

## *Genetic Testing*

MICHAEL BOYLAN

As one looks into the crystal ball concerning the future of medicine, what might be seen? One vision is of genetic testing being carried out by medical technicians and then, as a result of this analysis, patients will be given a diagnosis of what is wrong with them. Next, they will be given a list of courses of action based on the tests. (Again, this list could be obtained by a technician who merely transfers the test results to the accepted database.) Once the list is presented to the patient, then she will choose her treatment (with the help, perhaps, of some online tutorials). Then a clinician will inoculate her or otherwise administer the genetic therapy. The entire process might go forward without the intervention of a physician!<sup>1</sup>

Another scenario might proceed with the physician intervening at the stage of genetic counseling so that the patient might become more aware of the full implications of the various options that confront her. In this view of the future, the physician might become an expert counselor who advises the patient on the background of the choices that she will have to make. In some ways, this harkens back to the origins of medicine in which the physician was a counselor who talked to patients at length about their disease and the options that confronted them.

In the nearer term, one doesn't need a crystal ball to see that genetic testing is already making diagnosis of some hereditary diseases more accurate and that individuals at risk of diseases such as Huntington's disease can be tested and told whether they are at risk of developing the disease before symptoms commence. This essay critically examines the ethical issues involved with genetic testing in the following areas: diagnosis and prognosis, prospective parents, employers, insurance companies, and forensic population research.

### **Diagnosis and Prognosis**

In the crystal ball scenario it was suggested there might be a future in which the physician would be virtually replaced by genetic tests along with preprogrammed responses. I believe that such a model is essentially flawed. The source of the flaw is that it fails to recognize the role that physicians should play in healthcare. Physicians are trained in the art and science of healing. Now, it is true that there is some controversy about what constitutes health,<sup>2</sup> but regardless of how health is determined, essentially the physician is the one who can provide both the fact and the reasoned fact.<sup>3</sup> This distinction refers to an individual understanding both the raw data present in some event versus

one who recognizes the data *and* can assign a cause to it. Only when one has both sorts of knowledge can one say that he has scientific knowledge.

Technicians can be trained to recognize “the fact.” They can prepare and execute the genetic test. They can also plug the results into a computer for the “authoritative choices of action.” But what technicians cannot do is provide the understanding that only comes from knowledge of the reasoned fact. This understanding of causes is especially important when one is examining both the diagnosis (because even with precise tests there may be many “close calls”) and the prognosis (because subtle variations in the facts of the test along with the individuality of the specific patient may require expert interpretation to determine what will happen). This is evident because genetically based multifactorial disease will give an individual an increased risk for the expression of that gene, but the full expression will depend on the environment. For example, a gene for obesity will only make you fat if you overeat. Similarly, genes for hypercholesterolemia will only kick in if you have a high fat diet. These reasons require the intervention of a physician before any therapy should be undertaken.

In the second scenario, the physician is a counselor. This is an appropriate role for the physician, but a physician is more than a counselor. Under the role of the physician as counselor only, the physician becomes something like a “fact giver” who can answer questions posed by the patient, who in turn makes her health decision. This model of extended patient autonomy is too simplistic, and it carries us to the autonomy–paternalism debate.<sup>4</sup> How much control should each person have over her own healthcare choices? On the face of it, most of us would reply, “As much as possible.” Who would turn over control of her life to another? Doesn’t autonomy go hand in hand with the freedom and self-determination that are upheld by most moral theories?

The problem with this view is twofold: First, to be autonomous, one must have adequate knowledge through which all the options are explored and examined. This specialized knowledge is beyond the ken of most patients so that they must rely on others to fill in the gap (often in a simplified version). It is also the case that the professional’s judgment is generally superior to even an enlightened layman’s. Thus, the factual understanding along with the judgment of experience generally puts the physician/nurse into a paternalistic posture from the outset. (Paternalism here is acting in the best interests of the patient. It is especially troublesome when the patient does not understand what is in his or her best interests so that the physician is put in the position of ignoring the patient’s wishes and acting as the physician, rather than the patient, sees fit.) When the physician is only seen as a counselor, the implication is that the patient is competent to make informed judgments about the choice of treatments. But the overwhelming majority of patients do not possess the specialized knowledge requisite to make critical, independent judgments about what the physician puts forth in his depiction of the various alternatives.

In the practice of medicine, patients can (and should) be brought *into* the process, but they are rarely able to become full collaborators. Thus, knowledge and judgment are one pair of limiting factors on patient autonomy.

Second, the patient is often in an impaired state (of one sort) that makes fully deliberative decisionmaking rather difficult, at best. The patient either is in pain, emotionally traumatized, or in some way is not up to her full disinterested, rational capacity. To burden a patient with the full weight of being an autonomous partner in the healthcare decisionmaking process may be unfair to the patient.

Still, there is much to be said for including the patient in the process as much as circumstances permit (often time constraints involved in split-second life-and-death situations act as an exterior constraint). By including the patient in the process, the physician/nurse is recognizing and affirming the dignity of the patient. Too often physicians have included only their more intelligent patients in the decisionmaking process. Also, paternalism can cloak racist or sexist predilections on the part of the physician/nurse. Thus, some form of autonomy seems absolutely necessary.

If both autonomy (in some form) and paternalism (in some form) are inevitable, then how should they be balanced? I believe that a strategy that engages a patient at the level that she is able to comprehend the choices offered and then to enter into a semi-Socratic dialogue with the patient on this level is the best way to proceed because it optimizes autonomy while not recklessly allowing the patient to make an uninformed and clearly medically harmful choice (informed consent). Genetic testing will clearly change the practice of internal medicine, but it will not eliminate or diminish the role of the physician.

### Prospective Parents

Genetic screening and genetic counseling with respect to prospective parents involve two sorts of issues. The first concerns those prospective parents who are not already pregnant. These individuals are considering whether it would be prudent to become pregnant. On the face of it, this seems like a very responsible position to take. These prospective parents want to know the probability of whether their children will have deformities or fatal diseases. As a result of this knowledge, they will decide to have or not have children.

One difficulty with this position is the status of probability. There are several key ways that probability is often interpreted: actual frequency of events, subjectively interpreted frequency of events, hypothetical relative frequency of events, and the propensity interpretation of probability.<sup>5</sup> These various positions base probability on some interplay between theory and observation. For example, if theory predicts that a normal coin tossed in a uniform, nondiscriminatory fashion will turn up 0.5 heads and 0.5 tails, then any actual results that are different from this are likely to be discounted in some fashion. When people slavishly abide by the data in a relatively small sample space, then the "actual frequency" could very well be wrong. For example, I may throw up the coin in 50 trials and get 35 heads and 15 tails. Does this mean that this is the correct manner in which I should view the probability of this event?

In another case, I may think that the probability *must* turn out a certain way and so I discount the data because it *has to turn out* according to my hypothesis (subjective interpretation of data). In its extreme case this subjective interpretation turns science into an a priori exercise.

A third approach is that of hypothetical relative frequency of events. Under this approach one introduces the Law of Large Numbers. In this case the probability of heads ( $h$ ) equaling 0.5 increases as the error ( $e$ ) decreases. If I toss the coin  $n$  times, then as  $n$  approaches infinity,  $e$  approaches 0 and  $h$  approaches 0.5. Although this may sound like an improvement over subjective interpretation of data, is it really? One still solves the problem by a mathematical assertion that it must work that way through a thought experiment that no one can ever really carry out.<sup>6</sup> Thus, though it is a dogma in statistics that each

event is independent, this does not address the issue of how I come up with a reasonable method for determining the basis of statistical probability to begin with. It is not necessarily a mechanical process based on actual data but is instead a dialectical interaction between expected outcomes and the underlying accepted physical dynamics that would explain this sort of outcome. (But this misses the point. It doesn't matter how many times you toss the coin, you still do not have any better idea of whether it will come down heads or tails on the next toss.)

The final gambit of probability to be examined is the propensity approach, in which one is forced to insert a physical mechanism into a logical conditional that will supposedly solve the problem. For example, one might say:  $x$  is soluble if and only if  $x$  would dissolve if  $x$  were immersed under normal conditions.<sup>7</sup> This would seem to solve some problems via physical projectability (à la Nelson Goodman<sup>8</sup>) if it didn't beg the question of what is a "normal condition." Unfortunately, this problem leaves the propensity approach in a condition similar to the subjective interpretation approach.

What, then, should my disposition be concerning statistical confirmation? This is a difficult question and deserves a book of its own. It is not my point here to enter into a lengthy discussion on how probability in biology ought to be interpreted. But the reader should be aware that this is by no means an exact mechanical measure in biology. It is even possible that it is not the same for each science.<sup>9</sup> Instead, it is the intent here to suggest that probability is not an adequately fixed concept through which absolute informed consent can be achieved. Given that the foundation of the experimental principle itself is based on relatively low numbers (such as 200–300 patients in some experimental control group), the best one can achieve is a propensity-style understanding of the possibilities of success. But at worst, this may be merely a subjectively interpreted frequency of events. Such nuances are difficult enough for philosophers of biology who have studied statistics, but they are probably opaque for the average person. Thus, the couple contemplating whether to have children based on genetic screening must take the results of their tests (under the present state of knowledge) as leaning in a particular direction but not factually conclusive.

In the second group of potential parents, one is drawn into a situation regarding abortion. At this stage, the potential parents must evaluate the tests and then decide on an action that is most definitely more complicated. This is because there is another entity involved: the potential person/embryo within the mother. Now, if one accepts all the discourse about probabilities just enunciated, the parents have a very difficult choice to make: whether they should abort the fetus. Unlike the first example, in which the couple is contemplating whether or not to *try to conceive*, in this case the couple has already conceived. The issue of genetic testing in this case revolves around the issue of probability (involved in all experimental tests) and the issue of abortion (one of the possible reactions to the test).

This situation creates an ethical problem for the medical community. How should they advise (counsel) their patients? There are many issues here. For example, at the beginning, what should count as an adequate reason for an abortion? At the very least, this is a controversial issue.<sup>10</sup> It is my position that there must be a significant threat to the worldview of the mother to justify an abortion. But what counts as "significant"? Might it be the case that this is

rather subjective?<sup>11</sup> This is not the venue in which to argue this question, but nonetheless, it is an important issue.

There is also the distinction of “being disabled” (e.g., Down’s syndrome or other physical or mental disability) versus “having an incurable disease.” To be disabled means that one has either an abnormal body and/or an abnormal mind. The agent is not at risk to die or to be in intense, incurable pain. To have an incurable disease means that the agent will (according to the best understanding of modern science) die or be in intense, incurable pain. In the first case, there is, among some, an argument that potentially disabled people have no right to live. The foundation of this argument lies in two propositions:

- $\alpha$ : To have a disabled child is to incur a great deal of discomfort that will negatively affect the mother’s ability to actualize her own life plan.
- $\beta$ : To have a disabled child is to sentence another human being to a life of misery.

$\alpha$  acknowledges that a disabled child will be a burden and curb one’s lifestyle. But is this a significant level of threat? It may seem so, depending on the agent.

$\beta$  makes the paternalistic assertion that unless one is “normal” his life is not worth living. This proposition is patently wrong. There are countless examples of severely disabled individuals who have enriched families, communities, and society.<sup>12</sup>

Thus, if a parent wishes to abort because of disability, she should recognize that it is her own convenience that is at issue ( $\alpha$ , a self-oriented consideration) and not that of the child ( $\beta$ , an action of compassion on behalf of another).

When one’s child has an incurable disease or a condition that will incline it to unremitting pain, then I believe  $\beta$  is an authentic alternative.

These judgments become more acute as the pregnancy advances. But these issues essentially reduce to the abortion question and the grounds (if any) that might legitimate the termination of a pregnancy.

It is also the case that “testing for some genetic predisposition” automatically stigmatizes that trait and inclines prospective parents to believe that the phenotypic trait is a defect that should be “treated” (either by genetic therapy or by abortion). What counts as the normal variation between people and what counts as an abnormality? I believe that there is a strong tendency to treat all differences that are socially inconvenient or competitively disadvantageous as “deformities.”

Because abortion is such a controversial issue, there is a tremendous responsibility that physicians and others involved in genetic counseling (the consequence of genetic screening) incur.<sup>13</sup> As in any medical situation in which something happens contrary to one’s worldview expectations, individuals are very stressed. This creates the possibility of exploitation (paternalism in the bad sense). Some genetic counselor with his or her own agenda to promote can push a patient one way or the other. Informed consent becomes very difficult.

## Employers

As we consider genetic testing in the workplace, it is important to understand that not all businesses are based on the principle of exploitation. In a moral

world, employers seek to provide goods and services at a profit margin not too far from the standard manufacturing formula of materials + labor  $\times$  4 = retail cost of the finished product.<sup>14</sup> There are employers who sincerely desire to make their workplace a safe and congenial place and who seek to share the profits of a successful business with the employees.

However, in the real world, some individuals drawn into careers in business are driven almost exclusively by the desire for the greatest possible profit margin. In the case of business owners, this takes the form of trying to cut costs or to increase productivity. Both of these can involve exploitation—especially when employees are seen as mere extensions of their computers. One doesn't buy a computer without examining the hardware to ascertain whether it fully meets one's needs. Along the same line, one might wish to know as much as possible about an applicant before she is hired. If the employer knows that the applicant has a tendency toward alcoholism, then he might not hire her (even if she doesn't drink). One can also imagine sophisticated tests of the future capable of predicting levels of hormones that might be secreted upon negative sign stimuli (i.e., anger). Because no one wants a hostile employee, economic prudence would cause the business owner to avoid hiring such a worker.<sup>15</sup>

In addition to pre-employment tests, it is possible that present employees, too, might be subjected to these tests so that the organization could streamline its workforce toward more efficiency and greater profits.

What is wrong with these approaches is that they inherently dehumanize the agent. This is because they only view the transaction from the employer's point of view. Certainly it might be more efficient for the employer to test all his employees for their tendencies toward sickness and accident, but it might also be more efficient if the employer could put people in the houses of his choice and control employees' lives as much as possible (as many employers did in the late nineteenth and early twentieth centuries with factory towns). But this ignores the other half of the transaction—the worker. To exercise her basic human rights, the employee must feel free from assault by her employer. Thus, on this line of argument, mandatory genetic screening for purposes of employment is unethical.

Forcing an employee to undergo genetic tests as a precondition of employment (as hitherto described) or as a precondition for continued employment is an instance of unwarranted bodily harm. It is also an instance of exploitation in several respects. First, it makes one accountable for that over which she has no control: her genetic makeup. Penalizing anyone for her genetic composition is contrary to the notion of just desserts. I should only be rewarded or penalized for that which I have done. In this way the just desserts theory is always *retrodictive*. It looks to what you have done and says that, as a result of actions A, B, and C, you deserve  $\phi$ . Genetic tests are, by design, *predictive* so that they will look ahead to what *might be*. The outcome is not certain. The reason for believing that the outcome might occur lies in factors beyond the agent's control. I only deserve that which is in my control and is the result of past actions. Therefore, there is no ethically justified reason for either requiring a pre-employment genetic test or for penalizing someone for the results of the same. To do so violates the terms of the just desserts theory. To fail to respect that theory is to be exploitative. Freedom from exploitation is a basic good of agency.<sup>16</sup> Thus, on this line of argument, genetic screening for employment is unethical.

Second, it is exploitative because the good that the employer wishes to achieve seeks to elevate a lower-level rights claim (about how to most efficiently run a company) over the employee's more fundamental right to be protected against unwarranted bodily harm. To force supervenience of a lower good of agency (because it benefits the agent) over a higher good of agency for another is to be exploitative. Thus, again, this behavior is unethical and should be avoided.

Therefore, because genetic testing is exploitative, represents unwarranted bodily harm, and otherwise denies agents of basic goods of agency, it should be prohibited.

If this argument is sound, then various subsidiary applications also apply. For example, it would be immoral to supply employers with information that they have no legitimate need to know. For example, let's consider an employee's medical records. It is important to keep confidential medical records private for similar reasons. Employers have no moral right to this information, and they should not be allowed to use economic leverage to extract it from those who wish to work for them. Likewise, in countries in which governments work very closely with big business, it would be unethical for those governments to supply businesses with data on citizens that it might have available to it because of its sovereign status in order to control and exploit citizens. There are many such extensions of this sort of case through which some agent works to obtain the information that is, in turn, used by businesses unethically in order that they might make higher profits and obtain stability that is bought at the cost of basic human liberties.

### Insurance Companies

Insurance companies are in the gambling business—they make money by transferring risk from an individual or company to themselves for a price. To minimize their risk and make this transfer economically feasible, insurance companies require two things: (a) as much relevant information as possible, and (b) a large pool of applicants so that the Law of Large Numbers works in their favor. Factor (b) is a function of the sales department. Factor (a) is what is at issue here. The more information an insurer has on its applicants/policyholders, the more accurately it can tailor premiums to exceed expenses. However, blind allegiance to this goal has led to various excesses that with the new genetic information chest may become even more accentuated.<sup>17</sup>

We need only look to the recent past to get a glimpse of what the companies might make of their newfound information. These include (on the life insurance side) creating differential rates for African Americans and Caucasians. Such behaviors are unethical because (even if they are borne out by statistical correlation), they do not portray the *reasons* why this is the case. For example, let us consider the following hypothetical situation. Let us suppose that life insurers in 1970 were calculating rate tables based on the previous 40 years of data (1930–1970). Let us also suppose that African Americans had a much higher mortality rate due to being greatly overrepresented in the ranks of the poor.<sup>18</sup> Let us also suppose that African Americans were overrepresented in the ranks of the poor because they were the victims of Jim Crow laws and other vestiges of slavery. Let us also suppose that lynching also affected the mortality rate of African Americans. Further, let us suppose that lynching is an unjustified and immoral action. Given these facts, it is entirely possible that African

Americans *did* have a higher mortality rate than Americans of European descent. Does this mean that they should be singled out for higher rates? Absolutely not! This is because people should not be penalized by social institutions for that which is not their fault. Just desserts theory suggests that  $x$  deserves  $\phi$  just in case  $\phi$  is the logical consequence of some prior action. This is equally true whether  $\phi$  is something good or something bad. In the case at hand, African Americans are penalized by being charged higher insurance premiums ( $\phi$ ) even though there is no action-oriented reason for ascribing  $\phi$  to  $x$ . In fact, it is likely that the ascription of  $\phi$  to  $x$  is not due to  $x$ 's actions but to the actions of other agents,  $y$  (i.e., those perpetrating racism upon  $x$ ). To penalize  $x$  (African Americans) for the actions of  $y$  (the racist majority society) is to punish someone for being victimized.

Mere statistical correlation of health or mortality to insurance costs ignores the actual social dynamics of *why* the correlation exists in the first place and whether it is deserved or undeserved. (In fact, it is generally held to be the case that in medicine one should accept patients as they are without passing judgment on how they got that way.<sup>19</sup>) At the very least, insurers should not be allowed to take genetic factors into account when setting premiums or offering coverage. To act otherwise would be to create a genetic underclass that would go against the grain of the just desserts theory that lies at the heart of most theories of distributive justice.

### Forensic Population Research

It might be very efficient to create a genetic file on every person in a society so that if there were any physical evidence that lent itself to genetic testing (which is a very large sample) then there might be a very effective means of matching criminal to deed. Proponents of this approach might claim that in many ways this is similar to the advent of fingerprint files. The difference is that, with fingerprint files, the only people who are put in the database are those who have committed a crime or those who for other reasons (such as job clearance) have volunteered to have their fingerprints put into the central files.

However, there are some important differences between fingerprint files and DNA files. The most important is that DNA files are more than mere identifiers; they give a significant amount of information about an individual. This information can be used against a person. For example, if the DNA files showed that a person had the gene for alcoholism and that person was a prominent member of society, then this piece of information might be used as leverage (i.e., blackmail) to get preferential treatment. This is obviously a very great potential for corruption. To get to the root of this grave potential for evil I must consider what the likely consequences are of such a program. The widespread creation of genetic databases for the purposes of forensic files poses dangers concerning (a) privacy and human dignity and (b) informed consent. These two areas are linked, but let us examine each in order. First there is the issue of privacy and human dignity.

I hold that the right to privacy is not absolute but is contingent on other moral claims. This is not a position of utilitarianism but a recognition that there are times in which a person must give up privacy when others in his community face a pressing loss of basic goods. For example, if there were a fire or other natural disaster that occurred in town A, then people in town B ethically



should help the people from town A find food, clothing, and shelter until the process of reconstructing their homes might commence. It doesn't matter that some of the people in town B would rather not be bothered because they wish to maintain their privacy and isolation. The loss of basic goods by the people in town A and the correlative nature of rights claims and duties compel the people of town B to help.

However, the prospect of helping police create genetic databases is different from the scenario of natural disaster. The creation of genetic databases is only remotely (and not proximately) related to helping specific people and the danger of personal harm is much greater. For example, when one participates in such an experiment it is often unclear who might obtain access to the genetic records of Jane Doe. If governments, insurance companies, or local employers have any access, then there are all the potential problems outlined above.<sup>20</sup>

Also, it is a mark of autonomy and dignity to have control of your body (as much as possible). To pressure or force citizens into participating in widespread genetic mapping of a population is to fail to respect the dignity of the citizens. It is to treat them as means only in order that they might give blood for the genetic file. Jane Doe is seen only as a provider of genetic materials necessary for the grand conceptual scheme to be completed.

Obviously, this now runs into informed-consent difficulties. If Jane's dignity is to be considered, then she must be allowed to say "no." The very principle of informed consent in research situations involves the unforced choice of subjects to engage in the project or to decline to engage in the project.

The dynamics of a comprehensive genetic testing program of a population create the situation in which a conflict of interests exists. On the one hand, the police need a very large sample, and so there is incentive to do whatever is necessary to bring this about. On the other hand, there is the citizen's right to make her own choice through a careful process of informed consent (that may significantly lower the sample and may, in fact, invalidate it).

The unfortunate history of police departments' actions in the past is an additional factor. There are some (perhaps many?) who are attracted to police work because it offers them the legal opportunity to exert their dominant presence among others. In this situation, it may be inevitable that coercion and *not* implied consent is the order of the day.

If the police research team needs to cross the line and violate the rules of implied consent or otherwise fail to respect the privacy and dignity of the potential research subject, then that police research team is acting unethically in its "means" and has crossed the boundaries of the limits of science into forbidden territory.

To address these concerns, I feel that the same protocols that have been observed in the creation of fingerprint files (i.e., only charged criminals, who if found innocent will have their files deleted from the database, and those volunteering to be profiled) should apply. There will be no widespread genetic databases because of the interference with the issues of autonomy and informed consent.

## Conclusion

What makes the word "genetic" so significant when attached to "testing" is that the genome promises to contain so much information on an individual that

there is a significant potential for good and for ill. It will only be by vigilance and adherence to traditional moral distinctions about exploitation, autonomy, and a sensitivity to the hierarchy of various goods in relation to the fundamental conditions of agency that we will be able to effectively evaluate the new versions of traditional moral questions that genetic testing raises. This is why applied ethics will continue to be a growth industry in the years to come.

## Notes

1. Parts of this essay are based on my book (with Kevin Brown) *Genetic Engineering*. Upper Saddle River, N.J.: Prentice-Hall, 2002.
2. For example, see: Caplan A, Engelhardt, Jr., HT, and McCartney JJ, eds. *Concepts of Health and Disease: Interdisciplinary Perspectives*. Reading, Mass.: Addison-Wesley, 1981; and Engelhardt, Jr., HT, Wildes KW. Health and disease; IV: Philosophical perspectives. In: Reich WT, ed. *Encyclopedia of Bioethics: Vol. 2*, Rev. ed. New York: Simon & Schuster Macmillan, 1995:1101-6.
3. See: Aristotle. A.Po. II.1.
4. For an introduction to some of the most important questions in paternalism and autonomy, see the following: Annas GJ. The emerging stowaway: patient's rights in the 1980's. In: Gruzalski B, Nelson C, eds. *Value Conflict in Health Care Delivery*. Cambridge, Mass.: Ballinger, 1982:89-100; Bassford HA. The justification of medical paternalism. *Social Science and Medicine*. 1982;16(6):731-9; Beauchamp TL. The promise of the Beneficence Model for medical ethics. *Journal of Contemporary Health Law and Policy* 1990;6:145-55; Childress JF. *Who Should Decide? Paternalism in Health Care*. London: Oxford University Press, 1982; Childress JF, Siegler M. Metaphors and models of doctor-patient relationships: their implications for autonomy. *Theoretical Medicine*. 1984;5:17-30; Coleman L. *The Reign of Error*. Boston: Beacon Press, 1984; Dworkin G. *The Theory and Practice of Autonomy*. New York: Cambridge University Press, 1988; Hope T, Springings D, Crisp R. Not clinically indicated: patients' interests or resource allocations. *British Medical Journal*. 1993;306:379-81; Luna F. Paternalism and the argument from illiteracy. *Bioethics* 1995;9(3-4):283-90; Mahowald MB. Against paternalism: a developmental view. *Philosophical Research Archives* 1980;6:1386; Pinkus R. The evolution of moral reasoning. *Medical Humanities Review* 1996;10(Fall):20-44; Sulmasy D. Managed care and the new paternalism. *Journal of Clinical Ethics* 1995;6(4):324-6; Wicclair MR. Patient decision-making capacity and risk. *Bioethics* 1991;5:91-104; Wulff H. The inherent paternalism in clinical practice. *Journal of Medicine and Philosophy* 1995;20(3):299-311.
5. For a discussion of these various ways to understand probability in the context of biology see: Sober E. *Philosophy of Biology*, 2nd ed. Boulder, Colo.: Westview Press, 2000:chap. 3; Mills S, Beatty J. The propensity interpretation of fitness. *Philosophy of Science* 1979;46:263-88; Beatty J, Finsen S. Rethinking the propensity interpretation: a peak inside Pandora's box. In: Ruse M, ed. *What the Philosophy of Biology Is*. Dordrecht: Reidel, 1989:17-30.
6. This is also the problem with so-called exhaustive induction, in which one is theoretically forced to examine each and every possible case (when this is clearly impractical).
7. See note 4, Sober 2000:63.
8. Goodman N. *Fact, Fiction, and Forecast*. Cambridge, Mass.: Harvard University Press, 1955: chaps. 3-4.
9. I am thinking here of the Uncertainty Principle (the philosophy of physics), in which only actual frequencies seen in the context of the Law of Large Numbers will do. This would not be a fruitful interpretation of statistics from the point of view of the philosophy of biology.
10. My position on abortion is set out in: Boylan M. The abortion debate in the twenty-first century. In: Boylan M, ed. *Medical Ethics*. Upper Saddle River, N.J.: Prentice-Hall, 2000.
11. This sense of arbitrariness is mitigated by my Table of Embeddedness (chapter 2 of *Genetic Engineering*; see note 1, Boylan 2002). In this case various goods are ranked according to their proximity to the fundamental conditions of action. Those goods that are more primary ground a stronger rights claim. Thus, in this instance, the goods that the parent(s) will lose must be weighed against the depiction of the fetus and the development of the pregnancy (with a fetus past the first trimester demanding significantly more respect because of its developing powers of rational consciousness).

12. The examples are almost endless, but to name just a few: Helen Keller, Franklin D. Roosevelt, Stephen W. Hawking, and Lawrence C. Becker.
13. This question (particularly in the context of the rights of the disabled) has been discussed by: Chadwick R, Ten Have T, Husted J. Genetic screening and ethics: European perspectives. *Journal of Medicine and Philosophy* 1998;23(8):255-73; Henn W. Predictive diagnosis and genetic screening: manipulation of fate? *Perspectives in Biology and Medicine* 1998;41(2):282-9; Henn W. Genetic screening with the DNA chip: a new Pandora's box? *Journal of Medical Ethics* 1999;25:200-3. Then there is the issue of consistent rules for counseling patients. This is enormously complicated. For some of these issues see: Modell B et al. Informed choice in genetic screening for thalassaemia during pregnancy: audit from a national confidential inquiry. *British Medical Journal* 2000;320(5):337-42; Bennett RL et al. Inconsistencies in genetic counseling and screening for consanguineous couples and their offspring: the need for practice guidelines. *Genetics in Medicine* 1999;1(6):286-92. The relationship of these decisions to individual autonomy is explored by: Gavaghan C. Deregulating the genetic supermarket: preimplantation screening, future people, and the harm principle. *Cambridge Quarterly of Healthcare Ethics* 2000;9:242-80.
14. For an exposition of some of these principles, see: Boylan M. The principle of fair competition. In: Boylan M, ed. *Business Ethics*. Upper Saddle River, N.J.: Prentice-Hall, 2001.
15. Another twist on this scenario is the activities of insurance companies. Insurance companies long to obtain further information on their statistical sample space so that they might more precisely actuarially rate the proposed risk. Though this may be the most "efficient" way to operate, it is certainly not the best. Insurance companies need to be restrained from their desire for efficiency just in case their proposed action will make them act immorally. For a discussion of a few of these issues, see: Jaeger AS, Mulholland WF. Impact of genetic privacy legislation on insurer behavior. *Genetic Testing* 2000;4(1):31-42.
16. I argue in *Genetic Engineering* that ethical rights claims are based on their proximity to agency; see note 1, Boylan 2002:chap. 2.. This is similar to Alan Gewirth's argument in: Gewirth A. *Reason and Morality*. Chicago: University of Chicago Press, 1978:53-8.
17. For a discussion of the context of genetic testing and insurance practices, see: Anderson WF. Human gene therapy. *Nature* 1998;392:25-30; Gostin LO. Genetic discrimination: the use of genetically based diagnostic and prognostic tests by employers and insurers. *American Journal of Legal Medicine* 1991;17:109; Haim P. Insurers, consumers, and testing: the AIDS experience. *Law, Medicine, and Health Care* 1987;15:212-22; Hudson KL et al. Genetic discrimination and health insurance: an urgent need for reform. *Science* 1995;270:391-3; Jaeger A. An insurance view on genetic testing. *Forum for Applied Research and Public Policy* 1993;8:23-5; Pokorski RJ. Insurance underwriting in the genetic era. *American Journal of Human Genetics* 1997;60:205-16; Verma IM. Gene therapy: promises, problems, and prospects. *Nature* 1997;389:239-42; Warren ST, Nelson DI. Advances in molecular analysis of Fragile X Syndrome. *JAMA* 1994;271:536-42.
18. Being among the ranks of the poor, per se, will not increase mortality rate (though lack of nutrition and healthcare are certainly disadvantages). However, when one considers what it is like to be poor and to be a part of a persecuted minority group, then there are many possible physical disorders that may occur. The fact that hypertension (though the etiology of this disorder is not completely understood) is so high in African Americans leads one to believe that it may be environmentally caused and much of this cause may be attributable directly or indirectly to discrimination.
19. For a discussion of this position, see: Rhodes R. A review of ethical issues in transplantation. *The Mount Sinai Journal of Medicine* 1994;61(1):77-82.
20. For a further discussion of some of these issues concerning the abuse of genetic data, see: McEwen J. Forensic DNA data banking by state crime laboratories. *American Journal of Human Genetics* 1995;56:1487-92; and Mulholland WF, Jaeger AS. Genetic privacy and discrimination: a comprehensive analysis of state legislation. *Jurimetrics* 1999;39:317-26.