The Legal Regulation of Genetic Discrimination: Old Responses to New Technology

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The subject of genetic discrimination is one of obvious importance today, but it is one that I have reached only by a circuitous route. I published my book *Forbidden Grounds* in 1992. There I took the position that current anti-discrimination laws should be repealed insofar as they apply to private competitive employment markets. I relied on my libertarian bent to explain why a system of free entry and open markets can better cope with invidious forms of discrimination in employment markets than any system of government mandated and enforced norms. Prejudice in markets is always costly to the parties who practice it, so that there is a strong corrective against unthinking prejudice that works without the heavy administrative costs and logrolling mentality that often infect the political decision-making process. But whatever the strength of these arguments, there is today little chance that we shall depart from our current destructive regulatory policies, and little chance, either, that the underlying economics of the situation will improve.

The framework that I used to attack employment discrimination laws does not rest on any categorical or a priori belief that government intervention is always bad. Rather, it rests on the assumption that the valid reasons for government intervention are: (1) to counter the use of private aggression; (2) to limit the operation and influence of private monopolies;
and (3) to provide for classical public goods that cannot be supplied by a network of contractual arrangements, given the risk of holdout and strategic bargaining. Ironically, though, any approach that emphasizes freedom in private choice also calls for sharp limitations on the scope of government discretion, and, hence, more resistance to race-conscious programs than current law exhibits.5

All this is by way of prologue, for I thought that these arguments, whether sound or not, had been left behind when I decided to shift my research interests to another disaster area—health care.6 I was, however, rudely awakened to the ubiquity of certain problems when I was asked to participate in a radio talk show devoted to the topic of genetic discrimination. It took only seconds for me to realize that this topic plunges us back into the same set of issues on which I took such an unfashionable position in Forbidden Grounds. The reason is clear enough to see.

I. DISCRIMINATION: THE INESCAPABLE ISSUE

Medical and scientific technology recently has made significant advances in the field of genetic testing. These advances assist in the prediction, diagnosis, and mitigation of disease.7 Techniques mapping certain diseases to specific sites in the human genome have already been applied to diseases such as cystic fibrosis, Duchenne muscular dystrophy, and Huntington’s disease.8 In the case of Huntington’s disease, genetic testing accurately predicts the future onset of the invariably lethal disease and offers strong clues as to its severity and time of onset. Technology has given us the ability to see written in the future what, up to now, has been left to pure chance.

The advent of such genetic information creates the fear that this knowledge will be turned against those with undesirable conditions. Put simply, the question to be faced by society is whether the state, employers, and insurers—to mention only the most prominent institutions—should be

8 Id. (discussing the specific techniques that allow detection of altered genes). Other genetic defects include juvenile diabetes, Lesch-Nyan disease, sickle cell anemia, phenylketonuria, and hemochromatosis.
allowed to take into account genetically derived information that reveals an individual’s prospects for future disease and incapacity. This question affects all sorts of human interaction: from employment and the purchase of health, life, and disability insurance in the economic sphere, to the suitability of potential adoptive parents in the personal sphere. This Lecture will extend the analytic framework that I have applied to basic discrimination to encompass genetic discrimination.

The possibility that genetic information may be used at all creates the possibility that it may be used badly. The long history of the eugenics movement is evidence that the mere possession of information gives no assurance that it will be used for wise ends. Similarly, it is possible to misinterpret the results of IQ tests to the prejudice of intelligent persons who do not, for example, have a working mastery of the English language. But whatever the difficulties with the eugenic movement, the march of science makes it clear beyond argument that a wide number of important disease conditions have a genetic base, which can be identified by testing even before they manifest themselves. As stated above, the question is whether this genetic information should be used, and if so by whom, to make decisions in such contexts as jobs, insurance, and health.

For these purposes, genetic discrimination has been defined as “discrimination directed against an individual or family based solely on an apparent or perceived genetic variation from the ‘normal’ human genotype.” This definition reaches the cases that I wish to discuss. The use of the word “solely”, however, may make this definition far too restrictive if parallels to Title VII are accurate: It probably does not cover cases in which genetic information is one source of discrimination mixed in with others.

The dominant attitude today, as expressed both in legislation and judicial decisions, is strongly hostile to genetic discrimination, which is regarded as stigmatizing certain groups of individuals, and as playing into the hands of those antisocial people who, from base prejudice, wish to

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9 See Stephen J. Gould, The Mismeasure of Man 335-36 (1981) (criticizing Justice Holmes’s infamous “three generations of imbeciles are enough” statement in Buck v. Bell, 274 U.S. 200, 207 (1927), and discussing the personal suffering of Doris Buck because of her inability to conceive after her forced sterilization).

10 Id. at 146-233 (criticizing the entire testing movement). For a more balanced account of the testing movement, see Mark Synderman & Stanley Rothman, The IQ Controversy: The Media and Public Policy 1-41 (1988) (tracing the reasons for a rapid anti-testing consensus in the United States in the late 1960s and throughout the 1970s).

11 See Paul R. Billings et al., Discrimination as a Consequence of Genetic Testing, 50 Am. J. Hum. Genetics 476, 476 (1992) (stating that “the pace of development and application of DNA and biochemical genetic tests . . . may be accelerated”).

12 See id. I will comment on the practice of placing quotation marks around the word “normal” later in this paper. See infra notes 18-19 and accompanying text.

exclude and alienate deserving individuals from society.\textsuperscript{14} So stated, the question of genetic discrimination is a blend between the old and the new. The technology creates new situations to which principled answers must be provided. Yet, as is so often the case, the ultimate questions of value and choice depend less on the dramatic innovations in technology and more on the familiar inquiries into the relationship of individual to individual, and of the state to its citizens. Novelty in circumstance does not always require novelty in solution. Genetic discrimination provides an ideal laboratory experiment in which old principles, rightly conceived, supply the best answers to modern problems.

In one sense, this grand observation is congenial to persons on both sides of the genetic discrimination debate. The dominant professional response to genetic discrimination should come as no surprise, for intellectual movements and attitudes are rarely compartmentalized by subject matter or discipline. Attitudes on genetic testing are shaped by a familiar \textit{Zeitgeist}: a set of core beliefs that operate in society generally and elsewhere in the law.

The grounds for state intervention that I mentioned above—externalities and coordination—are surely not rejected in modern law and social practice. However, that short list is oftentimes augmented by other asserted grounds for intervention. Chief among these is the idea that luck, either good or bad, should not be a reason for one person to lead a better or worse life than others. The position of John Rawls that certain attributes are morally arbitrary surely carries over to the situation of genetic differences.\textsuperscript{15} Many people do not believe that individuals own their talents and abilities. Still more people believe that they should not be burdened with bad luck in the genetic draw. When differences in luck are attributable solely to external circumstances, this modern view holds that something ought to be done to rectify the situation. That is, we must equalize the positions of various individuals or groups, even if it means (as it always does) that property, wealth, and opportunities must be taken from one group of people and given to another.

There are of course many cases in which it is not clear whether bad luck or bad conduct is the source of a disability. This distinction may not matter—in the health care field, the extreme modern position is that all are deserving of care “no matter what.”\textsuperscript{16} So long as the individual positions are different, society should act to equalize these positions, without

\begin{footnotes}
\footnote{Larry Gostin, \textit{Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers}, 17 \textit{Am. J.L. & Med.} 109, 111 (1991).}
\footnote{JOHN RAWLS, \textit{A Theory of Justice} 506-12 (1971) (discussing the basis of equality in systems of justice).}
\footnote{For one illustration, see Carl Cohen \textit{et al.}, \textit{Alcoholics and Liver Transplantation}, 265 \textit{JAMA} 1299, 1299 (1991) (pointing out that in numerous situations, care is provided despite the level of moral negligence of the injured party). \textit{But see} Alvin H. Moss \& Mark Siegler, \textit{Should Alcoholics Compete Equally for Liver Transplantation?},}
\end{footnotes}
regard to the individual or institutional choices that brought about the initial disparity.

This general view offers fertile ground to support some general prohibition against genetic discrimination. Some persons are born ugly and others beautiful or smart or dumb. Oftentimes it is difficult to figure out how one could intervene to offset these types of differences, given their infinite gradations that are so difficult to identify and measure. But with genetic defects, the differences involved are often discontinuous: A person with a major genetic defect may suffer from juvenile diabetes, Lesch-Nyhan disease, Huntington’s disease, sickle cell anemia, phenylketonuria (PKU), or hemochromatosis. There are literally hundreds of unpronounceable genetic conditions that may or will result in some impairment of major life functions.

In some cases (as with PKU), knowledge of the existence of the condition can assist in the selection of a good diet, neutralizing the threat. In other cases, such as Huntington’s disease, the genetic trait may manifest itself late in life. But when it does, it is invariably lethal after extended periods of dementia and loss of bodily control. No wealth transfer to victims of Huntington’s disease could ever hope to equalize their positions in life. But some redistribution of wealth might bring about a modest redress of the imbalance. On this perception I think that there is consensus on both the conservative and liberal frontiers. For while liberals may well prefer a state solution and conservatives might prefer a voluntary one, no one thinks that this imbalance in natural fortunes justifies a moral response of total indifference.

The key question, alluded to in what has been stated above, is this: What kind of response is appropriate? One possible mode of response is to reflexively invoke the anti-discrimination laws to deal with genetic differences. But that response does not address the choice of means that allows the more fortunate to help the less fortunate. Instead, this approach forsakes the language of charity and embraces the language of rights by holding that private parties must disregard in business settings the same conditions, (i.e., impairments) that in informal social contexts prompt a compassionate response. The anti-discrimination principle, once said to reach its highest zenith on matters of race and sex, is now carried over to the use of genetic information. Employers are not allowed to take the handicaps of persons who suffer from various forms of genetic deficits into account when making their personnel decisions. Social work agencies cannot use this information to determine the fitness of adoptive parents. There is today a groundswell of academic opinion, in some instances translated into law, that genetic discrimination is a wrong that in many contexts should be stamped out by the state with all the

265 JAMA 1295, 1296 (1991) (an eminently sensible position arguing that one reason to deny alcoholics coverage is that their misbehavior renders them less deserving).
resources at its disposal. Indeed, I am not aware of any serious discussion of the issue that has a kind word to say for the employers and insurers who are condemned for genetic discrimination. Does this opinion make sense, or do the substantial costs of these proposals suggest the adoption of a somewhat different approach to the problem?

At a theoretical level, the issue is what should be done to regulate the flow of information that indicates that persons have, or are susceptible to, certain kinds of genetic diseases. Even to state the problem in this fashion marks one something of a conservative because it presupposes that a disease entails conditions that ought to be avoided. One thus runs into the teeth of the current wave of fashionable political theory that disease, like everything else under the sun, is socially constructed, and carries with it the risks of discrimination, stigmatization, and stereotyping. "What words should we use, for example, to describe genetic variation? Defects, flaws, deleterious genes, disorders, or the more neutral condition. Using words such as normal—and its corollary, abnormal—is likely to foster stigmatization and discrimination." Or so it has been said.

This exercise of political metaphor conceals more than it reveals. One may not want to discriminate against persons with certain traits. However, it is absurd to argue that these traits are just as good as any other, even if they turn out to be lethal, or cause enormous pain and suffering to the persons who are (old style English again) afflicted with them. Surely it does not make any sense in allocating resources for medical research to treat people as though they are healthy when they are sick. For instance, it would make little sense to treat the common cold as more serious than breast cancer or AIDS. The rules on discrimination thus force us to partition our view of the world. When employer regulation is on the table, the social response is that we cannot distinguish between good and bad health save by dubious means of social construction. Yet, when public

17 See R.I. GEN. LAWS § 28-6.7-1 (Michie Supp. 1993):
(1) No employer, employment agency or licensing agency shall directly or indirectly:
   (a) Request, require or administer a genetic test to any person as a condition of employment or licensure.
   (b) Affect the terms, conditions or privileges, of employment or licensure or terminate the employment or licensure of any person who obtains a genetic test.
(2) No person may sell or interpret for an employer, employment agency, or licensing agency a genetic test of a current or prospective employee or licensee.
Id. The remedies include actual and punitive damages, reasonable attorney's fees, and injunctive relief. Id. § 28-6.7-3.

18 Philip J. Boyle, Introduction to Genetic Grammar: 'Health,' 'Illness' and the Human Genome Project, 22 Hastings Center Rep., July/Aug. 1992, at S1 (discussing how the language used to describe genetic differences affects their social perception). "Normal" was also placed within quotation marks in the definition of genetic discrimination quoted from Billings et al., supra note 11, at 476. See supra note 12 and accompanying text.
support for disease is on the table, we now understand the natural world holds out enormous perils to everyone in society.

Our view of disease, however, should depend on what disease is and how it operates. It should not depend on the particular social purpose to which knowledge is turned at any given moment. It should depend on the evidence as to biological and social causation. The inescapable truth is that an abnormal trait, such as the gene for Huntington’s disease, is a sign of fatal complications; it does not offer any hidden potential for personal gain.19

In this context it is often said that there is no connection between the use of “normal” as a descriptive term and it use as a prescriptive one. And as a matter of logic, no one can establish a logical or necessary connection between a trait that is common in a population and a trait that is desirable. But while the connection may not be necessary or logical, it is surely contingent—that is, there is surely an empirical association that is far from random. Most traits that reduce the fitness of an organism tend to die out over time. Those traits that tend to advance an organism will over time appear with greater frequency than those that do not. Thus, at some level, an important link occurs between the “normal” of relative frequency and the “normal” of normative discourse. The logic of natural selection helps supply that connection. The willingness of people to pay to avoid the pain and limitations of disease thus reflects biological drives for survival and procreation that antedate our modern literary consciousness. People may differ in their tolerance of pain and disease, but there are few who treat it as a welcome benefit and not a condition to be devoutly avoided. Therefore, when medical research funding is at stake in the political arena, diseases are portrayed as insidious killers. Switch the topic to discrimination, though, and they are neutral and faceless conditions that belong in quotation marks, as if life under these disabilities is no worse than life without them.

II. FROM IGNORANCE TO KNOWLEDGE

How then, with an issue so freighted, is it possible to approach genetic discrimination from something of a distance? Rather than jump to the question of legal intervention, it is useful to ask how ordinary individuals, interested only in self-knowledge, would respond to the prospects of acquiring information about their own genetic condition. Once that is understood, we can ask about what happens under different legal regimes when that information is shared or withheld during human dealings. This

19 See Stephen J. Post, Huntington’s Disease: Prenatal Screening for Late Onset Disease, 18 J. MED. ETHICS 75, 75-78 (1992) (arguing that late onset diseases, despite the certainty of causing severe suffering, should not be automatic cases for abortion when detected prenatally). “Few would quarrel with the assumption that it is preferable to have healthy children who are not born into severe or chronic pain.” Id. at 76.
inquiry confirms an old insight about the use of information—it's revelation has consequences that are both allocative and distributive, both good and bad. At one level, information eliminates major problems, for it gives greater knowledge of the future and thus allows better use of scarce resources. But at another level, it only adds to difficulties already present, for its selective generation and use increases the possibility of mischief from strategic behavior. The arrival of new technological possibilities, such as genetic screening, neither alters the range of possible outcomes, nor changes the legal principles that might weed out the bad effects of information while preserving the good. Their arrival only expands the arena in which these established principles must work.

It is helpful at the outset to consider whether any individual would choose to avail himself of a costless and reliable test that pinpoints whether he has a particular gene. The most mooted case in the literature is the gene for Huntington's disease, which is especially apt for this discussion. The disease is caused by a single gene defect. Unlike most terrible and fatal diseases, this gene is dominant (but with low frequency in the general population) and survives across generations only because the onset of the disease is typically after age thirty-five, thereby allowing for successful reproduction. However, once the disease sets in, there is a long period of degeneration of physical and mental capabilities, followed by a painful death, leaving it as no accident that the suicide rate of persons with Huntington's disease is far higher than for the normal population.

Consider first a world in which there is complete ignorance about the transmission mechanism of the disease. Its occurrence is everywhere regarded as an act of God, or what we would call a random event. The correlation between parent and child remains undetected, and people must organize their lives without any ability to identify who is at risk and who is not. The only levels of preparation that are undertaken are those appropriate for any random event such as being struck by a meteor. On purely personal matters, everyone is in the same basic position. Similarly, in the contractual and public arena, no state, employer, or insurer can distinguish between one person and the next. The practical impossibility

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20 For a description of the relevant medical information, see Gwen Terrenoire, Huntington's Disease and the Ethics of Genetic Prediction, 18 J. Med. Ethics, 79, 79-85 (1992) (exploring the conclusions arrived at in the body of articles discussing the ethics of testing for Huntington's disease).
22 Terrenoire, supra note 20, at 79.
23 Id.
of discrimination eliminates any need to respond to it socially. Ignorance is bliss because the insurance markets instantaneously have all the private information possessed by any of its players—precisely none. The case thus folds into the class of events for which adverse selection is impossible. No special stipulations or conditions are appropriate.

Our own world has never really been like this completely ignorant one. For a long period of time before the advent of genetic testing, people realized that Huntington's disease was inheritable, and that if either parent had the condition, the offspring had a fifty percent chance of having it as well.25 Until genetic screening arrived, there was no way to tell prior to manifestation who would escape the disease and who was inevitably doomed to perish by it. Under the laws of Mendelian inheritance, a known subclass of individuals at risk must make important decisions in the face of critical uncertainty. These individuals must decide whether to marry and have children, whether to invest in years of education or training, and whether to take out a home mortgage, all in basic ignorance of their future fortunes. As planning must take into account two possible and distinct future states of the world, the necessary choices are at best unhappy compromises. Does one disclose to a potential marriage partner the possibility of having the disease? Does one decide to have children if one is a possible carrier of the disease? Does one abort an accidental pregnancy? It takes precious little information to pose these sorts of dilemmas for an individual—just enough to identify some persons at risk and others not.

III. FROM KNOWLEDGE TO FRAUD

I do not pretend to have the answer to the above questions, but only observe that the error costs are very high no matter which state of the world comes to pass. To avoid marriage and children, only to turn out to be free of the disease, is a cruel fate—even if it is preferable to having the disease itself. More important for our purposes, the asymmetrical nature of the information creates genuine problems for all types of routine interpersonal relations. It seems clear to me that there is at the very least a moral duty to disclose the potential risk to a possible spouse, given the intimate nature of the relationship and the devastating consequences of the information. Although there may be no statutory duties on potential spouses, I suspect that a deceived spouse could dissolve (if not annul) a marriage once the true condition came to light—assuming that other legal or emotional factors did not intervene.

Furthermore, the nature of the dynamics changes rapidly in the setting of impersonal institutional contracts. A person who knows that he is at

25 Sandra G. Boodman, Study Finds That Bad News Is Better Than Uncertainty, Wash. Post, Nov. 17, 1992 (Health), at 5 (noting that it has long been known that offspring of afflicted parents have a 50% chance of inheriting the gene).
risk for Huntington's disease has a strong incentive to acquire life and health insurance for the condition. This is because the expected payoffs are far greater than the stated premiums, which are based on the life expectancy and health needs of ordinary persons. Once this asymmetry is known to insurance companies, they have a counterincentive to equalize the information so that they can either avoid the risk altogether or charge a premium commensurate with its severity. By assumption, testing is not an option open to companies—they must rely on contractual techniques. They may inquire about family histories to discover the condition—the dominant gene surely must have manifested itself numerous times in the past. Or, they may quite simply exclude coverage for the disease and its sequelae, obviating the problem of risk (as they do with suicide given the evident moral hazard).

These insurance questions thus arise on the basis of any rudimentary difference in knowledge. The possible doctrinal escape route—that non-disclosure is no wrong—might in principle be available in personal settings (although I doubt it), but, available or not, it is just not important in this context. Companies, having been taken in the past, will adjust and create standard form contracts that will ask future applicants pointed questions, and force the applicant to lie in order to obtain coverage. Should companies be allowed to protect themselves in this matter?

I postpone the analysis of this question to consider the third stage in the progression: the modern period, when it is now possible to test for the gene causing Huntington's disease. People at risk now have options (and difficulties) brought on by the advent of knowledge. Recent survey results indicate that most people at risk think that they would like to know about the outcome, and I must say from a merciful distance that such is the choice that I would take. Uncertainty places enormous burdens on all at-risk individuals, including those who are actually free of the disease. But with a perfect and costless test, fifty percent of the at-risk people will have a great weight lifted from their shoulders and will be able to lead normal lives from that point on. And what of the fifty percent who receive a death warrant? First note that the test does not cause the disease; it only delivers the bad message. Yet that message is not all bad. With knowledge of the certain eventual onset of the disease in hand, extensive planning may be done—even absent information about the exact date of onset. It is easier to make career and marriage choices; easier to know what kind of house to buy, where to live, and what to do. On balance certain knowledge may be worse than fifty percent knowledge because it replaces uncertainty with despair, but from an ex ante

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26 Gorner, supra note 24, at T1.
27 Boodman, supra note 25, at 1.
28 Recent scientific research, however, suggests that it may be possible to predict the future age of disease onset by closely observing the abnormal expansion of the Huntington’s gene. Angier, supra note 21, at A1.
perspective this loss is more than offset by the enormous relief of a negative test. With costless tests and perfect information, individuals are likely to test for their own sake, even without the possibility of using that information against employers, insurers, or other institutional defendants.

In practice, the number of persons who actually take the Huntington's test is said to be smaller than surveys predict—but that result is not inconsistent with the general analysis here. The test itself is quite costly, averaging about $5000; it often requires (or at least required) participation of other family members. The result itself is generally reliable, but there are marginal risks of both false negatives and false positives. A negative result does not absolutely guarantee a clean bill of health. So long as the probabilities only shift, all the questions of planning for a dichotomous world remain, and the gains themselves evaporate at least for individual decisions. The likely result is that people would utilize an imperfect Huntington's disease prediction test only infrequently—if personal matters of lifestyle were all that turned on the result.

But now let us postulate that in other settings allocative and distributional consequences will arise. As explained earlier, knowledge of Huntington's disease does nothing to alter its time of onset or its anticipated severity. But with other genetically related diseases, such as PKU and diabetes, knowledge of the condition can have a marked effect in reducing both these risks. In these particular cases, the only question that people have to ask is whether the costs of the genetic test are worth the benefits that it generates. As with Huntington's disease, the highest payoffs are, of course, with guaranteed results, but even a shift in the odds will make a significant difference. The greater the likelihood that someone is prone to the disease, the more inclined that person will be to make changes in lifestyle and diet that will head the disease off. A shift in the odds can be matched with a shift in individual behavior that results in strong positive gains.

That knowledge prompts a distributional question that comes close to the nub of the insurance and discrimination question: Must the person disclose the information to other parties? I think that in the case of Huntington's disease it is immoral for a person to marry (or even take a job) and conceal the condition from the potential spouse or employer. This conclusion is valid in commercial settings as well as in marital ones so long as the concealment results in selective knowledge to one side that is denied to the other. When an individual has knowledge that he is at risk of incapacitation, perhaps from family history, then full disclosure should be the norm. When the individual knows to a certainty that he is a


30 See Nancy Ross-Planigan, Progress Reported on Disorder; U-M Team Helps Find Huntington's Gene, DET. FREE PRESS, Mar. 24, 1993, at B2 (noting that the test is 98% accurate and requires samples from relatives).
carrier of the trait, from a reliable genetic test, the same is true. The principle does not change; all that changes is the information that must be disclosed.

Yet there is at least this practical difference in the latter disclosure situation: Parties who have a need for certainty, like insurers, need not rely on medical histories and coverage exclusions to protect themselves. They can demand the right to administer and interpret the genetic tests themselves. They have the incentive to get the right result, for they gain little by turning away a healthy person whose parent has been affected by the disease. (Irrationality is a convenient crutch, but not one that explains stable market behavior.) This method of self-protection is more effective, and more intrusive. The question is whether the law should allow it to be available.

At this point it is critical to note that the plea for privacy is often a plea for the right to misrepresent one's self to the rest of the world. In and of itself that may not be a bad thing. We are certainly not obligated to disclose all of our embarrassing past to persons in ordinary social conversations; and it is certainly acceptable to use long sleeves to cover an ugly scar. White lies are part of the glue that makes human interaction possible without shame and loss of face. Strictly speaking, people may be deceived, but they are rarely hurt, and they may even be relieved to be spared an awkward encounter. However, when a major change in personal or financial status is contemplated by another party, the white lies that make human interaction possible turn into frauds of a somewhat deeper dye. In order to see why this is the case, recall that the traditional tort of misrepresentation stressed the usual five fingers: a false statement, known to be false, material to the listener, and relied on, to the listener's detriment. There is little question, whether we deal with marriage or with business, that concealment of relevant genetic information satisfies each element. The only question, therefore, is whether one can justify what is a prima facie wrong.

I am hard pressed to see what that justification might be. No doubt the individual who engages in this type of deception has much to gain. But equally there can be no doubt that this gain exists in all garden variety cases of fraud as well. To show the advantage of the fraud to the party who commits it is hardly to excuse or to justify it, for the same can be said of all cases of successful wrongs. On the other side of the transaction, there is a pronounced loss from not knowing the information when key decisions have to be made. For example, a woman may choose the wrong husband; an employer may pass up a good employee with a strong medical record and a clear upward path in favor of a worker who will, in the end, be the source of enormous personal and financial costs. To show that the condition is one for which the speaker is not responsible hardly

justifies concealment at all: Lying about one's age or about the place of one's birth is often fraud even though these facts are immutable—just ask the Immigration and Naturalization Service.

False statements about or deliberate concealment of genetic information is as much a fraud as false statements about or concealment of any other issue. The only possible justification for concealment, therefore, would be that it is unfair for the person with the pending disorder to deal alone with the suffering and financial loss. Yet, that loss is not sustained because of the wrong of another. Could the victim of a natural catastrophe keep it secret, and single out one other person to bear some substantial fraction of the loss? If not, then why give that same privilege to the victim of a genetic defect? Today, it is easy to find strong support for socializing losses. But why should a person laboring under a genetic defect be entitled to pick the person or group that has to pay the subsidy?

In sum, genetic discrimination raises problems no different from those associated with any other sort of misfortune, and calls for no different response. The greater knowledge that comes from testing increases the informational asymmetries that are always the bane of insurance markets. When testing is possible, dangers from strategic behavior are only enhanced. Accordingly, the case for insisting on standard insurance norms is greater than it was before. Full disclosure of material information in response to direct questions is an indispensable part of that system. If we have reason to suspect that a system of disclosure could prove unreliable, we should allow the employer or insurer to test in order to obtain the knowledge already available to the employee. The person who wants privacy need not apply for the position or the insurance coverage. But he should not be able to have it both ways, and at someone else's expense.

IV. KEEPING IT DARK UNDER THE ADA

Currently, our policy as a country is precisely the opposite. The situation is a variation of the policy "don't ask, don't tell," or, more accurately for this case, "can't ask, don't tell." This surely is the position with respect to disabilities that are now covered by the Americans with Disabilities Act (ADA). The only uncertainty for this analysis is whether a genetic trait that has not manifested itself counts as a disability within the meaning of the statute—a point on which the drafting of the statute is unclear, but on which the ultimate outcome is not.

It is still not certain whether an employee can blurt out the information that he has a clean bill of health. The problem here is no different from one in which a woman voluntarily tells her prospective employer that she

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33 See Gostin, supra note 14, at 124-27; Natowicz et al., supra note 7, at 470.
does not want children, or is sterile. If the voluntary disclosure legal regime carries over to the ADA, then volunteers may still take the initiative to bring their healthy condition to the attention of an employer or an insurer. If they do so, then all others must follow suit in order to prevent the possibility of discrimination, for otherwise their silence becomes deafening. So again the system works best only when people with disabilities are authorized to lie with impunity, just as they are allowed to remain silent with impunity. The legal regime actually evolves into, “can’t ask, may tell, may lie.” This policy is the inevitable result of our attempts to regulate information. Along the road, truth is discouraged and lies are protected, promoted, and necessary. Once the anti-discrimination norm becomes dominant, the older norms against force and particularly fraud must necessarily give way. Here as elsewhere the recognition of positive rights destroys negative liberties.

In practice, the situation is still more complicated when lies and concealment are not in a person’s self-interest. A prospective employee, for example, might not want to deny an employer complete access to information. Instead, he may only want selective restrictions. The ADA recognizes that dichotomy and contains extensive provisions to deal with permissible uses of medical information. On the one hand, the ADA strives to make sure that medical information is available for diagnosis and treatment, on the other, it precludes the use of that information in any initial hiring decision. Undoubtedly, if the ADA applies to genetic discrimination for carrier or nonmanifested traits, these would be subject to the same legal regime.

Under its basic approach, the ADA limits access to information that can be elicited by ordinary inquiries and by medical examination. Under ordinary circumstances outside of a medical setting, a job applicant cannot be asked if he suffers from a disability. He can be asked whether he can perform job-related functions. As it stands now, if the answer is no, it is not clear whether the ADA permits an employer to ask the reason why. A person giving a reference for an applicant faces the same dilemma: If the answer to the potential employer’s question is that the person cannot perform the job because he or she labors under a disability, then the person asked for a reference must not answer. Yet as that evasion itself pinpoints the reason for poor performance (but not the particular nature of the disability), the employer will have all the information that he needs to look elsewhere for employees (without, of course, noting

34 See Gostin, supra note 14, at 140.
36 Id. § 12112(d)(3).
37 Id. § 12112(d)(2).
38 Id. § 12112(d).
39 Id. § 12112(d)(2)(A).
40 Id. § 12112(d)(2)(B).
the reasons for the shift in focus on the paper record). Once again, the
question is whether a person asked for a reference is entitled to lie in
order to conceal the source of the poor performance, or indeed to lie on
the question of whether prior performance was poor at all. Also, will the
reference be motivated to lie in order to protect one friend, or to tell the
truth in order to protect another? Neither of these choices seems at all
appetizing, so perhaps the reference will decide that the best strategy is to
simply refuse to answer any inquiries about potential employees. If this is
so, capable employees will be left without an important method of per-
suading prospective employers of their skill. Handicapped employees
who have done well in particular contexts may find it harder to show that
they pose less of a liability than a potential employer might suppose.

The regulation of information has undesirable ripple effects; it is not
easy to contain the side effects of a regime that authorizes partial con-
cealment. The task of getting information about applicants is surely
made more complex for the able and disabled alike. We know that the
murky line that separates nondisclosure from concealment and fraud will
be crossed; we can only guess how often and when.

The rules for using medical information once an employee is hired are
also quite elaborate, for they reflect the same overall desire to allow the
information to be collected and used, but only for the applicant's benefit.
Thus, no medical examination can be made prior to the time that an offer
is extended.41 Thereafter, one may be required—but only if two condi-
tions are satisfied.

First, the examination has to be conducted on all employees, if it is to
be conducted on any.42 It seems as though one must drill where oil can-
ot be found in order to drill where oil might be (and, of course, drill with
the same equipment and at the same expense). The nondiscrimination
provision thus satisfies the legal but not the economic definition of dis-


41 Id. § 12112(d)(2)(A).
42 Id. § 12112(d)(3)(A).
43 Id. § 12112(d)(3)(B).
44 Id. § 12112(d)(3)(B)(i).
personnel if the disability might require emergency treatment. 45 Otherwise the information cannot be used at all, especially on matters of job assignment, promotion, and transfer. 46 The intention here is to separate the beneficial from the distributional uses of the information, by allowing the former and excluding the latter. Yet this law can only have partial success. Clearly, certain disabilities cannot be disguised, such as confinement to a wheelchair or deafness. Even if the disability is latent, as is the case with persons who will eventually suffer from Huntington’s disease, no set of administrative procedures can completely prevent employers from using this information for disallowed purposes once they possess it. The best that might be done for employees is to invoke the ubiquitous doctrines of “pretext” to counter hidden, rearguard campaigns by employers who seek to use medical information in ways not allowed by the ADA. 47 Notwithstanding the protective provisions of the ADA, I suspect that few workers whose conditions are latent will want the information about genetic traits to be revealed or discovered—given the questions of practical enforcement that surely remain. Workers can be expected to keep the information dark as long as they can, and employers can be expected to use surreptitious techniques to ferret it out.

The ADA’s system of partial disclosure has two further consequences that bear mention. First, it costs a great deal of money to enforce precisely because the regulated information is so valuable to the employer who is systematically denied access to it. Second, no firm will remain idle simply because the law denies it access to the relevant information. Instead, firms will adopt other strategies to cut their losses in a world that regards concealment as a employee birthright.

One trend that we should anticipate is a gradual movement toward higher wage and higher salaried workers. Offering these higher wages and salaries should allow the employer to be more selective in the workers hired, and one implicit criterion for employer selection will be the health of the hired workers: the better the health, the lower the costs of complying with government mandates on genetic discrimination as on all other aspects of health care. In addition, the total number of workers needed should be reduced as average worker fitness rises, and this in turn will further reduce the employer’s overhead on health costs.

45 Id. § 12112(d)(3)(B)(ii).
46 Id. § 12112(d)(3)(C).
47 For the origin of the pretext doctrine, see McDonnell Douglas Corp. v. Green, 411 U.S. 792, 804 (1973) (holding that an employee should “be afforded a fair opportunity to show that [the employer’s] stated reason for [the employee’s] rejection was in fact pretext”). For a recent change in pretext doctrine, see St. Mary’s Honor Ctr. v. Hicks, 113 S. Ct. 2742, 2753-54 (1993) (holding that even if pretext has been established, the plaintiff has the burden of proving intentional discrimination by the employer).
The pressures for the selection of workers will not only exert themselves on the number and quality of workers hired. They should also spill over to influence prior decisions concerning such matters as the location of plants and offices. The out-migration of business to the suburbs is in part driven by the desire to control the cost of labor. If workers in the inner city present greater health problems, then the costs of mandates will be greater for them than they are for workers who come from other locales. Businesses that locate in suburban locations, therefore, will find their relative advantages increased, and should be expected to expand relative to those who remain in the inner city. It does not matter that firms cannot foresee these possibilities when the various enactments are passed. It is enough that they learn of them before they must make their business decisions.

Additionally, the shift from employee to independent contractor should intensify. The independent contractor works on a short term basis for so many different employers that it is difficult for any one employer to bear the full burdens of the welfare state. Thus, the independent contractor pays his own social security and medical insurance costs. The decline in the traditional employment relationship will of course carry in its wake many individuals who are good risks for insurance pools, but who are excluded because they are not allowed to warrant their position. But no hard-pressed employer can be asked to take those consequences into account. Workers will be shed at the cost of some organizational efficiency in order to deflect a greater regulatory burden.

For those workers who do remain on an employer’s payroll, we should likewise expect to see some downsizing in the set of “neutral” medical packages that are offered, and some reduction in wages (or smaller increases) to offset the mandated costs. The great risk with insuring disabilities is that they will impose enormous costs in individual cases. Plans will be tailored to increase copayments and deductibles, and most importantly, to place sharper limits on the amount of catastrophic coverage that is available. The costs of these shifts will be borne in part by the employer (who cannot make the most efficient offer) and in part by other workers (who would get these benefits if employers could exclude persons with genetic risks and other latent conditions from the coverage within the pool). Finally, as the price of labor increases relative to that of equipment, employers will shift investments in human capital to investments in machinery.

48 See generally James Daly, To the Boondocks, FORBES, June 7, 1993, at 90 (reporting on the exodus of computer data centers to the suburbs); Barbara Vobejda, Critical Condition: The State of America’s Cities, WASH. POST, Feb. 12, 1993, at A1 (reporting on the “ills” of the inner city).

49 See 41 AM. JUR. 2D Independent Contractors §§ 21-22 (1968) (discussing the distinctions between an employee and an independent contractor).
At this point, the prohibition against genetic discrimination should be seen for what it is—an elaborate set of cross-subsidies that reduces the total level of social wealth as it transfers wealth between parties. The defenders of the ADA present their laws of redistribution as all gain and no pain. Would that it were so.

V. Irrationality and Regulation

The above account delineates the range of responses that rational employers and workers will adopt to the ADA legal regime. However, one common justification for regulation is the irrationality of employers and workers in their private activities. In particular, employers need to be prodded into doing the right thing by a state whose own officials seem to escape the occupational diseases that so afflict private firms. At the most general level, this assertion of employer irrationality has it all backwards. Individual employers driven by concerns of profit and loss are much more likely to rationally anticipate and control adverse consequences than government bureaucrats who cannot capture any portion of the gain from useful decisions, nor be made to suffer any portion of the loss from silly or mischievous ones.

Furthermore, similar claims that regulation would prevent irrational forms of sex discrimination have been unfounded. Instead, anti-discrimination principles have forced employers to behave irrationally by requiring them to ignore the known cost differentials of employing certain groups. The ADA regulations affecting the flow of genetic information create the same irrationality.

Employers have no incentive to discriminate against workers whose genetic conditions do not impose any cost, present or future, against them. Insurers have no incentive to discriminate against applicants whose genetic conditions pose no future risk. But both of these groups do have strong incentives to discriminate against parties who do pose greater risks. Efforts to keep genetic information secret do not make sense because employers or insurers are irrational. They make sense precisely because both groups are rational: If privy to information, employers and insurers will act to advance their own interests and blunt the implicit cross-subsidies that anti-discrimination laws attempt to create.

Nonetheless, it is often said that it is possible to collect empirical evidence that employers and insurers overreact to positive results on genetic tests and thus unfairly act towards individuals who do not pose any additional burden. One study provides self-selected cases in which asym-

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50 See Epstein, supra note 1, at 283-312 (discussing how the narrow interpretation of the exception to sex discrimination regulations (bona fide occupational qualifications) has resulted in unsound decisions that harm both employers and employees, whether male or female).

51 Id. at 291-97 (discussing how the law “disregards those factors most relevant to the operation of a sensible market”).
omatic individuals or carriers were denied employment, insurance, or permission to become adoptive parents because of their condition. However, neither the frequency of these incidents nor the possible justification for them has been determined.

If a person is a carrier of a deleterious gene, and the person's offspring are covered under a proposed insurance contract, a decision by the insurer not to cover is not irrational, given the greater costs that are imposed. If the worker thinks that the risk in question is small, then he probably could (if there were no regulations on the subject) get the desired insurance for unrelated conditions—so long as he is willing to waive coverage for himself (or family members) of the specified genetic condition.

In other contexts, it also seems wholly inappropriate to ignore genetic information. The Billings study included the case of a thirty-one year old woman who was denied the opportunity to seek adoption solely because she was at risk for Huntington's disease. How could anyone seriously protest the decision of the adoption agency? Adoption is not a short-term arrangement, but lasts as long as all shall live. Public authorities would be remiss in placing a child in the hands of a parent, however conscientious, who has a fifty (let alone one hundred) percent chance of becoming severely disabled at some point in the future. Such an outcome would have a grievous impact on any child. Of course, some dreadful outcome could occur in any adoption—a parent could be run over by a truck or contract a deadly disease from a flu shot. But from an ex ante perspective all that one can expect is to play the odds. A fifty percent chance of a cataclysmic outcome is too great a risk to bear.

The adoption agency, like the employer or insurer discussed above, acted in a rational manner. I doubt very much that any such applicant could survive full disclosure, given the number of other prospective parents ready, able, and willing to adopt. The adoption situation is an instance in which testing should be required as soon as a potential parent mentions a serious genetic defect. Additionally, serious criminal sanctions should be imposed on anyone who misrepresents his health status on an issue of this importance. Here, we should not allow charges of "genetic discrimination" to obscure the sensible conclusion that the decision is justified in order to protect innocent children from serious psychological harms.

VI. SOCIAL RESPONSES TO GENETIC DISCRIMINATION

It is now useful to consider what alternative proposals should deal with the question of genetic discrimination. I have already indicated why I

52 Billings et al., supra note 11, at 478 (reporting the findings of a pilot study on genetic discrimination in which 29 respondents reported 41 incidents: 32 involved insurance, 7 involved employment, and 2 involved adoption).
think it is inappropriate to use a system of one-on-one corrective justice to organize the social response to the use of genetic information. That response works well when there is one wrongdoer and one victim. It works far less well when there is an actual victim but no wrongdoer. At that point, one must leave the familiar bipolar arrangements of litigation and explore alternatives that prevent individuals from covertly singling out their own providers.

The first of these alternative responses is probably the best one: do nothing collectively at all, at least through the government. Today enormous charitable efforts are made on behalf of the handicapped. These should be continued, with or without the charitable deductions of our tax scheme. In addition, technical innovation (made easier in a world with open markets) can produce new workplace equipment that will assist disabled workers to assume more productive lives. Such technology will enable certain firms to specialize in hiring handicapped workers. Large firms in certain industries may find it difficult to make these commitments. But the potential for significant gains should prompt some firms to specialize in this market niche. Firms entering this market would probably be able to provide facilities suitable for workers with certain handicaps at a low capital cost. These firms will not have to make extensive renovations to their existing facilities in order to be fully accessible to disabled persons. Specialization can further reduce these firms' cost of accommodation by spreading the cost over a large number of workers. Unfortunately, none of these innovations are of immediate benefit to persons who are at risk to genetic diseases and disorders. However, once established, these institutions will be available to these persons when needed. There is nothing dramatic to this approach. It merely entails a steady expansion of opportunities without government intervention (which, in its effort to equalize wages and opportunities, is far more likely to lower them across the board).

Whatever its quiet virtues, it is painfully clear that the approach of benign nonintervention cannot weather the political abuse it is likely to invite. Individual tales of hardship and woe can be trotted out in great profusion to show a lack of compassion in the face of obvious need (a need—it will not be mentioned—that always grows when there is a government program to satisfy it). Thus, it is politically necessary to contemplate another alternative response to genetic discrimination that still avoids the one-on-one patterns of litigation and subsidy of the ADA. The correct response here should be the same one that is required whenever the social choice is between overt and covert subsidies. The subsidies must be made overt, and they must be in the form of direct charges.

63 See Susan Moran, Virtual Reality Moves Beyond Video Games to Help Disabled, Reuters, Nov. 28, 1993, available in LEXIS, News Library, Wires File (reporting that new computer technology that should enable more disabled workers to work at high tech jobs).
against the public purse. Specifically, the government should fund the additional costs associated with hiring or insuring individuals with genetic defects. If that cost is $10,000 per year, and the cost of hiring or insuring ordinary workers is $1,000 per year, then the government should fund the $9,000 difference from general revenues. Only in this manner will the full costs involved here be brought to the public consciousness, so that honest choices may be made.

There may appear to be little difference between this system of explicit subsidies and a universal requirement to hire or insure all persons regardless of their genetic defects. Both the subsidy tax and the anti-discrimination norm are uniform in their application: Since no one escapes the costs in either setting, it is only a matter of style or esthetics to prefer the tax route over the anti-discrimination route. However, this objection ignores three critical differences.

First, the anti-discrimination laws certainly cannot guarantee that social burdens will be distributed uniformly over society. If workers with genetic defects tend to gravitate towards certain industries, professions, or geographic regions, then however neutral the anti-discrimination approach appears on its face, it will be heavily disproportionate in its impact. Individuals will still retain private knowledge of their physical condition, which they need not disclose in order to move into positions that best minimize their associated health risks. As long as individual job or insurance selection is at work, some skewed distribution of the social costs of this system are assured. The rational actions of individuals will not equalize the burdens on potential employers; they will skew them further. Only a system of taxation and grants would equalize the burdens on the public at large.

Second, the use of the anti-discrimination law is likely to increase the total amount of expenditures for dealing with genetic discrimination beyond what they would be with a system of taxes and subsidies. When the costs of employing genetically defective workers is not made explicit, it becomes extremely difficult to resist new initiatives to aid the disabled, no matter how costly and ineffective the ones presently in place. The entire language of individual rights effectively works to conceal relevant budget constraints. The tendency is to consider each set of rights in isolation from the next, even though each set competes for the same set of limited resources. Placing the subsidy in plain view through an explicit tax forces tradeoffs earlier in the process. Once these conflicts are visible and realized, the aggregate commitment is likely to be reduced. Although that outcome might not please advocates of the disabled, it should please those who have a more disinterested view of proper social decision making; that is, those who think that the commitment to eradicate genetic discrimination can be too large as well as too small.

Third, the anti-discrimination approach often leads to the adoption of general and neutral rules that are inefficient for the firm and society at large. Thus, it is sometimes said that it is better to make conditions safe
for all workers than to select workers for certain kinds of dangerous employment in particular environments. Draper defends this view when she writes: “Priorities in health policy could be redirected toward reducing disease without needlessly penalizing individuals and groups perceived to be genetically at high risk. For example, reducing exposure hazards through engineering controls on chemical emissions can make the workplace safer for everyone.”

Unfortunately, Draper’s nondiscrimination approach contains no cost function, for it ignores the social losses that are generated by the higher capital expenditures that could be averted if only certain workers were hired for particular tasks. It is not the case that selective policy “needlessly” penalizes individuals in the at-risk category. To see why that discrimination is likely to have social benefits, suppose that it takes $1,000,000 to change the equipment so that any person could work, say, in a battery plant with an appreciable risk of lead poisoning. If five hundred workers are needed in the plant, then the average cost per worker of the improvements is $2000. Suppose for one group of workers the gains from these improvements are equal to only $1000 per worker, while for a second group of workers, equal in number to the first, the gains from these improvements are $10,000 per worker. If workers are randomly chosen, then the proposed capital improvement makes sense because the $1,000,000 cost is lower than the losses averted: $(250 \times $10,000) + (250 \times $1000) = $2,750,000$. But if worker selection is possible, the expenditure does not make sense for the anticipated gains are only $500 \times $1000 = $500,000$, when only the low risk workers are chosen. It is far better, therefore, to select one group of workers and avoid the expenditure. Indeed, it might be possible to improve the situation further by some less expensive innovation that is cost justified for this restricted pool of workers.

The more general point also bears noting. A firm that is free to vary either capital equipment or worker mix will always do as well or better than the firm that is constrained on the second variable. Within the firm, rules that ignore relevant information will rarely do better than those that take that information into account. Over and over again the economics literature points out the difficulties that arise when parties have to make joint decisions on the basis of imperfect and asymmetrical information. A sound system of law should allow parties to eliminate both forms of bias in making their decisions. The present attack on genetic discrimination only exacerbates these problems.


55 Id. at S17.
CONCLUSION

The difficulties attending general anti-discrimination law repeat themselves in the novel context of genetic discrimination. The basic approach to discrimination under Title VII of the 1964 Civil Rights Act is to transform contracting in employment markets. But once the absolute right to refuse employment or insurance is denied, win/win is no longer the anticipated outcome of any forced relationship. One party, the member of the protected class, is entitled to demand that others treat him as though the extra costs imposed under contract do not exist at all. Cases that are strongly different from a business point of view are treated as similar by legal fiat.

The consequences of this approach are both regrettable and predictable. When win/lose relationships are required by law, the designated loser has numerous incentives to avoid persons in the protected class. Thus, the level of discrimination actually increases—prompting calls for still more government intervention to combat it. What emerges is a cycle of regulation, evasion, and re-regulation with no obvious stopping point. Even so, today's dominant mode of analysis does not pay so much as a passing nod to the lessons of contracting economics or the logic of public choice. Instead, there is an eager willingness to assume that these situations involve only matters of fairness, and that the situations can be satisfied without taking into account the hidden costs that anti-discrimination policies impose on employers, workers, consumers, and suppliers. Needless to say, any serious questions as to how these policies affect the rate of firm formation, the choice of business projects, and the shift from the employment relationship to independent contracting, are simply not regarded as part and parcel of the overall picture. Similarly, the possibility that the choice of policies might influence the accident or disease rate, and the level of precaution that workers or others might take, is generally overlooked or belittled. When the question of loss prevention is addressed, there is a powerful bias in favor of general and neutral precautions, even when these turn out to be far more expensive than selecting suitable workers for particular environments. Dubious arguments are repeatedly used to conceal the allocative dislocations brought on by the system of anti-discrimination regulation. The issues raised by the advance of genetic knowledge fall into the same pattern. The unvarnished good that comes from the ability to understand and control disease is something we should all welcome. Even so, advances made by genetic testing should not be frittered away by a resort to the ever-coercive, ever-expanding application of the anti-discrimination norm.