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Life, Liberty and the Pursuit of Genetic Testing

By Phil Bereano and Richard Sclove
Sunday, March 22, 1998; Page C05

Bill Clinton has a bold vision for the future of genetic testing. Before long, such tests "will enable every set of parents that has a little baby to get a map of the genetic structure of their child," he declared during the 1996 presidential campaign. Forewarned that their child has a predisposition to kidney disease or stroke, parents will be able to "plan that child's life. . . to organize the diet plan, the exercise plan, the medical treatment that would enable untold numbers of people to have far more full lives."

Unfortunately, as Clinton noted in this year's State of Union address, the very same information about our genetic predispositions can also be legally used by insurers to deny medical coverage, by companies to deny employment and by telemarketers to tailor invasive come-ons. Thus, a technology with the potential to improve and prolong lives could be used to create a nightmarish brave new world.

The social dangers of genetic testing are not inevitable. But preventing them depends on greater public understanding of the politics of genetic testing -- an understanding often obscured by the perception that science and scientists are somehow above politics. Perhaps the biggest danger of genetic testing is that a healthy fascination with the possibilities of gene research can blur into an ideology of genetic determinism: the mistaken belief that genes are the decisive factor in an individual's behavior, character and future.

In blindly embracing genetic testing, we risk becoming environmentally complacent, culturally fatalistic and even genetically vindictive. Genetic determinism can reinforce a "blame the victim" mindset, in which individuals with "faulty" genes are seen to be the primary cause of illness or disease. Social conditions -- such as poverty or environmental pollution -- both of which correlate directly with poor health and higher mortality rates -- are downplayed by deterministic thinking.

We need to recognize the ways that the use of all kinds of tests reflect differences in power. Testing -- for drugs, academic skills, HIV or whatever -- does not equally benefit or penalize all segments of society, nor is it intended to do so. Employers test employees, insurance companies and health organizations test patients, universities test students, and legislators pass bills to test welfare recipients, immigrants and prisoners. In general, organizations or people or governmental agencies with power do the testing while individuals with less power get tested.

These practices simply reflect the fact that the time, money and knowledge necessary to deploy sophisticated technologies are available only to groups that are already powerful. When these groups act in their own self-interest, they naturally seek to express, consolidate and extend their powers. Proponents of testing, eager to minimize opposition, rarely acknowledge this.

One vivid illustration of the politics of genetic testing is the disturbing trend toward genetic surveillance.

The Defense Department, for example, now takes DNA samples from all its personnel, saying this will make it easier to identify soldiers killed in action or in military accidents. But the Pentagon plans to keep the DNA samples for 50 years (i.e., long after people have left active duty) and to include civilian employees. The Pentagon also will not accept waivers from next-of-kin who do not want a deceased soldier's tissues subjected to genetic testing, and refuses to issue regulations barring all third-party use of its DNA samples -- for example, by commercial biotechnology companies or genetic database services.

The FBI is promoting genetic screening of criminals to establish DNA-identification data banks in every state for use in criminal investigations.

Medical patients' records are already becoming commodities for sale. A panel of the U.S. National Research Council warned last year that the computerized medical records of millions of Americans are open to misuse and abuse.

While government and business are using genetic testing to advance their goals, more and more Americans are finding that they are paying a price. Scientists working with the Council for Responsible Genetics, a nonprofit advocacy group based in Cambridge, Mass., have documented hundreds of cases in which healthy people have been denied insurance or a job based on genetic "predictions." These cases include:

A health maintenance organization told a pregnant woman whose fetus tested positive for cystic fibrosis that it would pay for an abortion but that, if she elected to give birth, it would not cover the infant under the family's medical policy.

A healthy boy in California took medication that eliminated all the risk associated with his predisposition to a heart disorder. Even so, his parents' insurance company ruled him genetically ineligible for health coverage.

In the early 1990s, the Lawrence Berkeley National Laboratory secretly tested African American employees for sickle-cell genes and female employees for pregnancy. When a group of employees filed suit, the laboratory stopped the practice. A judge dismissed the case, but the U.S. Ninth Circuit Court of Appeals ruled last month that such a practice would be unconstitutional if the plaintiffs can prove that it occurred. The lower court is reconsidering.

Under the right circumstances, some genetic science can be developed in a truly beneficial manner. But broader public involvement is urgently needed. Testing policies should be based on an understanding that most genetic tests (even when accurate and correctly administered) cannot tell us if a genetic predisposition to disease will become manifest or, if it does, how severe the condition will be and when it will occur.

Genetic privacy, like medical privacy, is vital to the dignity and integrity of the individual. The American Civil Liberties Union argues that genetic data should only be collected voluntarily, using modern notions of informed consent. Mandatory testing, surreptitious testing or testing coerced as a pre-condition for insurance coverage or a job are invasions of privacy. Informed consent should clearly specify future allowable uses of genetic samples. Privacy is no less compromised by research uses without consent just because the violator is wearing a lab coat.

The government of Denmark has shown how to establish more farsighted policies for dealing with new technologies by involving the public in legislative deliberations. For more than a decade, panels of Danish citizens have cross-examined experts and stakeholders, and offered non-binding science policy recommendations. In 1989, a panel seconded expert support for basic genetics research, but called for more research on the interplay between environmental factors and genetic inheritance and on the social consequences of science. The panel also recommended a more "humanistic and interdisciplinary" national research portfolio that would stimulate constructive debate about research repercussions. The report of the citizens' panel helped influence the Danish parliament to prohibit the use of genetic-screening information in employment and insurance decisions. This carefully structured, participatory process is being emulated in the United Kingdom, Japan, the Netherlands and Switzerland.

U.S. genetic testing policies will improve when decision makers learn that -- along with research administrators, Nobel laureates and CEOs -- the average citizen must be heard, too. Although their proponents invariably proclaim that new technologies will bring unprecedented prosperity and freedom, they can also threaten our civic values. What Thomas Jefferson called "cherished liberty" is not determined by our genes. It is determined by our eternal vigilance.

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