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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
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
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). The genetic variation at issue may be at the level of the nucleotide sequence comprising a gene 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 patterns, 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. 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. 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. 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, and data suggest that genetic tests are commonly misunderstood by both the lay public and health professionals. 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. 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 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.”

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. 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 of disability determine one’s training or the inability to work. 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 requiring 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. 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.” 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. 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.

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. 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.

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. 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

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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. 44 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. 45 Many disability policies offer only limited benefits for “mental disorders.” 46 (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.)

An insured may claim that the genetic basis of his or her disease is physical rather than mental. 46 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.” 47 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.” 48 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 antici-
sisted 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. 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. 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. 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. 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.

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. Forty-three states 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. The question is where should private disability insurance fit along this spectrum.
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). 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. 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 shoulder 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 genetic information 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 monogenic 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.

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.

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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. 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. 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. 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. 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. 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. 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.

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.

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. In the Path 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 Path case is not unique; the court cited other cases that had reached identical results. Path 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. 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.” “Sickness,” in turn, is defined as an illness or disease that “begins,” “first manifests,” or “first appears” while the contract is in force. 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. 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.”

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. 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.

Furthermore, ADA protection against discrimination based on asymptomatic genetic conditions remains unclear. 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. 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, 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.

An Executive Order issued by President Clinton in 2000 confined federal employers’ use of genetic testing and information. 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. Mark Rothstein and colleagues have praised a Minnesota statute that confines prospective employers from access to medical information relevant to job functions. 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. 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. Oklahoma law is even broader, allowing an employer to use genetic testing to determine insurance coverage or benefits.

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.60 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.”60 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.61 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’ Compensation 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.62 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.63 Genetic screening is gaining increasing favor with employers seeking to reduce operational costs.64 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. 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. 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. This indicates that exclusion would require a scientifically supported and direct connection between a genetic vulnerability and a predicted significant harm. Further, the Court unanimously upheld the importance of “individualized medical determinations of risk” requiring medical evidence of a connection to a current health risk. 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. 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.

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. *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. Some writers are now addressing the genetic risks. The prevalent recommendation, which we endorse, is that employers should be required to make the workplace safer for all, a stated goal of OSHA. 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. 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.

Workers’ Compensation provides benefits for injuries, illnesses, or death caused by a worker’s job. It also covers those illnesses that worsen due to work or the work environment. 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. State law requires employers to purchase insurance or to self-insure in order to cover Workers’ Compensation claims. 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. 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.” 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.

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. 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. Programs now provide up to two-thirds of a worker’s pre-disability income, but place a cap on benefit payments. This means that the system better covers the needs of low- and middle-income workers than others. Because Workers’ Compensation is a short-term solution, continued support must come from other sources, most likely SSDI and SSI, which are the federal disability programs discussed below.

Workers’ Compensation law differs by state. In addition, federal Workers’ Compensation statutes govern certain workplaces. However, the essential question under all statutes is whether work or disease caused the injury. 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. 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. 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.

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. 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. 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. 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. 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 alternatively 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-inflammatory medications 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.\textsuperscript{162} There is an extensive Listing of Impairments;\textsuperscript{163} if the disability is not listed, then the SSA will compare it with those listed.\textsuperscript{164} A five-step process governs disability determinations under both SSI and SSDI.\textsuperscript{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.\textsuperscript{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),\textsuperscript{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.\textsuperscript{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.”\textsuperscript{169} In contrast, diagnosis of Amyotrophic Lateral Sclerosis (ALS) will suffice when “established by clinical and laboratory findings.”\textsuperscript{270}

When a medication or treatment can correct a condition, the claimant will not be found disabled.\textsuperscript{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.\textsuperscript{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”).\textsuperscript{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.\textsuperscript{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.” An applicant with Mosaic Down syndrome will be evaluated according to the severity of the disease, which the SSA notes is highly variable. The Administration concedes that it may sometimes be difficult to find a chromosomal analysis performed on an individual if some time has passed. In this case, the Administration will pay for a test; 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. 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.

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, it is more important now to determine how an individual is functioning with treatment and use of technological advances. 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. 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. 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. 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. 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. 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. 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. 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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. 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.

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References


See Abraham and Liebman, supra note 5.


13. See Soule, supra note 9, at 44-45.
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 do not directly reveal a genetic disorder. Thus, our definition does not threaten to include all health tests.
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, he 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, rather the best that can be achieved at the moment.


31. See Vaughan and Vaughan, supra note 29.


33. See Soule, supra note 9, at 60-61, 94.


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.


43. Id. at 8-9.

44. See 42 U.S.C. §§ 300gg (2006); supra note 14 (listing state statutes that address limits in the context of disability insurance).


46. Id. (noting that in some jurisdictions even fraud discovered after the contestability period expires will not void a policy).


51. Ark. Blue Cross and Blue Shield, 733 S.W.2d 429.


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).
60. See Daniels, supra note 15, at 133-140.
62. See American Council of Life Insurers, supra note 32, at 137-142.
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.”).
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 (5th 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).”
74. See id., at Glossary-4; see also Soule, supra note 9, at 243-44.
75. See text and note supra, id., at 243-44.

131. See cases cited at supra note 127.


133. See Brock & Blevins Inc., 775 So. 2d 824.

134. See Melhost v. Weyerhauser Co., no. 168621, 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. Weyerhauser 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 at employer box factory).


136. Id.


139. See Degonge v. Nana/Marriott, 1 P.3d 90 (Alaska 2000); Brock and Blevins Inc., 775 So. 2d 824.


145. Id.

146. Id.


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.”)


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. § 1382e (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.


155. Id., at vol. 2, § 13.01.


158. Id.

159. See Diller, supra note 156, at 440.


162. 20 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”).

171. See 20 C.F.R. §§ 404.1530, 416.930 (2005); see also Johnson v. Bowen, 864 F.2d 340, 348 (5th Cir. 1988) (referring to 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 supra note 163.
173. See supra note 164.
175. Id.
176. Id.
177. Id.
178. Id.
186. Id.
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, and Disability Insurance: Understanding the Relationships,” Journal of Law, Medicine, 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”).