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Genetic Technology: Constructing a New Language for International Human Rights

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By Maha F. Munayyer

After exploring outer space and cyberspace, scientists are now returning to a local but perhaps more challenging frontier: human genetics. The progress of genetic research has accelerated dramatically over the past fifteen years, marked most recently by the Human Genome Project, an international effort to map and document humanity's genetic resources. The potential of genetic technology to alleviate the physical, emotional, and financial pain of disease makes it extremely attractive. It may, however, increase social control over the human condition, evoking fierce human rights debates.

The Technology

Scientists are focusing primarily on the development of genetic tests and gene therapy. Genetic tests attempt to diagnose or predict whether a patient will develop or be a carrier of a hereditary condition. Gene therapy attempts to treat genetic conditions by giving predisposed patients normal copies of defective or missing genes. Gene therapy can be used to prevent diseases, to influence hereditary physical features such as hair color, eye color, height, and athletic ability, and to alter genetically-linked behavioral features, such as personality, talent, intelligence, and, some argue, sexual orientation. Many geneticists are convinced that two forms of gene therapy — somatic cell manipulation (SCM) and germ-line manipulation (GLM) — will be available in the coming decades

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and will revolutionize medicine by enabling patients to thwart disease.

Geneticists have made the most progress in the area of somatic cell manipulation. SCM involves inserting normal genes into body tissue cells, such as lung cells in cystic fibrosis patients. The new gene enables the diseased cells to function properly. However, SCM does not "erase" the disease permanently. The effects of the normal gene die with the patient. The defective

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gene, though stunted in the patient, passes on to the patient's children.

By contrast, germ-line manipulation (GLM) produces permanent genetic changes. GLM involves inserting normal genes into the sex cells of a patient, or, more feasibly, into the undeveloped cells of an early embryo that is fertilized in vitro. The effects of the genetic change, whether beneficial or harmful, pass on to future generations, permanently altering a family's gene pool.

Social Implications

Genetic technology raises controversial ethical questions about society's right to "play God." Social institutions such as employers, insurers, and schools may use large-scale genetic testing to discriminate against people predisposed to certain conditions. Practiced widely, gene therapy may result in repression of socially undesirable physical or behavioral traits and a resurgence of eugenics, the use of genetics to 'enhance' the human race. By making many conditions seem avoidable, genetic technology may exaggerate the influence of genetic factors on the development of the human personality and encourage narrow, socially-determined standards of health and normality. This viewpoint may reinforce existing prejudices against individuals with disabilities or traits that do not satisfy the cultural ideal.

The potential for genetic discrimination brings unprecedented challenges to the traditional concept of international human rights law. Should future generations fall within the definition of personhood employed by most human rights agreements? Do future generations have a right to inherit an unmanipulated gene pool? Does the right to life encompass how that life is genetically expressed? Should people predisposed to certain genetic conditions receive group protection as do racial, ethnic or religious groups? How is the state accountable when it is society that demands, creates, and applies the technology that causes human rights violations? The traditional definitions of human rights violations, violators and victims do not adequately address the ethical issues raised by reproductive technology. Genetic technology thus presents an extraordinary human rights challenge because it creates a conceptual paradox requiring governments to safeguard human rights threatened by parents, doctors, scientists, employers, and insurers.

Traditional Concepts

Traditional human rights scenarios typecast the state as the human rights violator. They portray governments as awesome, centralized monsters that actively abuse their people. Because of the state's leading role, traditional scenarios limit human rights issues to the public sphere, where individuals clash with state agents. As a result, claims of abuse by private actors fall outside the scope of the international human rights framework.

Conventional analyses also depict the human rights victim as a living member of a defined group, one that is easily circumscribed by a mental boundary.

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In most cases, members of this group are physically distinguishable by race or gender, or by a natural affiliation with an

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ethnic, national, linguistic, or religious group.

Furthermore, the traditional framework forces human rights organizations into a reactive position. Because violations are normally unforeseeable, organizations can address violations only after they occur. Consequently, the role of human rights organizations focuses on responding to rather than preventing violations.

New Definitions

By adding new players and new issues to the human rights framework, genetic technology defies the concepts underlying the existing model and reveals the need for a revised language.

Genetic technology privatizes human rights issues by placing the power to violate rights in the hands of private actors throughout society — the biotech companies that develop the technology, the public that demands it, and the health care professionals that implement it. Through their specialized and concentrated expertise, biotech companies develop a kind of power that is analogous to state power. Accordingly, their conduct deserves scrutiny under international human rights standards.

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The expanding role of private actors also reveals a diffusion of power from the centralized state to individuals dispersed throughout society. Strong public demand for and aggressive commercial supply of genetic technology can transform the nature of eugenics from a state-managed program (such as that of Nazi Germany) to a grassroots movement. Furthermore, genetic technology will ultimately affect broad sectors of society rather than clearly defined groups. Thus, by requiring genetic tests to generate a pool of desirable or fit people, employers, insurers and other institutional actors can disguise new versions of eugenics in application forms and clinical files. By performing GLM on individual embryos, physicians can produce snowballing genetic alterations that may subject entire families to harmful mutations or societal prejudice.

Privatization of abusive power could alter the nature of the human rights victim as well. When the power to violate human rights diffuses throughout society through testing and therapy applications, the effects of abuse become large-scale. Discrimination could transcend racial, ethnic, or other conventional classifications to affect large cross-sections of society. Moreover, by extending this discrimination to future generations, genetic technology adds a temporal dimension to human rights infringement. Given this potential for violations on an unprecedented scale, the conventional image of the discrete human rights victim becomes inadequate. Technological innovations that cross social and generational boundaries enlarge the victim pool from specific groups of humans to humanity in general. The current human rights regime needs to expand its language to encompass not only the individual incident, but the ongoing condition.

Gene-ocide

The intergenerational and cross-sectoral effects of genetic technology defy conventional definitions of many human rights violations, including genocide, which relies conceptually on state aggression, a conspicuous violation, and a demarcated group victim. The new concept of a victim raised by biotechnology invites exploration into the definitional frontiers of genocide. Broad application of genetic technology is arguably comparable to genocide as defined by the Genocide Convention. It involves the intentional destruction of the physical integrity of a genetic group and the implementation of measures to prevent births within that group. These similarities raise the question whether the definition of genocide should include social repression of genetic traits. Does genocide apply to expressions of life as well as life itself, or is biotechnology cultivating a separate crime of "gene-ocide"?

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Freedom of Genetic Expression

The temporal implications of genetic technology will require human rights organizations to address whether future generations have rights to a genetic inheritance that is free of human tampering. Recent scholarly discussion focuses on the right of the individual fetus to be free from genetic manipulation based on a lack of informed consent or the unpredictable dangers of genetic alteration. The debate has not addressed whether humans, both living and future, have a collective right to live in a world that is genetically diverse. This new question imports policy concerns from international environmental law concerning biodiversity and applies them to human genetics. That is, genetic technology has the potential to jeopardize human genetic diversity, and international human rights organizations should respond by recognizing that human genetic diversity is both intrinsically valuable and instrumental to the cultural, scientific, and social development of the human race. Essentially, the biodiversity argument reconceptualizes the right to life in terms of the genetic diversity expressed throughout the human species.

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Conclusion

Further development of genetic technology is inevitable. Governments continue to postpone regulation on the assumption that it is a distant reality. Recent developments, however, including the successful cloning of a sheep and rhesus monkeys, bring this reality closer. As scientists overcome technical problems and the future looms nearer,

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governments will have to rethink the ethical implications of genetic technology and rewrite existing laws accordingly. Regulation requires language, language requires definitions, and definitions change with technological capability. Genetic technology magnifies human rights violations conceptually: it shifts power from few hands to many, raises stakes from an individual to a collective level and affects the health of families for centuries to come. Whether governments employ human rights principles to restrict or widen access to genetic technology, they need a human rights language that accommodates the spacial and temporal dimensions of technological advancement. That is, governments need a language that is as state-of-the-art as the technology itself.

Genetic technology allows human rights organizations to play an active role in preventing human rights violations. Because scientists can often predict the development of techniques years in advance, human rights organizations have time to reassess and upgrade their language, organize themselves and promote their agenda before human rights violations occur. Rather than responding to violations, they can use the lag-time to help states formulate policies that prevent violations from occurring. The scientific community's ability to foresee potential misuses of genetic technology may therefore bring about the 'rebirth' of human rights organizations by transforming them into effective players in the policy-making process. Through science, human rights organizations can learn some preventive medicine of their own.

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Scholars often compare geneticists to the Apollo astronauts who bravely explored the unknown frontiers of outer space. Ironically, the genetics race is more dangerous because it is local. Future development and application of genetic technology will ultimately affect how humans value themselves and treat one another. Behind all attempts to decode or alter the human genome is a global search for human identity. By spearheading this search, the scientific community can redefine life as humans know it. By providing a dynamic language, human rights organizations can redefine life as humans want to know it.

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Mr. Stanković lodged a complaint with UN police in Bosnia alleging that *he* was being harassed by the Bosnian government. He apparently had no anxiety about being arrested when he filed his complaint, despite the fact that he had been indicted by the War Crimes Tribunal in The Hague.

The fact that crimes of sexual assault heretofore have been largely neglected in internatinal law has meant that prosecutors in The Hague have had scant precedent to draw upon in shaping charges appropriate to crimes of sexual assault.

In the wake of these and other reports, the United States, France and Britain have recently endorsed the idea of creating a special unit to apprehend war criminals. Let us hope that the Administration and its Allies intend to talk less and do more.

In a recent column in the *New York Times*, Abe Rosenthal wrote:

"There is no lesson to be learned in the Holocaust except this: Evil beyond evil was done and can be done again, unless the living remember."

Of course, we must never forget. But when genocide occurs in our time, we must do more than remember.

My father taught me that the chief lesson of the Holocaust is that evil does not restrain itself. We must stop it. And we *can* stop it.

I hope that we do not find ourselves pondering half a century from now how it came to pass that we allowed a handful of genocidal bullies to cow *us* into silence. And, make no mistake about it, they are counting on us to be silent. If Jadranka Cigelj and Nusreta Sivač found the courage to stand up to Željko Mejakić, surely we can as well.

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Conclusion

The National Commission on Human Rights is a small step toward the recognition of international human rights norms in Indonesia. While the Commission itself was not created in the best political atmosphere and is lacking in many respects, its existence provides hope for change in Indonesia. In fact, the Commission's establishment is timely because it provides Indonesia's emerging middle class with reason to expect and demand respect for civil liberties. As Indonesia's economy grows, the middle class will become a greater political force for change and its voice, combined with the National Commission's findings, could eventually cause the Government to respond to its demands. The general elections for parliament which are proposed to be held on May 29, 1997, may be the harbinger of that change and the Commission could be the beginning of a path toward a freer, more vibrant Indonesia.

More information may be found at the Commission's web site: http://engine2.dnet.net.id/specialsites/komnasham/