by, contributed by, or resulting from your occupational sickness or injury.")
 39. *Id.*, at LTD-BEN-3, 4 ("Unum will subtract from your gross disability payment the following deductible sources of income: ...The amount that you, your spouse and children receive or are entitled to receive as disability payments because of your disability under the United States Social Security Act.")
 40. However, on health insurance, see Hall and Rich, *supra* note 1; Rothstein and Hoffman, *supra* note 24, at 866.
 41. See, e.g., N. J. Shaheen, "Insurance, Employment, and Psychosocial Consequences of a Diagnosis of Hereditary Hemochromatosis in Subjects without End Organ Damage," *American Journal of Gastroenterology* 95 (2003): 1175-1180; M. A. Rothstein and C. A. Hornung, "Public Attitudes," in M. A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy*, (Cambridge: MIT Press, 2004): 1-25; see also J. Norum and L. Tranebjaerg, "Health, Life, and Disability Insurance and Hereditary Risk for Breast or Colorectal Cancer," *Acta Oncologica* 39 (2000): 189-193, at 189.
 42. American Academy of Actuaries, *The Use of Genetic Information in Disability Income and Long-Term Care Insurance*, Issue Brief 7, 2002, available at <http://www.actuary.org/pdf/health/genetic_25apr02.pdf> (last visited February 21, 2007).
 43. *Id.*, at 8.
 44. See 42 U.S.C. §300gg (2006); *supra* note 14 (listing state statutes that address limits in the context of disability insurance).
 45. E. Wessling, "Contracts: Applying the Plain Language to Incontestability Clauses," *William Mitchell Law Review* 27 (2000): 1253-1271, at 1256.
 46. *Id.* (noting that in some jurisdictions even fraud discovered after the contestability period expires will not void a policy).
 47. See, e.g., *Ark. Blue Cross & Blue Shield, Inc. v. Doe*, 733 S.W.2d 429 (Ark. 1987); *Hess v. Allstate Ins. Co.*, Civ. No. 99-384-P-C, 2000 U.S. Dist. Lexis 12258, at *13 (D. Me. Aug. 2, 2000); *Pelletier v. Fleet Fin. Group*, NH Civ. No. 99-245-B, Me Civ. No. 99-CV-146-PH, 2000 U.S. Dist. Lexis 16456, at *17 (D.N.H. September 19, 2000).
 48. See J. M. Zitter, "What Constitutes Mental Illness or Disorder, Insanity, or the Like, within Provision Limiting or Excluding Coverage under Health or Disability Policy," *American Law Reports 5th* 19 (Lawyers Cooperative Publishing, 1994): 533-562, §1; see also Unum, "Lifelong Disability Protection," *supra* note 30, at 11; Unum, "Group Short and Long Term Disability Income Protection," *supra* note 30, at LTD-BEN-6; Lutheran Brotherhood, "Disability Income," *supra* note 30, at 10.
 49. See S. F. Befort, "Mental Illness and Long-Term Disability Plans under the Americans with Disabilities Act," *University of Pennsylvania Journal of Labor & Employment Law* 2 (1999): 287-302, at 289; see also *El-Hajj v. Fortis Benefits Ins. Co.*, 156 F. Supp. 2d 27 (D. Me. 2001).
 50. See *Fitts v. Fed. Nat'l Mortgage Ass'n*, 191 F. Supp. 2d 67, 70 (D.D.C. 2002); *Hess*, 2000 U.S. Dist. Lexis 12258, at *25; *Attar v. Unum Life Ins. Co.*, Ca-3-96-Cv-0367-R, 1997 U.S. Dist. Lexis 23254 (N.D. Tex. July 19, 1997).
 51. *Ark. Blue Cross and Blue Shield*, 733 S.W.2d 429.
 52. See *Hess*, 2000 U.S. Dist. LEXIS 12258, at 22.
 53. See Unum, "Group Short and Long Term Disability Income Protection," *supra* note 30, at Glossary-3; Unum, "Lifelong Disability Protection," *supra* note 30, at 12; Unum, "Individual Income Protection," *supra* note 30, at 8; Lutheran Brotherhood, "Business Overhead Expense," *supra* note 30, at 4; Lutheran Brotherhood, "Disability Income," *supra* note 30, at 4.
 54. For charts comparing state statutes, see the National Conference of State Legislatures, *Genetics and Life, Disability and Long-Term Care Insurance*, available at <<http://www.ncsl.org/programs/health/genetics/ndislife.htm>> (last visited February 21, 2007); National Conference of State Legislatures, *State Genetics Employment Laws*, available at <<http://www.ncsl.org/programs/health/genetics/ndiscrim.htm>> (last visited February 21, 2007).
 55. See American Academy of Actuaries, *supra* note 42, at 56.
 56. *Id.*, at 7.

57. *Id.*, at 2.
58. See *supra* note 54 (listing the statutes cited in this paragraph).
59. Ariz. Rev. Stat. § 20-448 (2006); Cal. Ins. Code §§10146-10149.1 (2006); Kan. Stat. Ann. §40-2259(d) (2005); Me. Rev. Stat. Ann. tit. 24, § 2159-C (West 2006); Mont. Code Ann. § 33-18-206 (2005); N.J. Stat. § 17B:30-12 (2006); N.M. Stat. Ann. §24-21-4 (2006); N.Y. Ins. Law. §§ 2613, 2615 (McKinney 2006); Or. Rev. Stat §§ 746.135, 192.531 (2005); Vt. Stat. Ann. tit. 18 § 9332 (2005); Wis. Stat. § 631-89(3) (2005).
60. See Daniels, *supra* note 5, at 133-140.
61. See American Academy of Actuaries, *supra* note 42, at 9.
62. See American Council of Life Insurers, *supra* note 32, at 137-142.
63. 42 U.S.C. § 300gg-1(a)(1) (2006).
64. Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. (2005). Although passed by the Senate in February 2005, the House failed to take action on this bill, thus allowing the bill to die with the closing of the 109th Congress in December 2006. The Senate's bill closely followed two bills proposed in the 108th Congress: Genetic Information Nondiscrimination Act of 2003, S.1053, 108th Cong., 1st Sess. (2003), and Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 1910, 108th Cong., 1st Sess. (2003). On H.R. 493 and S: 358, see note 18, *supra*.
65. See American Council of Life Insurers, *supra* note 32, at 139-141 (discussing short- and long-term disability plans and their coverage); Abraham and Liebman, *supra* note 5, at 81-82; Ken McDonnell et al., *EBRI Databook on Employee Benefits* (Washington, DC: Employee Benefit Research Institute, 1997): at 29-30.
66. See McDonough, *supra* note 21; E. Draper, "The Screening of America: The Social and Legal Framework of Employers' Use of Genetic Information," *Berkeley Journal of Employment & Labor Law* 20 (1999): 286-324 (stating that employers use genetic testing to eliminate high risks rather than making the environment safer for all).
67. See Soule, *supra* note 9, at 60-61.
68. See Unum, "Individual Income Protection," *supra* note 30, at 9; see also Provident, Accident Disability Income, *supra* note 30, at 7 ("Pre-existing Condition means a sickness or physical condition which, before the Effective Date of this policy, either: 1) results in your receiving medical advise or treatment; or 2) caused symptoms for which an ordinarily prudent person would have sought medical advise or treatment.")
69. See Unum, "Group Short and Long Term Disability Income Protection," *supra* note 30, at Glossary-3.
70. See, e.g., *Fath v. UNUM*, 928 F. Supp. 1147, 1149 (M.D. Fla. 1996).
71. See *McCorkle v. Life Gen. Sec. Ins. Co.*, 830 F. Supp. 1446 (M.D. Fla. 1993) (absence of recorded diagnosis of illness prior to commencement of policy is irrelevant in determining applicability of pre-existing condition exclusion); *Kirk v. Provident Life & Accident Ins. Co.*, 942 F.2d 504, 506 (8th Cir. 1991) (coverage denied where symptoms were present prior to the effective date of policy but were insufficient to allow an accurate diagnosis at that time).
72. *Haley v. Paul Revere Life Ins. Co.*, 77 F.3d 84, 90 (4th Cir. 1996).
73. See Unum, "Group Short and Long Term Disability Income Protection," *supra* note 30, at LTD-BEN-1.
74. See *id.*, at Glossary-4; see also Soule, *supra* note 9, at 243-44.
75. See text and state statutes, *supra* note 59.
76. 42 U.S.C. § 300gg(b)(1)(B) (2006).
77. 42 U.S.C. § 12112(d)(3) (2006); 29 C.F.R. §1630.14(b) (2006).
78. See M. A. Rothstein, "Genetics and the Workforce of the Next Hundred Years," *Columbia Business Law Review* 2000, no. 3 (2000): 371-402, at 387; see also NCD Position Paper, *supra* note 12; Congressional Research Service, *Genetic Information: Legal Issues Relating to Discrimination and Privacy*, Report, no. RL30006, July 19, 2001, at 13.
79. Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, Department of Justice, *Genetic Information and the Workplace*, January 20, 1998 [hereinafter cited as DOL Joint Report].
80. See 42 U.S.C. § 12102(2)(B) (2006) ("The term 'disability' means, with respect to an individual (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such an impairment; or (c) being regarded as having such an impairment.")
81. See *EEOC Compliance Manual 3* (March, 1995): 902-945.
82. S. 306, 109th Cong. (2005). Although passed unanimously by the Senate in February 2005, the House's failure to take action on this bill resulted in its loss of active status at the close of the 109th Congress. On more recent efforts, see note 18, *supra*.
83. Exec. Order No. 13,145, 65 Fed. Reg. 6877 (2000).
84. See *supra* note 54 (listing the National Conference of State Legislatures Genetics Tables).
85. M. A. Rothstein, B. D. Gelb, and S. G. Craig, "Protecting Genetic Privacy by Permitting Employer Access Only to Job-Related Employee Medical Information: Analysis of a Unique Minnesota Law," *American Journal of Law & Medicine* 24 (1998): 399-416.
86. Ariz. Rev. Stat. Ann. § 41-1463 (2006); Ark. Code Ann. §§ 11-5-403, 405 (2006) (exempts all insurers from anti-discrimination statute); Cal. Gov't. Code §§ 12926, 12940 (2006); Conn. Gen. Stat. § 46a-60 (2006); Del. Code Ann. Tit. 19, §§ 710-711 (2006); Haw. Rev. Stat. §§ 378-1, 2 (2005); Iowa Code § 729.6 (2006); Kan. Stat. Ann. §§ 44-1002, -1009 (2005); La. Rev. Stat. Ann. §§ 23:302, 23:368 (2006); Me. Rev. Stat. Ann. Tit 5, §§ 19301, 19302 (2006); Md. Ann. Code Art. 49B, §§ 15, 16 (2006); Mass. Gen. Laws Ch. 151B, §§1, 4 (2006); Mich. Comp. Laws §§ 37.1202 (2006) (exception if to protect worker safety); Nev. Rev. Stat. § 613.345 (2006); N.H. Rev. Stat. Ann. § 141-H:3 (2006); N.J. Stat. Ann. §§ 10:5-5, 10:5-12 (West 2006); N.Y. Civ. Rights Law §§ 48, 48-A (Consol. 2006) (only for Sickle Cell, Tay-Sachs, or Cooley's Anemia), N.Y. Exec. Law §§ 292, 296 (Consol. 2006) (permitting the employer to require test for susceptibility to known risk); N.C. Gen. Stat. § 95-28.1A (2006); Okla. Stat. Tit 36, § 3614.2 (2006); Or. Rev. Stat. § 659A.303 (2005); R.I. Gen. Laws §§ 28-6.7-1, 28-6.2.1, 28-6.7-3 (2005); S.D. Codified Laws §§ 60-2-20, 60-2-21 (2006); Tex. Lab. Code Ann. §§ 21.401, .402 (Vernon 2006); Utah Code Ann. §26-45-103 (2006) (except employer can get a court order compelling disclosure under certain circumstances such as when the health of a person poses a safety risk or when need outweighs one's privacy interest); Vt. Stat. Ann. Tit. 18, § 9333 (2005); Va. Code Ann. § 40.1-28.7:1 (2006); Wis. Stat. §§ 111.372, 111.32 (2005).
87. Iowa Code § 729.6 (2006) (testing for susceptibility or for workers' compensation purposes, only if employee requests); Mich. Comp. Laws §§ 37.1202 (2006) (can submit voluntarily and employer can use to protect worker's safety); N.H. Rev. Stat. Ann. § 141-H:3 (2006) (employee can request for purposes of workers' compensation or susceptibility and cannot be fired for results of tests); N.Y. Exec. Law §§ 292, 296 (Consol. 2006) (employee can test voluntarily for workers' compensation or susceptibility purposes or for other civil litigation); Okla. Stat. Tit. 36, § 3614.2 (2006) (can use testing for determination of coverage or benefits for all forms of insurance); Utah Code Ann. § 26-45-103 (2006) (can get court order for purposes of an administrative proceeding in which employee has placed his or her health at issue); Wis. Stat. §§ 111.372, 111.32 (2005) (employee can request genetic information for workers' compensation or susceptibility purposes).
88. Okla. Stat. Tit. 36, § 3614.2 (2006).
89. See, for example., N.H. Rev. Stat. Ann. § 141-H:3 (2006); Okla. Stat. Tit 36, § 3614.2 (2006); Vt. Stat. Ann. Tit. 18, § 9333(B) (2005).
90. N.H. Rev. Stat. Ann. § 141-H:3 (2006).
91. See H.R. 1227, 109th Cong. (2005); S. 306, 109th Cong. (2005); H.R. 1910, 108th Cong. (2003); S. 1053, 108th Cong. (2003); S. 16, 108th Cong. (2003); H.R. 602, 107th Cong. (2001); S.

- 1995, 107th Cong. (2001); S. 318, 107th Cong. (2001); H.R. 306, 106th Cong. (1999); H.R. 293, 106th Cong. (1999); H.R. 2457, 106th Cong. (1999); S. 543, 106th Cong. (1999); S. 1322, 106th Cong. (1999); H.R. 306, 105th Cong., 1st Sess. (1997); H.R. 2215, 105th Cong., 1st Sess. (1997); H.R. 341, 105th Cong. 1st Sess. (1997); S. 422, 105th Cong. 1st Sess. (1997); S. 89, 105th Cong. 1st Sess. (1997). On more recent efforts, see note 18, *supra*.
92. E. A. Draper, "Social Issues of Genome Innovation and Intellectual Property," *Risk* 7 (1996): 201-229, at 212; T. H. Murray, "Genetic Testing at Work: How Should It Be Used?" *Technology Review* 88 (1985): 51-59, at 54-55; see also DOL Joint Report, *supra* note 79, at 3. For data on corporate use of genetic screening, see Office of Technology Assessment, *supra* note 1, at 11-20.
93. See Murray, *supra* note 92, at 56-58; see also DOL Joint Report, *supra* note 79, at 3. For data on corporate use of genetic monitoring, see Office of Technology Assessment, *supra* note 1, at 35-45. Testing typically refers to use of genetic tests on individuals, while screening typically refers to use of tests on groups or populations. Either could be used in a workplace.
94. See Draper, *supra* note 92, at 212.
95. See Murray, *supra* note 92, at 54.
96. *Chevron U.S.A. v. Echazabal*, 536 U.S. 73 (2002).
97. L. M. Pesonen, Comment, "Genetic Screening: An Employer's Tool to Differentiate or to Discriminate?" *Journal of Contemporary Health Law and Policy* 19 (2002): 187-223, at 220-21; M. Barnes et al., "*Chevron v. Echazabal*: Public Health Issues Raised by the 'Threat-to-Self' Defense to Adverse Employment Actions," *American Journal of Public Health* 93 (2003): 536-540, at 537.
98. See Barnes et al., *supra* note 97, at 537.
99. N. Daniels, "*Chevron v. Echazabal*: Protection, Opportunity, and Paternalism," *American Journal of Public Health* 93 (2003): 545-548, at 548.
100. See Barnes et al., *supra* note 97, at 536-539.
101. *Id.*
102. See Pesonen, *supra* note 97, at 220-221.
103. See, e.g., *Int'l Union, UAW v. Johnson Controls*, 499 U.S. 187, 209 (1991).
104. See, e.g., P. Billings and J. Beckwith, "Genetic Testing in the Workplace: A View from the U.S.A.," *Trends in Genetics* 8, no. 6 (1992): 198-202; J. M. Eggen, "Toxic Reproductive and Genetic Hazards in the Workplace: Challenging the Myths of the Tort and Workers' Compensation System," *Fordham Law Review* 60 (1992): 843-912; M. S. Yesley, "Genetic Difference in the Workplace," *Jurimetrics* 40 (1999): 129-142.
105. See *Chevron U.S.A. v. Echazabal*, 536 U.S. 73, 84-85 (2002); Daniels, *supra* note 99, at 546-48; J. Weems, "A Proposal for a Federal Genetic Privacy Act," *Journal of Legal Medicine* 24 (2003): 109-126.
106. See P. V. Fishback and S. E. Kantor, "The Adoption of Workers' Compensation in the United States," *Journal of Law and Economics* 41 (1998): 305-336, at 306; J. T. A. Gabel, N. R. Mansfield, and R. W. Klein, "The New Relationship Between Injured Worker and Employer: An Opportunity for Restructuring," *American Business Law Journal* 35 (1998): 403-442, at 403; R. A. Epstein, "The Historical Origins and Economic Structure of Workers' Compensation Law," *Georgia Law Review* 16 (1982): 775-819, at 800; see also A. Larson and L. K. Larson, *Larson's Workers' Compensation Law*, vol. 1 (New York: Matthew Bender, 2002) § 100.01.
107. See Fishback and Kantor, *supra* note 106, at 45.
108. See Larson and Larson, *supra* note 106 at vol. 1, § 1.01, vol. 2, § 42.02, vol. 3 §, 52.07, vol. 4, § 80.01.
109. *Id.*, at vol. 1, § 4.04.
110. *Id.*, § 1.01.
111. L. R. Russ, T. F. Segalla, and G. J. Couch, "Workers' Compensation: Introduction," in *Couch on Insurance*, 3rd ed. (St. Paul, MN: West Group, 1997): § 133.17.
112. See Larson and Larson, *supra* note 106, at vol. 3, § 52.01. But other states, such as West Virginia, have incorporated occupational disease into the statute's definition of "injury." See W. Va. Code § 23-4-1 (2003).
113. J. V. Nackley, *Primer on Workers' Compensation*, 2nd ed. (Washington, D.C.: Bureau of National Affairs, 1989): at 23.
114. See, e.g., *Nelson v. Ponsness-Warren Idgas Enter.*, 126 Idaho 129 (1994); *Duval v. ICI Ams.*, 621 N.W. 2d 1122 (Ind. Ct. App. 1993).
115. See Epstein, *supra* note 106, at 809; Gabel, Mansfield, and Klein, *supra* note 106, at 409.
116. See Larson and Larson, *supra* note 106, at vol. 1, § 2.08.
117. See Soule, *supra* note 9, at 45.
118. *Id.*, at 45-46.
119. See McDonnell et al., *supra* note 65, at 423.
120. See, e.g., Federal Employers' Liability Act (FELA), 45 U.S.C. § 51 *et seq.* (2006); Longshoremen's and Harbor Workers' Act, 33 U.S.C. § 901 *et seq.* (2006); Federal Employees Compensation Act, 5 U.S.C. § 8101 *et seq.* (2006).
121. This is to be distinguished from legal cause or proximate cause, as lawyers usually refer to it, since Workers' Compensation is not concerned with culpability. Causation for Workers' Compensation purposes is more like "connection to the work." See Larson and Larson, *supra* note 106, at vol. 1, § 1.03.
122. See *id.*, at vol. 1, § 90.02; see also, e.g., *Sisbro v. Indus. Comm'n*, 797 N.E.2d 665, 672 (Ill. 2003) ("It is axiomatic that employers take their employees as they find them. When workers' physical structures, diseased or not, give way under the stress of their usual tasks, the law views it as an accident arising out of and in the course of employment."); *Peitz v. Indus. Accident Bd.*, 264 P.2d 709, 712 (Mont. 1953) ("[I]t is a fundamental principle that the employer takes the employee subject to his physical condition at the time he enters employment."); *Marshall v. C.F. Mueller Co.*, 50 A.2d 158, 160 (N.J. 1946) ("The employer takes his employees with their mental, emotional, glandular and other physical defects or disabilities."); *Hamilton v. Keller*, 229 N.E.2d 63, 68 (Ohio Ct. App. 1967); *Rogers v. Shaw*, 813 S.W.2d 397, 399 (Tenn. 1991) ("It is axiomatic that the employer takes the employee as he is, that is, with his defects and pre-existing conditions."); *Swift & Co. v. Howard*, 212 S.W.2d 388, 391 (Tenn. 1948); *Wheeler v. Supervalu*, 2002 IA Wrk. Comp. LEXIS 144, *20-*21 (Mar. 15, 2002) (McManus, Jr., Arb.) ("The employer takes the employee 'as is' and, therefore, takes him subject to any active or dormant health impairment...[T]he duty of 'exercising care to avoid injury to the weak and infirm is precisely the same as toward the strong and healthy....'" (quoting *Hanson v. Dickinson*, 188 Iowa 728, 732 (1920)).
123. See Larson and Larson, *supra* note 106, at vol. 1, § 9.02; see also *Wheeler*, 2002 IA Wrk. Comp. LEXIS 144, at *20-*21.
124. See Larson and Larson, *supra* note 106, at vol. 5, § 91.01. ("It has been said...that within the thirty days following the announcement of the non-apportionment rule in *Nease v. Hughes Stone Company*, between seven and eight thousand one-eyed, one-legged, one-armed, and one-handed workers were displaced in Oklahoma.")
125. *Id.*
126. *Id.*
127. See, e.g., *Deyonge v. Nana/Marriot*, 1 P.3d 90, 98 (Alaska 2000) (addressing whether work was a substantial factor in aggravating claimant's pre-existing arthritis); Scholl, No. 1059419, 1998 IA Wrk. Comp. LEXIS 307, *6 (November 30, 1998) (addressing whether bunion, described by physician as a genetic condition, was substantially caused by the work); *Holmes v. Bruce Motor Freight*, 215 N.W.2d 296, 297 (Iowa 1974). ("The claimant has the burden of proving by a preponderance of the evidence that some employment incident or activity brought about the health impairment on which he bases his claim. A possibility is insufficient; a probability is necessary.")
128. See, e.g., *Dept. of Corr. v. Workers Comp. App. Bd.*, 64 Cal. Comp. Cas. 1356, *12 (Cal. Ct. App. Dec. 2, 1999).
129. *Wis. Comp. Rating & Inspection Bureau v. Mortensen*, 277 N.W. 679 (Wis. 1938).

130. See, e.g., *Short*, AWCB Case No. 9103418, 1996 AK Wrk. Comp. LEXIS 4056, at *24 (June 28, 1996); *Keller v. Wilson Foods Cont'l Deli*, No. 1-1034, 2002 Iowa App. LEXIS 704, at *8 (Iowa Ct. App. July 3, 2002); *Tee Jays Mfg. Co., Inc. v. Stults*, 723 So. 2d 684, 685 (Ala. Civ. App. 1998); *Brock & Blevins Inc. v. Cagle*, 775 So. 2d 824, 827 (Ala. Civ. App. 1999); *Kuikan*, no. 803877, 1993 IA Wrk. Comp. LEXIS 506, at *5 (May 27, 1993); *Sapp*, No. 1093703, 2000 IA Wrk. Comp. LEXIS 362, at *11 (July 17, 2000).
131. See cases cited at *supra* note 127.
132. See, e.g., *Kuiken*, 1993 IA Wrk. Comp. LEXIS 506; *Sapp*, 2000 IA Wrk. Comp. LEXIS 362.
133. See *Brock & Blevins Inc.*, 775 So. 2d 824.
134. See *Meihost v. Weyerhaeuser Co.*, no. 1168621, 1999 IA Wrk. Comp. 244, at *3 (September 22, 1999) (Mormann, Arb.) (finding that claimant failed to prove by a preponderance of the evidence that he incurred a work-related and noise-induced hearing loss after the date the employer purchased assets of his former employer and formed a new employer-employee relationship with claimant); *Grundmeyer v. Weyerhaeuser Co.*, no. 1168507, 1999 IA Wrk. Comp. LEXIS 650, at *6 (September 22, 1999) (Mormann, Arb.) (evidence supported finding that employee did not suffer any hearing loss after point that employer purchased box factory).
135. See *Sapp*, 2000 IA Wrk. Comp. LEXIS 362.
136. *Id.*
137. See *Short*, AWCB Case No. 9103418, 1996 AK Wrk. Comp. LEXIS 4056, at *24 (June 28, 1996).
138. See *Scholl*, No. 1059419, 1998 IA Wrk. Comp. LEXIS 307 (Nov. 30, 1998).
139. See *Deyonge v. Nana/Marriot*, 1 P.3d 90 (Alaska 2000); *Brock and Blevins Inc.*, 775 So. 2d 824.
140. See, e.g., S.C. Code Ann. § 38-93-20 (2005) (excluding Workers' Compensation from the restrictions placed on insurers' use of genetic information); Utah Code Ann. § 26-45-103 (2006) (can get court order for purposes of an administrative proceeding in which employee has placed his or her health at issue).
141. Iowa Code § 729.6 (2006) (testing for susceptibility or for Workers' Compensation purposes only if employee requests); N.H. Rev. Stat. Ann. §141-H:3 (2006) (employee can request for purposes of Workers' Compensation or susceptibility and cannot be fired for results of tests); N.Y. Exec. Law § 292, 296 (McKinney 2006) (employee can do it voluntarily with specific written informed consent for Workers' Compensation or susceptibility purposes or other civil litigation); Wis. Stat. §§ 111.372, 111.32 (2005) (employee can request genetic information for Workers' Compensation or susceptibility purposes).
142. Americans with Disabilities Act, Pub. L. No. 101-336, § 102(c)(2)(A), 104 Stat. 327, 332 (1990) (codified as amended at 42 U.S.C. § 12112 (2006)).
143. 29 C.F.R. pt. 1630, app. at 381 (2006) (Interpretive Guidance on Title I of the Americans with Disabilities Act, § 1630.14(b)); see also Larson and Larson, *supra* note 106, at vol. 5, § 91.03.
144. See Social Security Amendments of 1956, Pub. L. No. 84-880, § 103, 70 Stat. 807, 815; Nat'l Org. of Social Security Claimants' Representatives, *Social Security Practice Guide*, vol. 1, § 9.02 (New York: Matthew Bender, 2002) [hereinafter cited as *Social Security Practice Guide*].
145. See *Social Security Practice Guide*, *supra* note 144, at vol. 1, § 9.02.
146. *Id.*
147. See Social Security Administration, *A Brief History of Social Security* (Baltimore, MD: Social Security Administration, 2000): at 10, available at < <http://www.ssa.gov/history/pdf/2005pamphlet.pdf>> (last visited February 23, 2007); *Social Security Practice Guide*, *supra* note 144, at vol. 1, § 9.02.
148. 42 U.S.C. §423(d)(1)(A) (2006); see also 20 C.F.R. §§ 404.1505, 416.905 (2006).
149. See *Social Security Practice Guide*, *supra* note 144, at vol. 1, § 9.02[1], vol. 1, § 9.03[5].
150. *Id.*, at vol. 1, § 9.02[1]. ("The purpose of this amendment is unclear, except as a bar to the finding of disability where a claimant refuses to assist or tries to block the Social Security Administration in obtaining medical reports on himself. This has never been a significant problem in Social Security disability claims.")
151. Contract with America Advancement Act of 1996, Pub. L. No. 104-121, 110 Stat. 847 (1996). Although alcoholism is a disability under the ADA, it is specifically excluded from coverage under Title II and Title XVI, the two federal programs that pay benefits to disabled individuals. The SSA has a long history of hostility to the idea that alcoholics are disabled for the purposes of the Social Security Act. See J. K. Barlow, "Alcoholism as a Disability under the Social Security Act: An Analysis of the History, and Proposals for Change," *Journal of the National Association of Administrative Law Judges* 18 (1998): 273-302. In 1996 Congress eliminated alcoholism and drug addiction as bases for benefits under the Act. See Contract with America Advancement Act of 1996, Pub. L. No. 104-121, § 105 (a)(1)(c), 110 Stat. 847, 852-55. Congress enacted the 1996 amendments as Section 105 of former President Clinton's Contract with America Advancement Act. These amendments made it impossible for alcoholics or drug addicts to collect disability benefits unless there was some other medical basis for the application. Under the new provision, "an individual shall not be considered to be disabled for purposes of this subchapter if alcoholism or drug addiction would (but for this subparagraph) be a contributing factor material to the commissioner's determination that the individual is disabled." 42 U.S.C. § 423(d)(2)(C) (2006).
152. Supplemental Security Income; Determining Disability for a Child Under Age 18; Interim Final Rules With Request for Comments, 62 Fed. Reg. 6408, 6417 (Feb. 11, 1997) (codified at 20 C.F.R. pts. 404, 416). At present, a child will be found disabled under the Social Security Act if he "has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." 42 U.S.C. § 1382c (2006). This definition was changed as part of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105.
153. See B. Samuels and V. Fusco, *Social Security and SSI Disability* (New York: Practising Law Institute, 2001): at 29.
154. See *Social Security Practice Guide*, *supra* note 144, at vol. 1, § 9.02[2].
155. *Id.*, at vol. 2, § 13.01.
156. See M. Diller, "Entitlement and Exclusion: The Role of Disability in the Social Welfare System," *UCLA Law Review* 44 (1996): 361-465, at 431; National Organization of Social Security Claimants' Representatives Home Page, available at <<http://www.nosscr.org>> (last visited February 23, 2007).
157. See Disability Policy Panel Interim Report, J. L. Mashaw and V. P. Reno, eds., *The Environment of Disability Income Policy: Programs, People, History and Context* (Washington, D.C.: National Academy of Social Insurance, 1996): 13-29.
158. *Id.*
159. See Diller, *supra* note 156, at 440.
160. See *Social Security Practice Guide*, *supra* note 144, at vol. 1, §§ 608, 9.01[2][f].
161. See, e.g., 20 C.F.R. §§ 416.1331, 416.1338 (2006).
162. 42 U.S.C. §423(d)(1)(A) (2006); 20 C.F.R. §§404.1505, 416.905 (2006) (defining disability as the "inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months").
163. 20 C.F.R. pt. 404, subpt. P, app. 1 (2006) (Listing of Impairments); 20 C.F.R. pt. 416, subpt. I (2006).

164. See *Social Security Practice Guide*, *supra* note 144, at vol. 1, § 9.01[2].
165. See 20 C.F.R. §§ 404.1520, 416.920 (2006).
166. See 20 C.F.R. §§ 404.1508, 416.908 (2006).
167. See 20 C.F.R. § 404.1527 (2006).
168. See 20 C.F.R. pt. 404, subpt. P, app. 1 (2005) (listing the category of impairments).
169. 20 C.F.R. pt. 404, subpt. P, app. 1, sec 11.09 (2005).
170. 20 C.F.R. pt. 404, subpt. P, app. 1, sec 11.10 (2005).
171. See 20 C.F.R. §§ 404.1530, 416.930 (2005); see also *Johnson v. Bowen*, 864 F.2d 340, 348 (5th Cir. 1988) (referencing 20 C.F.R. §§ 404.1530, 216.930 for the proposition that “[i]f an impairment reasonably can be remedied or controlled by medication or therapy, it cannot serve as a basis for a finding of disability”); *Lewis v. Sec. of HHS*, 782 F. Supp. 56 (E.D. Tex. 1991) (citing *Johnson* for the proposition that an impairment that can be controlled by therapy or medication is not severe).
172. See 20 C.F.R. §§ 404.1512-1516, 416.912-916 (2005).
173. See *supra* note 163.
174. 20 C.F.R. pt. 404, subpt. P, app. 1, sec. 10.00B (2006).
175. *Id.*
176. *Id.*
177. *Id.*
178. *Id.*
179. See 20 C.F.R. pt. 404, subpt. P, app. 1, secs. 3.04, 103.04 (2006).
180. See *Garror v. Apfel*, Civ. 00-0250-RV-M, 2001 U.S. Dist. LEXIS (S.D. Ala. 2001); *Higgins v. Apfel*, 136 F. Supp. 2d 971 (E.D. Mo. 2001); *Rudder v. Chater*, 94 Civ. 8431, 1997 U.S. Dist. LEXIS 7703 (S.D.N.Y. 1997); *Simmons v. Chater*, 966 F. Supp. 241, 242 (S.D.N.Y. 1997).
181. See Revised Medical Criteria for Determination for Disability, Musculoskeletal System and Related Criteria, 66 Fed. Reg. 58,010, 58,023 (November 19, 2001) [hereinafter cited as Revised Medical Criteria].
182. See 20 C.F.R. § 404.1527(c)(3) (2006); see also *Warner v. Heckler*, 722 F.2d 428, 431(8th Cir. 1983); *Rudder*, 1997 U.S. Dist. LEXIS 7703.
183. See *Social Security Practice Guide*, *supra* note 144, at vol. 1, §13.01.
184. For litigation over date of onset, see *Kraemer v. Apfel*, 97 Civ. 8638, U.S. Dist. LEXIS (S.D.N.Y. Jan. 14, 1999) (myotonic dystrophy), *affirmed on reconsideration by Kraemer v. Apfel*, 97 Civ. 8638, U.S. Dist. LEXIS 1548 (S.D.N.Y. Feb. 10, 1999); *Sonda v. Bowen*, Civ. No. S85-411, U.S. Dist. LEXIS 19359 (N.D. Ind. July 29, 1988) (Alzheimer disease).
185. See Samuels and Fusco, *supra* note 153, at 13.
186. *Id.*
187. See, e.g., American Medical Association, Council on Ethical and Judicial Affairs, *Code of Medical Ethics* (Chicago: ABA Press, 2005): at E-2,138, *available at* <<http://www.ama-assn.org/ama/pub/category/8439.html>> (last visited February 23, 2007); A. Rosen, S. Wallenstein, and M. M. McGovern, “Attitudes of Pediatric Residents toward Ethical Issues Associated with Genetic Testing in Children,” *Pediatrics* 110 (2000): 360-363; American Academy of Pediatrics Committee on Genetics, “Molecular Genetic Testing in Pediatric Practice: A Subject Review,” *Pediatrics* 106 (2000): 1494-1496; American Academy of Pediatrics Committee on Bioethics, “Ethical Issues with Genetic Testing in Pediatrics,” *Pediatrics* 107 (2001): 1451-1455; J. G. Twomey, “Genetic Testing of Children: Confluence or Collision between Parents and Professionals?” *AACN Clinical Issues* 13 (2002): 557-566; E. Campbell and L. F. Ross, “Parental Attitudes Regarding Newborn Screening of PKU and DMD,” *American Journal of Medical Genetics* 120A (2003): 209-214; American Society of Clinical Oncology, “Policy Statement Update: Genetic Testing for Cancer Susceptibility,” *Journal of Clinical Oncology* 21 (2003): 2397-2406; C. C. Hook, E. P. DiMagna, and A. Tefferi, “Primer on Medical Genomics Part XIII: Ethical and Regulatory Issues,” *Mayo Clinic Procedure* 79 (2004): 645-650. For commentary on genetic testing for childhood-onset conditions, see L. F. Ross, “Predictive Genetic Testing for Conditions that Present in Childhood,” *Kennedy Institute of Ethics Journal* 12 (2002): 225-244.
188. See *Mitchell v. Apfel*, 19 F. Supp. 2d 523, 525 (W.D.N.C. 1998).
189. *Id.*
190. See Daniels, *supra* note 5; Rothstein, *supra* note 5.
191. Contemplating an extension of the regulatory framework of HIPAA to disability insurance, Robert Jerry has advocated for just this sort of reform, suggesting that the distinction between group and individual insurance might serve as the appropriate basis on which to draw a line between segments of the disability insurance market in which insurers can and cannot use genetic information. R. H. Jerry, II, “Life, Health and Disability Insurance: Understanding the Relationships,” *Journal of Law, Medicine & Ethics* 35, no. 2, Supplement (2007): 79-88.
192. See also Testimony of John W. Rowe, M.D., Chairman and CEO, Aetna, Inc., before the House Judiciary Subcommittee on the Constitution, September 12, 2002, *available at* <http://www.aetna.com/news/2002/pr_20020912.htm> (last visited February 23, 2007) (health plans should not determine eligibility based on genetic testing, “[r]equest or require genetic testing results as a condition to providing...coverage...[or] [u]se genetic testing for risk selection or risk classification”).