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WHERE IN THE WORLD ARE WE GOING WITH THE NEW GENETICS?

John C. Fletcher, Ph.D.*

INTRODUCTION

Where in the world are we going with the new genetics? In attempting to answer this question, this article will first introduce the reader to the new genetics and highlight features of the old genetics.1 Second, it analyzes the main findings of a cross-cultural study of the approaches taken by medical geneticists in eighteen nations to ethical problems in genetic counseling, prenatal diagnosis and screening.2 It identifies the major ethical problems in a cross-cultural perspective and finally it proposes a set of ethical standards which can be supported by geneticists in any nation who will not permit destructive ethical relativisms to dominate their choices. It concludes by leaving it to the reader to evaluate the relevance of this author's ethical reflections to law, public policy and regulation bearing upon research and clinical practice in human genetics.

I. "THE NEW GENETICS"

Before the development of DNA technology and its first use in prenatal diagnosis,3 geneticists4 tested for harmful genetic mutations in two main ways: 1) tests applied to proteins assumed to be defective due to an inherited gene; and 2) measurements of the molecular weight of compounds assumed to be abnormal due to inheritance. Observation of infants and children with

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* Professor of Biomedical Ethics and Religious Studies, University of Virginia. This article derives from a Brendan F. Brown Lecture delivered on October 13, 1988 at The Catholic University of America, The Columbus School of Law, Washington, D.C. 20064. Although I did not know Brendan F. Brown, I feel spiritual companionship with him and his work and will try to do justice to his legacy.

1. For those who are unaware of such a major milestone in human genetics, see D. Weatherall, The New Genetics and Clinical Practice (2d ed. 1985), for an excellent review of the new genetics that non-geneticists can readily understand.


4. Medical geneticists study the relationship of heredity and disease and provide genetic counseling, screening and access to prenatal diagnosis.
genetic abnormalities and abnormal chromosomal findings were two additional methods of confirming hereditary disorders. The "old genetics" involved tests or observations of the expression of harmful genes. The "new genetics" exactly reverses this method and uses a direct test of DNA obtained from nucleated cells of any tissue.

The most relevant public policy considerations for use of DNA technology in the U.S. were raised by Holtzman: 1) Potentially, DNA tests for affected persons and carriers of all major genetic disorders will become available as the human genome is mapped, although the validation of these tests will be very difficult due to genetic heterogeneity. 2) DNA tests will also become available to detect genotypes that make persons more susceptible to common diseases (e.g., familial cancers, heart disease, and diabetes). The same caveat about validation also applies here. 3) The number of persons to be screened will be extremely large. 4) The number of interested third parties, besides family members, family physicians, and health authorities (e.g., insurers and employers) will multiply, and this increases the chances for genetic discrimination. Privacy and confidentiality issues will multiply. 5) Because DNA must often be collected from members of whole families, and in some cases, from generations of family members, their awareness of the ethical implications of testing will be deeper; secrets will be virtually impossible to keep. 6) Disclosure dilemmas will multiply, especially because harmful genes will be detected presymptomatically in persons at high risk for disorders of late onset, like Huntington disease. 7) Earlier prenatal diagnosis (9-11 weeks) is now possible and will see greater demand since chorionic villus sampling has proved to be as safe and accurate as amniocentesis. Because information about gender will be more available earlier in pregnancy, the opportunities for sex choice abortions, unrelated to genetic disease, will greatly increase.

The six ethical problems in human genetics identified in the final section of

7. Id. at 624.
8. Id. at 625.
9. Id. at 626.
10. Id. at 629-30.
12. See id. at 55.
14. The same public policy considerations are applicable to other nations as well.
this article preexisted the "new genetics." My main thesis is that these new techniques do not create new ethical problems but magnify each preexisting problem. DNA approaches to genetic diagnosis intensify and complicate ethical problems that emerged in the late 1960s and 1970s, when medical genetics became a new field. The final section will also describe how trends in human genetics will interact with trends in fetal and reproductive medicine to create a more complex set of technological possibilities with far-reaching ethical concerns.

II. A CROSS-CULTURAL STUDY OF MEDICAL GENETICISTS

To gather data on ethical problems frequently encountered in the practice of medical genetics, I conducted field studies in 1984 at 25 genetic centers in 12 nations. Valuable contacts with one or more key geneticists were made to help with the future study. Dr. Wertz and I then developed a questionnaire with 14 clinical cases frequently faced by geneticists in these and other nations. Our goal was to study the degree of consensus and variation in the geneticists' approaches to ethical problems they described as frequent and difficult. Respondents were asked what they would do, from a list of possible responses, and why, in their own words, they had chosen this particular course of action. There were five questions on screening for genetic disorders in populations and in the workplace. Finally, there were questions about goals and approaches to counseling originally proposed by Fraser, as surveyed by previous researchers.

The questionnaires took two hours to complete and were answered anonymously. We selected geneticists who held an M.D., Ph.D., or equivalent degree and were engaged in delivering or administering genetic services (testing, counseling, prenatal diagnosis, laboratory work). Although in some nations (notably the U.S.), counseling is sometimes done by specially-trained persons who do not hold a doctorate, we decided to omit these persons to control for consistency of training across the entire sample.

In each country, including the U.S., our contact geneticists tried to include all qualified medical geneticists in the survey. Lists were compiled from certifying boards, genetic centers and the International Directory of Ge-


16. See Fraser, Genetic Counseling, 26 AM. J. HUM. GEN. 636 (1974).

Of the 1053 geneticists asked to participate, 677 or 64 percent returned questionnaires by the close of the study in February, 1987. 67 percent of these answered all parts of the questionnaires, including stating in their own words why they had chosen particular courses of action. 87 percent held M.D.s, 16 percent Ph.D.s, and 3 percent held other degrees. They had a median of 14 years in the practice of genetics; 82 percent were members of their national genetics society, and 77 percent were board certified or accredited in countries where certification in genetics was possible (Canada, Hungary, United Kingdom, United States). Respondents spent an average of 45 hours a week in genetics. 65 percent were male, and 82 percent were married with a median of 1.5 children. Religious backgrounds were 40 percent Protestant, 18 percent Catholic, 17 percent Jewish, 12 percent none, 13 percent other. As a whole, they were nonpracticing, attending a median of one religious observance a year. 49 percent characterized themselves as politically liberal, 15 percent as conservative, and 36 percent as both equally.

Our criteria for consensus were those frequently used in legislative processes, in the absence of an accepted scientific criterion for consensus. We used a "3/4's rule" (3/4's of the respondents in each of 3/4's of countries) to define a "strong consensus." This method allows representation to each country. If we had used percentages of the total number of responses, the U.S., with 44 percent of all respondents, would have been disproportionately represented.

**Cases with Consensus**

There was strong consensus on 5, 36 percent, of the 14 clinical cases. Three cases involved full disclosure of laboratory results that were conflicting, ambiguous, or artifactual, or had new and controversial interpretations. The problem with "full disclosure" of such results is that some parents may decide for abortion on problematic information. In case 1, involving conflicting findings about the possibility of a minor neural tube defect in the fetus, 98 percent of respondents would disclose all findings and 90 percent would counsel nondirectively (greater than 66 percent in all nations except Hungary) about continuing or terminating the pregnancy.

In case 2, involving disagreement with colleagues about ambiguous laboratory results of prenatal diagnosis, 97 percent would disclose the disagreement. In case 3, 94 percent would inform patients with a low measurement

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19. See infra Appendix TABLE 1.
of a fetal enzyme (alpha-fetoprotein) in a maternal blood test about a (then) new and controversial interpretation suggesting Down syndrome; 82 percent would disclose that geneticists disagreed about this interpretation.

In case 4, involving a problem of false paternity, which is often discovered in genetic testing, 96 percent of the respondents believed that protection of the mother's confidentiality overrode disclosure of true paternity. 81 percent said that they would tell the mother in private, without the husband present, and let her decide what to tell him; 13 percent would lie (e.g., tell the couple that they are both responsible); and the remaining 2 percent would ascribe the child's disorder to a new mutation, a one-in-a-million occurrence. As their reasons for such answers, 58 percent cited preserving the family unit, 30 percent gave the mother's right to decide, and 13 percent gave the mother's right to privacy.

In case 5 involving counseling strategies after prenatal diagnosis of chromosomal disorders of relatively low burden, (i.e., Turner syndrome (the female infant will have only one X chromosome-XO) and XYY (the male infant will have an "extra Y" chromosome)), there was strong consensus that counseling should be nondirective for both disorders. The exceptions were the German Democratic Republic, Hungary, and France, where 43 percent, 60 percent, and 65 percent respectively would advise carrying an XYY fetus to term or would give optimistically slanted information; and Hungary and India, where 40 percent and 46 percent respectively would advise aborting an XO fetus or would give pessimistically slanted information.

**Cases without Consensus**

There was no strong international consensus in the remaining nine cases. Unlike the above "disclosure problems," these cases involved significant conflicts between ethical principles and/or between the interests of different parties.

Two cases reflected conflict between the geneticist's duty to preserve patient confidentiality and the duty to warn third parties (relatives at risk for genetic disorders) of harm. In each case, the person with a mutant gene (Huntington disease or hemophilia A) refused to permit disclosure of the diagnosis to relatives at high risk for the same disorder. We expected that more would disclose a diagnosis of hemophilia A than of Huntington disease because the first is treatable. This was not the case. Instead, 58 percent (63 percent excluding the U.S.) would tell the relatives of the Huntington pa-

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20. *E.g.*, the woman knows who the true biological father is, but her husband believes falsely that he carries a recessive gene like the mother.
tient, and 60 percent (66 percent excluding the U.S.) would tell the relatives of the hemophilia A patient. These averages included 24 percent and 29 percent respectively who would seek out and tell the relatives even if they did not ask for information. Overall, 32 percent would preserve the confidentiality of the Huntington patient and 10 percent would refer the matter to the patient's family physician for decision. For hemophilia A, the corresponding rates were 27 percent and 12 percent. There was strong consensus for disclosure of the Huntington diagnosis in five nations: Australia, Brazil, Denmark, Italy, and Norway, and strong consensus for disclosure of the hemophilia A diagnosis in three nations: Australia, Brazil, and Denmark.

Two situations involved disclosure of psychologically sensitive information that might harm the patient. In one case, disclosing which parent had a balanced translocation might enable the couple and relatives at risk to use reproductive options that would prevent the birth of another Down child, but could also cause guilt in the carrier or threaten the marriage. In another case, disclosing an XY genotype in an infertile woman could severely damage her self-image, but could resolve doubts about fertility. Both cases involve conflicts between the geneticist's duty to tell the truth (which also may be phrased in terms of the patient's right to know) and the duty to do no harm. In both cases, patients have asked for information about causation, but have not asked specific questions about their carrier status or genotype.

On average, respondents were equally divided about disclosure, with 54 percent (46 percent outside the U.S.) saying that they would disclose, unasked, which parent was a carrier and 51 percent (41 percent excluding the U.S.) disclosing XY genotype. In the translocation case, 43 percent would tell the couple that the information exists and give them the choice of knowing or not knowing. There was strong consensus in Switzerland in favor of disclosure of which parent carried the translocation, and strong consensus in Japan against such disclosure. There was strong consensus in 7 nations, Brazil, France, German Democratic Republic, Greece, Hungary, Norway, and Switzerland, against disclosure of XY genotype; whereas in two countries, Canada and United States, a majority (68 percent and 64 percent, respectively) would do so.

A further case involved a genetic disorder (tuberous sclerosis) that cannot be diagnosed prenatally. Would counselors discuss all reproductive options with parents, including new techniques like artificial insemination by donor (AID), in vitro fertilization (IVF) of a donated egg, and insemination of a surrogate mother with the husband's sperm? AID was widely accepted: 83 percent would present this as an option (72 percent excluding the U.S.). IVF with donor egg was less widely accepted, 66 percent (52 percent outside
The New Genetics

A total of 46 percent (28 percent excluding the U.S.) would present surrogate motherhood as an option. Adoption as an option received strong consensus. Surprisingly, there was not consensus about presenting "taking a chance," contraception, or sterilization.

Three cases concerned prenatal diagnosis. In one, 85 percent (76 percent excluding the U.S.) would perform prenatal diagnosis, or refer, for a couple who refused abortion. This information is very important in nations that ration prenatal diagnosis through universal health insurance. Respondents reasoned that giving prenatal diagnosis should not depend on the use patients intended to make of the information. 34 percent stated that patients might change their mind about abortion. Refusals were largely based on lack of resources.

In a second case, 73 percent (61 percent excluding the U.S.) would either perform prenatal diagnosis for maternal anxiety in the absence of any other medical indications (63 percent) or refer the patient to a doctor who would perform it for this reason. Of those in favor, 56 percent gave patient autonomy as their major reason and 46 percent gave the removal of anxiety. Among those opposed, 61 percent gave possible harm to the fetus as their major reason, and 70 percent gave waste of resources.

The final case was the most controversial in the entire survey; 42 percent (26 percent excluding the U.S.) would either perform prenatal diagnosis for sex selection (25 percent) or refer the couple to another medical geneticist or genetics unit who might do so (17 percent). There was strong consensus against performance in ten nations. Only in the United States, Hungary, and India would a majority expedite the diagnosis. Their reasons differed widely.

In the U.S., 68 percent of those who would perform it or refer would do so out of respect for parental autonomy; in Hungary, all 15 of those offering prenatal diagnosis would do so in order to prevent the otherwise certain abortion of a normal fetus. In another five countries substantial minorities would either perform prenatal diagnosis or refer: Canada (47 percent), Sweden (38 percent), Israel (33 percent), Brazil (30 percent) and Greece (29 percent). In their reasoning 30 percent of respondents (the same rate as in the U.S.) said that they opposed the abortion of a normal fetus or that the interests of the fetus should be weighed equally with those of living persons. Of the 605 persons who gave reasons for their actions in this case, only 4.7 percent brought up the position of women in society, 0.5 percent mentioned maintaining a balanced sex ratio, 0.6 percent mentioned limiting the population, and 4.9 percent cited setting a precedent that would harm the moral order. The exception was India, where 61 percent evoked at least one of
these social issues. 28 percent of all respondents brought in issues related to justice, such as wise use of medical resources or diversion away from patients at genetic risk.

Genetic Screening

There was strong consensus on four out of five questions about screening and access to results. Respondents substantially agreed that mass screening for carriers of cystic fibrosis or for genetic susceptibility to work-related disease should be voluntary. There was very strong consensus that third parties, such as employers and insurers, should not have access to the results of screening without the patient's consent. Although there was more consensus about screening than about clinical cases, all the examples of screening were hypothetical, exceeding scientific capabilities in 1985. When fully developed, the tests may be accompanied by unforeseen technical, economic, and social problems that will reduce the degree of consensus.

Significance and Implications

This cross-cultural study found more variation than consensus about fourteen clinical cases and found consensus on most of the screening questions. What conclusions can be drawn?

First, cultural differences in approaches to ethical problems arising from genetic technologies still seem to be substantial. This finding tends to refute the view that the diffusion of technology is socially determined, carried by a Western cultural tradition that resolves ethical disputes in favor of the diffusers of technology.21

Second, the main lesson of the study is that the central thrust of the moral reasoning of medical geneticists in these nations is to protect the autonomy of the individual patient (or parents) and exercise responsibility to meet the needs of the patient. The study found strongest consensus in cases in which it is relatively easy to enhance and protect the welfare of the patient, (e.g., that counseling should be nondirective, that genetic information should be protected from insurers and employers, and that ambiguous test findings ought to be fully disclosed). Cases judged to be the most difficult (i.e., confidentiality vs. interests of relatives, disclosure of XY in a female, and sex selection) had conflicts between respect for the autonomy of patients and the welfare of others. In the new genetics, these problems involve the welfare of many others and the best interests of society itself. Compared with the claims of autonomy, the concerns of justice appeared less frequently in re-

responses, except for strong recognition of problems of distributive justice in inadequate genetic services.

Thirdly, attempts to gain consensus about approaches to ethical problems have strengths and weaknesses. On the positive side, consensus-seeking helps to consolidate experience and enable older practitioners to transmit what they have learned to younger ones. Findings about consensus are useful in conveying clear positions to the public and to policy makers. Also, formulating consensus on older problems releases valuable energy to focus on new, unfamiliar problems.

On the negative side, the mere fact that consensus exists about an approach to an ethical problem is not the primary source of ethical grounding of the approach. As Mareno correctly points out, consensus should be primarily regarded as a condition of ethical inquiry rather than its goal. The goal of ethical reflection is a well-reasoned conclusion of an argument, based on a premise which soundly appeals to ethical principles, and which takes into account all sides of a question and all rational approaches. The conclusion, with the accompanying argument, should be within the ethical reach of many and also teachable. That many, perhaps most, persons will be persuaded by the argument is an important condition but does not by itself win the day for the argument.

Appeal to consensus can also mask cultural dominance. Preference for individual over societal interests, a U.S.-Western cultural bias, is clearly evident in the study's findings. Also, excessive attempts at consensus could suppress vital minority positions, often the most creative and critical. Finally, some geneticists objected to an effort at consensus because it could lead to "written guidelines" that invite legal vulnerability for those who act differently. Others pointed out that the field of medical genetics is too technologically fluid to find strong consensus on some issues.

The major tension in health care ethics is between the interests of individuals and families and the larger interests of society. Based on the ethical perspective outlined in the next section, it appears that the major weakness of the approaches that have evolved in most nations in the West is that interests of society are too heavily outweighed in crucial cases by the interests of individuals. A stronger balance between societal and individual interests can help to reshape an overly individualistic approach that could have harmful consequences to other persons, to society, and also to medical genetics.

III. ETHICS IN A CROSS-CULTURAL PERSPECTIVE

Any viable practical approach to ethical problems in medical genetics must be able to address cross-cultural problems in ethics. Increasingly, medical geneticists see patients from other cultures with different ethical beliefs and world views. Also, medical geneticists from a wide variety of religious, cultural, and social backgrounds must work together under the same roof, and in the same national and international professional and scientific societies. Geneticists confront the same serious ethical problems. Can the problems be understood and resolved without adopting absolutist ethical views, or without falling back on a view of ethical relativism with no limits to toleration of harmful or oppressive acts, if these are considered morally right in some society? Is there some "common ground" in ethics?

The findings of this study would not surprise anthropologists or dismay advocates of cultural or ethical relativism. Cultural diversity in moral views is a social fact observed since Herodotus. One response to cultural diversity is to treat it as a factual datum for ethics, without drawing any conclusion about what is right or wrong. Another response is to draw conclusions by taking a position of ethical relativism. Ladd, defines ethical relativism as:

the doctrine that the moral rightness and wrongness of actions varies from society to society and that there are no absolute universal moral standards binding on all men at all times. Accordingly, it holds that whether or not it is right for an individual to act in a certain way depends on or is relative to the society to which he belongs. What is right in one society may be wrong in another society and may be neither right nor wrong in a third society.

An ethical relativist viewing this study would deny that any common ground exists for a cross-cultural perspective in ethics and would advise tolerance. At its extreme, the relativist view would permit approaches to ethical problems in human genetics that most rational persons would find intolerable. Therefore, it is necessary to go beyond the relativist view and seek ethical guidance on a cross-cultural basis.

Ethical guidance on a cross-cultural basis involves respect for the dominant moral opinion found in different cultures and also in various sectors of a pluralistic society. But this respect is not unlimited. Following MacBeath, Ladd states that culturally variable moral opinions ought to be

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24. J. LADD, ETHICAL RELATIVISM 1 (1985). This is an outstanding text on the subject of ethical relativism.
seen as “experiments in living” which provide data for ethics, and which ethics should not neglect.\textsuperscript{26} In this sense, giving respect to the differing moral opinions of geneticists is the equivalent of what Ladd calls “constructive relativism.”\textsuperscript{27} This position elevates popular moral opinion (such as the moral views held by geneticists in this study) to the moral level. Ladd adopts this position, and likens popular moral opinion in a society to the legislative will. He accords it a leading, but not absolute role, in constituting morality. He notes that this view of moral opinion or custom has “affinities with the general ethical position known as voluntarism, for, by analogy, we can conceive of popular opinion as embodying the will of the people, which determines what is right and wrong.”\textsuperscript{28} The connection between Ladd’s thought and the work here concerns approaches taken by medical geneticists should be viewed as voluntary and chosen by them as morally serious persons, rather than imposed on them unwillingly. The good response rate to a questionnaire requiring several hours to complete supports an impression of moral seriousness among geneticists.

The opposite of constructive relativism is “destructive relativism,” a view that reduces morality itself to the level of popular opinion and drains all of its moral character away.\textsuperscript{29} Ladd observes that this form of reductionism is commonly used to convert a moral proposition into a statement about the proposer or the society of the proposer.\textsuperscript{30} Thus, the normative character of moral statements is neutralized and morality is understood as not binding at all.

Alongside the voluntaristic element in morality, Ladd requires a “nonvoluntaristic element,” independent of the received moral opinions.\textsuperscript{31} He moves between two descriptions of the nonvoluntaristic element. Ladd describes it in one place as “a principle, however formal and general, that confers authority and legitimacy” on “quasi-legislative cultural definitions of what is right and wrong.”\textsuperscript{32} In another place, he calls it a “schema for morals, which is to be filled in by the culture itself as it ‘experiments in living.’”\textsuperscript{33} He notes that the “schema” is necessary to answer the objections against ethical relativism that ethical relativism would require recognition of the moral opinion that fostered Nazism and its atrocities as “equally

\begin{thebibliography}{99}
\bibitem{26} See Ladd, supra note 24, at 123.
\bibitem{27} Id. at 121.
\bibitem{28} Id. at 123.
\bibitem{29} Id. at 124.
\bibitem{30} Id. at 124-25.
\bibitem{31} Id. at 123.
\bibitem{32} Id.
\bibitem{33} Id.
\end{thebibliography}
Constructive relativism is thus a form of restricted relativism, permitting variety in moral institutions, but ruling out the intolerable. Destructive relativism, i.e., reductionism, leaves room for no ethical response in the face of the intolerable, since mere opinion is seen to be the essence of morality.

Perhaps the clearest example of a totally nonvoluntaristic element, (but not what I espouse), is the concept of natural law. Brendan Brown's legal thought was based on a version of natural law. Natural law embodies the idea that objective ethical standards are "given" in human nature itself, independent of a society's laws or religion, and that these standards can be known by all rational persons. As applied to human genetics, a natural law view would hold that certain actions, e.g., sex selection, attempts to make chimeras by human-animal hybrids, or causing harmful mutations in a population, are wrong because they are "unnatural." This judgment would be made independent of harmful consequences because of the violation of natural law. Today, moral judgments made in terms of natural law as applied to human genetics are most often made in opposition to the practice of selective abortion.

Natural law is, of course, not the only example of a "schema" or nonvoluntaristic element. Schema-building in contemporary Western cultures mainly employs ethical principles widely recognized across religious, philosophical, and cultural boundaries. Several anthropologists, most notably Hatch have evoked *prima facie* principles to "use in evaluating cultures, including our own." In fact, he chooses four principles but only one is recognizably "ethical." He refers to a "humanistic" principle, namely, that "the well-being of people ought to be respected." He uses well-being to make moral judgments on starvation and violence wherever these occur. Contemporary moral philosophers have used other terms to describe what Ladd calls the "schema," e.g., a "second tier of the moral life," "the critical level of basic ethical principles," or "the ethical level *per se.*" All of these terms describe a move from a level of popular, intuitive morality in particular communities to a more general and impartial level of principles.

Instead of using the term "schema," I prefer to use "a cross-cultural per-
perspective” in ethics. Just as Ladd requires that “popular moral opinion” be limited by a “schema” or nonvoluntaristic element, I would require that geneticists’ be limited by a cross-cultural perspective in ethics when approaching ethical problems. Ordinarily, the term “cross-cultural” conveys a relativistic approach. I hold, with Ladd, that constructive relativism is the correct view of cultural diversity in morality. Therefore, in my view a cross-cultural perspective is a schema both to prevent the intolerable and to encourage cross-cultural “experiments in living” that would help geneticists be open to change. A cross-cultural perspective would encourage experimentation in breaking out of old moral molds, drawing new lines where none existed before, or in redrawing moral lines that have been allowed to blur.

I agree with Ladd that the “schema” or the “perspective” is culture-dependent, or “must be filled in by the culture.” No view in ethics is entirely free from its cultural origins and dependency. Ethical absolutism will always founder on this historical reality as well as on the coercion and dislocation required to impose it on those with different views. The perspective taken here (basic ethical principles and relationships) is characteristic of some contemporary Western ethical reasoning. The middle way, however, between ethical relativism and absolutism lies precisely in the claim that ethical principles make demands on everyone alike and that the responsibilities inherent in certain relationships (e.g., physician-patient) make demands on all who are in these relationships. Basic ethical principles are universal and objective in just this sense, namely, that everyone ought to do what the principles say, assuming that persons 1) know the principles and 2) “can” do what they require.42 In ethics, “ought implies can.”43 Therefore, if it is impossible to respond to the ought, allowances must be made. This principle, “ought implies can,” is the antidote for ethical absolutism. Below, are recommendations that geneticists in most nations are capable of following.

Ethical Problems and Standards in Medical Genetics Today

There are two types of situations commonly identified as “ethical problems.” The first is when a person or group is perceived by others to be in basic violation of responsibilities to the welfare of a significant human community. The ethical problem is how the community ought to respond. The second situation finds persons, like the geneticists in this study or their patients, confronting sharply conflicting duties, making a decision that expresses the conflict. These two situations can and often do, coalesce.

Every ethical problem arises in a situation that has elements of: 1) collec-
tively defined loyalty; and 2) individuals or groups confronting decisions that express conflicts. These conflicts may be among ethical principles, among responsibilities transmitted in roles like “physician” and “patient,” or among loyalties owed to communities beyond the medical situation, (e.g., familial, legal, or religious).

The study shows that geneticists and their patients, even in nations with very different cultural traditions, tend to face a similar set of ethical problems. These problems are: 1) access to and adequacy of genetic services; 2) abortion choices; 3) confidentiality conflicts; 4) disclosure dilemmas; 5) indications for prenatal diagnosis; and 6) exceptions to the practice of nondirective counseling. I rank these problems using three criteria: 1) the study’s results; 2) frequency of discussion;44 and 3) by numbers of persons whose welfare is adversely affected by the problem.

1. On a cross-cultural basis, the two-sided problem of unfairness in access to genetic services (i.e., counseling, screening, prenatal diagnosis) and insufficient services to meet needs, is the most ubiquitous ethical problem in human genetics. This problem is especially acute for individuals, families and pregnant women who are not referred to genetic services by physicians, who suffer from poverty or lack of education, or who live far from a genetic center.

2. Abortion choices for genetic reasons present difficult conflicts and concerns in every society due to several causes: a) beliefs about the higher moral status of the fetus at midtrimester; b) the wide spectrum of severity in some disorders; c) the treatability of some disorders; d) concern that a practice of selective abortion creates a precedent for neglect of genetically affected persons who survive, including precedent for a practice of pediatric euthanasia; and e) the possibility of diagnosing twins where one is healthy and the other affected. A decision not to abort after a positive genetic finding can also be an ethical problem if the woman or couple involved are pressured to abort or threatened with loss of medical care.

3. The duty to protect patients’ privacy and to maintain the confidentiality of the patient-geneticist relationship is a problem in every nation. Geneticists have a duty to prevent unconsenting disclosures of their patients’ genetic diagnoses and health prognoses. This duty can sometimes conflict with the interests of relatives at risk and especially with the collective interests of institutional third parties, (e.g., insurers, employers, or government health authorities).

4. Disclosure dilemmas in medical genetics exist in every society. They arise largely from the geneticist’s access to psychologically sensitive informa-

44. See supra notes 15-22 and accompanying text.
tion. For example, when the geneticist knows, but a married couple does not yet know which one has transmitted a disorder to a child; when tests reveal that a phenotypical female has an \( XY \) genotype; when tests show false paternity; when a woman has had previous elective abortions and her husband does not know; when scientific conflicts occur about the interpretation of findings and an abortion might ensue; or when disclosure of a genetic diagnosis to a vulnerable or fragile individual may carry a risk of harm.

5. Some patient requests or preconditions for prenatal diagnosis, (e.g., maternal anxiety, refusal of abortion, and sex selection) are ethically controversial, especially the latter. However, ethical problems in indications for prenatal diagnosis affect the welfare of far fewer persons than the four problems introduced above.

6. This study shows that nondirectiveness is the most widely ingrained approach to genetic counseling, when viewed cross-culturally. However, ethical problems do arise in choices to be nondirective, especially in counseling patients whose capacity to participate in counseling and decision making is impaired. These patients may be mentally ill, significantly retarded, or abusers of alcohol or drugs. Some patients may be disadvantaged in terms of communication because they lack adequate education. Further, some patients from a different culture may hold different views about science and nature than the geneticist. For such reasons, all of the above patients may be functionally unable to appreciate the significance of genetic risks. These cases were infrequently mentioned by our respondents, but were the subject of notes on questionnaires pointing out that such problems exist, especially in cases of severe retardation and substance abuse.

These six ethical problems in medical genetics have been present since the introduction of amniocentesis and carrier screening in the late 1960s, but the problems magnify in complexity and frequency as genetic technologies improve and the numbers of persons attending genetic clinics increases. This magnification is especially obvious in the context of the “new genetics.”

My arguments in the section above are based on a conviction that there are serious limitations to the toleration of wide cultural differences on some ethical problems, despite apparently wide cultural differences.

*Proposed Ethical Guidelines*

When the claims of basic ethical principles are considered together with the needs of patients and families and the responsibilities of geneticists, the following guidelines should and *can* be adopted in each of the participating nations:

1. Medical geneticists should disclose all clinically relevant information to
patients and family members, consistent with considerations of immaturity and psychological well-being. Psychological assessments are best done in consultation with mental health professionals.

2. Confidentiality is a strong but not absolute norm in medicine and in medical genetics. When claims of nonmaleficence to prevent harm to others places a limit on the physician's or counselor's duty of confidentiality, four conditions should be satisfied before breaching confidentiality:

   (1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability both that harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed.

3. Medical geneticists should safeguard the options of parents in genetic services, including the option of abortion. An important moral line about selective abortion exists in the public mind. As stated by Elias and Annas: "as controversial as elective abortion is, the use of abortion when a woman is carrying a fetus with a severe genetic defect is very well accepted by a vast majority of both the public and physicians." Data collected by the National Opinion Research Center between 1972 and 1987 on trends in U.S. public opinion on genetic reasons for abortion show that between 75 percent and 77 percent of those surveyed support abortion of a serious genetic disease. The American public's views also overwhelmingly supports 89 percent making genetic testing available for serious and fatal genetic diseases.

4. Medical geneticists should not acquiesce to patient requests for sex selection unrelated to the diagnosis of a sex-linked disease. Three reasons support this position: 1) gender is not a genetic defect; 2) equality between males and females is violated; and 3) sex selection is a precedent for eugenics, i.e., "tinkering" at parental whim with characteristics unrelated to any genetic disease. If patients have a genetic reason for diagnosis and also show

45. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Screening and Counseling for Genetic Conditions 44 (1983).


48. Id.
excessive interest in the gender of the fetus, geneticists can consider delayed
 disclosure of gender after timely disclosure of clinical findings.

5. Genetics services programs should be voluntary in nature. Forcing
persons to accept genetic services in order to prevent disorders may be "cost-
beneficial" but it would be morally destructive and self-defeating in the long
run.\textsuperscript{49} It would be completely contradictory to espouse an institution of
parenthood based on companionate choice and privacy and then impose
mandatory genetic testing. However, sufficient genetic services should exist
in modern societies to offer to everyone who needs them. Genetic burdens
are among the most arbitrary and punishing that life imposes on human
beings. From the standpoint of ethics grounded either in religious or secular
sources, remedying natural injustices and injustices that stem from lack of
opportunity for education and access to health care are at the heart of the
enterprise of human genetics.

Use of these guidelines to overcome diversity strengthens the profession to
meet the very complex problems immediately on the horizon. Of course, the
main forums in which these propositions should be deliberated are national
and international organizations of medical geneticists.

IV. CONCLUSION: TRENDS IN GENETICS AND ALLIED FIELDS

Some steps in identifying problems and standards for geneticists, even in a
cross-cultural perspective, are possible. In short, it can be done and it ought
to be done. The stakes are too high, in terms of the potential for relief of
human suffering, to do otherwise.

However, it promises more complexity on every side of the developing
field of medical genetics. Trends in human genetics will interact with trends
in fetal and reproductive medicine to create a complex, interrelated set of
technological possibilities with important ethical concerns: 1) Earlier
methods of prenatal diagnosis, including the potential for diagnosis in the preim-
plantation human embryo;\textsuperscript{50} 2) the potential for general pregnancy screening
in a population; 3) Potential for fetal therapy, including attempts on the
molecular level;\textsuperscript{51} 4) The potential for using fetal cells and tissues after in-
duced abortion for treatment of disorders, including genetic disorders, in

\textsuperscript{49} See Smith, Genetics, Eugenics, and Public Safety, 1985 So. Ill. L.J. 438-440 for an
historical analysis of the concept of eugenics.

\textsuperscript{50} See generally Prenatal Diagnosis Before Implantation: Opportunities and Problems, 5
Prenatal Diagnosis 85 (1985).

\textsuperscript{51} See M. Harrison, M. Golbus & R. Fully, The Unborn Patient: Prenatal
Diagnosis and Treatment (2d ed.) (in press).
older persons and children; \(^{52}\) 5) Screening for genotypes that render individuals more susceptible to common diseases like cancer and heart disease; \(^{53}\) 6) Screening in the workplace for genotypes that render individuals more susceptible to harms from toxins and other industrial hazards; \(^{54}\) 7) Opportunities for clinical treatment of DNA-diagnosed genetic disorders \(^{55}\) and for somatic cell human gene therapy; \(^{56}\) 8) In vitro fertilization and the potential it creates for: a) genetic research on the human pre-embryo \(^{57}\) b) future attempts at human germline gene therapy \(^{58}\) c) eugenically-inspired genetic engineering. \(^{59}\)

These possibilities in human genetics and related fields raise ethical, social and legal concerns that require study and guidance by councils at the highest level of government and the professions.

\(^{52}\) See generally Sladek & Shoulson, Neural Transplantation: A Call for Patience Rather Than Patients, 240 SCIENCE 1386 (1988).


\(^{55}\) See White & Caskey, supra note 51, at 1487.


\(^{57}\) See West, Angell, Thatcher, Gosden, Hastie, Glasier, Baird, Sexing the Human Pre-Embryo by DNA-DNA in-Site Hybridization, 2 LANCET 1345 (1987).

\(^{58}\) See Anderson, Human Gene Therapy: Scientific and Ethical Considerations, 10 J. MED. PHIL. 275 (1985); Fletcher, Ethical Issues In and Beyond Prospective Clinical Trials of Human Gene Therapy, 10 J. MED. PHIL. 293, 294 (1985).


## APPENDIX

### Table 1. Participating Nations

<table>
<thead>
<tr>
<th>Nation</th>
<th>Number Asked To Participate</th>
<th>Number of Persons Responding</th>
<th>Response Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>14</td>
<td>12</td>
<td>86</td>
</tr>
<tr>
<td>Brazil</td>
<td>51</td>
<td>32</td>
<td>63</td>
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<tr>
<td>Canada</td>
<td>73</td>
<td>47</td>
<td>64</td>
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<tr>
<td>Denmark</td>
<td>28</td>
<td>15</td>
<td>58</td>
</tr>
<tr>
<td>Federal Republic of Germany (FRG)</td>
<td>55</td>
<td>47</td>
<td>85</td>
</tr>
<tr>
<td>France</td>
<td>35</td>
<td>17</td>
<td>49</td>
</tr>
<tr>
<td>German Democratic Republic (GDR)</td>
<td>25</td>
<td>21</td>
<td>80</td>
</tr>
<tr>
<td>Greece</td>
<td>11</td>
<td>7</td>
<td>64</td>
</tr>
<tr>
<td>Hungary</td>
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<td>15</td>
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<tr>
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<tr>
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<tr>
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<td>51</td>
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<td>33</td>
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<tr>
<td>United States</td>
<td>490</td>
<td>295</td>
<td>60</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>1,503</strong></td>
<td><strong>677</strong></td>
<td><strong>64</strong></td>
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