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Genetic Decision-Making: Parental Responsibility

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In Roman Catholic moral theology, it has always been held that one can make an adequately moral decision only when all the reasonably available pertinent information is in hand. With regard to the moral problems of procreation, Pope Paul VI has adopted the phrase "responsible parenthood," and noted that a variety of circumstances may lead responsible parents "to avoid for the time being, or even for an indeterminate period, a new birth."

The notion of genetic responsibility has taken on great significance in recent years. In the past, parents have of course always hoped that their children would be born healthy; they have struggled, sometimes heroically, to care for children during illness or through infirmity. But only recently has the possibility of determining ahead of time the genetic well-being of children become a reality.

Genetic counseling can provide, for many people, precise information about genetic disease in children already born, about the risk of recurrence, about prognosis, and even about the genetic status of a fetus in the womb. This kind of information has helped transform procreation into an activity subject to more deliberate choices than used to be the case.

It is to be expected that society, both secular and ecclesial, will increasingly consider that mature persons should demonstrate active responsibility with respect to the genetic health of their prospective children. We already look for this in terms of such things as provision of a place to live, financial resources to insure adequate food, clothing, education, etc.

For purposes of this discussion, concern for genetic well-being of as-yet-unborn persons is eugenics. It is important to distinguish two types of eugenics. Positive eugenics is the systematic attempt to increase desirable hereditary traits. Negative eugenics is the systematic attempt to decrease undesirable hereditary traits.
Eugenic programs are societal structures designed to change the genetic heritage of whole populations. Eugenic decisions are made by individual families (one husband and one wife) concerning the genetic heritage and status of their own present and/or prospective child(ren).

One can isolate at least thirteen major ethical issues which obtain in genetic counseling (Table I). Some issues pertain exclusively to those who run the genetics clinic, while others concern the family which comes for genetic counseling. In this essay, I propose to explore the dimensions of parental genetic responsibility and the considerations which enter their genetic decision-making.

Table I
Ethical issues in human genetics
1) informed consent for experimentation
2) parental responsibility for genetic health (a priori)
3) parental responsibility for nurture of the defective child (a posteriori)
4) privacy of information vis-a-vis at-risk relatives
5) privacy of information vis-a-vis society at large
6) methods of family plan implementation
7) abortion
8) methods of weighing factors in decision-making
9) eugenic concerns
10) qualifications of a genetic counselor
11) structure of genetic counseling (clinic)
12) provision/withholding of information to/from counselee
13) quality of participation in the process of decision-making.

It should be explicited here that my concern is exclusively with negative eugenic decisions. There is virtually unanimous agreement that eugenic programs, whether positive or negative, do not yet offer sufficient promise to warrant the compromising of human freedoms which they would inevitably entail. Furthermore, positive eugenic decisions (with the exception of deliberate assortative mating) are not at this time possible except as experimental procedures. As such, they entail unquantified risks which may constitute a strong argument against their acceptability. While these deserve attention, they are of less immediate urgency than are negative eugenic decisions, which for a long time will continue to occupy most of the energies expended in and around genetics clinics. Positive eugenic decisions, in any case, can be subjected to an ethical dissection very similar to the one applied here to negative eugenic decisions.

I undertake this discussion with certain presuppositions. First, I assume that parents have a strong desire to act responsibly in this matter, and that they are of average intelligence and education. Second, I assume that
the increasing publicity about genetic counseling has reached them, whether through the mass media or the agency of family physicians, clergy, relatives or friends. (If they are unaware of the availability and applicability of genetic counseling, they cannot be expected to seek it.) Third, I assume that genetic counselors adhere to the strictest discipline of non-directive counseling, seeking always to be helpers, informers, supporters, encouragers for the family, but always insisting that the family must make its own decision(s). Fourth, I assume that the genetic condition about which a decision is to be made is one that poses a serious burden of suffering to the family (i.e., a non-trivial negative eugenic decision).

To Whom Responsible?
We cannot impute moral responsibility to a person in a vacuum; we must make it clear to whom (s)he is answerable for actions. Table II lists (in roughly descending order of weight) those dimensions of responsibility which can be identified for genetic decision-making.

Table II
Dimensions of genetic responsibility*

1) between spouses
2) parents to child(ren) a posteriori
3) parents to child(ren) a priori
4) genetic counselee(s) to relative(s) at risk
5) spouses to society at large
6) spouses to posterity at large
7) genetic counselee(s) to genetic counselor(s)

*spouses = parents = genetic counselees = decision-makers

1) Between spouses. Most people never have any reason to suspect that they may have or carry a genetic disease posing a threat to prospective children. (Choice of a spouse may involve, to be sure, a more or less conscious positive eugenic consideration.) But occasionally one's family or personal health history reveals a hereditary problem. In such cases, it is a matter of basic honesty that this be disclosed to one's prospective spouse. It is simply an element in the mutual self-revelation that is part of the specially intense human relationship of marriage. I have argued elsewhere that deliberate concealment of such information probably constitutes grounds for annulment of marriage even within the strict canonical discipline of the Roman Catholic Church.8

Whether the genetic bad news antedates marriage or enters as an unpleasant surprise with the birth of an affected child, spouses are responsible to one another for an adequate approach to the necessary subsequent decision-making. It is not sufficient for one to acquiesce silently to the other's reproductive inclinations. To do so would compromise the mutuality of decision-making which is essential in the marriage relationship. A one-sided decision in matters of genetics can set the stage for major problems in the
future, especially if the consequences of the ill-made choice include birth of a seriously affected child.

2) Parents to child(ren) a posteriori. Extant children, whether or not they are suffering from the disease in question, have a claim on their parents to reach genetic decisions carefully. The child (ren) must share the consequences of these decisions.

3) Parents to child(ren) a priori. Over 2000 hereditary health problems are now known. Their severity ranges from complete triviality to tremendous burdens of protracted suffering. Depending on the severity of the condition in question, parents will need to take account of the risk of suffering to which they may expose the prospective child(ren) whose conception is being contemplated. The quality of life reasonably foreseeable should be considered. A child who suffers, later, from a preventable condition, may accuse his or her parents of negligence. On the other hand, if the choice is life with suffering as opposed to non-existence, the child's case may be difficult to argue.

4) Genetic counselee(s) to relatives at risk. Most genetic counselors and commentators on medical ethics agree that a person found to have or carry a serious genetic disease ought to allow his or her physician to inform any relatives who may also be at risk of suffering the condition themselves or in their children. It has been argued that this is a threat to privacy or may lead to social or familial stigmatization. But if adequate counseling is provided to all involved, it should be possible to maintain a balanced understanding of the problem and its implications. There is a significant moral obligation resting on a person who holds important information about someone else to reveal that information in order to provide that person at least the opportunity of using it in his or her own life decisions.

5) Spouses to society at large. The relationship of a family to society at large is complex. Each makes certain demands of the other. But society is not a single monolithic entity, much less a person. A family will not relate to its society as it does to its friends, relatives, neighbors or colleagues. Its sense of responsibility to society takes the shape of an active desire to play a constructive role in the wide sweep of human progress. There will be concern to avoid demanding of its city, state, or nation any assistance which it can reasonably provide for itself.

In turn, the people who make up society, and who contribute to whatever common fund may be available for special needs, have legitimate claim on the individual family to actively avoid unnecessary withdrawals.

6) Spouses to posterity at large. Prospective grandchildren may be at risk of suffering or
gaining by genetic decisions. So might prospective great-grandchildren. There is some virtue in recognizing that any really important decision made by me in 1976 may have repercussions not only in the 1980's, but also during the 2080's. I have argued elsewhere, at some length, that the legitimate place for large eugenic concerns in the genetic decision-making process is the place freely given to them by the decision-makers: the (prospective) parents. If a eugenic counselor has personal eugenic views, (s)he will act responsibly to keep these from being an obstacle to the counselees, since it is to the latter that the decision falls as an act of a moral agent. Nor should a society that claims to be democratic, and to hold freedom of self-determination as a prime value, contemplate any legislative interference in this decisional process. To do so would be not only a compromise of the moral process (decision-agency, which can reside only in a person or a family but not in a state), but also a betrayal of stated secular values. Calculating genetic responsibility to posterity many generations removed is perhaps an empty theoretical exercise. But it is reasonable to expect that the persons of the 23rd century, in examining history, will hold us responsible for having opened or closed our eyes to the challenges and possibilities of the 20th.

7) Genetic counselee(s) to genetic counselor(s). It is of course important that genetic counselees and genetic counselors establish a good working relationship if their encounter is to make a positive contribution to the difficult process of genetic decision-making. Primarily, the counselor team is cast in roles of service. But it should be obvious that the counselees will receive help only to the extent that they are open to it. This calls for a) providing diagnosticians and counselors with adequate answers to their questions, and b) making the best effort to “hear” what is being offered them in the counseling sessions, even though the news may be unwelcome.

How to Reach a Decision
It is hopefully clear that the seven persons and groups of persons discussed above do not have equal claim on the attention and moral agency of genetic decision-makers. Listing the elements to be considered in reaching these decisions, I likewise do not wish to imply equal gravity. At least ten such elements can be recognized in dissecting the complex dynamics of genetic decision-making process (Table III).

Table III
Considerations in parental genetic decision-making
1) own capacities for care, for suffering
2) status of marital relationship
3) impact on extant child(ren)
4) foreseeable suffering of prospective child(ren)
5) financial capacities
6) reproductive options
7) moral commitments and conflicts
8) burden to society for support
9) eugenic considerations
10) reasons for technological optimism

1) Own capacities. People who have given birth to a child with some unexpected deleterious genetic condition often suffer feelings of "cosmic guilt." They may undergo severe strains of doubts about themselves and their own goodness as persons. This kind of shock-reaction may last for days, weeks, or months, and may be further complicated by an understandable sense of loss and appropriate grief reaction. (In a sense, they have lost the healthy child whose birth had been anticipated.) Genetic decisions under such circumstances are difficult if not impossible.

A good counselor will help them through this period to a time when they can rationally take stock of themselves in terms of their capacity, as persons, to care for an (other) affected child. Foreseeing one's stamina in the face of suffering is notoriously difficult, but it should be obvious that self-evaluation must be part of an adequate decision process.

2) Marital relationship. I have noted above that spouses are responsible to each other for self-disclosure in the matter of serious genetic health problems and/or risks to offspring, and for mutuality in entering the genetic decision process. It can further be observed that a couple experiencing marital stress should never initiate a pregnancy, genetic risks aside. Responsible persons will wait until such storms resolve, and then include the quality of their ever-unfinished relationship among the factors pertinent to undertaking the risks of procreation.

3) Extant children. There are two kinds of extant children in a family faced with a genetic decision.

a) There may be genetically "healthy" children (at least, unaffected by the condition in question). If they are already living with a handicapped sibling, it may be seen as an undue burden on them to risk another's birth. On the other hand, the experience of dealing with the special problems of living with an affected person may be seen as a positive element in their education as sensitive persons. They may also perceive parental activity in deliberately choosing at least one major aspect of children's genetic makeup as an indirect affirmation of themselves (that their parents chose and value them as they are). Or they might perceive this as a threat (that they could have been judged inadequate, never brought to life, or selectively aborted). I am not aware of any research having been done to quantify these potential hazards and benefits.

b) If the genetic condition in question first came to attention with the birth of an affected child (as opposed to having been as-
certained prior to any procreation), that child may be living during and after genetic decisions. All the same considerations apply here as were mentioned for “normal” children, except that for this child the possible feelings of affirmation or rejection may be amplified due to recognition of self as being at the center of the crisis and its sequela.

Furthermore, the prognosis for the extant affected child will be a factor in decision-making. Does the foreseeable burden of management obviate the human possibility of caring for another such child... or even of an additional healthy child?

Finally, some of the genetic decisions parents face focus not primarily on further procreation, but on the extant affected child. Based on the natural history of a known condition (as explained to them by genetic counselors), parents will have to make choices among management options, which may include almost any imaginable combination of the following:\(^\text{18}\) ordinary tender loving care, repeated medical follow-up visits, special dietary regimen, medications, special education, therapy, prosthesis, surgery, respite care, adoption out of the family, institutionalization, epallobiosis,\(^\text{19}\) enthetobiosis,\(^\text{19}\) heroic experiments,\(^\text{20}\) allowing the child to die by withholding all but minimal care.\(^\text{21}\)

4) Foreseeable suffering of prospective child(ren). Some parents will consider the burden of, for example, hemophilia too great to tolerate giving birth to a son when they know themselves to be at risk. Others will think that current therapy for the type of hemophilia they face is adequate for them to expect a reasonably normal, happy and productive life for their child. These two families will make different decisions, but the need to assess the foreseeable burden to the prospective child is obvious.\(^\text{22}\)

Burden calculus may depend largely on the quality of counseling provided to the family. In conditions for which prenatal diagnosis does not apply, or for families who completely reject selective abortion as a means of avoiding birth of an affected child, the recurrence risk will be an important factor in decision. Not many people would look quietly upon a 50% risk for a major disease, but some would be comfortable with a 25% risk. Others would avoid procreation because of a 5% risk, even for a condition which an outside observer thinks to be relatively minor. \textit{Et cetera.}

Not every genetic problem is necessarily always to be shunned. It is impossible to conclude that giving birth to a child with, for example, the Down syndrome, is \textit{per se} a moral evil; “normality” is “better,” but persons with this condition are not unmitigated defects to family and society.\(^\text{23}\)

The possibility of experimental procedures may enter here. Parents’ informed consent is a delicate matter. Assuming it can be adequately informed, that con-
sent may be appropriate to attempt novel approaches to prevention, treatment, etc.

5) Financial capacities. It is an unfortunate anomaly in our society that we affirm freedom of self-determination in matters like genetic decision-making, but fail to follow through with unconditional commitment to help bear the weight of management in health crises. This is true even for situations in which there was no opportunity to anticipate the problem. As a society, we are in need of a radical conversion to mutual support in catastrophic health problems. Until such a commitment is made, the spectre of bankruptcy haunts those making genetic decisions. 24

6) Reproductive options. Assuming, with Pope Paul VI, that responsible parents deliberately choose the number and spacing of their children, one should expect that genetic counseling may further their understanding of the reproductive options available and applicable to effect their genetic decisions. These include, of course: periodic abstinence from intercourse, contraceptive devices and chemicals, sterilization, by various means, of one partner, artificial insemination by husband or donor, prenatal diagnosis and selective abortion, adoption, experimental procedures (e.g. embryo implantation), divorce, and the status quo.

The last-mentioned is important. Some families will decide to make no changes in their previous family plans. When I go to such lengths to delineate the dimensions and considerations of parental genetic responsibility, I do not assume that responding to new information necessarily leads to any concrete changes in procreative plans. I intend only to urge that there exists a moral obligation to respond actively and make decisions deliberately. Thus, I do not think it will ever be considered “responsible” for parents to consciously avoid acquisition and implementation of available information pertinent to the health of their prospective children, 26 provided of course that this information includes some options and is not simply an imposition of additional tension.

7) Moral commitments and conflicts. People have moral commitments. They have cherished notions of what is right and what is wrong. Often, these are only partially explicit. Often, they are part of larger personal dedications to religious systems of belief. Unfortunately, genetic decisions often present parents with a direct conflict of two or more deeply cherished values. This may plunge them into what has been called “moral suffering.” 27 Support and encouragement by clergy, physicians, or others who share the parents’ moral attitudes can be a creative service. Decision-making seen in light of moral suffering is evidently a profound challenge to the moral agent. One can hope that people who enter such a struggle with generosity

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and courage will emerge victorious at least in the sense that they will have grown together as persons and as a family. But to say this is not in any way to suggest that they will not be in pain, as they weigh genetic facts against conflicting values. Cursory inspection of the management and reproductive options listed above will provide a host of immediately obvious conflicts that may arise in the minds and hearts of conscientious, highly motivated (prospective) parents.

8) Burden to society. Parents will sometimes fall back on societal resources to help them cope with the problems of caring for an affected child. The other side of this coin, of course, is that they should consider their neighbors’ potential sacrifices in this regard. This is not to extenuate societal responsibility to provide such help (as noted above). But it is important that the individual family disdain to perceive societal structures of support as guaranteed cushions on which to rest while abrogating responsibility to reach difficult decisions for themselves.28

9) Eugenic decisions and future generations at large. Earlier I asserted that what we know about human genetics and the potential problems or hopes in eugenic programs is insufficiently compelling to justify compromising the values of freedom of self-determination in genetic decision-making. This does not remove eugenic concern in the wide population sense from the list of legitimate considerations in the minds of parents.29 Like family size limitation partially motivated by environmental concern and a sense of responsibility for population size limitation, eugenic decisions may well rest in part on an awareness of the possible wide repercussions of an individual’s procreative decisions.

To reiterate, however, the place for this kind of eugenic concern is only the place given it by the genetic counselees. So long as their freedom of choice remains unimpaired by intrusive legislation, no counselor is justified in imposing a eugenic program.30 To do so is to betray the trust on which counseling relationships must be founded.

10) An element of hope. Naiveté and despair are extreme positions, and as such are both deplorable.31 Insofar as is possible, persons who serve as genetic, religious or other types of counselors should lead the expectations of their patients/clients/counselees into a realistic middle ground. For some genetic conditions, wonderful advances have already been made. For others, it is realistic to hold a certain amount of technological optimism. Others threaten to remain intractable for a long time, if not indefinitely. Responsible parents/decision-makers will try to assess the appropriateness of hope in new developments as a consideration in their deciding. As has been mentioned above, however, this does not exonerate willful ignorance in situations
where available information could make a concrete difference in the genetic well-being of children.

**Conclusion**

The reader will have discerned that this treatment of the dimensions of and considerations in genetic decision-making has been decidedly shallow. Each of the seventeen aspects presented deserves considerable expansion and analysis. My purpose, however, has been to expose the breadth of the question of parental genetic responsibility. I hope to have provided an adequate framework within which others can join in the pursuit of these important matters in greater detail.

I would like to observe, in concluding, that there exist important differences between moral obligations and ethical reflections on the one hand, and legal sanctions on the other. Legality and ethicality are by no means co-terminous. I propose that we impute moral obligations to prospective parents, and anticipate social and ecclesial atmospheres of opinion in which people increasingly expect active responsibility-taking for genetic well-being of offspring. But this should be tempered by a sincere concern for persons who are faced with the exceedingly painful and complex decisions which arise in this area. I would not wish to be perceived as a fashioner of new burdens for others to carry. Rather, I would insist that all of us have an obligation to protect the moral agent from any kind of short-circuiting of the decisional process. Therefore, any legislative intervention or other coercive measures compromising that process are vehemently to be opposed.

There are and will be cases in which conflicts of opinion arise between a family and its physicians; it can be appropriate to appeal to court-appointed arbitrating, presumably dispassionate, third parties. Finally, because they are decidedly exceptional, those parents whose procreative behavior is grossly irresponsible, to the extent of perhaps necessitating public intervention, have not been considered here. There are ample precedents for court intervention in parallel child-rearing circumstances, and it does not seem likely to me that future judgments should stray far from these.

**REFERENCES**


4. Table I is taken from R. R. Lebel (1976) Ethical Issues Arising in the Genetic Counseling Relationship, Master of Sacred Theology thesis, Jesuit School of Theology at Berkeley, California, p. 75.


6. This means that I consider the problem of the mentally disabled or retarded as a special case which is not to be addressed here. J. Mattinson has published a study of such special cases, Marriage and Mental Handicap, University of Pittsburgh Press, 1970. For a helpful recent view of the question of sterilization in such cases, see J. C. Perrin et al., “A considered approach to sterilization of mentally retarded youth,” Am. J. Dis. Child. 130:288-290 (1976), and also C. H. Baron “Voluntary sterilization of the mentally retarded,” in A. Milunsky and G. J. Annas, Genetics and the Law, Plenum Press, 1976, pp. 267-284.


9. Baumiller, R. C., “Genetic counseling,” Linacre Quarterly 40(4):263-270 (1973). Baumiller offers an illustrative example of the delicacies involved here. A man with a repaired cleft lip and palate may be very concerned to avoid having his children go through the same childhood problems he did; his wife, who does not consider his scar repulsive (or she would not have married him), may find this concern difficult to share.


12. Twiss, op. cit.

13. “Society is not one thing ... embraces many conflicting interests and goals ... does not set goals ... has no mind or personality.” J. C. Fletcher (1974) “Genetics, choice and society,” in Lipkin and Rowley, op cit., pp. 93-100.


15. This list is adapted from Lebel (1976), op. cit., pp. 31-33.


17. Baumiller, op. cit. and Fletcher (1974) op. cit. both expect that well-made genetic decisions should operate as stabilizing experiences for a family.


Epallobiosis: life dependent upon a non-biotic support system which remains external to the body (e.g. heart-lung machine).

Enthetobiosis: life dependent upon a non-biotic implant.
an often advertised artificial heart).

20. One is never morally obliged to acts of heroism, although such deeds are sometimes heralded as the marks of sanctity or greatness. J. M. Gustafson (1973) "Genetic counseling and the use of genetic knowledge — an ethical overview," in Hilton et al., op. cit., pp. 101-119.


22. For a good brief analysis of this particular case, see S. Bok and M. Lappé, "Options in dealing with the threat of hemophilin," Hastings Center Reports 4(2):8-10 (1974).


24. For a discussion of the wide scope of this failure of our society to provide important health backup and prevent the tragedy of bankruptcy being superimposed upon the tragedy of catastrophic illness, see E. M. Kennedy, In Critical Condition: the Crisis in America's Health Care System. Pocket Books, 1972. More directly to our point, see H. Bender (1974) "The right to choose or to ignore," in Lipkin and Rowley, op. cit., pp. 71-74.


26. Bender, H., op. cit., has presented about as good a case for the opposite viewpoint as one is likely to find. In fairness, I should add that on other points in his brief remarks, I am in agreement with him.

27. See J. C. Fletcher, (1973), op. cit., for a fine discussion of the dynamics of decision-making in amnio-centesis-abortion situations.

28. In fact, of course, parental goals and societal goals almost always coincide in these matters. Mr. and Mrs. Jones want healthy children; the city officials want Mr. and Mrs. Jones to have healthy children: so does the governor of Wisconsin, etc.

29. For a confusing and unhelpful exposition on "responsibility for genetic heritage" by a major Roman Catholic theologian reputed to be authoritative on matters of bioethics, see B. Häring, Ethics of Manipulation: Issues in Medicine, Behavior Control and Genetics, Seabury Press, 1975, pp. 159-172.

30. Crow, J. F., quoted in Lebel (1976) op. cit., p. 65. S. Twiss, op cit., observes that the function of society is to protect freedoms, and concludes there is no unmitigated societal "right" to intervene in genetic decision-making.


32. This point has also been made by B. Hilton, "Will the baby be normal? ... and what is the cost of knowing?" Hastings Center Reports 2(3): 8-9 (1972).


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Aesculapius and Zadok: Medical and Priestly Authority

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Physicians and priests have much in common. Friends and detractors of each group have generally been in agreement on that. Those who find physicians to be a beneficent lot, generally think well of priests; those who are "turned off" by physicians and find them aloof and arrogant, often entertain dark thoughts about the priestly caste.

Detractors have noted traits common to the two groups. Each — at least sometimes — wears special garb; each seems a trifle overconcerned with being addressed by proper title; each caste, no matter how narrow its education may be, offers to its members at least a special technical vocabulary which seems — to the hostile — designed to baffle the outsider.

Perhaps one further common denominator is found between the hard-working priest outside academe and the harried physician in practice. Neither of them has opportunity to do much reflecting on the nature of his professional life. There is too much to be done to waste time thinking about it!

Others have more leisure. A fairly recent book, the work of a medical sociologist and a research physician, offers an unusual opportunity for reflection. (Models of Madness, Models of Medicine: Siegler and Osmond, MacMillan, 1974). In the major insight that interests us, the two authors lean heavily on an unpublished manuscript by T. T. Paterson. The results of that study may be properly rephrased as follows: medical authority derives from three sources; some of it is moral; some of it is sapiential; what remains, the most important part, is simply Aesculapian. This last is not simply charismatic. It does not flow from personality. But it is not precisely sapiential or moral. No government confers it with a license. (A non-licensed medical student may be possessed of