Predictive Genetic Testing: Congruence of Disability Insurers’ Interests with the Public Interest

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The idea that disability insurers would benefit if the use of predictive genetic testing expands may seem little short of obvious. If individuals with higher than species-typical genetic propensities for illness or disease are identified, and barred or discouraged from participating in disability insurance programs, is it not obvious that the amount that disability insurers pay out will decrease? Is there any reason to doubt that insurers thus would gain advantage by promoting genetic testing? Writers on this subject typically have taken on faith that advantage goes to whoever knows most about the genetic characteristics of the individual seeking insurance. They therefore have assumed, without proving, that insurers’ interests lie with proliferating genetic information about insurance seekers.

Consequently, from a perspective that gives priority to commercial interests, denying insurers the freedom to obtain genetic information about insurance seekers or holders appears obviously damaging and even unfair. On the other hand, from a perspective that gives priority to the interests of citizens who may use insurance, the greater use of and access to predictive genetic testing sets off ethical alarms. From this latter perspective, applying molecular technology so as to place an unlucky subset of the population – potentially a very large subset – at greatly heightened financial risk simply to lessen the financial risk of insurance programs appears ethically problematic at best.

In sum, benefiting insurers by providing them with more information about the genetic vulnerabilities of potential clients would seem to endanger insurance seekers whose tests show them to be genetically vulnerable. Denied disability insurance on this basis, some insurance seekers would find themselves without income replacement, even if their work disability resulted from a cause unrelated to the genetic condition for which they tested positive. Of course, some of those whose tests revealed them to be at heightened risk of an inherited disease would never become seriously symptomatic from their inherited condition, nor from any other cause, while they are of working age and so would always be able to work.

Even those members of the vulnerable group who never needed to draw down on disability insurance would be harmed by the insecurities that would trouble and jeopardize the genetically uninsurable. Such insecurities, I argue in this article, are more imminent and more threatening than are usually understood. Considering that public funds supported the research from which the technology for genetic testing aimed at finding ways of providing medical help (at least in part for precisely this same biologically vulnerable group), applications of this technology that result in harm to this group seem especially grievous.

If we accept both these contentions – that using predictive genetic tests may benefit disability insurers, but also that doing so may harm an innocent subset of citizens – as being plausible, then a dilemma looms. Certainly, the conjunction of these beliefs entails an incongruence between the interests of insurers and the public interest, at least insofar as protecting genetic minorities is in the public interest. In this article, I attempt to resolve the dilemma by discrediting the commonplace idea that disability insurers benefit by expanding genetic testing. To the contrary, I argue that proliferating genetic testing to predict disability may not serve, and indeed may injure, disability insurers’ interests. Once it is understood that disability insurers

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need not be pitted against the insurance-using public, one horn of the threatened dilemma is removed. We thus escape ethical problems that the proliferation of using predictive genetic tests could create.

To investigate how predictive genetic testing might affect disability insurers, and whether their programmatic interests compete or are in concert with the personal interests of citizens seeking to be insured against disability, we first need to understand the meaning of disability. The next step will be to consider how disability relates to the work status of individuals who are not yet, and perhaps never will be, impaired.

The current state of the intersection between disability law and employment law, I argue, leads to counting some symptomatic persons as being disabled. Predictive genetic testing invites the expanded influence of such a view. Predictive genetic testing may itself become disabling in the sense that individuals who test positive for alleles associated with genetic disease may for that reason be disqualified from being able to work. Once the legal and policy context conducive to this possibility is considered, we will be positioned to see why disability insurers may be wise to defer to, rather than to disparage, potential clients’ wariness about predictive genetic testing.3

“Disability” Means “Work-Disability”
Let us consider what is meant by “disability.” According to a standard dictionary, it is the “inability to pursue an occupation because of physical or mental impairment.”4 The conception of disability is thus strictly work related. More precisely, it is about not working. Go to the search engine “Ask.com” and type in “disability.” You will find the page advertising a book titled Get Your Disability Money, a “how-to” guide to qualifying for public benefits from Social Security Disability Insurance and private benefits from long-term disability insurance. Chapter One of the book is entitled “How to exit work.”5

From antiquity, there have been programs that help certain groups of biologically anomalous people to exit or be ushered from the workforce. In early sixth century BC Athens, disabled war veterans could obtain income replacement paid out at public expense. By Aristotle’s time, men whose means fell below a specified line, and who were too impaired to work, received daily public payments through a treasurer elected by lot.6 If we fast-forward 2,000 years to 1776, we find the Continental Congress resolving to provide half-pay for officers and enlisted men, including those on warships and armed vessels, who had become so impaired as a result of their service to the United States that they were made incapable of earning a living.7 Today, federal disability support is provided by using public funds acquired from a range of mandatory contributions, and some citizens receive disability income from private insurance purchased while they are part of the workforce, prior to a time when they exit work.

Although impairment occasions disability, and disability carries with it social permission to exit work, impairment does not by itself justify leaving the workforce. Having a certain impairment may rule out an individual’s pursuit of some occupations, but not others. Which occupations people with particular impairments are permitted or assigned to undertake is not solely a matter of their biological limitations.

In the United States, blind people have been thought incapable of, and therefore do not pursue, the very occupations for which other cultures consider them well-suited. For example, in traditional China and Japan, blind people specialized in massage therapy and money-lending, while in the United States they were watchmakers and piano tuners.8 It is extremely unusual for a blind person to practice massage therapy in the United States, while in Korea until recently only blind people have been licensed to practice this profession.9 Cultural suppositions and social arrangements thus exercise an enormous influence over whether people with biological anomalies can work and what work they do, if any.10

In this regard, disability insurance departs importantly from health insurance because work capability is not simply a matter of having sufficient health to execute work. Individuals healthy enough to do so nevertheless may be barred from working. Individuals’ health deficits are most influential in determining who is permitted to draw down on health insurance benefits and who is denied them. For example, people may be prohibited from drawing down on health insurance because their health deficits are pre-existing conditions or because their insurance does not cover their health deficits. But as I argue in the following section, biases regarding workers’ health conditions can and do influence who is permitted to work.11 Thus, social and legal arrangements affect who leaves the workforce for health-related reasons, and thereafter can lay claim to disability insurance benefits.

Excluding Asymptomatic Persons from the Workforce
The case of Mario Echazabal, whose exit from the workplace was facilitated by the U.S. Supreme Court, illustrates the influence of social bias, specifically about disability bias.12 Having worked in a Chevron oil refinery for two decades, Echazabal twice attempted to change his status from contract worker to regular employee. In the first instance, he initiated an application to be employed directly by Chevron, rather than...
by a contractor who supplied extra workers to Chevron, and subsequently was offered a regular position by Chevron at the same refinery. But medical testing executed as part of the employment offer showed a liver abnormality subsequently traced to Hepatitis-C. Chevron’s physician, no expert in either occupational medicine or liver disease, had no evidence that continued work at the refinery would be any more damaging to Echazabal’s liver than taking acetaminophen. Nevertheless, the refinery withdrew its offer to hire Echazabal as a regular employee on the grounds that workplace exposure would further harm him, so Echazabal continued at the Chevron refinery as a contract worker.

Echazabal’s second attempt to change his employment status ran a similar course. In this instance, the refinery’s management invited him to apply for a position as a regular Chevron employee, doing the same work he was doing for the contractor at the same refinery. Once again the response to his application was an offer of employment, but the employment offer was rescinded when post-offer medical testing identified the presence of the hepatitis virus.

This outcome of his second attempt to change his job status from contract worker to regular employee induced Chevron to have him fired by the contracting firm that had kept him at the refinery for over twenty years, during which he had never evinced symptoms of illness from hepatitis, nor had his level of productivity or quality of work been challenged. Tellingly, Echazabal had continued working at the refinery for nearly half a decade after the initial post-employment offer medical testing discovered his health status, during which time there was no issue of his inability to work or of deteriorating work quality due to illness.

Chevron’s adverse actions thus were not prompted by Echazabal’s hepatitis infection having impaired his ability to do a satisfactory job. He sued under the Americans with Disabilities Act (ADA), charging Chevron with disability discrimination, that is, with biased refusal to employ an individual otherwise qualified for a job just because of disability. Chevron did not defend against the suit by denying that the company regarded Echazabal as disabled or by asserting that his ability to do the job was inadequate or impaired. Instead, Chevron defended by predicting that in the future, his ability to do the job might become inadequate or impaired, that is, in the future the hepatitis infection might erode his work capability.

The Supreme Court endorsed Chevron’s adverse action against Echazabal, considering it to be necessitated by the refinery’s reasonable wish “to avoid time lost to sickness [and] excessive turnover from medical retirement or death.” The Court reasoned that even if Echazabal agreed not to hold the refinery liable for any liver-related illness he might develop, such illness still would impose on the employer excessive employee absence and turn-over costs. Yet, nothing in Echazabal’s previous years of work performance, in the same job at the same site, demonstrated unusual use of sick time, nor was there evidence in his prior work performance that hiring him courted the other problems.

Had his work record raised such questions, it is unlikely that Chevron would have extended either of the two offers of regular employment the refinery management made to him, nor would the company (as in the second instance) have invited him to apply to be a regular employee rather than a contract worker. Therefore, it is hard to think otherwise than that Echazabal lost his employment based on his anomalous biological condition simpliciter – on nothing more than the diagnosis that he was infected with Hepatitis C – rather than based on the manifestation of the infection in the workplace and its negative effects on his ability to fulfill his employment duties.

Although nothing occurred to suggest that Echazabal’s prior capacity for work had decreased, the discovery of his biologically anomalous condition precipitated his being identified as disabled. What caused Echazabal to become work-disabled thus was neither illness nor disease, but rather the outcome of a required medical test, paired with the employer’s reaction to the test’s result. Although Echazabal’s supporters characterized Chevron’s reaction as “alarmist,” the employer insisted, and the Court affirmed, that keeping Echazabal in the workforce subjected Chevron to prospective harms such as disruption in the workplace, having to use inexperienced workers to fill-in for absences, lower employee morale, unnecessary Workers’ Compensation claims, and “the cost to a team culture when even one experienced and valued person leaves.”

The Court’s opinion in this case maintained the consistency of its record of finding against individuals who want to work and can do a job, but who are denied equitable work opportunity because they are in some respect biologically anomalous. For example, in Kirk-ingburg, a physician whose charge was to examine the plaintiff’s back discovered serendipitously that he was functionally blind in one eye. Kirk-ingburg himself did not realize he was seeing anomalously, both because to him his way of seeing was the normal way and because he had always passed the tests of depth perception mandated for interstate truck drivers. In other words, Kirk-ingburg could make the perceptual judgments required for driving safety; he just perceived depth in a species atypical way. Although the U.S. Department of Transportation agreed to renew his trucker’s license, his employer fired him, and the Supreme Court
endorsed the employer's removal of Kirkingburg from the workplace. Like Echazabal, Kirkingburg was fired after years of satisfactory work and with no evidence that his work performance had become unsatisfactory. Both Echazabal and Kirkingburg were fired, after a medical test revealed they had a biological condition that might have impaired their work performance in the future, despite all the evidence to the contrary.

In only two cases tried under the ADA has the Court given any hope to biologically anomalous people who sued in order to continue in their occupation. Golfer Casey Martin prevailed by proceeding under Title III (Public Accommodations), rather than Title I (Employment), claiming that golf was not a job but a game, and therefore the PGA did not have the latitude the Court had extended to employers in Title I cases. Of course, very few workers will be able to survive disability discrimination in this way, that is, by virtue of their doing work that courts can construe as recreational. In Cleveland, the Court challenged the tight connection of disability to not working, but placed the burden of demonstrating work capability on those who seek work but are biologically anomalous.

In the Kirkingburg and Echazabal decisions, the Supreme Court discounted the evidence of the plaintiffs' work capability and their excellent work records, compiled despite their biological anomalies, and compiled in precisely the jobs (not just the occupations) from which they subsequently were removed on the basis of a medical test. The extrapolation to genetic testing should not escape us. In scenarios very much like those suffered by Echazabal and Kirkingburg, employees with genetic mutations associated with illness, impairment, or disease could be banished from work they do very well, not on the basis of deficits in their work performance or changes in their work capability. Rather, they could be fired because genetic testing reveals biological anomalies that (imprecisely) suggest higher than species-typical susceptibility to some speculative future reduction in their ability to work.

What the Legal Climate Portends
During argument in Echazabal, Justice Kennedy wondered whether requiring employers to employ biologically anomalous workers in environments possibly harmful to them but safe for species-typical persons might undermine hard-won workplace safety policies that now keep employees from harm. Thus a decision to protect individuals to whom working risks injury from "unsafe" work could be portrayed as serving the public's interest.

Yet ultimately this interpretation of the consideration that prompted Chevron's adverse action is unconvinced. First, in the years prior to and succeeding Echazabal's termination, the refinery had a dismal record of protecting both workers and the general public from harm, making implausible any claim that benevolence toward Echazabal was a main or decisive concern. A second point is that the Echazabal Court itself characterizes the refinery's motivation in terms of self-interest rather than beneficence. In its opinion, the Court did not describe the employer's motivation as occurring under the banner of concern for Echazabal or for disabled people generally. These observations suggest that the Court did not interpret Chevron's defense as being an (acceptable) excursion into benevolent paternalism.

A related worry is occasioned not just by Chevron's action but by the Court's endorsement of it. This problem may have grave implications for health law in general. Competent individuals usually are expected to make decisions about undergoing medical treatment, and concomitantly to acquire responsibility for taking risks in respect to their health. Expectations that individuals with decisional capacity can and should assume medically related risk shape the principle of informed consent, which is the bedrock concept for the assignment of responsibility in current health care practice that is well-ensconced in case law. Absent an emergency, health care professionals are required to fully and accurately inform patients of the risks of a course of treatment so that the patients can exercise their decisional capacity in consenting or refusing treatment, but this rule is infeasible where a condition that attenuates decisional capacity is involved. No claim was made that Echazabal lacked decisional capacity to accept medical risk. This is clear from the fact that liver function and other tests, for which his consent was necessary, were performed. Yet some aspects of the way this case was decided seem to imply the contrary and therefore undercut crucial assumptions about assigning responsibility for assuming medical risk.

According to Justice Breyer during argument in Echazabal, the Court would not be inclined to announce a legal rule that would apply to a suicidal worker who might seek the means to die in a workplace. This remark suggests that the protective formulation needed to secure workplace access against disability discrimination is a hazard to individuals whose disability impairs their decisional capacity. To safeguard members of the disability class with decisional capacity deficits, the entire class should be blocked from exposure to workplace situations where their biological anomalies might place them at risk, regardless of whether most of the class's members are competent to decide whether to assume health risks.
If courts thus treat the class of people with biological anomalies considered to be disabilities as rashly self-destructive rather than responsibly risk assuming, then they deny the autonomy due to persons who do have decisional capacity to weigh their own interests against any risks to their health.

Similar denials would affect the very large number of people who, having tested positive for inherited propensities to some kind of disease, nevertheless preferred assured employment and its benefits over tenuous dangers to their health. Their choice to assume the risks that their working might incur would be systematically disregarded. Although such an outcome would undermine years of legal, social, and ethical commitment to supporting individuals’ rights to decide the future course of their health, the legal interpretations embedded in Echazabal invite such an eventuality in an era of widespread workplace-related genetic testing.

Another direction in which Echazabal may be extrapolated also has additional implications for the interests of disability insurers. The Court’s decision may influence employers’ approaches to workplace safety. Invoking the federal Occupational Safety and Health Act (OSHA) as delimiting employers’ obligations under the ADA, the Echazabal Court stated:

Congress specifically obligated an employer to “furnish to each of his employees employment and a place of employment which are free from recognized hazards that are causing or are likely to cause death or serious physical harm to his employees.”

The Court construed the potentially conflicting interface of OSHA with the ADA as a defense for removing anyone at more than species typical-risk from a work environment from that place. By doing so, the Court reversed by a full turn the commonplace interpretation of employers’ obligations under OSHA. OSHA has been understood as requiring the employer to eliminate risky work conditions from the work site. To the contrary, Echazabal suggests, employers henceforth may satisfy OSHA obligations by eliminating from the workplace individuals who can be depicted as being at risk. With the advent of genetic testing, such a defensive strategy becomes feasible.

Instead of addressing poor air quality, for example, employers could purge from their workforces individuals whose genes dispose them to more than species-typical risk from workplace conditions. For example, workers genetically disposed to asthma could be fired because their work sites are dusty. On the Echazabal standard, operators of such work sites could ban people who never have nor will display asthmatic symptoms because they test positive for the gene(s) associated with asthma. In other words, individuals could be diagnosed as disabled in the core sense of disability – the “inability to pursue an occupation because of physical or mental impairment” – and thereupon be prevented or discouraged from continuing to work because they have tested positive for a molecular impairment that neither has nor will express itself. Surely this is a scenario disability insurers should fear for the flood of claims it would create.

### What Disability Insurers Should Fear

The preceding discussion prefigures some difficulties, if not disasters, that the unreflective use of genetic technology in today’s employment environment may introduce. In sum, in the current legal and policy environments, molecular impairments that have not rendered and may never render an individual unable to execute the performance her occupation requires may nevertheless make her unable to pursue that and other equivalent or related occupations. By definition, such an individual can be conceived of as disabled. The proportion of people excluded from the workplace because they are considered disabled would skyrocket when expanded to include all workers whom employers could exclude based on a genetically informed belief that they might need sick time or take early retirement or that work could trigger or exacerbate a genetic disposition to ill health.

How employers react to the news that an employee’s health is at future risk is an additional consideration. Many prefer urging workers newly diagnosed with chronic or degenerative conditions to accept retirement on disability benefits rather than attempting to reasonably accommodate them so as to keep them at work. In the era of genomics, this practice could readily precipitate the departure from the workplace of already insured individuals, who could then receive disability benefits. Rather than focusing on staying at work, individuals with newly discovered genetic propensities for disease are invited by this practice to step into the “sick role.” As sociologist Erving Goffman analyzed it half a century ago, the “sick role” is the social script to which biologically anomalous individuals are assigned when their social participation is labeled as troublesome, with associated stigma.

It seems obvious that the interests of both the public and disability insurers lie in keeping workers at work. First, the greater the number of formerly employed people with disability coverage who are driven to draw on their disability benefits, the smaller the pool of resources to cover them and the greater the threat of continued viability of disability insurance programs. Second, the larger the proportion of
people excused from work by being excluded from the workplace, the smaller the proportion of contributors to public disability funds. Third, the market for proprietary disability insurance will shrink, since fewer in the population of workers will be “nondisabled.” Arguably, the threat of adverse selection may be less damaging to the economics of private insurance than the disability insurance market’s sharply contracting. The scenario posited here might be described as one of adverse de-selection, for people, whose very presence in the workforce evidences their lack of vulnerability to genetically mediated disabilities, would know that comparatively few causes could make them work disabled and therefore would have less reason to become insured.

While disability insurers often are proactive in rehabilitating covered clients so that they return to work by regaining their former species-typical condition, they have been considerably less active in encouraging employers to keep capable biologically anomalous people at work. Nevertheless, this discussion indicates how imprudent it may be in the current scientific era and legal climate for them to disregard the question of whether biologically anomalous individuals should remain at work (as distinct from whether biologically anomalous individuals should be eligible for disability insurance). Such anomalies often will fit the definition of being disabled because there continues to be ineffective protection against molecular impairments being used as a pretext to define individuals unable to pursue their occupations.

Permitting the presumptions embedded in Echazabal threatens to curtail workplace participation for an ever-expanding number of individuals whom tests reveal to have genetic anomalies. A countermeasure is available, however. To initiate it, we must impose on employers a high standard of proof of such individuals’ inability to work, and a concomitant duty to combat commonplace fears about uncertain futures.

In itself, this notion should be welcome to insurers because, in promoting a rigorous standard for proof that a genetic anomaly prohibits work, insurers also would be imposing rigor on eligibility for drawing on disability benefits. We should notice that pursuing this strategy would have the effect of reducing the incentives to use genetic testing because comparatively, few genetic tests can meet this standard, for relatively few genetic anomalies would have so high a probability of expressing the requisite level of disease.

It is important to be very clear about the recommended strategy. By no means does this require a different understanding of the facts of genetic anomalies and tests for them. It already is well-known that predictive and genetic testing can identify some individuals with higher than species-typical risk of developing an impairment that has been associated with disability. It also is known that, in the large number of cases, psychological and social factors contribute to whether such a disability (understood as the inability to pursue an occupation) actually occurs. Nor is it rare for nonbiological factors to be decisive in whether a biologically impaired person is work disabled.

Whether we treat people with higher than species-typical health risks as work disabled, burdening them with the restrictions imposed by the “sick role,” is a matter of strategic decision. In this regard, disability insurers’ interests line up with the interests of the ordinary citizen. Proliferating genetic testing in ways that will disrupt the workforce by imposing the restrictions of the “sick role” on work-capable individuals is contrary to the interests of disability insurers, workers, and the public. As this congruence of interests becomes apparent, erroneous beliefs about the advantage that increased use of genetic testing bestows on disability insurers should fade away.

References
1. See, for example, R. Epstein, “The Legal Regulation of Genetic Discrimination: Old Responses to New Technology,” Boston University Law Review 74, no. 1 (1994) and C. Diver and J. M. Cohen, “Genophobia: What Is Wrong with Genetic Discrimination?” University of Pennsylvania Law Review 149 (2001): 1439-1482. Both articles argue that prohibiting insurers from having access to, or acting upon, genetic information about prospective insurance seekers illegitimately transfers wealth from the former in order to subsidize the latter. Both assume that advantage (and the material resources advantage procures) naturally will redound to insurers generally, but for the interference of legal regulation that curtails insurers’ free access to genetic information and to action on that information. This assumption is driven by narrowly imagining that benefit and loss for insurers are determined solely or mainly by the insurers’ power to keep unfavorable risks out of the insured pool.
3. For example, Francis Collins, Director of the Human Genome Project, has testified before Congress that even now citizens are declining to serve as subjects in genetic research out of fear that the results, preserved in their medical records, could limit their opportunities to be employed or insured. See Genetic Information in the Workplace: Hearing Before the Senate Comm. on Health, Education, Labor and Pensions, 106th Cong., 2000, (prepared testimony of Francis S. Collins, M.D., Ph.D., Director of the National Human Genome Research Institute).
5. Available at <http://www.survivorsguide.org/>. 


12. For purposes of this discussion, to be asymptomatic is to manifest no health-related inability to perform the activities of work or of daily life. An individual who tests positive for the presence of an infectious agent or of an allele associated with an inherited disease can be asymptomatic in the sense used here. This is a somewhat more stringent account of being asymptomatic than is usually invoked by the concept. See *Chevron U.S.A. v. Echazabal*, 122 S. Ct. 2045 (2002).

13. *Chevron U.S.A., Inc. v. Mario Echazabal*, Brief of the American Public Health Association, the American Association for the Study of Liver Disease, the Hepatitis C Action and Advocacy Coalition, the Hepatitis C Association, the Hepatitis C Outreach Project, and LAMBDA Legal Defense and Education Fund, as Amici Curiae, available at <http://www.bazelon.org/public-healthbrief.html> (last visited March 20, 2007). Overdoses of Tylenol, or acetaminophen (the generic name), can cause liver damage. However, people with Hepatitis C infections, even those who already have sustained liver damage, do not appear to be at increased risk of liver damage from acetaminophen. See <http://hepcvets.com/drugs/tylenol.html> (last visited March 20, 2007). The APHA et al. amicus brief argues that hepatotoxic chemicals such as those present at the Chevron refinery cause liver damage only if present in toxic amounts, in which case exposure threatens liver damage in all workers equally.


16. See Brief of APHA et al., *supra* note 13. See also *supra* note 10. This summary is drawn from A. Silvers and M. A. Stein, “Human Rights and Genetic Discrimination: Protecting Genomics’ Promise for Public Health,” *Journal of Law, Medicine & Ethics* 31, no. 3 (2003): 377-389. For a detailed analysis of the Supreme Court decision, see this article.


25. It is important to note the difference between rash action and risk-assuming action. The latter is responsibility-catering, while the former is irresponsible. To fail to make this kind of distinction in the context of *Echazabal* threatens our basic conception that responsibility for the future course of their health lies largely with asymptomatic and pre-symptomatic individuals.
