Chapter 13 Genetics and Society

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Chapter 13 **Genetics and Society**

Genetics and modern science

In 1979, the organization for Economic Cooperation and Development (OECD)* published a survey of mechanisms for settling issues involving science and technology in its member countries. The OECD report noted that:²

Science and technology . . . have a number of distinguishing characteristics which cause special problems or complications. One is ubiquity: they are everywhere. They are at the forefront of social change. They not only serve as agents of change, but provide the tools for analyzing social change. They pose, therefore, special challenges to any society seeking to shape its own future and not just to react to change or to the sometimes undesired effects of change.

After surveying member countries, OECD identified six factors that distinguish issues in science and technology from other public controversies.

- 1. The rapidity of change in science and technology often leads to concern. The science of genetics is one of the most rapidly expanding areas of human knowledge in the world todayy. And the technology of genetics is causing quick and fundamental changes on a variety of fronts. The news media have consistently reported developments in genetics, often with front-page stories. Consequently, the public has become increasingly aware of developments in genetics and genetic technologies and the speed with which knowledge in the field is gathered and applied.
- 2. Many issues in today's science and technology are entirely new. Protoplasm fusion, re-

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combinant DNA (rDNA), gene synthesis, chimeras, fertilization of mammalian embryos in vitro, and the successful introduction of foreign genes into mammals were the subjects of science fiction until a few years ago. Now they appear in newspapers and popular magazines. Yet the genera] public's understanding of these phenomena is limited. It is difficult for people to evaluate competing claims about the dangers and benefits of this new technology.

- 3. The scale, complexity, and interdependence among the technologies are greater than people suspect. As in other fields, applications of biological technology often depend on parallel developments in areas that provide critical support systems. Breakdowns in these systems are often as limiting as failures in the new technology itself. In other parts of this report for example, sophisticated breeding systems in farm animals and large-scale fermentation processes for single-cell cultures are described. Besides the biological technology required to support these systems, precise computerized operations are required to ensure purity, safety, and process control in fermentation and to provide the population statistics necessary for breeding decisions.
- 4. Some scientific and technological achievements may be *irreversible* in their effects. Because living organisms reproduce, some fear that it will be impossible to contain and control a genetically altered organism that finds its way into the environment and produces undesirable effects. Scenarios of escaping organisms, pandemics, and careless researchers are often drawn by critics of today's genetics research. The intentional release of recombinant organisms into the environment is a related issue that will need to be resolved in the future.

Another example of irreversibility, brought about by the demands placed on

members , are: Austria, Belgium, Finland, France, West Germany, Greece, Morway, Control of Trial Public Participation in the Methodogy [Paris: organiza-tion]

tion and Dev and Development, 1979). tion p. 16.

world resources, is the accelerating loss of plant and animal species. Concern over this depletion of the world's germplasm arises because genetic traits that might meet as yet unknown needs are being lost.

- 5. There exist strong public sensibilities about real or imagined threats to human health. Mistrust of experts has been stimulated by such events as the accident at the Three-Mile Island nuclear plant and the burial of toxic chemical wastes in the Love Canal. Regardless of the real dangers involved, the public's perception of danger can be a significant factor in decisionmaking. At present, some perceive genetic technologies as dangerous.
- 6. A challenge to deeply held social values is being raised by scientific and technological is-

sues. The increasing control over the inherited characteristics of living things causes concern in the minds of some as to how widely that control should be exercised and who should be deciding about the kinds of changes that are made. Furthermore, because genetics is basic to all living organisms, technologies applicable to lower forms of life are theoretically applicable to higher forms as well, including human beings. Some wish to discourage applications in lower animals because they fear that the use of the technologies will progress in increments, with more and more complex organisms being altered, until human beings themselves become the object of genetic manipulation.

Special problems posed by genetics

Genetics is just one among several disciplines of the biological sciences in which major advances are being made. other areas, such as neurobiology, behavior modification, and sociobiology, arouse similar concerns.

Genetics differs from the physical sciences and engineering because of its intimate association with people. The increasing control over the characteristics of organisms and the potential for altering inheritance in a directed fashion is causing many to reevaluate themselves and their role in the world. For some, this degree of control is a challenge, for others, a threat, and for still others, it causes a vague unease. Different groups have different reasons for embracing or fearing the new genetic technologies. Religious, political, and ethical reasons have been advanced to support different viewpoints.

The idea that research in genetics may lead some day to the ability to direct human evolution has caused particularly strong reactions. One reason is that such capability brings with it responsibility for retaining the genetic integrity of people and of the species as a whole, a responsibility formerly entrusted to forces other than man. Others find the idea of directing evolution exciting. They view the development of genetics technologies in a positive light, and see opportunities to improve humanity's condition. They argue that the capability to change things is, in fact, a part of evolution.

Religious arguments on both sides of this challenge have been made. Pope John Paul 11 has decried genetic engineering as running counter to natural law. On the other hand, one Catholic philosopher has written:³

... We have always said, often without real belief, that we were and are created by God in His own image and likeness, "Let us make man in our image, after our likeness" logically means that man is by nature a creator, like his Creator. Or at least a cocreator in a very real, awesome manner. Not mere collaborator, nor administrator, nor caretaker. By divine command we are creators. Why, then, should we be shocked today to learn that we can now or soon will be able to create the man of the future? Why should we be horrified and denounce the sci-

entist or physician for daring to "play God?" IS it because we have forgotten the Semitic (biblical) conception of creation as God's ongoing collaboration with man? Creation is our God-given role, and our task is the ongoing creation of the yet unfinished, still evolving nature of man.

Man has played God in the past, creating a whole new artificial world for his comfort and enjoyment. Obviously we have not always displayed the necessary wisdom and foresight in that creation; so it seems to me a waste of time and energy for scientists, ethicists, and laymen alike to beat their breasts today, continually pleading the question of whether or not we have the wisdom to play God with human nature and our future. It is obvious we do not, and never will, have all the foresight and prudence we need for our task. But 1 am also convinced that a good deal of the wisdom we lack could have been in our hands if we had taken seriously our human vocation as transcendent crea-

Science and society

The public's increasing concern about the effects of science and technology has led to demands for greater participation in decisions on scientific and technological issues, not only in the United States but throughout the world. The demands imply new challenges to systems of representative government; in every Western country, new mechanisms have been devised for increasing citizen participation. An increasingly informed population, skilled at exerting influence over policymakers, seems to be a strong trend for the future. The media has played an important role in this development, reporting both on breakthroughs in science and technology and on accidents, pollution, and the side-effects of some technologies.

one result has been the growing politicization of science and technology. While perhaps misunderstanding the nature of science as a process, the public has become disenchanted by recent accidents associated with technology, by experts who openly disagree with one another, and by the selective use of information by some scientific supporters to obtain a political objective. The public has seen that technology affects tures, creatures oriented toward the future (here and hereafter), a future in which we are cocreators.

Genetics thus poses social dilemmas that most other technologies based in the physical sciences do not. Issues such as sex selection, the abortion of a genetically defective fetus, and in vitro fertilization raise conflicts between individual rights and social responsibility, and they challenge the religious or moral beliefs of many. Furthermore, people sense that genetics will pose even more difficult dilemmas in the future. Although many cannot fully articulate the basis for their concern. considerations such as those discussed in this section are cited. The strong emotions aroused by genetics and by the questions of how much and what kind of research should be done are at least partly rooted in deeply held human values.

the distribution of benefits in society; it can have unequal impacts, and those who pay or who are most in **need are not necessarily always those who benefit.**

A national opinion survey of a random sample of 1,679 U.S. adults conducted for the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research⁴ made clear that there is public doubt concerning equity. Sixty percent of those polled felt that new tests and treatments deriving from medical research are not equally accessible to all Americans. Seventy percent felt that those most likely to benefit from a new test or treatment of limited availability were those who could pay for it or who knew an important doctor. This should be compared with the 85 percent who felt that a new test or treatment should be available to those who apply first or who are most in need.

¹⁵Special Study, Implications of Advances in Riomodical and Rabasingal Research ¹¹⁷ Report and Recommon dations of the National (ommission for the Protection of Human Subjects of Riomodical and Rehavior il Research DHRW publication No. **(OS) 78-00 15.**

Public concern and demand for involvement in the policy process is illustrated by the response of communities to plans for laboratories that would conduct rDNA research. Perhaps the best known example is Cambridge, Mass., where plans were announced for construction of a moderate containment laboratory at Harvard University. Concern over this facility led to the formation of the Cambridge Experimentation Review Board (CERB). Composed of nine citizens-all laymen with respect to rDNA research-the CERB spent 6 months studying the subject and listening to testimony from scientists with opposing points of view. Their final recommendations did not differ substantially from the NIH Guidelines; but the process was crucial. CERB demonstrated that citizens could acquire enough knowledge about a highly technical subject to develop realistic criteria and apply them. Similar responses to proposed laboratories have occurred in a number of other American communities, including Ann Arbor, Mich., and Princeton, N.J.⁵

These reactions, and similar phenomena surrounding controversies like nuclear power, indicate that the desire for citizen participation is strong and widespread. Recognizing this, each Federal agency has its own rules and mechanisms for citizen input. Special ad hoc commissions are sometimes formed to collect information from private citizens before decisions are made on particular projects. Congressional hearings held around the country and in Washington, D. C., are perhaps the best known of these inquiries. While these mechanisms sometimes slow the decisionmaking process, they help legitimize some decisions, and their role will probably expand in the future.

In corporate science and technology, public demands are being felt as well. Present regulations for environmental protection and worker and product safety have significantly altered corporate research and development efforts. The public is also becoming more involved in corporate decisionmaking—e. g., through "'public accountability" campaigns by stockholders to influence company policies.

With the politicization of science, the process of research itself is coming under increasing public scrutiny-most recently in cases of possible biohazards, research with human subjects, and research on fetuses. Some efforts are underway to require better treatment of research animals as well.

The relationship between science and society, between human beings and their tools, is a constantly evolving one. The process that has been called the "dialogue within science and the dialogue between the scientific community and the general public"⁶ will continue to search for standards of responsibility. It is likely that as long as science remains as dependent on public funds as it has over the past **40 years**, it will be **held accountable** to **public values**. As has been **noted**:⁷

The technologies of war, industrialization, medicine, environmental protection, etc., appear less as the demonstrations of superior claims of knowledge and more and more as the symbols of the ethical and political choices underlying the distribution of the power of scientific knowledge among competing social values.... This cultural shift of emphasis from the role of science in the intellectual construction of reality to the role of science in the ethical construction of society may indicate a profound transformation in the parameters of the social assessment of science and its relations to the political order.

Richard Jutton, 3io-Revolution: DNA and he Sthics of Man-Made iffe New Jork: Jew American jbrary Mentor), 1978).

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The "public" and '(public participation"

These are terms with vastly different meanings to different people. Some take "the public" to mean an organized public interest group; others consider such groups the "professional" public and feel they have agendas that differ from those of the less organized "general" public. As OECD stated.[§]

Public participation is a concept in search of a definition. Because it means different things to different people, agreement on what constitutes "the public" and what delineates "participation" is difficult to achieve. The public is not of course homogeneous; it is comprised of many heterogeneous elements, interests, and preoccupations. The emergence over the last several decades of new and sometime vocal special interest groups, each with its own set of competing claims and demands, attests to the inherent difficulty of achieving social and political consensus on policy goals and programmed purporting to serve the common interest.

"Nichol- op. cit., J 7.

Because publics differ with each issue, no definition will be attempted here. It is assumed that "the public" is demanding a greater role in decisions about science and technology, and that it will continue to do so. The different publics that coalesce around different issues vary widely in **their basic interests**, **their** skills, and their ultimate objectives. They are the groups that will be heard in the widening debate about scientific and technological issues, and are part of what has been called the "social system of science."⁹

The public has already become involved in the decisionmaking process involving genetic research. As the science develops, new issues in which the public will demand involvement will arise. The question is therefore: What is the best way to involve the public in decisionmaking?

Issues and Options

Three issues are considered. The first is an issue of process, concerning public involvement in policymaking; the second is a technical issue; and the third reflects the complexity of some issues associated with genetics that may arise in the future.

ISSUE: How should the public be involved in determining policy related to new applications of genetics?

The question as to whether the public should be involved is no longer an issue. Groups demand to be involved when people feel that their interests are threatened in ways that cannot be resolved by representative democracy,

The more relevant questions are whether current mechanisms are adequate to meet public desires to participate and whether a deliberate effort should be made to increase public knowledge. The last can only be accomplished by educating the public and increasing its exposure both to the issues and to how people may be affected by different decisions.

OPTIONS:

- A. Congress could specify that the opinion of the public must be sought in formulating all major policies concerning new applications of genetics, including decisions on funding of specific research projects. A "public participation statement" could be mandated for all such decisions.
- B. Congress could maintain the status quo, allowing the public to participate only when it decides to do so on its own initiative.

If option A were followed, there would be no cause for claiming that public involvement was

[&]quot;J. N. Zimar, Puble Knowledg ((Cambridge Cambridg [University Press, 1968

inadequate (as occurred after the first set of Guidelines for Recombinant DNA Research were promulgated). However, option A can be implemented in two ways. In the first, the opportunity for public involvement is always provided, but need not be taken if there is no public interest in the topic. In the second, public involvement is required. A requirement for public involvement would pose the problem that if the public does not wish to participate in a particular decision, then opinion will sometimes be sought from an uninterested (and therefore probably uninformed) public simply to meet the requirement. Option A poses additional problems: What is a "major" policy? At what stage would public involvement be required—only when technological development and application are imminent or at the stage of basic research? Finally, it should be noted that under option A, if the public's contribution significantly influences policy, the trend away from decisionmaking by elected representatives (representative democracy) and toward decisionmaking by the people directly ("participatory" democracy) may be accelerated.

Option B would be less cumbersome and would permit the establishment of ad hoc mechanisms when necessary. On the other hand, by the time some issues are raised, strong vested interests would already be in place. The growing role of single-issue advocates in U.S. politics, and their skill in influencing citizens and policymakers, might abort certain scientific developments in the future.

Regardless of which option is selected, it would be desirable to encourage different forms of structuring public participation and to evaluate the success of each method. Many different approaches to public participation have been tried in the United States and Western Europe in attempts to resolve conflicts over science and technology. Some have worked better than others, but most have had rather limited success.¹⁰ Because public demands for involvement are not likely to diminish, the best ways to accommodate them need to be identified.

ISSUE: How can the level of public knowledge concerning genetics and its potential be raised?

If public involvement is expected, an informed public is clearly desirable. Increasing the treatment of the subject, both within and outside the traditional educational system, is the only way to accomplish this.

Within the traditional educational system, at least some educators feel that too little time is spent on genetics. Some, such as members of the Biological Sciences Curriculum Study Program, are considering increasing the share of the curriculum devoted to genetics. Because science and technology cause broad changes in society, not only is a clearer perception of genetics in particular needed, but more understanding of science in general. For about half the U.S. population, high school biology is their last science course. Educators must focus on this course to increase public understanding of science. Because students generally find people more interesting than rats, and because human genetics is a very popular topic in the high school biology course, educators responsible for the Biological Sciences Curriculum Study Program are considering increasing time spent on its study in hopes of increasing public knowledge not only of genetics but of science in general.

At the **university level**, **more funds** could be provided to develop courses on the relationships between science, technology, and society, which could be designed both for students and for the general public.

Several sources outside the traditional school system already work to increase public understanding of science and the relationships between science and society. Among them are:

• Three programs developed by the National Science Foundation to improve public understanding of and involvement in science: Science for the Citizen; Public Understanding of Science; and Ethics and Values in Science and Technology.

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- Science Centers and similar projects specifically designed to present science information in an appealing fashion.
- New magazines that offer science information to the lay reader-another indication of increasing interest in science.
- Television programs dealing with science and technology. Examples are the two PBS series, NOVA and Cosmos, and the BBC series, Connections. CBS has also begun a new series called The Universe.
- Television programs dealing with social issues and value conflicts. Particularly interesting is the concept behind *The Baxters*. In this half-hour prime time show, the network provides the first half of the show, which is a dramatization of a family in conflict over a social or ethical issue. The second half of the show consists either of a discussion about what has been seen or of comments from people who call in.

One interesting possibility would be to combine a series of Baxter-type episodes on genetic issues with audience reaction using the QUBE system, a two-way cable television system in Columbus, Ohio (now expanding to other cities). In this system, television viewers are provided with a simple device that enables them to answer questions asked over the television. A computer tabulates the responses, which can either be used by the studio or immediately transmitted back to the audience. QUBE permits its viewers to do comparison shopping in discount stores, take college courses at home, and provide opinion to elected officials. It could be effectively combined with a program like The Baxters, to study social issues. If several such programs on genetics were shown to QUBE subscribers, audience learning and interest could be measured.

Any efforts to increase public understanding should, of course, be combined with carefully designed evaluation studies so that the effectiveness of the program can be assessed.

OPTIONS:

A. Programs could be developed to increase public understanding of science and the rela -

tionships between science, technology, and society.

Public understanding of science in today's world is essential, and there is concern about the adequacy of the public's knowledge.

B. Programs could be established to monitor the level of public understanding of genetics and of science in general and to determine whether public concern with decisionmaking in science and technology is increasing.

Selecting this option would indicate that there is need for additional information, and that Congress is interested in involving the public in developing science policy.

C. The copyright laws could be amended to permit schools to videotape television programs for educational purposes.

Under current copyright law, videotaping television programs as they are being broadcast may infringe the rights of the program's owner, generally its producer. The legal status of such tapes is presently the subject of litigation. As a matter of policy, the Public Broadcasting Service negotiates, with the producers of the programs that it broadcasts, a limited right for schools to tape the program for educational uses. This permits a school to keep the tape for a given period of time, most often one week, after which it must be erased. otherwise, a school must rent or purchase a copy of the videotape from the owner.

In favor of this option, it should be noted that many of the programs are made at least in part with public funds. Removing the copyright constraint on schools would make these programs more available for another public good, education. On the other hand, this option could have significant economic consequences to the copyright owner, whose market is often limited to education] institutions. An ad hoc committee of producers, educators, broadcasters, and talent unions is attempting to develop guidelines in this area.

ISSUE: Should Congress begin preparing now to resolve issues that have not yet aroused much public debate but that may in the future?

As scientific understanding of genetics and the ability to manipulate inherited characteristics develop, society may face some difficult questions that could involve tradeoffs between individual freedom and societal need. This will be increasingly the case as genetic technologies are applied to humans. Developments are occurring rapidly. Recombinant DNA technology was developed in the 1970's. In the spring of 1980, the first application of gene replacement therapy in mammals succeeded. Resistance to the toxic effect of methotrexate, a drug used in cancer chemotherapy, was transferred to sensitive mice by substituting the gene for resistance for the sensitive gene in tissue-cultured bone marrow cells obtained from the sensitive mice. Transplanted back into the sensitive mice, the bone marrow cells now conferred resistance to the drug." In the fall of **1980**, the first gene substitution in humans was attempted.¹²

Although this study was restricted to nonhuman applications, many people assume from the above and other examples that what can be done with lower animals can be done with humans, and will be. Therefore, some action might be taken to better prepare society for decisions on the application of genetic technologies to humans.

OPTIONS:

A. A commission could be established to identify central issues, the probable time-frame for application of various genetic technologies to humans, and the probable effects on society, and to suggest courses of action. The commission might also consider the related area of how participatory democracy might be combined with representative democracy in decisionmaking. B. The life of the President's Commission-for the Study of" Ethical Problems in Medicine and Biomedical and Behavioral Research could be extended for the purpose of addressing these issues.

The n-member Commission was established by Public Law 95-622 in November 1978 and terminates on December 31, 1982. Its purpose is to consider ethical and legal issues associated with the protection of human subjects in research; the definition of death; and voluntary testing, counseling, information, and education programs for genetic diseases as well as any other appropriate topics related to medicine and to biomedical or behavioral research.

In July and September 1980, the Commission considered how to respond to a statement from the general secretaries of the National Council of Churches, the Synagogue Council of America, and the United States Catholic Conference that the Federal Government should consider ethical issues raised by genetic engineering. The request was prompted by the Supreme Court decision allowing patents on "new life forms." The general secretaries stated that "no government agency or committee is currently exercising adequate oversight or control, nor addressing the fundamental ethical questions (of genetic engineering) in a major way, " and asked that the President "provide a way for representatives of a broad spectrum of our society to consider these matters and advise the government on its necessary role, "13

After testimony from various experts, the Commission found that the Government is already exercising adequate oversight of the "biohazards" associated with rDNA research and industrial production. The Commission decided to prepare a report identifying what are and are not realistic problems. It will concentrate on the ethical and social aspects of genetic technology that are most relevant to medicine and **biomedical research**.

The Commission could be asked to study the areas it identifies and to broaden its coverage to

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Statement V the general scretaries, US **.S.** atholic Confernce, Crigins, $V^{(1)}$ -boundentary Service, vol. (10, 5, 5, 7, 4) (30)

additional areas. This would require that its term be extended and that additional funds be appropriated. The Commission operated on \$1.2 million for 9 months of fiscal year 1980 and \$1.5 million for fiscal year 1981. Given the complexity of the issues involved, the adequacy of this level of funding should be reviewed if additional tasks are undertaken.

A potential disadvantage of using the existing Commission to address societal issues associated with genetic engineering is that a number of issues already exist and more are likely to appear in the years ahead. Yet there are also other issues in medicine and biomedical and behavioral research not associated with genetic engineering that need review. Whether all these issues can be addressed by one Commission should be considered. There are obvious advantages and disadvantages to two Commissions, one for genetic engineering and one for other issues associated with medicine and biomedical and behavioral research. Comments from the existing Commission would assist in reaching a decision on the most appropriate course of action.

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