Committee 2
Genetic Knowledge, Human Values
and Human Responbility

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PUBLIC POLICY ISSUES: GENETIC KNOWLEDGE AND ITS USE

by

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Knowledge of human genetics is currently undergoing an explosion, largely the result of new capabilities to diagnose and identify genetic diseases and disorders. This increased knowledge, and our emerging capacity to apply it for diagnostic and therapeutic purposes, promise tremendous benefits to many individuals and to society as a whole in the coming decades. As we learn more about the mechanisms of human genetics, however, it is inevitable that we will learn how to manipulate the human genome, which will result in many critical ethical dilemmas and policy problems as to when and how to use this new-found knowledge.

There is no doubt that we have entered an era characterized by increasingly sophisticated intervention into the human genome. The significance of this emerging genetic revolution is illustrated by Lappé (1987:5) when he states: "Researchers armed with powerful new techniques are unstripping the secrets of three and a half billion years of molecular evolution." Moreover, because these interventions force us to "confront in its most irreducible form the direct, minute, and purposive design of life" (Boone, 1988:9), we are presented with moral dilemmas that are new in kind.

The public policy implications of this new genetic knowledge and intervention capabilities are extensive and intimately related to underlying ethical dimensions. This is reflected in the extensive literature built up over the last decade. For instance, the ELSI Bibliography (Yesley, 1993)

contains over 5600 entries on the ethical, legal and social implications of the Human Genome Project. Rather than attempting to summarize the full scope of policy issues, this paper focuses on several critical areas in more depth. Specifically, it will examine uses of genetic knowledge that raise concerns of discrimination, stigmatization and privacy; problems raised by commercialization of the human genome; and questions concerning the allocation of scarce health care resources. I argue that although none of the policy problems raised by the new genetics is insolvable, all require serious attention by policy makers charged with the protection of citizens (See Blank, 1990).

Genetic Diagnosis and Testing

Until recently, genetic diagnosis focused on screening for carrier status for a handful of single-gene recessive diseases, most prominently sickle cell anemia and Tay-Sachs disease. Once identified, individuals with the trait could be educated as to the risk of having an affected child, or offered prenatal diagnosis if available for that particular disease. Although innovations over the last two decades in carrier screening and prenatal diagnosis have been impressive, the recent development of a broad array of new molecular techniques promises revolutionary and dramatic possibilities for human genetic intervention. For instance:

Genetic disorders are estimated to account for more

than half of severe mental retardation in developed countries. Advances in DNA technology are proceeding at a rapid and accelerating pace. It is likely that not long after the year 2000, it will be possible to define all of the more than 1,000 genetic disorders that are associated with severe mental retardation (Moser 1992:146).

At present, two types of tests are being performed on the DNA cells taken from blood samples. When a gene responsible for the disease has been identified, the tests use a DNA probe, or labelled segment of DNA that binds directly to the defective gene. For those conditions where the specific gene is not yet known, genetic markers are identified that are close enough to the gene to be inherited with it. These restriction fragment length polymorphisms (RFLPs) indicate the approximate chromosome location of an unknown gene. By using overlapping RFLPs related to a gene disorder, the actual gene eventually can be isolated. These indirect marker tests are more expensive, complicated, and probabilistic than the DNA probes. Through the use of increasingly sophisticated cloning and sequencing techniques, however, tests to uncover these markers in individuals can be developed to be used either prenatally, neonatally, or for carrier status.

Following the discovery of a molecular probe for the Huntington's disease gene in 1983 (See Hayes 1992), efforts have been initiated to identify genetic markers for Alzheimer's disease, sickle cell anemia, manic-depression,

malignant melanoma, and a host of other conditions. Out of this research, a gene for cystic fibrosis was found in 1989 (Lamontagne 1992). The identification of the retinoblastoma gene on chromosome 13 in 1986 and the discovery of its linkage to breast cancer in 1988 have led to considerable interest in the genetic bases of cancer (Steel 1993).

In addition, research is now underway to identify genetic factors that might predispose a person to be alcoholic. Although no single gene or gene complement has yet been found, researchers are accumulating a great deal of information associating genetic factors with alcohol abuse. In 1991, the National Institute on Alcohol Abuse and Alcoholism launched a massive study on the genetics of alcoholism. The $25 million budget for the first five years will provide funding for the first systematic, multilevel study of the subject (Holden 1991). Similar research on cocaine abuse is in the preliminary stages.

One particularly sensitive area of research is directed toward discovering which genes are associated with intelligence. Work on the "fragile-X" chromosome that is associated with mental retardation is the first wave of this investigation (Young 1993). The discovery of genetic markers for some forms of Alzheimer's disease on chromosome 21 (the same chromosome involved in Down's Syndrome) also suggests hypotheses for genetic linkages, particularly since older Down's patients exhibit Alzheimer-type symptoms. Eventually, genetic tests may allow scientists to identify not only the

course of genetic abnormalities, but also traits that put certain individuals at higher risk for susceptibility to a host of environmental factors.

Major commercial applications of genetic technology center on the development of new diagnostic and therapeutic products. In addition to the production of human insulin, human growth hormone, and new drugs for individuals with heart disease, DNA techniques are being used to improve a number of diagnostic tests for infectious diseases. One rapidly emerging set of applications that promise a large market for diagnostic products are tests for common conditions that have a genetic component, such as hypertension, heart disease, or cancer.

Policy Issues in Diagnosis and Testing

As new diagnostic tests and genetic probes emerge, public expectations will intensify and the demand for accessibility to information derived from such efforts will heighten. Such screening "need not be required, people can be made to want it, even to insist upon it as their right" (Annas, 1989:20). Once the tests become accepted by policy makers as legitimate, it is likely that legislatures and courts will recognize professional standards of care that incorporate them. Employers are likely to be caught in the middle of conflicting demands regarding use of available tests.

These new capabilities and trends will accentuate rather than reduce the political/legal/ethical issues of genetic

screening. When testing leads to aversion or treatment of genetic disease, the policy issues, although often controversial, are reasonably straightforward. When testing involves the identification of heightened risk or susceptibility for particular conditions, it is considerably more problematic. When it is based on controversial assumptions, such as found in media stories on research involving the possible tie between height and intelligence, it is politically explosive.

Eugenic Uses of New Knowledge and Techniques

Although genetic probes cannot account for all the phenotypic variance in the expression of the genes, many persons are likely to perceive a positive gene probe test as an indicator of a person's biological destiny (Nelkin and Tancredi, 1989). Should this tendency prove true, DNA probes might "acquire a misleading status in our medical armamentarium as indicators of a new kind of biological determinism" (Lappé, 1987:10).

Recent history demonstrates clearly that some elements in every society are likely to embrace such tests as evidence of biological inferiority or superiority, despite the vacuousness of such perspectives. Though speculative and incomplete, these tests could serve as a basis for a "new eugenics". For instance, Allen (1989:9) sees the form of eugenics now "creeping back into science" as different in detail, but identical at its base to eugenics of the past. Similarly, the

Office of Technology Assessment (1988:84) concludes that "new technologies for identifying traits and altering genes make it possible for eugenic goals to be achieved through technological as opposed to social control."

Two eugenic approaches can be served by the new genetics. Negative eugenics could be implemented through the use of genetic profiles by discouraging or prohibiting carriers of markers for genetic diseases or "undesirable" traits from procreating. Likewise, positive eugenic strategies could be instituted through the use of germline gene therapy designed to enhance or improve the human condition. Although neither of these scenarios is likely in democratic societies since there are many inbuilt institutional and value protections, given the inherent attractiveness of genetic determinism to elements in every public, it is critical that societies be constantly on guard against slippage in the use of genetic knowledge toward such ends.

More likely than a governmentally-mandated eugenic use is a gradual value shift as to what is considered responsible individual action in procreation. Torts for wrongful life and legal notions of the right of each individual to be born with a "sound mind and body" demonstrate that eugenic goals can be at some level interwoven with conceptions of individual rights. If it is viewed as socially irresponsible not to use genetic knowledge in approved ways, to produce "healthy" children, a not so subtle eugenic environment might prevail.

Discrimination and Privacy Issues

More immediate policy issues on the uses of genetic knowledge center on problems of discrimination and stigmatization. Genetic information of the type now promised is self defining and can easily stigmatize individuals, thus enabling others to discriminate against them on the basis of such information. In fact no information is potentially more invasive of personal privacy than tests which provide precise and inclusive knowledge of a person's genetic makeup.

One policy issue which requires urgent attention concerns access to sensitive information collected through voluntary screening programs. Because such information is potentially embarrassing and stigmatizing, individuals must be protected from unauthorised disclosure. Even when confidentiality is assured, however, maintaining the security of genetic records will be difficult. According to Annas and Elias, "current procedures for maintaining the confidentiality of medical records are woefully inadequate, and new strategies will have to be designed" (1993:396).

This problem is all the more difficult, however, because there are circumstances that may warrant disclosure despite the risks to the privacy of the patient. Because genetic traits might be present in other family members, the question is what right they might have to any information that affects their well being? Under what circumstances may a genetic counsellor or physician disclose genetic information that might affect another family member or future progeny? To some

extent the issues surrounding HIV testing are applicable directly to genetic tests. These issues of confidentiality and privacy, of course, are heightened significantly if mandatory genetic screening programs are instituted. The resolution of these issues should, therefore, proceed any such policy initiatives.

Policy problems concerning access and use of genetic information is complicated further when considering other third parties. Given the technological developments, genetic tests will soon become as routine as contemporary health screening indicators. This will lead employers and insurance companies to screen potential employees or insurees for an array of genetic traits. One approach of companies might be to include such tests as part of their health promotion or preventive medicine programs. For instance, persons identified as having a genetic proclivity toward hypertension or malignant melanomas could be put into early diagnosis programs. It is important to remember, however, that the same tests might be used to preclude that person's employment in order to reduce health care expenditures of the company.

When, if ever, is the individual's right to genetic privacy to be sacrificed for the interests of the employer? Under what circumstances does the genetic counsellor's or physician's responsibility to society outweigh his or her responsibility to the patient? As more knowledge is gained about specific susceptibilities related to genetic traits and more accurate tests are found for a wide variety of these

traits, debate on workplace screening will heighten. Harsanyi and Hutton (1981:248) expect the "art of prediction" of screening genetic markers "will be refined to the point where an individual's identification with various groups, along with the genes that he carries, will pinpoint the risks he faces from specific environmental conditions." They go on to contend that, although the workplace should be made as safe as possible for all workers, those who are found to be at greater risk should "either find another job or accept responsibility for the illness to which they are predisposed" (1981:262). Although such action might protect some vulnerable workers from health hazards, however, it does so only at the cost of individual freedom to decide what risks are acceptable.

As health care costs continue to escalate, employers might also find it attractive to use genetic screening to exclude individuals who may cost them large sums of money in terms of future health bills. This is particularly critical if predictive tests are developed for general health status or for susceptibility to heart disease, cancer, diabetes, or alcoholism. Similarly, employers might also want to exclude workers who are at heightened genetic risk for early death or debilitating disease especially where the investment in job training is high. The danger of over-dependence on predictive genetic tests is most apparent here because individuals will be discriminated against on grounds of statistical probabilities not their actual health status. Clarification of antidiscriminatory policies such as the Americans with

Disabilities Act are needed to decide how far employers can go in using genetic screening in the workplace.

Insurance companies, too, have a substantial stake in data obtained through these methods (Kass, 1992). Genetic tests could be used either to determine insurability, thus denying coverage to those identified as carrying the target genes, or to establish premium rates on the basis of test results. In the latter case, persons who are at risk for various health-impairing conditions could be charged higher premiums based on the results of the DNA tests. Life insurance companies, which traditionally have excluded people because they are poor health risks, are interested in the results of tests which place certain individuals at high risk for a wide range of conditions or diseases. A 1989 report of the American Council on Life Insurance specified that the insurance industry will demand access to such data about persons seeking life and disability insurance (Bishop and Waldholz, 1990: 299).

Likewise, health insurance companies, particularly in light of recent developments in procompetitive models such as Health Maintenance Organizations (HMOs), will want access to test results, particularly if they pay for the tests. Insurers know that a large proportion of the health care costs are attributable to a small proportion of the population. As tests become available to identify individuals who are genetically predisposed to ill health or to conditions which increase health care costs, third-party carriers will be under

market pressure to identify those persons and eliminate coverage for them, thus reducing overall costs significantly. Insurance companies, therefore, are likely to put pressure on employers to screen their prospective employees and might increase substantially insurance premiums for those corporations which do not.

Confidentiality questions become more problematic when DNA or gene data banks are created where samples of a person's blood or other tissue are maintained for future use. The creation of such banks for criminal justice uses will continue to elicit intense controversy. The issue is even more complex because unlike traditional finger prints or even other records (medical, credit, criminal) that are now maintained, the DNA record will contain information that cannot now be contemplated. Because each new genetic discovery permits new information to be decoded from the sample, no one including the individual tested knows what information it potentially contains. Therefore, samples collected for a specific use could be used for totally unrelated purposes as science advances. As a result, "record-keeping rules for DNA banks must be spelled out before individuals are asked to have their samples stored" (Annas and Elias, 1993:396). This, however, will be virtually impossible given the uncertainty of just how much and what type of data can be decoded from the sample in the future. Furthermore, the question remains as to who has access to this storehouse of knowledge on individuals.

Commercialization Issues

Although considerable public resources are being invested in human genome initiatives by governments around the world, it is becoming clear that genetic tests and other applications will largely be the domain of commercial interests. Huge profits are likely as routine tests are developed, particularly predictive tests for common disease categories. In the U.S. the largely private medical sector will profit enormously from genetic diagnosis and therapy. Moreover, it is likely that DNA banking will include a significant entrepreneurial component. It is critical, particularly in light of the concerns over record-keeping, confidentiality, etc., that the genetic industry now emerging be monitored closely and regulated where appropriate given the sensitivity of the data, the possibilities of error, and the high economic and personal stakes involved. Explicit legislation might well be necessary to ensure protection of the public. International cooperation will be essential.

Resource Allocation Issues

Another policy issue inherent in the development of all medical technologies including the new genetics involves decisions as to where society can best place priority in order to maximize the health of the population. Resource allocation questions are becoming more critical as we come to realise that while resources are finite, demands and expectations fueled by new technologies have few bounds. As budget limits are set, competition for scarce medical resources will

intensify. What priority should the search for genetic knowledge and for ever expanding uses of this knowledge have vis-a-vis other strategies and health care areas? Although the generous funding of the human genome initiatives infers a high social priority indeed, it has been carried out without a meaningful public dialogue. Edlin, for instance, argues that while the strong emphasis on a genetic approach to disease is "both scientifically unjustified and ethically questionable," it has serious consequences as to how we allocate research funds and formulate health care policies (1987:48).

The proliferation of medical technology more than any other factor explains the growth in heath care spending (Aaron, 1991:48). Medical technology affects outlays by adding to the arsenal of feasible treatments and by reducing the invasiveness of existing interventions, thus increasing the number of patients who might enjoy net gains from diagnosis and treatment. In addition to producing new areas of utilization and intensity of care, many new treatments are expensive.

Over the last several decades, there has been a proclivity to develop and widely diffuse expensive curative techniques without first critically assessing their overall contribution to health (Blank, 1992). Similarly, research has been rapidly transferred to the clinical setting, thus blurring the line between experimentation and therapy (Mathieu, 1993). Recent examples include organ transplantation, neural grafting, and many reproductive-

assisting technologies. In contrast, research into the causes of health problems, disease prevention, health promotion, and public health in general have enjoyed considerably less enthusiastic support.

Although genetic diagnosis and testing in themselves raise resource allocation questions, one goal of such interventions is ultimately to provide genetic therapy. Gene therapy, including pre-implantation therapy, although still in its infancy promises innumerable applications in the near future. While it is premature to speculate about the relative costs and benefits of yet undeveloped procedures, it is logical to assume that pre-implantation therapy especially will be a very complicated procedure that is reliant upon in vitro fertilization and other costly techniques. It is critical at this juncture in the development process to analyze broader questions. What benefits will it hold for the population as a whole, compared to other spending options? Will access to pre-implantation therapy be equitable and coverage universal, and, if so, how will it be funded? Or, will it be yet another reproductive technology available to an affluent middle class but largely denied to those persons lacking sufficient private resources?

Conversely, the availability of effective and inexpensive genetic tests could provide valuable information for disease prevention and health promotion by targeting individuals who are at heightened risk for diseases that could be reduced by early intervention. To the extentit furthers preventive

efforts, therefore genetic technology could be cost-effective. However, even tests that are inexpensive on a per case basis, cumulatively could be costly when applied to large populations. Given the predisposition of Western societies for testing and the high stakes to commercial interests, the overall investment in genetic applications could be substantial.

It is possible that we would be better served by putting higher research priority on finding the causes of environmental mutations and expanding significantly societal resources devoted to ameliorating these causes rather than attempting to develop yet another set of technological solutions. Moreover, there is already considerable evidence that we could substantially reduce mortality and morbidity through preventive programs designed to alter individual behavior and social conditions. The linkages of individual behavior (especially smoking, diet, and alcohol/drug abuse) and social conditions (poverty, unemployment, inadequate housing and education) with acute and chronic diseases and premature deaths are well documented (Mechanic, 1994: Fries, Koop, and Beadle, 1993). The burden of proof should be on the advocates of new technologies, including genetic ones, to demonstrate that such expenditures will enhance significantly the health of the population over and above more traditional preventive efforts.

The principal resource allocation question is not whether we should proceed with human genome initiatives and the search

for new genetic knowledge and applications: given the potential benefits for many persons it would be foolish and uncaring not to do so. Rather, it is what the most appropriate level of support should be given competing uses for these substantial societal investments, including non-medical approaches such as improved education; reduction of poverty, crime, and unemployment; encouragement of healthier lifestyles; and safer workplaces. The current preoccupation with the genetic approach although understandable within Western societies' individual-oriented, medical orientation of health care, must be reevaluated and placed within a broader allocation context.

Predictive tests for genetic susceptibilities will pose especially difficult policy dilemmas because, unlike direct tests for single gene diseases, the effect of the genes is moderated by environmental factors. There is a case for not allowing predictive tests to be made routinely available, and certainly not to be mandated by public policy, until clinical data clearly demonstrate that either medical intervention or change in lifestyle will benefit identified individuals. Before widespread predictive testing is implemented, considerable behavioral research is necessary to determine whether individuals identified as high risk are likely to be willing or able to alter their lifestyle and thus justify the screening investment.

Conclusions

This brief discussion of selected policy issues that accompany the new genetic knowledge and our expanding capacities to apply it demonstrates the challenges facing all societies. The revolutionary nature of these developments and their far-reaching implications for how we view ourselves and others requires a re-evaluation of how far we ought to proceed in human genetic intervention. There is an urgent need for dialogue at both the national and international levels over the uses of genetic knowledge because the speed of discovery is currently outstripping our capacity to design appropriate policies.

To date genetic policy making has been at best reactive in scope. Although national commissions or similar bodies have studied these issues and made recommendations in some countries (see Canada, 1993) and there has been considerable professional analysis of the issues, most governments have chosen either to take an affirmative stance through funding genome research and encouraging diagnostic and, more recently, therapeutic applications, or they have attempted to avoid the issues. Enlightened public debate over goals and priorities and consideration of regulatory policies in those areas where such action can be effective in minimizing the negative effects of genetic intervention are warranted.

Governments have a responsibility to replace reactive policy approaches with anticipatory approaches that attempt to shape the direction of technological development and use.

Hans Jonas' notion of an ethics of responsibility to the future where "responsibility is a correlate of power and must be commensurate with the latter's scope and that of its exercise," is especially appropriate to genetics (Jonas 1984:x). Although there is no complete knowledge of the future upon which to base our decisions, the analysis here suggests contingencies which must be considered. Without such an effort to anticipate such contingencies and make proactive policy, there is a danger that this powerful genetic knowledge will reshape values and control human destiny instead of serving the health needs of the population. While the benefits of this new knowledge appear boundless, there are also risks which accompany the changes it promises.

Although it is clear that the issues discussed here are global, debate continues as to whether national or international policy initiatives are preferable. Macer, for instance, sees a need for international approaches that reflect the shared biological heritage and destiny of human beings of all nations, the need for international guidelines to provide some minimal standards, and the common perceptions and bioethical reasoning of peoples around the world (1994: 243). In contrast, Bonnicksen argues that national policies should precede international normative codes in the genetic arena (1994:47). While I agree with Bonnicksen that formal international guidelines in human genetics are at best premature, this should in no way preclude vigorous efforts to develop a global understanding of the policy implications

outlined here and to encourage the emergence of international forums to explicate the universal values which may help shape a foundation for human control of the new genetics.

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