Informed Decisionmaking in Genetic Counseling: A Dissent to the "Wrongful Life" Debate

Alexander Morgan Capron
University of Pennsylvania

Follow this and additional works at: https://www.repository.law.indiana.edu/ilj

Recommended Citation
Available at: https://www.repository.law.indiana.edu/ilj/vol48/iss4/4

This Article is brought to you for free and open access by the Law School Journals at Digital Repository @ Maurer Law. It has been accepted for inclusion in Indiana Law Journal by an authorized editor of Digital Repository @ Maurer Law. For more information, please contact rvaughan@indiana.edu.
INFORMED DECISIONMAKING IN GENETIC COUNSELING: A DISSENT TO THE "WRONGFUL LIFE" DEBATE*

ALEXANDER MORGAN CAPRON†

The relationship between a genetic counselor and his patients is a delicate, complex and important one. Treating, as it does, subjects of great moment—the prevention of crippling diseases, and even life and death themselves—it commands growing public interest and scrutiny, especially as the counselor's predictive skills increase. It involves not only parents but also geneticists, physicians, clergymen and others in more lengthy and careful contemplation of the conception and birth of a child than occurs in any other type of "planned parenthood." Its highly charged subject matter and deeply involved participants open it to the internal and external pressures which encumber all significant decisions. Yet when we look at the moral and legal rights of the participants in genetic counseling, we inevitably see only the sharp features, outlined in black and white, and not the interesting shadings of gray.

While this difficulty is inherent in any attempt to state general rules about complicated and varied relationships, it will be particularly pronounced in the discussion which follows. There are any number of rights which could be asserted on behalf of those who play a role in the relationship—including the rights of the genetic counselor, the parents, the unborn child, other family members and even of professional and public institutions. In this essay I have chosen to focus on the immediate participants—counselors and parents—and on one right which seems to be of central importance—the right to be an informed decisionmaker.

OF RIGHTS: MORAL AND LEGAL

What do we mean when we say a person has a right? The term "right" is customarily used when a person has a claim on the way another person or group behaves, especially toward himself. The concept is often defined by its reciprocal: to say that A has a right is to say that B has a duty to do, or abstain from doing, something affecting A's interests. Sometimes "right" and "privilege" are used interchangeably, but "right" is by far the stronger term, suggesting that B's duty cannot be

---

*This article is based on a paper presented at a symposium on "Genetic Counseling and the Uses of Genetic Knowledge," Oct. 10-14, 1971, sponsored by the Fogarty International Center for Advanced Study in Health Sciences (National Institutes of Health) and the Institute of Society, Ethics and the Life Sciences.

† Assistant Professor of Law, University of Pennsylvania.
altered without A's approval. If A has a "legal right," he can compel B to perform his duty by calling on the organized power of the state; if his right is a "moral" one, he has to rely on B's conscience (abetted perhaps by persons or groups possessing moral authority) to compel B to fulfill his duty.

My premise is that in genetic counseling the parents have a legal right to be fully informed decisionmakers about whether to have a child; and, likewise, the genetic counselor has the duty to convey to those he advises a clear and comprehensible picture of the options open to them, the relative risks and benefits, and the foreseeable consequences of each option, to the best of his ability. This formulation is basically a legal one, and it suggests that the parents have recourse to the authority of the state should the counselor breach his duty by negligently or intentionally withholding options or misdescribing their risks, benefits and so forth. This right can also be seen from a "moral" vantage point, however. A dominant ethic in Western culture is the importance and inviolability of each human being, from which is derived a right to make decisions about one's life and to be "master of one's fate."

Despite the broad way in which this right to be an "informed decisionmaker" can be stated, it is certainly narrower than many rights which have been asserted in genetic counseling. I would defend the primacy of this right for a number of reasons. First, it reflects the basic underlying moral and legal principles such as the sanctity of life or the protection of members of the community as well as any other, such as "the right of every child to be born with a sound physical and mental constitution based on a sound genotype." Second, it avoids, from a legal point of view, ticklish problems concerning "the quality of life" which inhere in other such formulations. Third, it limits the issues under review to those which are resolvable given the present state of genetic knowledge.

This limitation on the definition of the right may meet with objection, since discussions of genetics often range over a host of moral principles which in this view are not necessary to the discussion. The question

1. The term "moral right" is something of an anomaly. While we speak easily of a "moral duty," the legal unenforceability of that duty makes strained any reference to a corresponding "right." We usually say a person has a "moral right" precisely when we believe that he ought to be able to compel another's behavior but legally cannot.

2. For the moment, I shall use the phrase "parents' rights" to include both those they assert on their own behalf and those they assert as the representatives of others, particularly their unborn child. See p. 596 infra.


is thus raised whether the moral conclusions reached in discussions of
genetic policies are necessarily translatable into legal conclusions. In
seeking to answer this question I hope to demonstrate two things about
my formulation of the legal right set forth above: (1) that it operates
in the genetic counseling situation independently of any "moral" con-
cclusions; and (2) that, for the time being at least, it is not only a neces-
sary but also a sufficient standard for regulating the participants in genetic
counseling. To do so, I must first ask whether legal rights can stand
apart from moral ones.

**HOW ARE LAW AND MORALITY CONNECTED?**

I shall take the hypothesis that "there is no necessary connection
between law and morality" as the starting point for this discussion.
While this is an unresolved issue among philosophers, it is useful to
consider, first because it shows the need for building separate, albeit re-
lated, lines of argument in the moral and legal spheres, and second be-
cause it may demonstrate that courts, in disposing of the legal issues in
genetic counseling cases, need not venture into the "moral thicket," to
paraphrase Justice Frankfurter.

The term "connection" can imply an historical relationship, a chance
overlap or a strict cause-and-effect nexus. In an historical sense, there
can be no denying that our system of laws has been closely related to
morality, particularly that body of conventional morality known as re-
ligion. Even when a link is not provable as a matter of historical fact, the
occurrence of similar rules in the legal and moral domains suggests the
existence of a connection, perhaps one with an anthropological explana-
tion. Yet neither of these meanings, nor even that of cause-and-effect is
adequate once "connection" is modified by "necessary," for one is then re-
fering to a conceptual relationship. In this sense, to speak of a "necessary
connection" between a moral right and a legal right is to argue that the
ultimate rationale for the existence and validity of the legal right is to be
found in the moral one. Any less rigorous meaning of "necessary con-
nection" raises the danger of *post hoc* reasoning: For even without a
knowledge of the moral views of a society, one can, from a careful ex-

---

1971); Hart, *Are There Any Natural Rights?*, 64 PHIL. REV. 175 (1955).
7. It is often assumed that the asserted connection between law and morality
refers to law incorporating, or resting on, morality. The opposite meaning is equally
plausible, but the interesting questions this raises go beyond the scope of this article.
What is at issue here is whether the Old Testament view of the law as "a lamp unto
the feet and a light unto the path," _Psalm_ 119:105, should be taken as a description of
law's effect on morality or merely on conduct.
amination of its legal system, derive a statement of that system's view of
man which could be cast in moral (or psychological or political) terms;
but this falls far short of demonstrating the necessity of the connection,
or even of showing which way it runs.

Law as Codified Morals

There are two ways in which "morals" might be said to be related
to the law. The first—the one which people most often have in mind
when they speak of law enacting morality—is illustrated by the set of
criminal laws which has punished abortion, prostitution, homosexual
activities and the like. As an historical matter, it is undeniable that the
felt immorality of feticide and of variant sexual practices accounts for
their prohibition by statute; however, since an examination of such re-
lationships shows them to be merely historical, our standard for "con-
nection" has not been satisfied.

Over the years, ethical thinkers have contributed to the growth of
society's legal system and have guided the conscience and behavior of
its members. Most prominently, organized religion has had profound
direct and indirect impact, through ecclesiastical law and general reli-
gious precepts, on legal rules not only on the Continent but also in the
common law and in our own constitutional system. This influence is
even reflected in the language and customs of the law: for example, the
"repentence" for which a judge looks in setting the sentence of a con-
victed man, or the oath on the Bible by which witnesses affirm that they
will tell the truth.

During the period when the Anglo-American legal system was
molded by the common law judges, legal rules represented what the
courts took to be the community's view of the proper relationship of moral
men. In these circumstances, the law was merely a formal endorsement
by the community of views which its members (or most of them) al-
ready held. However, once legislation began to play an important or
predominant role in the legal system, the more complex motivations
of law-makers became apparent. It became more difficult simply to assert
that since the people create the law and the people hold moral views, there-
fore the law enacts morality. This syllogism fails because under it we

8. Under our constitution, the historical connection between a statute and that
body of morality known as religion can present some intriguing questions of legislative
intent and legal effect, but these need not detain us now. See generally Ely, Legislative
9. Or at least, so the decisions articulate. We need not here explore the relative
impact of moral views compared with economic and class interests on the outcome of
common law cases.
could as well say that law enacts biology, economics, psychology, astrology or any other set of views which people hold and often believe in strongly.

**Law in Place of Morals**

The other sense in which law and morals might be said to be connected—a sense in which a law-biology connection would not be even facetiously asserted—relates to the role law has as replacement for morality. Usually in peaceful, smoothly-functioning relationships and stable societies, there is little need for law to play an active role in many areas, such as the family or education. The conduct of individuals is guided by the commonly-accepted norms for these relationships: for example, children obey their parents and teachers, achieving greater independence with their increased maturity; parents are responsible for the well-being of their children; old people can rely on their position within the family to provide respect and, if need be, sustenance. These norms are not only provided by custom but also are explicitly sanctioned by moral codes enforced either by internally-assimilated standards or by outside forces operating with moral authority. Once this system breaks down, once the commonly accepted view of proper behavior is more widely questioned and less commonly accepted, however, people may turn to law to restore relationships. In the process, law brings along new sanctions, new actors and new modes of action; in effect, new relationships are created although they may bear traditional names. While it is possible to see this as just another instance of law enforcing morality, the operant fact here is the moral system's failure to function. The legal system's intrusion, then, might more accurately be seen as a desertion of morals for law, and law may be regarded as a set of regulations fashioned on the basis of the science of human behavior rather than on a priori principles.

**Justice and Fairness**

In neither of these senses, then, does it seem accurate to say there is any necessary link between law and that notion of morals with which it is commonly associated. Yet one principle is not so easily disposed of—the principle of fairness. To hold that a law does not comport with a person's standards of sexual behavior is one thing, but to declare that it does not square with his standards of fairness or justice is quite another. The standard of fairness, like the standard of sexual behavior, can be

---

12. Comparable, for example, to a common law judge creating the crime of "larceny by trick." King v. Pear, 158 Eng. Rep. 208 (1779).
seen as a moral one, but unlike the latter, its connection to law seems almost indisputable. It provides the yardstick by which individual laws and decisions as well as whole legal systems are judged; its connection with "the very notion of proceeding by rule is obviously very close." In deciding on the distribution of benefits and burdens or the compensation of injuries, it is the precept to which the law turns. As Professor Hart has formulated it, the principle of fairness commands that we "[t]reat like cases alike, and treat different cases differently." All this does not, however, make out a necessary connection between law and morality. First, the "treat like cases alike" precept is functionally incomplete; a definition of likeness must also be given, and this need not be in "moral" terms. Some would argue that other standards of judgment (e.g., rationality or reasonableness) are thereby simply made part of the concept of justice and that the overall concept remains a moral one. Under this view, to state that it is unreasonable to punish blue-eyed thieves but not brown-eyed ones is to make a moral statement. It can be argued equally well that the nonmoral judgment (i.e., the rational definition of where lines are drawn for "like" classes) is the determinative one and the principles of fairness and justice are only secondary.

The Necessity of Justification

My hypothesis—that law is not necessarily connected to morality—assumes that there is some difference between the two concepts. A moral system serves as a guide to conduct which is considered "good" in itself or which will lead to "the good" (variously defined as happiness, holiness, etc.). The system may be seen as a discoverable natural pattern or as a strictly human creation, or somewhere in between; that does not alter the basic definition. Law can be viewed as a collection of enforceable rights and responsibilities through which the members of a society relate to one another and to their society as well as the system by which the society assigns rights and responsibilities and resolves asserted conflicts among its members.
Law and morality are similar in that both attempt to prescribe human behavior according to a set of rights and duties. If one adheres to a moral or legal system, one does nothing more than it gives him the right to do, and nothing less than it makes it his duty to do. Yet these definitions also suggest some differences between morals and law. First, the heart of a moral system is its judgments of right and wrong in an outward-referencing sense, while the heart of the legal system is the ordering of relationships, in which only consistency with the system's own rules need be sought.

A second difference arises from this matter of "reference." If you found yourself alone on the proverbial desert island, you might find cause to employ a moral system, but you would have no use in any reasonable sense for a legal system. If, however, I were then to be washed ashore on your island, a need for laws would arise. If I decided that I did not like a law, you would then have to make reference to some "justification," which demonstrated my obligation to obey the law.

To do this, you would make reference to a principle that I acknowledged as binding which either justified the particular disputed rule or established my general obligation to obey all valid rules including the one in question. Law, in other words, has two meanings: that of individual rule and that of a system of rules. The positivists argue that law in the narrower sense can find its justification by reference to law in the broader sense. Binding legal duties (or, more generally, legal rules) are those which meet the criteria of what Professor Hart calls the "rule of recognition," which in turn rests on its acceptance by members of the society. Thus, neither individual rules nor the system as a whole need be traced back to a "moral" wellspring. The role of morality in this

incorporating them for the present, ought to be regarded as part of our concept of law. However, what is said hereafter is not affected by these distinctions.

17. We might decide not to have any "laws" as such, but to talk through each matter on its own merits; that decision, however, would in itself create a legal system, one of negotiation without precedent.

18. The question of justification is what really lies behind most discussions of the connection between law and morality. The question underlying such discussions is whether one need obey a law for which the connection is missing.

19. Hart, supra note 13, at 92 passim. In our society a law which meets Professor Hart's rule of recognition is one which has been adopted by the legislature and signed by the chief executive.

20. Id. at 54-60. In addition, in Hart's scheme some rules—or customs, really—are binding because they are accepted by most members of the society, rather than achieving validity by means of the master rule. Id. at 54-60.

21. Extra-legal (possibly moral) principles do have a place in Hart's system. When a "hard case" is not decided by an existing rule, or when an existing rule leads to a harsh result, the "rule of recognition" gives certain people, typically judges, discretion to fashion a new rule. In exercising this discretion the judges may rely on extra-legal standards; consequently, some individual laws may, but need not, be grounded in moral principles. This explains the connection between morals and certain laws which was discussed in the text. Critics of the positivist model insist
system is to supply a standard of judgment or criticism based on the "fairness" or "justice" of a rule.

INFORMED DECISIONMAKING: A LEGAL RIGHT?

As this brief survey suggests, the thesis of "no necessary connection between law and morality" is valid to a limited extent. If we adopt the positivist view, reference need not be made to moral rights or duties to justify either individual legal rights or duties or the aggregate legal system. We may sometimes invoke the moral judgment that "this law is unjust," but this is only a criticism of the law and does not reduce the law's binding force on its addressees, provided its valid pedigree is recognized.22

Does the "informed decisionmaker" rule set forth at the outset, then, state a legal right? There are two aspects to the right, information and decision, both of which have been recognized by the law. The right to receive certain information is of recent origin and stems from the recognition that knowledge is necessary to make meaningful the power to decide.23 The doctrine of "informed consent," for example, has been fashioned in cases involving malpractice claims arising out of the physician-patient relationship—a situation which resembles and usually parallels the relationship of genetic counselor and parents.24 The second

that the legal system is more than just a collection of individual laws. For example, Professor Ronald Dworkin's contextualist approach attempts to supply a theory of legal obligation that squares with our social practices; he is particularly concerned with avoiding the positivist's use of "discretion" which leads to ex post facto results inconsistent with our social practice of blaming someone only for the breach of an existing social obligation. Unlike the positivist judge who may refer to standards outside the law as a guide to decisionmaking, a Dworkinian judge is bound by certain principles which, as such, are part of the law. In other words, Dworkin denies the dichotomy between law and morals and locates the notion of legal duty in the general practice of social obligation. Dworkin, The Model of Rules, 35 U. Chi. L. Rev. 14, 31 passim (1967).

22. Our discussion of this point would have to go into much greater detail if we were faced with deciding whether to punish a person who engages in civil disobedience against a law he believes is unjust, or conversely, a person who committed what is now regarded as an unjust act in compliance with an apparently valid law which he believed was binding on him. The questions raised by the present topic, while complex, are less knotty.


The doctrine of "informed consent" is a hybrid; its parentage includes both battery and negligence actions. In analyzing genetic counseling, negligence provides the most relevant precedent because the issue is the failure to convey the diagnosis rather than the lack of permission for any "touching" involved in making the diagnosis.

24. An ongoing study of genetic counselors in this country being conducted by
right, the right to self-determination, has a fundamental place in Anglo-American law; its indisputable position is reflected in the rules of consensual agreements in contract law and consent as a defense to assault and battery in tort law. As previously suggested the two rights have joined together in an

obligation of a physician to disclose and explain to the patient as simply as necessary the nature of the ailment, the nature of proposed treatment, the probability of success or of alternatives, and perhaps the risks of unfortunate results and unforeseen conditions 25

before obtaining the patient's consent.

The Problems with Therapeutic Privilege

Despite this rather clear rule, physicians often withhold information from their patients. Usually this reflects only an understandable desire to "keep things simple" and "move patients along." If challenged in such a case, a physician would probably admit that he had not adhered to the standard of full disclosure but argue that no harm had been done thereby. In some instances, however, failure to disclose is based on intention rather than inadvertence. When he believes his patient's "best interests" would be served by ignorance, a physician may decide to withhold diagnosis, prognosis or information about an impending medical intervention. This may occur, for example, in the case of a patient who is found to have a malignant tumor but is told that the growth is benign in order that "his final days can be happy ones." All the problems raised by this "therapeutic privilege," 26 and few of its justifications, seem to be present in genetic counseling, although it is apparent that most counselors presently believe they have an unqualified right to withhold information from their patients. 27 While the question is surely a difficult one, it must be stated

sociologist James R. Sorenson of Princeton indicates that upwards of 80 per cent hold medical degrees. (Sorenson is still analyzing his data. He describes the scope of his study in a monograph in the Russell Sage Foundation's "Social Science Frontiers" series. J. SORENSON, SOCIAL ASPECTS OF APPLIED HUMAN GENETICS (1971).) Assuming then that genetic counselors are physicians with special advanced training or fall into a special professional class, it seems likely that they will be held to a higher standard of skill and knowledge than ordinary medical practitioners and will not be able to escape under the "locality rule" in those jurisdictions in which it is still applied.


26. See, e.g., Smith, Therapeutic Privilege to Withhold Specific Diagnosis from Patient Sick with Serious or Fatal Illness, 19 TENN. L. REV. 349 (1946); 75 HARV. L. REV. 1445 (1962).

27. This is an impression drawn from conversations with a wide range of genetic counselors, including many who describe themselves as "nondirective." See generally
that "therapeutic privilege" is not wise or proper in this setting. Counselors should instead proceed on the premise, in the words of one court, that "the law does not permit [the physician] to substitute his own judgment for that of the patient by any form of artifice or deception."28

Theoretical Issues: The Role of Freedom

The theoretical problems involved are highlighted by Dr. Robert Murray's statement that a patient's freedom is limited if knowledge (specifically, that he carries the sickle cell trait) is communicated when no treatment is possible.29 Yet, under this flag of "enhancing freedom," freedom—in Isaiah Berlin's "positive" sense of being able to make choices for oneself—has been severely limited. We deny the person before us freedom of choice (by depriving him of the knowledge which would inform, or even prompt, his choice) in order to increase his "true freedom" as we perceive it. Substituting our view of what should be done for that of the persons affected is always a dangerous course, and it is particularly so in the case of genetic counseling because of the great risk that counselors will not choose as their patients would or even in their patients' best interests.

Practical Issues: Values and Training

The practical objections to the modus operandi adopted by such genetic counselors are as follows. First, genetic counselors, unlike the family doctors of yore, are not intimately acquainted with their patients, their families or their communities. Even the amount of sensitivity and time which is expended by the few first-rate counselors at present cannot be expected on the part of all counselors, particularly once the demands on counseling facilities increase substantially, as they are bound to do. As counseling becomes more routine, part of accepted practice should not be the withholding of information from the counselees on the spurious grounds that the counselors know what is best for patients whom they hardly know at all.

A second objection derives from the innumerable internal and external pressures operating on counselors which will interfere with an accurate assessment of their patients' best interests. The easier course for most counselors is not full disclosure on a computer print-out,30 but the withholding of information which if disclosed would involve the coun-

Ethical Issues in Human Genetics (B. Hilton, D. Callahan, M. Harris, P. Conliffe & B. Berkley eds. 1973) [hereinafter cited as Ethical Issues].

30. Ethical Issues, supra note 27, at 92 (discussion of D. Brock).
sor in a long and arduous process of truly counseling his patients. In short, it is more efficient for him to make the choices himself rather than to bring into open discussion facts such as carrier status which are difficult to explain or discuss. This indicates another pressure, namely, the well-known tendency of physicians to overreact to disease. The phenomenon of regarding disease as an enemy to be conquered has its origins, I suspect, in the medical fraternity itself. Professor Renée Fox has observed that this frame of mind may be quite necessary for physicians, particularly those working on the frontiers of medical science. Whether it is necessary or merely a reflection of doctors’ training or the pre-existing psychological makeup which brought them into the profession, this attitude hardly aids a counselor in making a good choice for his patient. Dr. Michael Kaback, a pioneer in mass screening for Tay-Sachs disease heterozygotes, has remarked that he is more upset and distressed by the diagnosis of the trait than are the carriers to whom he communicates this fact.

Third, a physician’s judgment may also be clouded by his own set of values, which will not necessarily correspond to his patient’s. The potential for conflict is especially great in genetic counseling in which the options elected depend on one’s traditional concept of family, the morality of divorce and of abortion. The physician’s map of social goals may also differ markedly from the one held by the patient. A counselor who, for example, strongly believes in the elimination of a genetic disease for eugenic reasons ought to convey his eugenic premises to any woman to whom he suggests an abortion for that disease, lest her choice be uninformed.

33. We forthwith acknowledge our awareness of the sensitive and emotional nature of the abortion controversy, of the vigorous opposing views, even among physicians, and of the deep and seemingly absolute convictions that the subject inspires. One’s philosophy, one’s experiences, one’s exposure to the raw edges of human existence, one’s religious training, one’s attitude toward life and family and their values, and the moral standards one establishes and seeks to observe, are all likely to influence and to color one’s thinking and conclusions about abortion. Roe v. Wade, 410 U.S. 113, 116 (1973).
34. This formulation highlights the question of what “facts” must be disclosed. Ordinarily, this question may not be an easy one, due to the uncertainty of how much of a diagnosis or description of risks, side-effects and so forth is fact, but at least it is limited to facts about the patient, such as the result of lab tests. But what of further information about the significance of the diagnosis or about the counselor’s premises? I believe that these too must be included in the information required to be disclosed; while we may for economy’s sake refer to disclosing facts, I recognize that this phrase
The withholding of information is not only theoretically and practically unwise, but unjustified since the opposite course is perfectly acceptable. The terms in which the alternatives have been posed—revealing the "brutal truth" or keeping the patient in "benign ignorance"—give a false impression of the courses open to the counselor. They are reminiscent of the early discussions of how much dying patients should be told which also obscured much due to the blinding dichotomies employed. Only slowly did a few practicing physicians and sociologists suggest that the question was not whether to tell but how to tell and how fast to tell. Dr. Jerome Lejeune's method of informing couples which partner is a trait carrier\(^6\) illustrates the advantages of beginning with the assumption that the information should be conveyed and then applying one's creativity to devising a sensitive, humane means of conveying it.\(^3\)

Recent cases which have enlarged the physician's duty to disclose will probably have a like effect on the rights of the participants in genetic counseling. These cases have made it clear that the standard for disclosure is what a reasonable patient would want to know about his condition rather than what other physicians in the community typically disclose. In some instances, of course, counseling may be sought where no encompasses hard factual data as well as opinions, beliefs and interpretations. Indeed, the very nonfactual nature of the latter category suggests the great need that it be disclosed and that the disclosure include as full a statement of the competing opinions, beliefs, and interpretations as is possible.

35. See, e.g., B. GLASER & A. STRAUSS, AWARENESS OF DYING (1965); Becker & Weisman, The Patient With a Fatal Illness: To Tell or Not to Tell, 201 J.A.M.A. 646 (1967).

36. ETHICAL ISSUES, supra note 27, at 69-70 (discussion of J. Lejeune).

37. Another way of stating my thesis is that the best interests doctrine is acceptable to the extent it mirrors the physician's Hippocratic duty to "do no harm," but that it should be abandoned to the extent it would permit a physician to substitute his judgment for his patient's. Thus, this modified best interests would place a floor under the standard of acceptable conduct by physicians by refusing to excuse intentional or reckless harm to patients, without allowing this protection against potential harm to swallow up the patient's whole right to information and consent.


39. The requirement that a patient obtain an expert to evaluate the disclosures made in the light of the prevailing practice in the locality undermines the very basis of the informed consent theory—the patient's right to be the final judge to do with his body as he wishes. Blind adherence to local practice is completely at odds with the undisputed right of the patient to receive information which will enable him to make a choice—either to take his chances with the treatment or operation recommended by the doctor or to risk living without it. . . . [T]he patient is entitled to receive material information upon which he can base an informed consent. The decision as to what is or is not material is a human judgment, in our opinion, which does not necessarily require the as-
treatment of the condition (such as carrier status) is possible, or testing may reveal a condition other than the one on which diagnosis was sought. These situations pose difficult problems. The court in *Canterbury v. Spence*⁴⁰ observed in passing that "[d]ue care may require a physician perceiving symptoms of bodily abnormality to alert the patient to the condition,"⁴¹ but this issue was not directly confronted. Liability for failure to convey an accurate diagnosis has been found, however, in screening programs separate from any therapeutic relationship.⁴² Thus, since the expectation of persons seeking genetic counseling is that they will receive facts relevant to their reproductive decisions, a strong presumption is created against the withholding of material information and the law would look skeptically on any claim of "therapeutic privilege" or other excuse for nondisclosure.

*Justice and Liberty*

Since its articulation by the courts establishes the "informed decisionmaker" right as a valid legal rule (by reason of the "rule of recognition"), no moral justification need be given for its application to the participants. We may wish, however, to ask "Is it just?" In legal terms, as we have already noted, the right to be an informed decisionmaker is an application of the same rule that is applied in tort and contract law: that each person is free to govern his life as he chooses subject only to those constraints or interferences which have his voluntary assent. This principle also has its reciprocal: that each person is responsible for the consequences (sometimes limited to the foreseeable consequences) of his choices. A statement of rights in genetic counseling which denied parents "informed decisionmaker" status would run afoul of the "like cases" precept on both points; the right is therefore necessary to a "just" treatment of counseling.

To conclude that the "informed decisionmaker" right states a just legal rule in no wise denies that it also has moral equivalents.⁴³ Indeed, the very concept of man as a "moral being" is closely linked with this

⁴¹. Id. at 781.
⁴³. One moralist's approach to informed consent is found in Professor Paul Ramsey's description of the deontological dimension of consent: "The principle of an informed consent is a statement of fidelity between the man who performs medical procedures and the man on whom they are performed." P. RAMSEY, THE PATIENT AS PERSON 5 (1970). Fidelity is thus an aspect of "the faithfulness that is normative for all the covenants or moral bonds of life with life." Id.
principle. In the view of many philosophers, as well as biologists and anthropologists, man's distinctive characteristics are his abilities to communicate, to reason, to imagine alternative possibilities so as to anticipate future events and to act so as to alter them. Given his faculties, if man is to act morally he must take responsibility that each of his acts comports with moral rules (howsoever conceived, e.g., "do no harm," "help thy neighbor," etc.). Giving each person power, as well as responsibility, for his own conduct also, in the view of some philosophers, assures that the good of the whole community is maximized.

This raises a question which has been skirted. Our primary interest in the "informed decisionmaker" right is to identify its relationship to the division of authority and responsibility between parents and counselor. Thus far, the state has entered the picture only as the enforcer of the right. One implication of the right, however, is that the parent's decision takes precedence not only against the counselor's wishes but also against those of the state. I raise this point not to discuss it at any length, but because it reflects one of the major forms of the law-morality debate. The view that one should have free choice about his own conduct is, of course, identified with John Stuart Mill. His critics argue that Mill's concept of liberty is not and should not be accepted by society, for each member of a society owes the collectivity a duty to keep himself "physically, mentally and morally fit." This argument provides another perspective on the question of a necessary connection between law and morality. Rather than asking whether it is possible to view the legal system as a justified entity independent of morality, it asks whether one can conceive of a society operating successfully without imposing its moral views on its members. While this debate, between libertarians on the one hand and paternalists and collectivists on the other, is as fascinating as that between positivists and naturalists, we need not go into it here.

RIGHTS AND DUTIES IN GENETIC COUNSELING: A CASE ANALYSIS

Suppose that a couple who believe their potential offspring to be at

44. The issues involved require treatment in a separate paper. The state's right to act against the parents' wishes would probably depend on such issues as: (1) in whose behalf is the state acting, that of the unborn child, the community, future generations or science; (2) is its action premised on paternalism, the "common good" or the limitations which it places on the exercise of certain privileges it grants; and (3) how does it enforce its decisions, by prohibiting or commanding abortions or by compulsory amniocentesis, contraception, sterilization or other similar procedures.

45. As Lord Devlin has observed: "Mill's doctrine has existed for over a century and no one has ever attempted to put it into practice." P. DEVLIN, THE ENFORCEMENT OF MORALS 125 (1965).

46. Id. at 104.

47. Suffice it to say that I believe the full implications of the right to be an informed decisionmaker are defensible even against an assertion of state authority.
risk of manifesting a genetically-linked disorder consult a physician who specializes in genetics. Assume that the parents seek out the counselor after the child has been conceived but in time to terminate pregnancy safely. Further assume that the data which is obtainable for the disease in question indicates only the probability of risk, and not a definite diagnosis. Finally, assume that the advice given is the straightforward assertion that there is no known special risk of the disease occurring. On this assumed set of facts, what consequences follow if the counselor intentionally withholds information or makes a negligent mistake in his advice and a child with the feared genetic disorder is born?

Although no such case has yet been litigated, analogies are available. Perhaps the closest of these is the decision of the Supreme Court of New Jersey in *Gleitman v. Cosgrove.*

"Gleitman deserves examination in some detail because it is a leading case and because I believe that both the New Jersey court and its critics have mistaken the rights and duties involved. By using the analysis developed above we come to a different, and I hope better, resolution of the contentions raised by the case.

The *Gleitman* court held that there was no cognizable claim against a physician who erroneously advised a woman that the German measles she suffered during the first month of pregnancy "would have no effect at all on her child." Apparently Dr. Cosgrove knew the risk of rubella damage to be about 25 per cent, but he withheld this information because three out of four fetuses aborted due to such a risk would be normal and he believed it unfair to abort three healthy fetuses to avoid one diseased one. By a divided vote, the justices ruled that neither parents nor child could sue for the child's substantial birth defects, since the mother had testified that had she been properly warned of the risks she would have sought an abortion. The parents were foreclosed because an abortion, even if legal (which the court assumed), would have violated "the preciousness of human life," and the child was foreclosed because he would "not have been born at all" had his parents carried out the abortion. While it is not difficult to understand why the New Jersey court reached this conclusion, its opinion rests on a misunderstanding of legal principles, a misapplication of precedent and a misapprehension of the consequences.

48. 49 N.J. 22, 227 A.2d 689 (1967); accord, Stewart v. Long Island College Hospital, 30 N.Y.2d 695, 283 N.E.2d 616, 332 N.Y.S.2d 640 (1972) (mem.).
49. 49 N.J. at 24, 227 A.2d at 690.
50. The court's assumption accords with one of the grounds for abortion proposed by the American Law Institute: that a licensed physician believes there is substantial risk the child will be born with grave physical or mental defects. *Model Penal Code* § 230.3 (Proposed Official Draft, 1962).
of the result it reached compared with the consequences it attempted to avoid.\footnote{51}

\textit{Misunderstood Principles}

The first question which arises is whether the legal rule established in this case is a just one. The reason it seems unjust is that the general rule—that a person who suffers injuries will be made whole by the person whose fault caused the injuries—was not applied here. Consequently the court is open to criticism for not treating like cases alike.

In analyzing tort liability in this case, one must first inquire into the infant plaintiff's standing to sue. Is Jeffrey Gleitman, the defective child, "a person" in the eyes of the law?\footnote{52} Justice Proctor looked to \textit{Smith v. Brennan},\footnote{53} in which the court upheld the right of a child to sue for injuries sustained \textit{in utero} for the rule that "justice requires that the principle be recognized that a child has a legal right to begin life with a sound mind and body."\footnote{54} In other words, the court relied on the principle of fairness to reach the conclusion that the protection of, and redress for, postnatal harm to "mind and body" should likewise be available to persons alleging prenatal injuries.

As to the second element of tort liability— injuries—no question arose since the judges all agreed that Jeffrey suffered severe impairment. If we skip momentarily over the third element—compensation—we reach the fourth, which poses the question whether Dr. Cosgrove was the person who caused Jeffrey's injuries. The physician did not, of course, cause the impairment in the sense of having given Mrs. Gleitman rubella; how-

\footnote{51. The discussion herein is limited to the child's right to recover. I assume that the "informed decisionmaker" right is held by both sets of patients: the parents, primarily the mother, as to choices affecting her health and well-being, and the fetus as to its own health and well-being. I further assume that the parents will be the ones who exercise the fetus' right. \textit{But see} text accompanying notes 47 \textit{supra} & 77-80 \textit{infra}. Even as to the breach of the duty owed to the parents in their own right, the injuries suffered still center on the child: (a) his physical injuries and suffering; and (b) the additional financial and emotional burden placed on the parents as a result. The latter poses no problems if a duty to the parents is established. If the duty were found to be \textit{limited to the parents}, since the fetus is not yet a legal person at the time when abortion is possible, Roe v. Wade, 410 U.S. 113 (1973), then an interesting problem arises. The duty is owed to A but the injury occurs to B. Is the defendant liable? Does it depend on whether his breach of duty is negligent or intentional? \textit{See} Palsgraf v. Long Island R.R., 248 N.Y. 339, 346, 162 N.E. 99, 101 (1928) (plaintiff "sues for breach of duty owing to himself"); \textit{Restatement (Second) of Torts} § 281 (1965). \textit{Compare} Christianson v. Thornby, 192 Minn. 123, 255 N.W.2d 620 (1934) \textit{with} Custudio v. Bauer, 251 Cal. App. 2d 303, 59 Cal. Rptr. 463 (1967) (whether injury is suffered where sterilization fails and an unwanted but healthy child is born).

52. Nothing said in note 51 \textit{supra} nor in the Supreme Courts' recent abortion decisions would undercut the "personhood\textit{ in utero} of the child subsequently born alive.


54. \textit{Id.} at 364, 157 A.2d at 503.
ever, he was the proximate cause of the impairment since his mistaken advice prevented the Gleitmans from avoiding the manifestation of injuries. Had Jeffrey been a grown man who received negligently inaccurate advice from Dr. Cosgrove about a neurological disorder which thereafter, in the absence of treatment, rendered him blind and deaf, the legal rules governing the doctor-patient relationship would require Dr. Cosgrove to compensate Jeffrey for his impairment. The court's contrary conclusion that Dr. Cosgrove's conduct "was not the cause of infant plaintiff's condition" is nonsensical—since the court itself recognized that the plaintiff would not have been in his present condition had Dr. Cosgrove told the Gleitmans of the risk of impairment.

The real reason the New Jersey court felt constrained to deny Jeffrey a "just" application of the usual rule of recovery is not that Dr. Cosgrove did not cause the injuries. Rather it was the court's conclusion that there was no way to calculate how to make Jeffrey "whole" again. This aspect of Gleitman is very pertinent to the present state of genetic counseling, since the only "treatment" available in most cases is to abort the fetus.

There are two grounds on which the court's holding is open to criticism. First, the conclusion that a court "cannot weigh the value of life with impairments against the nonexistence of life itself" is contradicted by the fact that courts make similar subjective calculations such as the value of lives cut short, of pain and suffering, and other intangibles every day. Second, if the New Jersey court intended the broader point, that life with any handicap is per se better than no life at all, it gave no reason for this conclusion, other than citing Professor Tedeschi's argument that "no comparison is possible since were it not for the act of birth the infant would not exist." But this adds nothing to the court's own a priori judgment in favor of impaired life rather than abortion, and only serves to create confusion over the act for which plaintiff is suing. Jeffrey did not sue Dr. Cosgrove "for his life," although such a suit is not as illogical as Justice Proctor, relying on Professor Tedeschi, suggests. Rather, Jeffrey sued the physician for his failure to give accurate

55. Cf. Smith v. Makaroff, 149 Cal. App. 2d 655, 308 P.2d 912 (1957). Jeffrey's legal right to competent advice from an expert and Dr. Cosgrove's duty to provide it are paralleled by the moral rights and duties set forth in AMERICAN MEDICAL ASSOCIATION, OPINIONS AND REPORTS OF THE JUDICIAL COUNCIL (1969) which states that physicians should render "to each [patient] a full measure of service and devotion." Id. § 1, at vi.

56. 49 N.J. at 28, 227 A.2d at 692.

57. Id.


59. Would a court deny recovery by a patient who had contracted a disabling injury through a physician's negligence in administering transfusions simply because
advice on which a decision could be made by Jeffrey's parents, acting in their child's behalf, that for him not to be born would be preferable to being born deformed. If one objects to awarding damages for the violation of this right, it would seem that the objection is directed either at the policy of allowing abortions (the court assumed one could have been legally obtained) or at giving parents who may have conflicting motivations the authority to make this decision. The fact remains that the Gleitman court departed from the rule that the choice in this matter lies with the patient, not the physician. Its action is no more defensible than that of a court which, faced with a patient who was ravaged by an untreated disease, were to dismiss the suit on the grounds that the standard, accepted treatment (about which the physician negligently failed to inform the patient) is highly dangerous and nearly always fatal.

Misapplied Precedent

If the New Jersey court's failure to heed prevailing legal doctrines led it into one sort of error, its application of prior cases led it into other errors, although certainly not all of its own making. The Gleitman court relied on "two cases from other states which have considered the theory of action for 'wrongful life,'" an Illinois case, the physician proved that but for the transfusions the patient would have died? Although the plaintiff would owe his life to the physician, he could, of course, still sue him.

Needless to say the idea that parents would be acting in the best interest of their child-to-be by preventing its birth does not ring true for some. Yet once it is recognized as a permissible choice, see Roe v. Wade, 410 U.S. 113 (1973), it falls within the range of authority to make choices traditionally assigned to parents out of a respect for family integrity and a desire to foster the diversity it brings; ... a willingness to bear the risks of harm this allocation entails [based] on a belief that in most cases "harm" would be hard for society to distill and measure anyway; or simply the conclusion that the administrative costs of giving authority to anyone but the parents outweigh the risks for children and for society unless the parents are shown to be unable to exercise their authority adequately.


This choice may even extend to a patient's refusing "life-saving" therapy. See In re Brooks Estate, 32 Ill. 2d 361, 205 N.E.2d 435 (1965). The imposition of such therapy against a patient's wishes in In Re President & Directors of Georgetown College, Inc., 331 F.2d 1010 (D.C. Cir.), cert. denied, 377 U.S. 978 (1964) was defended by the judge there because the patient had shifted the "legal responsibility" for the choice to the hospital. Moreover, cases involving adult patients turn on the applicability and interpretation of the policy against suicide which does not apply to cases involving fetuses under a "liberal" abortion law. And both the Brooks Estate and Georgetown lines of cases start from the position that if the patient's choice is overridden, it can only be done by someone (usually a judge) officially empowered to act as his guardian, and not by the physician alone as in Gleitman.

62. 49 N.J. at 29, 227 A.2d at 692.
and *Williams v. New York*. 64

The New Jersey court's reliance on these cases is misplaced because, as the court observed, they "were brought by illegitimate children for damages caused by their birth out of wedlock, and in both cases policy reasons were found to deny recovery." 65 Policies relevant to illegitimacy clearly have limited, if any, application to a suit by a child made deaf and blind by rubella. Moreover, the opinions of the New York and Illinois courts are unsatisfactory on their own facts. In *Williams*, for example, the plaintiff was an infant who had been conceived when her mother, a mental defective in the custody of a state hospital, was raped by another patient. The child claimed that the state's negligence in protecting her mother had caused her (the child) to be deprived of a normal childhood and rearing and "to bear the stigma of illegitimacy." 66 The New York Court of Appeals recognized the "unfair burdens" the plaintiff would bear, as do "many other sons and daughters of shame and sorrow." 67 But, it concluded, "the law knows no cure or compensation for it, and the policy and social reasons against providing such compensation are at least as strong as those which might be thought to favor it." 68 If "the policy and social reasons" against making illegitimacy a "suitable wrong" are of no assistance to the *Gleitman* court, perhaps it had in mind the arguments presented by Judge Keating's concurring opinion in *Williams*. 69 These concerned the "logico-legal" difficulty (a term which Judge Keating derived from Tedeschi's article) "of permitting recovery when the very act which caused the plaintiff's birth was the same one responsible for whatever damage she has suffered or will suffer." 70 We have already seen the error in the "same act" approach which, by characterizing the claim as one for "wrongful life," fails to distinguish between the act of conception and the circumstances under which it is done. Having intercourse is not a crime, but having it when unmarried is, which in this case was a result of the state's negligence. Of course, "had the State acted responsibly," as Judge Keating noted, the plaintiff "would not have been born at all." 71 Yet the state's failure to do so created not only the infant plaintiff but also her cause of action.

---

65. 49 N.J. at 29, 227 A.2d at 692.
66. 18 N.Y.2d at 482, 223 N.E.2d at 343, 276 N.Y.S.2d at 886.
67. Id. at 484, 223 N.E.2d at 344, 276 N.Y.S.2d at 887.
68. Id.
69. The Appellate Division, whose decision was being reviewed, had based its decision in part on the Keating line of reasoning that damages cannot be ascertained because they rest "upon the very fact of conception." *Williams v. New York*, 25 App. Div. 2d 907, 269 N.Y.S.2d 786 (1966).
70. 18 N.Y.2d at 483, 223 N.E.2d at 345, 276 N.Y.S.2d at 888.
71. Id. at 485, 223 N.E.2d at 345, 276 N.Y.S.2d at 888.
In Williams not only were the act (conception) and the tort (negligence in failing to protect the mother from men to whom she was not married) separable, but the latter was even partly remediable without abortion, since the illegitimacy could have been "cured" by subsequent marriage, adoption and so forth. This is not so in the genetic counseling situation nor in the Zepeda case, where the defendant father was already married when he fraudulently induced the plaintiff's mother to have sexual relations with him by promising to marry her. Yet the Zepeda case gives little support to the Gleitman result since the Illinois court agreed with plaintiff Zepeda "that the elements of a willful tort are presented by the allegations of the complaint." 72 The Zepeda court saw no barrier to the suit because the tortious act or omission occurred at, or even before, the plaintiff's conception; nor was the suit barred by the nature of the injury, which "is not as tangible as a physical defect but . . . is as real." 73 Yet the "radical "nature of the injury alleged—loosely, "bad parentage"—was the factor which led the court to deny recovery for the tort. If the Gleitman court relied at all on the "policy" set by Zepeda, then it must be on that aspect of the opinion which held that recovery should be permitted only after the legislature had undertaken a "thorough study of the consequences." 74

Misapprehended Consequences

The Illinois court was not merely worried that entertaining infant Zepeda's suit would open the floodgates of litigation, leaving the courts inundated by the claims of the quarter million illegitimate children born each year in the United States, but also that damages would soon be sought

for being born of a certain color [or] race; . . . for being born with a hereditary disease, . . . for inheriting unfortunate family characteristics; [or] for being born into a large and destitute

72. 41 Ill. App. 2d at 259, 190 N.E.2d at 858.
73. Id. at 258, 190 N.E.2d at 857. The court built its theory of injury on a detailed review of the "lot of a child born out of wedlock," It contrasted the ignominy and hardships of illegitimacy in the past with the enlightened attitude of modern statutes which do much to equalize the rights of bastards with those of legitimate offspring. It concluded, nonetheless, that: "Praiseworthy as they are, they do not, and no law can, make these children whole. Children born illegitimate have suffered an injury." Id. at 258, 190 N.E.2d at 857. Earlier in the case the court had concluded that three other specific types of injury were not made out by the complaint: mental suffering was not properly averred; defamation requires communication to third persons and was not alleged; and no child, legitimate or illegitimate, has a legal right to love or a happy home. Id. at 253-55, 190 N.E.2d at 855-56.
74. Id. at 262, 190 N.E.2d at 859.
family, [or to] a parent [who] has an unsavory reputation.\textsuperscript{75}

There is a surface appeal to the court's reasoning. Being born into a minority group or a "disadvantaged" family may subject a child to burdens similar to those of illegitimacy, and hereditary disease may cause greater suffering still.

But opening the court to the infant Zepeda would not necessarily open it to the others cited by the court, for poverty, race and genetic makeup do not constitute "moral wrong[s] and . . . criminal act[s]\textsuperscript{76}" which the court held Mr. Zepeda's sexual relations with the plaintiff's mother to be. Being poor or carrying an hereditary disease are not crimes; procreating in these circumstances violates no legal right of the child conceived.

Nevertheless, although nothing in the policy reasons of Williams or Zepeda is either convincing or applicable to Gleitman, we owe it to the New Jersey court to puzzle through the consequences of the result it should have reached before criticizing as unjust the one that it did reach. Can it be said of the Gleitman decision

that, regrettable though it is, the demands of justice . . . must be overridden in order to preserve something held to be of greater value, which would be jeopardized if . . . discriminations (between Jeffrey Gleitman and other plaintiffs injured by a negligent failure to give competent medical advice) were not made?\textsuperscript{77}

An alteration of the facts of the Gleitman case brings one possible countervailing value into view. Suppose the child alleged that the physician gave accurate advice to the parents but that the parents disregarded the risks and did not abort, resulting in his being born deformed. If the claim against Dr. Cosgrove is good, must not that against the parents also succeed? Even if we assume that there is no longer intrafamilial immunity in the jurisdiction,\textsuperscript{78} the simple fact remains that such suits are

\textsuperscript{75} Id. at 260, 190 N.E.2d at 858.
\textsuperscript{76} Id. at 253, 190 N.E.2d at 855.
\textsuperscript{77} HART, supra note 13, at 158.
\textsuperscript{78} English common law permitted tort actions as well as those involving property and contracts between children and parents.

But beginning in 1891 with Hewlett v. George [68 Miss. 703, 9 So. 885 (1891)], a Mississippi case of false imprisonment which cited no authorities, the American courts adopted a general rule refusing to allow actions between parent and minor child for personal torts, whether they are intentional or negligent in character.

W. PROSSER, HANDBOOK OF THE LAW OF TORTS § 122, at 865 (4th ed. 1971). This result was justified as necessary to avoid introducing "discord and contention where the laws of nature have established peace and obedience." Wick v. Wick, 192 Wis. 260, 262, 212 N.W. 787 (1927); the danger of fraud has also been stressed. The
unlikely because the child's parents, as his guardians or "next friends," actually instigate suits on the child's behalf, and it is unlikely that they would, in effect, sue themselves. Yet even if the state routinely appointed special guardians for all defective children (or all children for that matter) with instructions to bring any necessary lawsuits, such suits would be of little practical value. Parents are already legally obliged to support their children, and most do so to the limits of their ability whether the child is normal or not. Consequently, unlike a recovery against an outside party like Dr. Cosgrove, a recovery against the parents would just shift family funds (less lawyers' fees and court costs) from one pocket to another.

While there is at least some merit to these practical reasons why a suit against parents would be unlikely had Gleitman been differently decided, a more persuasive argument denies that there is any claim against the parents at all. For there to be a recovery, the defendant must have breached a duty legally owed the plaintiff. Dr. Cosgrove violated such a duty when he failed to give competent medical advice; by contrast, parents, in choosing not to abort, have exercised their legal right to make this choice. This right of the parents has two sources: (1) one derived from the child's right, in which case the parents are considered to be making their decision on behalf of their offspring, in what they judge to be the child's "best interests;" and (2) one which focuses on the parents' own right to exercise control over an event which is of major importance to their lives (directly so in the mother's case, and indirectly in the father's). Since the decision not to have an abortion would probably be viewed by the courts as being based on both rationales, absent proof of intentional disregard of their child's interests or gross negligence in the exercise of their discretion, such an exercise of judgment would not subject the couple to liability. In the view of the law, it is up to them to weigh the probabilities and risks and to decide whether life with any defects is better than abortion or whether in some cases life with defects is "a fate worse than death."79

"retreat from this rule is now underway," as Professor Prosser notes, and parent-child immunity for personal torts may soon be a thing of the past. See, e.g., Gibson v. Gibson, 3 Cal. 3d 914, 479 P.2d 648, 92 Cal. Rptr. 288 (1971); Gelbman v. Gelbman, 23 N.Y.2d 434, 245 N.E.2d 192, 297 N.Y.S.2d 529 (1969); Goller v. White, 20 Wis. 2d 402, 122 N.W.2d 193 (1963). The courts continue immunity, however, for matters subject to "parental discretion" over the care of children. E.g., Balts v. Balts, 273 Minn. 419, 142 N.W.2d 66 (1966). This would serve as a further bar to suits for inherited diseases unless they resulted from wanton disregard of or intentional injury to the child's health.

79. This is not to suggest that the legal rights and responsibilities of parents could not be altered. For the moment, however, so long as the only means of preventing illness in a fetus with a serious genetic defect is abortion, it seems unlikely that the
CONCLUSION

We may thus conclude that our hypothetical genetic counselor has a legal duty to give competent advice so as to place the parents into the position of informed decisionmakers, and that if by his negligent or intentional breach of this duty a defective child is born, the child and his parents have a valid claim for damages against him. This is true whether the parents come to him for advice on whether to abort or on whether to conceive in the first place.

Unless we accept as a valid legal rule the Gleitman court’s dictum that every child has “a legal right to begin life with a sound mind and body,” however, a child who suffers a genetic disease does not have a claim against its parents because they decided to give it birth despite the risks of the disease. The Gleitman court did not accept its own dictum at face value and neither should we. As a moral precept it states an admirable guide for conduct and aspiration; as a legal rule it is too far-reaching. The legal rule which I have suggested should be applied protects courts from the nearly impossible task of reviewing the parents’ good faith judgment about the “quality of life” which a child will experience; the child is protected against intentional harm by the parents, as he would be after birth; and the parents are protected in the prudent use of the capabilities with which nature endowed them. This comports with our moral sense that it is unjust to blame someone for something, such as his genetic makeup, which he cannot (presently) control. It would be state would intervene to force an abortion in the face of a couple’s decision to have a baby with a potential genetic defect. State intervention prior to the conception of such a child raises a harder question. In the past, the state’s power to deny a parent the right to bear children for genetic reasons has been upheld. Buck v. Bell, 274 U.S. 200 (1927). Were the legislature to extend such a statute to mandate sterilization of noninstitutionalized persons for the wide range of single gene disorders now identifiable in their heterozygous form, I doubt that its action would be upheld simply on the authority of Buck in light of the Supreme Court’s increasing concern with such “fundamental rights” as the freedom to make decisions concerning marriage and procreation. See, e.g., Loving v. Virginia, 388 U.S. 1, 12 (1967); Griswold v. Connecticut, 381 U.S. 479, 486 (1965); Skinner v. Oklahoma ex rel. Williamson, 316 U.S. 535, 541 (1942).

This discussion has focused solely on the rights and duties relating to liability for negligent advice. Space does not permit an exploration of the myriad other rights and duties which arise from the geneticist-patient relationship or of the limitations and their remedies, if any, which are placed on the exercise of these rights and duties by internal and external constraints. Some exploration of these problems, especially concerning informed consent, appears in Capron, The Law of Genetic Therapy, in THE NEW GENETICS AND THE FUTURE OF MAN 133 (M. Hamilton ed. 1972). See also Beecher, Consent in Clinical Experimentation: Myth and Reality, 195 J.A.M.A. 124 (1966); Jonas, Philosophical Reflections on Experimenting with Human Subjects, 98 DAEDALUS 219 (1969).

I take the latter situation to be an easier case to establish liability and consequently have addressed myself only to the former.

cruel to add to the injury of a defective gene (and the undeserved self-blame which is felt when the disease manifests itself in an offspring) the insult of a suit by the offspring. On the other hand this rule does not speak to the issue whether parents who knowingly and recklessly take a drug with a substantial teratogenic risk would be liable if their offspring were deformed. Similarly, major manipulations of the birth process, done in the face of adverse or incalculable risks, might expose their creators (including the “biological” parents) to liability for injuries suffered.

None of these eventualities are pleasant to contemplate, and one can hope that they never pass from the hypothetical to the real. But if they do, I believe that the makers of law, be they judges or legislators, will make clear the right of children to recover for their injuries. Gleitman v. Cosgrove neither will, nor should be, the final word on the subject.

83. Two examples of such manipulation are clonal reproduction and in vitro fertilization.