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Maha F. Munayyer

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Genetic Testing and Germ-Line Manipulation: Constructing a New Language for International Human Rights

Maha F. Munayyer*

"[I]t would be more appropriate to speak of human rights as the vocabulary of our time rather than the idea of our time: it provides the terms in which discussion of . . . values in international politics is carried on." — R. J. Vincent

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* J.D. Candidate, 1998, Washington College of Law, American University, B.S. in Foreign Service, 1994, Georgetown University. The author would like to thank her family and friends for their tranquilizing effect, Kristen Belz and Paul Williams, Esq., for their guidance and enthusiasm, and Nicole Behrendt and Emily Allt for their well-timed pearls of wisdom. This Comment is dedicated to Teta, with love.

INTRODUCTION

After exploring outer space and cyberspace, scientists are now returning to a more local but perhaps more challenging frontier: human genetics.¹ The progress of genetic research has accelerated dramatically over the past fifteen years,² marked most recently by the Human Genome³ Project, an international effort to map and document humanity's genetic resources.⁴

Scientists are focusing primarily on the development of tests to diagnose genetic conditions⁵ and surgical techniques to treat them.⁶ The potential of genetic tech-

1. Genetics is the study of biological functions that transmit hereditary characteristics and create physical and behavioral variation among living beings. WEBSTER'S II NEW RIVERSIDE UNIVERSITY DICTIONARY 525 (1984) [hereinafter WEBSTER]. This Comment refers to "human genetics" as the study of genetics applied to the human species.

2. See Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, in CONTEMPORARY ISSUES IN BIOETHICS 637 (Tom L. Beauchamp & LeRoy Walters eds., 4th ed. 1994) [hereinafter Billings Surveys] (discussing rapid development of genetic tests over the last decade); W. French Anderson, *Human Gene Therapy*, in CONTEMPORARY ISSUES IN BIOETHICS, *supra*, at 659 (describing successful uses of retroviruses in the early 1980s to transfer genes in gene therapy experiments); Mary Warnock, *Ethical Challenges in Embryo Manipulation*, BRIT. MED. J., Apr. 18, 1992, at 1045 (stating that scientists are collecting new data on human genetics with extraordinary speed); Darrell E. Ward, *Gene Therapy: The Splice of Life; Ethical Implications*, USA TODAY (MAGAZINE), Jan. 1993, at 63 (noting that scientific progress in the detection of new hereditary diseases is moving so quickly that researchers refer to the "gene of the week").

3. A genome is all of the genetic material in the cells of an organism. *Glossary*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES 277 (George J. Annas & Sherman Elias eds., 1992). The human genome comprises all of the genetic material in the human species. *Id.*

4. See *id.* at 278 (defining "Human Genome Project" as the United States-funded component of the international initiative to map humanity's genetic resources and develop new techniques for genetic analysis). Government research bodies and private companies from several countries have guaranteed three billion dollars to fund the Human Genome Project over fifteen years. RUTH HUBBARD & ELIJAH WALD, *EXPLODING THE GENE MYTH* 3 (1993). The Project is scheduled for completion in 2005. Victor A. McKusick, *The Human Genome Project: Plans, Status, and Applications in Biology and Medicine*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 622. For more background on the Human Genome Project, see generally Alexander M. Capron, *Which Ills to Bear?: Reevaluating the "Threat" of Modern Genetics*, in CONTEMPORARY ISSUES IN BIOETHICS, *supra* note 2, at 629 (outlining objectives of Human Genome Project as background for a discussion of the dangers of genetic screening); Alasdair T. Iles, Comment, *The Human Genome Project: A Challenge to the Human Rights Framework*, 9 HARV. HUM. RTS. J. 27 (1996) (advocating the use of human rights analysis to confront potential social consequences of the Human Genome Project).

5. This Comment defines "genetic conditions" broadly to mean any disease, disability, disorder, physical or behavioral trait, or predisposition (susceptibility) that is genetically-linked.

6. See Capron, *supra* note 4, at 630 (noting that scientific efforts have traditionally focused on gene therapy and only recently on genetic screening); Sherman Elias et al., *Carrier Screening for Cystic Fibrosis: A Case Study in Setting Standards of Medical Practice*, in

nology⁷ to alleviate the physical, emotional, and financial pain of disease makes this technology extremely attractive.⁸ It may, however, create mechanisms of social control that evoke fierce ethical debate.⁹ Practiced widely, genetic testing¹⁰ and gene therapy¹¹ could invite institutionalized discrimination against people predisposed to certain conditions,¹² repression of socially undesirable behavioral or physical traits,¹³ and a rise of a popular eugenics¹⁴ movement.¹⁵

The potential for discrimination raises many questions in international human rights law¹⁶ about the legal status of genetic groups,¹⁷ the rights of posterity, and

GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 186, 200 (predicting that the Human Genome Project will encourage development of "tens, if not hundreds" of new genetic screening tests that will compete for widespread use).

7. This Comment refers to genetic testing and germ-line manipulation collectively as "genetic technology" or "genetic innovations."

8. See Ward, *supra* note 2, at 63 (describing both the suffering that victims of genetic disease and their families experience and the costs of treating afflicted patients).

9. See Bob Groves, *Building a Better Being? An Ethics Debate*, RECORD, Feb. 22, 1993, at B1 (stating that for twenty years, critics have debated what kinds of genetic manipulation are morally justifiable).

10. See *infra* notes 22-26 and accompanying text (defining genetic testing and explaining its purposes).

11. See *infra* notes 27-31 and accompanying text (defining gene therapy and explaining its purposes).

12. See *infra* notes 53-63 and accompanying text (explaining discriminatory practices that can result from widespread use of genetic technology).

13. See *infra* notes 64-68 and accompanying text (discussing the effects of germ-line manipulation).

14. Eugenics is the use of genetic controls to enhance the human race. Ward, *supra* note 2, at 63. Historically, governments instituted eugenic policies to "cleanse" the citizenry of morally or biologically weak individuals (negative eugenics) and promote the breeding of healthy individuals (positive eugenics). Robert N. Proctor, *Genomics and Eugenics: How Fair is the Comparison?*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 60 (describing eugenics as state-managed social control). Eugenics experienced its golden age under Germany's Nazi regime, which instituted legislation requiring the sterilization or "mercy killing" of many disabled people. ARTHUR ROGERS & DENIS DURAND DE BOUSINGEN, *BIOETHICS IN EUROPE* 25-29 (1995). In the 1920s, U.S. laws required the compulsory sterilization of the mentally-ill, crippled, blind, deaf, alcohol and drug addicts, criminals and those afflicted with tuberculosis, syphilis, and other diseases. Ward, *supra* note 2, at 63. Currently, several Asian countries promote or tolerate eugenic practices. ROGERS & DE BOUSINGEN, *supra*, at 30. The governments of India and China permit the systematic elimination of thousands of female fetuses after pre-natal examinations. *Id.* at 30-31. Authorities in Singapore offer grants to encourage wealthy, educated couples to have children. *Id.*

15. See Billings Surveys, *supra* note 2, at 641 (arguing that surveys indicate a social myth of genetic perfection that may be a form of eugenics).

16. Traditional international law generally governs relations between states and grants legal rights to states and certain intergovernmental organizations to exercise against each other. THOMAS BUERGENTHAL, *INTERNATIONAL HUMAN RIGHTS: IN A NUTSHELL* 2 (1988).

the nature of human rights violators and victims. International human rights organizations,¹⁸ however, may be inadequately equipped to address the state-of-the-art legal issues that these innovations introduce.¹⁹ Genetic technology thus presents an extraordinary human rights challenge because it is rooted in societal rather than political power. It presents a conceptual paradox where governments safeguard human rights, and parents, doctors, scientists, employers, and insurers jeopardize them.

This Comment examines the responsiveness of traditional international human rights concepts and agreements to the challenges of genetic technology. Part I defines genetic testing and germ-line manipulation²⁰—one form of gene therapy—and analyzes their ethical implications using traditional human rights definitions and international human rights instruments.²¹ Part II examines how genetic technology challenges traditional definitions of violators and victims in international human rights law. Part III evaluates whether proposed international instruments addressing genetic technology recognize and adequately confront these challenges. Part IV proposes broadened definitions of human rights concepts and encourages international human rights organizations to market these revised definitions at the state level. Rather than recommend regulation, this Comment attempts to provide international actors with a revised human rights language with which to regulate society's control over human diversity.

I(A). THE SCIENTIFIC FRAMEWORK

A. GENETIC TESTING

Genetic tests are techniques that diagnose or predict whether a patient will develop or be a carrier of a hereditary condition.²² These tests seek to identify people

By contrast, international human rights law focuses primarily on state obligations towards the individuals within their borders, integrating individual rights into international law. R. Bilder, *An Overview of International Human Rights Law*, in BARRY E. CARTER & PHILLIP E. TRIMBLE, *INTERNATIONAL LAW* 894, 895 (2d ed. 1995).

17. This Comment defines a "genetic group" broadly as any group of individuals with a common genetic condition.

18. For purposes of this Comment, an international human rights organization is any international governmental organization that creates international human rights law and policy.

19. See *Iles*, *supra* note 4, at 44 (addressing several shortcomings of the existing human rights framework within the context of the Human Genome Project).

20. See *infra* notes 32-49 and accompanying text (defining and explaining the purposes of germ-line manipulation).

21. This Comment defines an "international instrument" as a declaration or treaty adopted by or entered into by many state parties on a global level.

22. Tabitha M. Powledge, *Ethical and Legal Implications of Genetic Testing: A Synthesis*, in *THE GENOME, ETHICS AND THE LAW: ISSUES IN GENETIC TESTING* 1, 3 (Am. Assoc. for the Advancement of Science ed., 1992).

who will be affected by a condition early in life, those who will be affected later in life, and those who will remain unaffected but pass the gene on to their children.²³ Currently, genetic tests can only reveal whether a patient²⁴ is likely to have a genetic condition.²⁵ They cannot reveal the degree to which the condition will affect the patient.²⁶

B. GERM-LINE MANIPULATION

Gene therapy attempts to treat genetic conditions by giving predisposed patients normal copies of defective or missing genes.²⁷ Many geneticists believe that two

23. *Id.*

24. Scientists are also developing genetic tests to perform on embryos in a process called "embryo diagnosis" or "pre-implantation diagnosis." Leroy Walters, *Ethical Issues in Human Gene Therapy*, in CONTEMPORARY ISSUES IN BIOETHICS, *supra* note 2, at 656. This process is the initial step in both germ-line manipulation and selective pregnancy (also called selective abortion). *Id.* (indicating that diagnosis allows parents to decide whether to discard or treat an embryo). An embryo is an organism in its early developmental stages, before its cells have assumed specific bodily functions. WEBSTER, *supra* note 1, at 427. To form embryos, doctors remove sex cells from each of the parents and fertilize them in a test tube in a laboratory procedure called in vitro fertilization (IVF). Walters, *supra*, at 657. An IVF clinic then uses pre-implantation diagnosis to detect potential genetic abnormalities in an embryo before it begins to develop. *Id.* at 656. Parents choose whether to continue the pregnancy based on the results of the test. See Arthur L. Caplan, *The Ethics of In Vitro Fertilization*, in CONTEMPORARY ISSUES IN BIOETHICS, *supra* note 2, at 219 (explaining the "standard" process of IVF). In selective pregnancy, doctors select and implant one or more viable embryos into the mother's womb, hoping that one develops into a healthy fetus. HUBBARD & WALD, *supra* note 4, at 113-14. About ten percent of pregnancies achieved through IVF result in liveborn children, which is similar to the rate of births that result from pregnancies caused by sexual intercourse. *Id.* For further background on IVF, see generally Susan Sherwin, *Feminist Ethics and In Vitro Fertilization*, in CONTEMPORARY ISSUES IN BIOETHICS, *supra* note 2, at 224; J. Henahan, *Fertilization: Embryo Transfer Procedures Raise Many Questions*, 252 JAMA 877 (1984). In germ-line manipulation, doctors use embryo diagnosis to detect conditions that are responsive to gene insertion techniques. Walters, *supra*, at 656.

25. HUBBARD & WALD, *supra* note 4, at 27. Gary Hodgen, the president of the Jones Institute for Reproductive Medicine in Norfolk, Virginia, predicts that within "a handful of years," scientists will be able to perform preimplantation embryo screening for traits such as eye color, hair color, and height. Erik Parens, *Autonomous Consumers: Respecting the "Autonomy, Privacy, and Confidentiality" of Consumers in the Biotechnology Market*, HASTINGS CTR. REP., July, 1994, at 3.

26. HUBBARD & WALD, *supra* note 4, at 27.

27. Pete Moore, *Genetic Manipulation*, NEW SCIENTIST, Nov. 13, 1993, at 11. Genes are segments of DNA that form the chromosomes in our body cells. HUBBARD & WALD, *supra* note 4, at 11. Chromosomes carry hereditary information. *Id.* Genes provide instructions for the creation of proteins that are the building-blocks of the human body. *Id.* Genes transfer hereditary characteristics by deciding whether and how fast the body should make proteins and how proteins should interact with one another. *Id.*

forms of gene therapy—somatic cell manipulation²⁸ (SCM) and germ-line manipulation²⁹ (GLM)—will be available in the coming decades³⁰ and will revolutionize medicine by enabling patients to thwart disease.³¹

If testing reveals that an embryo has or is predisposed to a certain condition, parents may use GLM to alter or correct it.³² GLM involves inserting³³ normal genes into the sex cells of a patient or, more feasibly, into the undeveloped cells of

28. Somatic cell manipulation, the more developed of the two forms of gene therapy, involves inserting normal genes into somatic cells (cells that make up body tissues), HUBBARD & WALD, *supra* note 4, at 109-10, such as lung cells in cystic fibrosis victims. Ward, *supra* note 2, at 63. The new gene enables the cell to function properly. HUBBARD & WALD, *supra* note 4, at 109. Unlike germ-line cells, somatic cells do not pass on hereditary information to offspring. Ward, *supra* note 2, at 63. Therefore, SCM does not "erase" the disease in a permanent sense; the effects of the inserted gene, both positive and negative, die with the patient. Moore, *supra* note 27, at 11. The defective gene, though stunted in the patient, may pass to the patient's children. *Id.* SCM does not evoke as much controversy as GLM because it puts less power in human hands. *Id.* In addition, SCM does not raise questions about the rights of future children to inherit an unmanipulated genome. *See id.* (explaining that germ-line manipulation raises issues about hereditary rights and lack of consent of the unborn child).

29. For more background on germ-line manipulation, see generally John C. Fletcher & W. French Anderson, *Germ-line Therapy: A New Stage of Debate*, J.L. MED. & HEALTH CARE 20 (1992); Eric Juengst, *Human Germ-line Engineering*, J. MED. & PHIL. 16 (1991); Gregory Fowler et al., *Germ-line Therapy and the Clinical Ethos of Medical Genetics*, THEORETICAL MED. 10 (1989); Nelson A. Wivel, *Germ-line Modification and Disease Prevention: Some Medical and Ethical Perspectives*, SCIENCE, 1993, at 262.

30. *See* Parens, *supra* note 25, at 3 (reporting that James M. Wilson, director of the Institute for Human Gene Therapy at the University of Pennsylvania, predicted that GLM will be feasible within his lifetime); *see also* Walters, *supra* note 24, at 655 (predicting that scientists will propose to perform GLM on humans within the decade); Human Genetics Committee, Council for Responsible Genetics, *Position Paper on Human Germ Line Manipulation*, in CONTEMPORARY ISSUES IN BIOETHICS, *supra* note 2, at 668 (stating that scientists perform widely both SCM and GLM on laboratory animals). In a widely reported GLM experiment, scientists fertilized mouse eggs and inserted an extra gene into them that directs the production of a growth hormone. *Id.* at 670. The growth hormone caused the mice to grow to twice their natural size. *Id.*

31. *See* Sherman Elias & George J. Annas, *Somatic and Germline Gene Therapy*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 150 (articulating the efficiency argument that GLM may be used to prevent disease in future generations).

32. *See* EUGENE BRODY, BIOMEDICAL TECHNOLOGY AND HUMAN RIGHTS 131 (1993) (describing the process of gene insertion in GLM to correct defective genes).

33. To insert a gene, scientists use a vector, a carefully controlled virus, to deliver the gene to a site on the chromosome. Walters, *supra* note 24, at 656. The vector acts as an "unguided missile," randomly adding the gene to the original set of genes. *Id.* The desirable and the undesirable gene therefore co-exist at different sites on the chromosome. *Id.* Scientists hope to develop a "guided missile," a vector that can deliver a gene to a precise site on a chromosome, so that the desirable gene replaces rather than upstages the undesirable gene. *Id.*

an early embryo that is fertilized in vitro.³⁴ The technique can be used to cure genetic diseases,³⁵ to influence hereditary physical features, such as hair color,³⁶ eye color,³⁷ height,³⁸ and athletic ability.³⁹ It may also alter genetically-linked behavioral features, such as personality,⁴⁰ talent,⁴¹ intelligence,⁴² and, some argue, sexual orientation.⁴³ The effects of the genetic change, beneficial and harmful, pass on to future generations.⁴⁴ GLM can permanently alter the gene pool⁴⁵ within a family.⁴⁵

34. Elias & Annas, *supra* note 31, at 144.

35. See Walters, *supra* note 24, at 651 (explaining that GLM, if performed successfully, would reduce or prevent the incidence of genetic disease among a patient's descendants).

36. See Groves, *supra* note 9, at B1 (quoting Andrew Kimbrell, lawyer and policy director of the Foundation on Economic Trends, who argues that thousands of people will demand GLM to change their hair color and other physical characteristics).

37. See Barbara J. Culliton, *Gene Therapy: Research in Public; With the First Human Gene Trials on the Horizon, Extensive Review Procedures are Being Put in Place*, SCIENCE, Feb. 1, 1985, at 493 (arguing that if GLM is used to cure diseases, it may also be used to change eye color).

38. See Elias & Annas, *supra* note 31, at 147 (discussing the insertion of a gene coded to produce a growth hormone that will create a taller child).

39. *Id.* at 149. Because these traits are polygenic (determined by the instructions of several genes), however, they are more difficult to alter and require advanced insertion techniques that scientists do not anticipate will be available in the near future. *Id.*

40. See *id.* (stating that enhanced intelligence is one goal of eugenic gene therapy).

41. See Georges B. Kutukdjian, *UNESCO and Bioethics; United Nations Educational, Scientific and Cultural Organization*, UNESCO COURIER, Sept., 1994, at 23 (raising the possibility that GLM research may narrowly focus on altering people's talents, abilities, and abnormalities).

42. *Id.*

43. See HUBBARD & WALD, *supra* note 4, at 93-98 (discussing studies performed to determine if sexual orientation has a genetic component).

44. See Elias & Annas, *supra* note 31, at 145 (stating that GLM involves a deliberate decision to pass on genetic alterations to future generations); Human Genetics Committee, *supra* note 30, at 669 (stating that GLM involves the introduction of a gene into a family's hereditary line); HUBBARD & WALD, *supra* note 4, at 113 (stating that the purpose of GLM is to alter the genetic make-up of future people).

45. See HUBBARD & WALD, *supra* note 4, at 113 (stating that GLM alters the genetic make-up of the future population). A "gene pool" is the total number of genetic combinations in a population. STEPHEN MOLNAR, RACES, TYPES, & ETHNIC GROUPS: THE PROBLEM OF HUMAN VARIATION 38 (1975).

46. See Human Genetics Committee, *supra* note 30, at 669 (stating that early embryonic alterations result in germ-line modifications that pass from generation to generation); see also HUBBARD & WALD, *supra* note 4, at 114 (warning that mistakes resulting from GLM could permanently alter a hereditary line). Some scientists believe that widespread use of GLM can substantially affect the genetic diversity of the human species. See, e.g., TOM WILKIE, PERILOUS KNOWLEDGE: THE HUMAN GENOME PROJECT AND ITS IMPLICATIONS 160 (1993) (arguing that extensive GLM use would result in "major alterations" to human genome); BRODY, *supra* note 32, at 132 (discussing scientific concerns that GLM may reduce genetic diversity among human populations); Andrea Bonnicksen, *Genetic Diagnosis of Human Embryos*, HASTINGS CTR. REP., July-Aug., 1992, at S5 (recognizing that widespread

Scientists successfully performed GLM on laboratory animals⁴⁷ and have confidence that they will overcome the technical obstacles⁴⁸ of human application.⁴⁹

embryo diagnosis may eliminate genetic diseases by the end of the decade). The Human Genetics committee, in contrast, argues that GLM cannot eliminate "harmful" genes from the human population as a whole. Human Genetics Committee, *supra* note 30, at 669. The genetic make-up of the human race that has evolved over thousands of years cannot be easily overridden. *See id.* (arguing that the elimination of undesirable genes from the human genome could only be accomplished over thousands of years through massive programs of coercion, which are not feasible); Gina Kolata, *Ethicists Wary Over New Gene Technique's Consequences*, N.Y. TIMES, Nov. 22, 1994, at C10 (quoting opinion of lawyer and ethicist Alta Charo, who argues that because the genetic inheritance of the human race is immense, using GLM to eliminate some genes will only marginally effect the gene pool). Moreover, environmental factors such as diet, personal habits, socio-economic status, and occupation affect genetic expression to a considerable extent. Proctor, *supra* note 14, at 76-77; *see also* HUBBARD & WALD, *supra* note 4, at 36 (criticizing the presumption that environmental factors play no role in genetic expression); Iona Jane Brown & Philippa Gannon, *Confidentiality and the Human Genome Project: A Prophecy for Conflict?*, in CONTEMPORARY ISSUES IN LAW, MEDICINE & ETHICS 215, 216 (Sheila A. M. McLean ed., 1996) (asserting that many genetic illnesses, such as Down's Syndrome, can arise from environmental rather than hereditary factors).

47. *See supra* note 30 (describing the progress of GLM experiments on mice that receive growth hormone).

48. *See* Elias & Annas, *supra* note 31, at 145. Current gene therapy techniques are inefficient because they involve damaging instrument manipulation that requires attempts on several embryos. *Id.* at 146; Human Genetics Committee, *supra* note 30, at 670. Technical problems also arise because scientists do not fully comprehend how genes function. *See id.* (asserting that biologists cannot predict how genes interact with one another or their environment). At this point, scientists cannot deliver a gene to the precise site of a defective gene on a chromosome. *See supra* note 33 (comparing the current method of gene insertion to an "unguided missile"). An inaccurate insertion could disrupt or mutate other genes, potentially causing cancer. *See* Elias & Annas, *supra* note 31, at 146. Altering a genetic trait may also have unexpected effects on how body cells interact, producing new gene combinations that could damage future generations of offspring. *See* Human Genetics Committee, *supra* note 30, at 670. Scientists may discover in the future that a defective trait today, may be neutral or beneficial for other reasons. Elias & Annas, *supra* note 31, at 146-47; BRODY, *supra* note 32, at 132. For example, sickle cell trait, a condition which causes blood loss, painful joints and infections, also increases resistance to malaria. Elias & Annas, *supra* note 31, at 146-47. Scientists cannot foresee when GLM techniques will be advanced enough to alter physical traits, such as eye or hair color, which are polygenic, or controlled by many genes. *Id.* at 149. Despite its technical obstacles, GLM may be easier to perform than SCM in certain circumstances. *Id.* at 151; Robert Cooke, *Experts Debating Gene Therapy*, NEWSDAY, May 21, 1991, at 59; *see also* HUBBARD & WALD, *supra* note 4, at 115 (indicating that sometimes embryonic cells are easier to manipulate than differentiated cells of adults or children). SCM cannot be used to treat hereditary diseases of the central nervous system. Elias & Annas, *supra* note 31, at 150-51. Because inserted genes travel through a person's blood, they cannot pass the blood-brain barrier and therefore cannot reach the target cells. *Id.* In such circumstances, the geneticist can only alter a cell before the distinction between somatic and germ cells develops. *Id.* In fact, GLM was more effective than SCM in

C. ETHICAL IMPLICATIONS

Genetic testing and GLM have serious biological implications,⁵⁰ but they create social perceptions of "normality" that are even more dangerous.⁵¹ Together, the social perceptions and biological realities create new issues for human rights analysis.⁵²

Institutions may use genetic screening⁵³ to discriminate against people predisposed to certain conditions.⁵⁴ Employers may use screening to select the most fit employees in order to increase productivity,⁵⁵ reduce expenditures on insurance benefits,⁵⁶ and ameliorate pressure to ensure safe working conditions.⁵⁷ Insurance

several experiments using laboratory animals because the undifferentiated (unspecialized) embryonic cells accepted and processed the new gene more easily than the specialized body tissue cells of a more developed organism. Human Genetics Committee, *supra* note 30, at 670.

49. See Elias & Annas, *supra* note 31, at 145 (stating that scientific advances in gene therapy are developing more quickly than expected); P. Elmer-Dewitt, *The Perils of Trading on Heredity*, TIME, Mar. 20, 1989, at 71 ("Like atomic energy, genetic engineering is an irresistible force that will not be wished or legislated away.").

50. See *supra* note 46 and accompanying text (discussing the effect of GLM and embryo diagnosis on a family's gene pool).

51. See Proctor, *supra* note 14, at 59 (arguing that the use of genetic technology is not as dangerous as social misperceptions about its utility).

52. See Billings Surveys, *supra* note 2, at 638 (explaining that discrimination can result from real or perceived genetic differences).

53. "Genetic screening" is genetic testing performed on populations rather than individuals. Glossary, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 186.

54. See McKusick, *supra* note 4, at 633-34 (arguing that extensive genetic screening practices may jeopardize employability and insurability of many people with genetic conditions).

55. See HUBBARD & WALD, *supra* note 4, at 131 (explaining that genetic screening may be used to predict a worker's effectiveness); Proctor, *supra* note 14, at 72 (explaining that in the 1970's, many companies screened for carriers of sickle-cell anemia whom they feared would perform poorly and consume medical resources); McKusick, *supra* note 4, at 634 (arguing that employers will use genetic screening to avoid hiring workers who are often sick and therefore expensive trainees and unreliable employees); George J. Annas & Sherman Elias, *Social Policy Research Priorities for the Human Genome Project*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 273 [hereinafter *Research Priorities*] (arguing that employers may use genetic screening to lower training costs or maintain a high experience level among employees).

56. See HUBBARD & WALD, *supra* note 4, at 131 (stating that employers may use genetic screening to reduce insurance costs); McKusick, *supra* note 4, at 634 (arguing that employers who pay for part of their employees' health care have an interest in hiring people who are less likely to generate high medical costs); *Research Priorities*, *supra* note 55, at 273 (arguing that employers will use genetic screening to exclude individuals who would increase company health bills).

57. See HUBBARD & WALD, *supra* note 4, at 133 (arguing that widespread genetic

companies, who already discriminate based on age, gender, and profession,⁵⁸ may begin to require personal genetic data for consideration when fixing premiums and granting coverage.⁵⁹ Schools may use the results of genetic screening to justify inadequate accommodation of the educational needs of their students.⁶⁰ Adoption agencies may use the results of genetic tests to reject prospective parents.⁶¹ Widespread, institutionalized screening practices can create a "genetic underclass"⁶² that society marginalizes based on factors beyond its control.⁶³

GLM offers individuals unprecedented control over the genetic make-up of their descendants.⁶⁴ While scientists often praise GLM as an efficient form of preventive medicine,⁶⁵ many scholars worry that its use will invite a general acceptance of eugenics.⁶⁶ Used in this manner, GLM may allow parents to prevent their children from having mild disabilities⁶⁷ or design their children's hereditary physi-

screening in the workplace could lead to lax enforcement of safety precautions).

58. See Proctor, *supra* note 14, at 72-73 (stating that insurers discriminate based on age, gender, occupation, place of residence, cholesterol level, and blood pressure); HUBBARD & WALD, *supra* note 4, at 140 (arguing that insurance companies make a business out of discrimination because they base their decisions on factors such as sex, age, and occupation).

59. See Proctor, *supra* note 14, at 73 (arguing that insurers will increasingly rely on genetic information to determine insurance rates, resulting in genetic discrimination); HUBBARD & WALD, *supra* note 4, at 141; McKusick, *supra* note 4, at 633 (arguing that genetic screening may allow insurers to broaden the class of pre-existing or foreseeable conditions that do not receive coverage); Billings Surveys, *supra* note 2, at 639 (arguing that genetic screening may result in the use of genetic "labeling" to deny employment or insurance coverage). The Billings Surveys analyzed 29 claims of genetic discrimination describing 41 separate incidents of discrimination, 39 of which involved employers or insurers. *Id.* at 638.

60. See HUBBARD & WALD, *supra* note 4, at 128-30 (arguing that genetic tests may be used to excuse schools for poor academic performance among students).

61. See Billings Surveys, *supra* note 2, at 641 (arguing that agencies that deny adoptions based on genetic information exhibit eugenic prejudice, which assumes that the healthiest families make the best families).

62. Proctor, *supra* note 14, at 74 (asserting that discrimination by employers and insurance companies could create a genetic underclass).

63. See HUBBARD & WALD, *supra* note 4, at 140 (stating that insurance companies group people according to factors they cannot control).

64. See BRODY, *supra* note 32, at 39 (stating that technology has dramatically expanded human capability to affect the evolution of the human species).

65. See Elias & Annas, *supra* note 31, at 150 (articulating the argument that GLM may prevent diseases, eliminating the need for SCM in subsequent generations); Human Genetics Committee, *supra* note 30, at 668 (explaining that GLM can avoid multiple treatments of SCM).

66. See, e.g., Human Genetics Committee, *supra* note 30, at 669 (warning that the long-term commercial attraction of GLM is the enhancement of desirable traits); Elias & Annas, *supra* note 31, at 148-49 (drawing attention to the social danger of eugenics in the form of germ-line therapy); HUBBARD & WALD, *supra* note 4, at 116 (examining GLM's eugenic implications); *Pair Seeks to Patent 'Designer' Sperm Cells*, CHI. SUN-TIMES, Apr. 8, 1994 (expressing concerns about the use of genetics to improve the human race).

67. Scholars often ethically distinguish between treatment of painful or seriously crip-

cal and behavioral traits.⁶⁸

Because of the permanent nature of GLM and its potential cosmetic application,⁶⁹ GLM is illegal in several countries.⁷⁰ Scholars predict that huge profit opportunities will propel biotechnology⁷¹ companies to develop GLM further⁷² and

pling conditions from those that cause impairment or inconvenience. Arthur L. Caplan, *If Gene Therapy Is the Cure, What Is the Disease?*, in *GENE MAPPING: USING LAW AND ETHICS AS GUIDES*, *supra* note 3, at 136 (arguing that albinism is not a disease but an abnormality that is "readily amenable to various interventions and coping strategies"). Many scholars assert that the use of GLM to treat serious diseases is morally justifiable. *Id.* at 140 (arguing that GLM application to prevent fatal or serious diseases outweighs its potential harm); Proctor, *supra* note 14, at 67 (arguing that disease does not enhance human diversity). Others argue that parents' use of GLM to prevent less serious conditions in their children unjustifiably diminishes the diversity in the human gene pool. *Id.* at 139-40 (articulating the diversity argument made by several bioethicists); WILKE, *supra* note 46, at 160 (arguing that the use of GLM to alter a "reasonably normal" trait is much more problematic than using it to treat a diseased embryo).

68. See Elias & Annas, *supra* note 31, at 147 (explaining the fear that parents will use GLM to enhance their children's physical and mental capabilities); BRODY, *supra* note 32, at 132 (addressing the possibility that parents may use GLM to impose their prejudices on their descendants); Roger Highfield, *A Mighty No to Designer Babies: Poll Paradox*, *DAILY TELEGRAPH*, Aug. 16, 1993, at 12 (discussing surveys addressing "designer babies"); Cooke, *supra* note 48, at 59 (discussing GLM's possible use to create stronger, smarter children).

69. See *supra* notes 32-49 and accompanying text (explaining the effects of GLM on a family's hereditary line and its potential use for enhancement purposes).

70. Bartha M. Knoppers & Sonia LeBris, *Recent Advances in Medically Assisted Conception: Legal, Ethical and Social Issues*, 17 *AM. J.L. & MED.* 329, 342 n.39 (1990) (providing an exhaustive list of countries currently banning GLM). For background on the regulation of biotechnology applications outside the United States, see generally Noelle Lenoir, *International Symposium on Law and Science at the Crossroads: Biomedical Technology, Ethics, Public Policy, and the Law: French, European, and International Legislation on Bioethics*, 27 *SUFFOLK U. L. REV.* 1249, 1249-60 (1993) (discussing French regulation of biotechnology applications).

71. See BRODY, *supra* note 32, at 133 (quoting NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES, *THE NEW HUMAN GENETICS: HOW GENE SPLICING HELPS RESEARCHERS FIGHT INHERITED DISEASES* 14, 20 (1986)). "Biotechnology" is the genetic alteration of cells to induce the production of substances that are desirable or useful to humans. *Id.* Biotechnology companies produce these innovations for commercial profit. Powledge, *supra* note 22, at 15. This Comment defines a "biotechnology company" as a commercial producer of gene therapy and/or genetic testing methods.

72. See, e.g., Marc Bossuyt, *International Human Rights Systems: Strengths and Weaknesses*, in *HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE* 51 (Kathleen E. Mahoney & Paul Mahoney eds., 1993) (arguing that genetic technology will be available because commercial interests will overcome human rights concerns); HUBBARD & WALD, *supra* note 4, at 134 (projecting that genetic test sales in United States will hit several hundred million dollars before the year 2000); Powledge, *supra* note 22, at 15 (explaining the commercial pressure on biotechnology developers to see doctors apply the new techniques); Diane Paul, *Is Human Genetics Disguised Eugenics?*, in *GENES AND HUMAN SELF-KNOWLEDGE* 67 (Robert F. Weir et al. eds., 1994) (arguing that genetic screening tech-

that GLM will enjoy a large market when and where it becomes available.⁷³

GLM evokes controversy about the right of future generations to be free of genetic alterations⁷⁴ made without their consent,⁷⁵ particularly when alterations can result in uncontrollable mutations in a family's gene pool.⁷⁶ In addition, GLM raises the issue whether the genome itself has an intrinsic right to diversity.⁷⁷

The new level of scientific control that genetic testing and GLM offer may popularize genetic determinism.⁷⁸ By making many genetic conditions seem avoidable,⁷⁹ genetic testing and GLM may encourage narrow, socially-determined

nology offers biotechnology companies huge entrepreneurial opportunities).

73. See, e.g., John P. Boyle, *Response to Walters*, in GENES AND HUMAN SELF-KNOWLEDGE, *supra* note 72, at 243 (stating that surveys indicate that more people approve of GLM use to correct genetic defects than disapprove of it); Paul, *supra* note 72, at 73 (quoting Neil Holtzman and Andrew Rothstein who argue that more women will request prenatal tests because avoiding the birth of an at-risk child is often less expensive than clinical treatment); Parens, *supra* note 25, at 3 (describing a 1992 Harris poll indicating that 43% of Americans approve of using GLM to improve a baby's physical characteristics). *But see* Highfield, *supra* note 68, at 12 (describing a 1993 poll indicating that 78% of people polled oppose GLM for enhancement purposes).

74. See Margaret Somerville, *Introduction to Section V(d): Reproduction, Technologies and Human Rights*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 873 (raising the question whether future generations have rights to an unmodified gene pool); Anderson, *supra* note 2, at 665 (asking whether children have the right to unmanipulated genetic inheritance).

75. See Anderson, *supra* note 2, at 665 (questioning whether the doctrine of informed consent applies to future people); Caplan, *supra* note 67, at 139 (articulating the argument that it is wrong to impose the risks of GLM on descendants who cannot consent).

76. See HUBBARD & WALD, *supra* note 4, at 114 (stating that diseases which result from medical alterations to the germ-line are beyond the control of genetic surgeons).

77. Cf. Sionaidh Douglas-Scott, *Environmental Rights: Taking the Environment Seriously?*, in UNDERSTANDING HUMAN RIGHTS 423, 440-41 (Conor Gearty & Adam Tomkins eds., 1996) (discussing the recognition of rights in natural objects based on their intrinsic value rather than their usefulness to humans).

78. See Kutukdjian, *supra* note 41, at 23 (arguing that genetic research, which focuses solely on explaining human behavior, will result in genetic determinism and stigmatization based on genetic make-up); George J. Annas & Sherman Elias, *The Major Policy Issues Raised by the Human Genome Project*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 13 [hereinafter *Policy Issues*] (asserting that the Human Genome Project may cultivate a misperception that human decisions are the products of genetic make-up or that people are manufactured goods subject to quality control). Genetic determinism, also called genetic reductionism, is the exaggerated view that a large part of people's talents and abilities are rooted in their genetic make-up. Evelyne Shuster, *Determinism and Reductionism: A Greater Threat Because of the Human Genome Project?*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 115.

79. See Margrit Eichler, *Human Rights and the New Reproductive Technologies: Individual or Collective Choices?*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 883 (arguing that reproductive technologies that promise to "enhance" children may create discrimination by making disability seem pre-

standards of "health" and "normality."⁸⁰ This viewpoint reinforces existing prejudices against individuals with disabilities or physical characteristics that do not live up to a cultural ideal.⁸¹ Such standards can also generate social animosity toward parents who allow their children to be born "defective" despite knowledge of a potential genetic condition.⁸² As a result, the social focus, whether scientifically realistic or not, shifts from encouraging tolerance of human diversity to developing methods to avoid it.⁸³

(B). THE HUMAN RIGHTS FRAMEWORK

A. TRADITIONAL LANGUAGE

International human rights law evolved from several international instruments that attempt to interpret⁸⁴ the United Nations Charter provision promoting "universal respect for, and observance of, human rights and fundamental freedoms for all . . ."⁸⁵ These international instruments include: the Universal Declaration of Human Rights (UDHR),⁸⁶ the International Covenant on Civil and Political Rights

ventable).

80. See HUBBARD & WALD, *supra* note 4, at 31 (describing the stereotype that people with genetic conditions should not be born); see also *Policy Issues*, *supra* note 78, at 14 (arguing that diseases and abnormalities are social rather than biological creations); Ward, *supra* note 2, at 63 (asserting that "health" is culturally and socially defined).

81. See Human Genetics Committee, *supra* note 30, at 671 (arguing that GLM will create a technically-achievable health ideal based on social and political attitudes, rendering people that fall short of it as "damaged goods"); Proctor, *supra* note 14, at 67 (stating that Jeremy Rifkin, a vocal critic of genetic engineering, argues that gene therapy applications will stigmatize culturally deviant individuals); HUBBARD & WALD, *supra* note 4, at 36 (referencing Troy Duster's view that "screening" implies something bad and that genetic screening brands people as "defective" or "abnormal").

82. See Eichler, *supra* note 79, at 883 (quoting Theresa Degener, who argues that genetic tests will preclude women from exculpating themselves for bearing children with genetic defects by claiming lack of previous knowledge).

83. See Ward, *supra* note 2, at 63 (arguing that genetic testing to screen out the disabled may eclipse efforts to promote their social progress).

84. See John P. Humphrey, *The Universal Declaration of Human Rights: Its History, Impact and Juridical Character*, in HUMAN RIGHTS: THIRTY YEARS AFTER THE DECLARATION 21, 24, 34-37 (B. G. Ramcharan ed., 1979) (discussing several measures in which the U.N. General Assembly and Security Council used the UDHR to interpret terms of the U.N. Charter).

85. U.N. CHARTER art. 55(c).

86. Universal Declaration of Human Rights, G.A. Res. 217(A), U.N. Doc. 810 (1948) [hereinafter UDHR]. The United Nations Human Rights Commission drafted the UDHR as a first attempt to catalogue and define civil, political, economic, and social rights. Humphrey, *supra* note 84, at 24. The initial drafts of the UDHR originate in texts prepared by western democratic nations. *Id.* The U.N. General Assembly adopted the UDHR unanimously in 1948. ALESSANDRA LUINI DEL RUSSO, INTERNATIONAL PROTECTION OF HUMAN

(ICCPR)⁸⁷ and its Optional Protocol,⁸⁸ and the International Covenant on Economic, Social and Political Rights⁸⁹ (ICESCR).⁹⁰ Together, they constitute what scholars often refer to as the International Bill of Human Rights (IBHR).⁹¹

RIGHTS 36 (1971). When drafting the UDHR, the Commission did not intend it to carry binding legal force. *Id.* There is however international consensus that the UDHR is now binding on all U.N. members and arguably on all nations as customary international law. Humphrey, *supra* note 84, at 29; BUERGENTHAL, *supra* note 16, at 29-30.

87. International Covenant on Civil and Political Rights, Dec. 19, 1966, 999 U.N.T.S. 171, *reprinted in* 6 I.L.M. 368 [hereinafter ICCPR]. The U.N. Commission drafted the ICCPR as the first of two treaties to bind states to the principles articulated in the UDHR. DEL RUSSO, *supra* note 86, at 40. The ICCPR expands the number of civil and political rights in the UDHR and defines them with greater specificity. BUERGENTHAL, *supra* note 16, at 30. Although the ICCPR articulates some affirmative state responsibilities, human rights scholars often characterize the ICCPR as a list of immediately-effective restraints on government action. Geraldine Van Bueren, *Deconstructing the Mythologies of International Human Rights Law*, in UNDERSTANDING HUMAN RIGHTS, *supra* note 77, at 599. The ICCPR also creates a Human Rights Committee to review human rights reports submitted by each state party and establish reporting guidelines that encourage state compliance with ICCPR principles. BUERGENTHAL, *supra* note 16, at 38. One hundred twenty-five states are parties to the ICCPR, including the United States, which ratified the Covenant in 1992. BARRY E. CARTER & PHILLIP R. TRIMBLE, INTERNATIONAL LAW: SELECTED DOCUMENTS 387 (1995) [hereinafter CARTER & TRIMBLE].

88. Optional Protocol to the International Covenant on Civil and Political Rights, Dec. 16, 1966, U.N. G.A. Res. 2200 (XXI), *reprinted in* 6 I.L.M. 383 (1967). The Optional Protocol allows individual victims of human rights violations to file complaints with the Human Rights Committee against state parties. Bossuyt, *supra* note 72, at 49. The Committee reviews the written communications of the complainant and the implicated state and communicates its findings to the parties and to the General Assembly in an annual report. BUERGENTHAL, *supra*, note 16, at 42. Committee decisions serve as tools to interpret and implement the ICCPR. *Id.* As of December 31, 1993, there are 74 parties to the Optional Protocol. CARTER & TRIMBLE, *supra* note 87, at 407. The United States is not a party to the Protocol. *Id.*

89. International Covenant on Economic, Social and Cultural Rights, Dec. 16, 1966, 993 U.N.T.S. 3, *reprinted in* 6 I.L.M. 360 [hereinafter ICESCR]. The ICESCR expands in detail the economic, social, and cultural rights contained in the UDHR, such as the right to work, adequate standards of living, and education. BUERGENTHAL, *supra* note 16, at 42-43. Unlike the ICCPR, scholars often characterize the state responsibilities in the ICESCR as positive, requiring state intervention to provide goods and services. Van Bueren, *supra* note 87, at 599. *But see id.* (arguing that both the ICCPR and the ICESCR contain affirmative, cost-generating duties on states). Consequently, the ICESCR serves as a blueprint for future state action rather than a set of immediate constraints on state conduct. DEL RUSSO, *supra* note 86, at 47. As of 1993, one hundred twenty-seven states are parties to the ICESCR. CARTER & TRIMBLE, *supra* note 87, at 410. The United States has not ratified the Covenant. *Id.*

90. The U.N. General Assembly adopted all three instruments in 1966, and they entered into effect in 1975 upon ratification by 35 states. CARTER & TRIMBLE, *supra* note 87, at 387, 407, 410.

91. Humphrey, *supra* note 84, at 22; BUERGENTHAL, *supra* note 16, at 24.

The instruments of the IBHR contain language that can support the development and use of genetic testing and GLM.⁹² The UDHR, ICCPR, and ICESCR require the protection of the family as society's basic unit.⁹³ Both the UDHR and the ICCPR forbid arbitrary interference with an individual's "privacy, family, [or] home,"⁹⁴ and guarantee the right of men and women "to found a family."⁹⁵ The emphasis on personal privacy⁹⁶ and individual choice⁹⁷ that permeates this language supports the argument for parental discretion to test and alter their prospective children.⁹⁸ In addition, all three instruments affirm the right of parents to select the form of their children's education.⁹⁹ Parental liberty to monitor or control their children's genetic make-up may logically derive from this right.¹⁰⁰ Such an interpretation would be consistent with the overall spirit of the IBHR, which seems to exclude family decisions from the scope of human rights discussion.¹⁰¹

92. See BRODY, *supra* note 32, at 24-29 (discussing the applicability of several human rights instruments to health issues).

93. UDHR, *supra* note 86, art. 16(3); ICCPR, *supra* note 87, art. 23(1); ICESCR, *supra* note 89, art. 10(1).

94. UDHR, *supra* note 86, art. 12; ICCPR, *supra* note 87, art. 17.

95. UDHR, *supra* note 86, art. 16(1); ICCPR, *supra* note 87, art. 23.

96. See Aart Hendricks & Manfred Nowak, *Western European Case Study: The Impact of Advanced Methods of Medical Treatment on Human Rights*, in THE IMPACT OF TECHNOLOGY ON HUMAN RIGHTS: GLOBAL CASE STUDIES 243, 248 (C. G. Weeramantry ed., 1993) (explaining the emphasis on the right to privacy in the ICCPR); Walters, *supra* note 24, at 657 (arguing that familial autonomy to use gene therapy to prevent disease would be a natural extension of the freedom to seek genetic counseling); Billings Surveys, *supra* note 2, at 641-42 (arguing that the threat of losing insurance coverage pressures couples to abort fetuses with certain genetic conditions, infringing on the couple's right to bear a child).

97. See DEL RUSSO, *supra* note 86, at 255 (concluding that individual rights are still the focus of international human rights); Iles, *supra* note 4, at 51 (criticizing the emphasis on the individual in the existing human rights framework). But see H. Gros Espiel, *The Evolving Concept of Human Rights: Western, Socialist and Third World Approaches*, in HUMAN RIGHTS: THIRTY YEARS AFTER THE UNIVERSAL DECLARATION, *supra* note 84, at 51 (arguing that the period of 1947-1977 marked the end of individualist concepts of human rights).

98. See Recommendation 934 of the Council of Europe on Genetic Engineering, Eur. Parl. Ass., 22nd Sess., Doc. Nos. 4832-33 (1982), reprinted in ROGERS & DE BOUSINGEN, *supra* note 14, app. at 304 [hereinafter Recommendation 934] (permitting parental consent for experimentation on embryos or fetuses).

99. UDHR, *supra* note 86, art. 26, para. 3; ICCPR, *supra* note 87, art. 18, para. 4; ICESCR, *supra* note 89, art. 13, para. 3.

100. See Bob Wylie, *Genes Pose Sequence of Difficult Questions*, SCOTLAND ON SUNDAY, Feb. 27, 1994 (articulating the argument that if parents can give their children social advantages through private schooling, then they should be able to give them biological advantages as well); Brian Appleyard, *Our Plunge into the Gene Pool*, INDEPENDENT, May 12, 1993, at 21 (articulating the argument of some moral philosophers that if parents can use money "and other wiles" to improve their children, then they should also be able to use biotechnology).

101. See Van Bueren, *supra* note 87, at 597 (explaining that family issues fall outside the scope of traditional international human rights law, which only operates within the public sphere).

Both the UDHR and the ICESCR protect the individual's right to benefit from scientific advancement.¹⁰² In the genetic context, this right belongs to the unborn child rather than its parents.¹⁰³ An individual's right to life,¹⁰⁴ liberty,¹⁰⁵ and "security of person,"¹⁰⁶ as well as the economic, social, and cultural rights "indispensable for his dignity and the free development of his personality"¹⁰⁷ support the right of the unborn child to benefit from genetic testing and GLM. Inherent in this language is an emphasis on individual well-being that arguably presumes a right to be free from the suffering that genetic technology can prevent.¹⁰⁸

Ironically, this human rights language is equally relevant to the counter-arguments.¹⁰⁹ The counter-arguments shift the conceptual focus of the genetics debate from individual rights of privacy and autonomy to collective rights of humanity.¹¹⁰ From this perspective, the freedom to enjoy the benefits of scientific advancement requires a patient's consent, which is impossible when the patient is an embryo.¹¹¹ The ICESCR provides protection against the "social exploitation"¹¹² of children, arguably prohibiting parents from using biotechnology to impose their cultural preferences onto their descendants.¹¹³ In addition, critics of genetic technology argue that insurance companies may violate their right to found a family by denying them insurance for knowingly giving birth to children with genetic condi-

102. UDHR, *supra* note 86, art. 27, para. 2; ICESCR, *supra* note 89, art. 15, para. 1(b). In particular, the ICESCR recognizes "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." ICESCR, *supra*, art. 12, para. 1. It calls upon states to take steps to prevent and treat diseases, *Id.* art. 12, para. 2(c), ensure "the healthy development of the child," *Id.* art. 12, para. 2(a), achieve the "development and the diffusion of science" and preserve the "freedom indispensable for scientific research." *Id.* art. 15, paras. 2-3.

103. See Iles, *supra* note 4, at 36 (asserting that the right to benefit from scientific advancement arguably protects individuals from the potential dangers of the Human Genome Project).

104. UDHR, *supra* note 86, art. 3 (protecting an individual's right to life); ICCPR, *supra* note 87, art. 6, para. 1 (protecting individual's right to life).

105. *Id.* art. 3 (protecting individual liberty); ICCPR, *supra* note 87, art. 9, para. 1 (protecting individual liberty).

106. UDHR, *supra* note 86, at art.3; ICCPR, *supra* note 87, art. 9.

107. UDHR, *supra* note 86, art. 22.

108. See Somerville, *supra* note 74, at 873 (asking if failure to use technological advances to relieve pain is equivalent to torture).

109. Cf. James Kingston, *Human Rights: The Solution to the Abortion Question?*, in UNDERSTANDING HUMAN RIGHTS, *supra* note 77, at 467-68 (asserting that both pro-choice and pro-life activists can use human rights arguments to support their positions).

110. See BRODY, *supra* note 32, at 6 (arguing that health care issues often require individual autonomy to yield to greater community interests).

111. See Hendricks & Nowak, *supra* note 96, at 274 (indicating the difficulty of applying the informed consent requirement to unborn children).

112. ICESCR, *supra* note 89, art. 10, para. (3).

113. See Hendricks & Nowak, *supra* note 96, at 272 (criticizing the use of genetic technology to impose current aesthetic ideals on future generations).

tions.¹¹⁴

This viewpoint conceptualizes the family not as a group of presently living individuals, but as a line of descendants that share equal rights through time.¹¹⁵ The inviolability of the family functions as a prohibition on any actions that would subject descendants to forced alterations or unexpected mutations.¹¹⁶ The right to life, entailing a respect for diverse genetic expression and bodily integrity, is a prerequisite to the full development of the human personality and dignity.¹¹⁷ The right of individuals to "enjoy . . . fully and freely their natural wealth and resources,"¹¹⁸ guaranteed in the ICCPR and ICESCR, translates into a human genome that, as a natural resource, should be free of excessive human control.¹¹⁹

The ICCPR specifically guarantees that "no one shall be subjected without his free consent to . . . scientific experimentation."¹²⁰ Critics of GLM argue that even if scientists develop reliable insertion techniques,¹²¹ GLM may generate unexpected and irreversible mutations in the patient's offspring.¹²² By knowingly imposing these risks on an embryo, scientists can subject future people to scientific experimentation without their consent.¹²³

The majority of international human rights instruments currently do not address whether the right to life applies to the unborn.¹²⁴ They do, however, protect spe-

114. See Billings Surveys, *supra* note 2, at 641-42 (arguing that the threat of losing insurance coverage pressures parents to abort a fetus with a genetic condition, possibly infringing their right to bear children).

115. See BRODY, *supra* note 32, at 36 (asserting that the reproductive rights of parents must balance those of their descendants in a continuum).

116. See *supra* note 48 and accompanying text (explaining that GLM may cause unexpected genetic mutations in descendants).

117. See Hendricks & Nowak, *supra* note 96, at 272 (arguing that the use of GLM for enhancement purposes violates the right of the unborn child to be treated with dignity).

118. ICCPR, *supra* note 86, art. 47; ICESCR, *supra* note 89, art. 25.

119. See Hendricks & Nowak, *supra* note 96, at 268 (expressing concern over man's enlarged control over humanity through genetic research).

120. ICCPR, *supra* note 87, art. 7.

121. See *supra* note 48 and accompanying text (explaining the technical problems of gene insertion).

122. See *supra* note 48 and accompanying text (explaining the lack of scientific knowledge about how genes interact with each other and their environment).

123. See HUBBARD & WALD, *supra* note 4, at 114-15 (stressing scientists' deficient understanding of gene functions and interactions); Human Genetics Committee, *supra* note 30, at 668 (stating that scientists cannot predict the full effects of gene modification).

124. Philip Alston, *The Unborn Child and Abortion Under the Draft Convention on the Rights of the Child*, 12 HUM. RTS. Q. 156 (1990). An exception is the American Convention on Human Rights, which states that the right to life shall be protected "from the moment of conception." *Id.* at 156-57. Hendricks & Nowak, *supra* note 96, at 268 (stating that international law has not defined rights of posterity). The international community has addressed the rights of the unborn only within the abortion debate where there is a general consensus that international human rights protection does not extend to the unborn. See Alston, *supra*, at 161 (stating that drafters repeatedly rejected attempts to recognize a right to life for the

cific, enumerated groups from discrimination based on their group identity.¹²⁵ Although the UDHR, ICCPR, and ICESCR recognize that group affiliations based on "other status" deserve protection,¹²⁶ none specifically address the legal status of victims of genetic discrimination.¹²⁷

Since the promulgation of the International Bill of Rights, other United Nations declarations have recognized the potential dangers that scientific advancement poses to human rights.¹²⁸ These instruments provide states with little guidance for regulation because they do not specifically address the situations in which dis-

unborn). Draft proposals to the ICCPR providing that human life begins at conception were ultimately excluded from the right to life provision in Article 6. Kingston, *supra* note 109, at 458. The European Commission concluded in *Paton v. UK* that the right to life provision in Article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms did not protect the unborn. *Id.* at 459. Finally, several attempts to grant the fetus legal status failed during the drafting stages of the Convention on the Rights of the Child primarily because the Working Group of the U.N. Human Rights Commission, charged with the drafting of the Convention, wanted to allow state parties latitude to formulate their own policy on the abortion issue. Alston, *supra*, at 163. Although the third preambular paragraph of the Convention recognizes that children require special legal protection "before as well as after birth," the international legal community considers this a policy statement carrying no binding force, particularly because it is not reaffirmed within the body of the Convention. Alston, *supra*, at 167, 169, 177.

125. The UDHR and the ICCPR both state that "[a]ll are equal before the law and are entitled without any discrimination to the equal protection of the law." UDHR, *supra* note 86, art. 7; ICCPR, *supra* note 87, art. 26. Along with the ICESCR, they prohibit discrimination based on "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." UDHR, *supra* note 86, art. 2; ICCPR, *supra* note 87, art. 26; ICESCR, *supra* note 89, art. 2, para. 2.

126. UDHR, *supra* note 86, art. 2; ICCPR, *supra* note 87, art. 26; ICESCR, *supra* note 89, art. 2, para. 2.

127. UDHR, *supra* note 86, art. 2; ICCPR, *supra* note 87, art. 26; ICESCR, *supra* note 89, art. 2, para. 2.

128. The Tehran Declaration of 1968, issued by the International Conference on Human Rights, calls for "continuing attention" to the potential negative implications of scientific projects for human rights. Final Act of the Int'l Conf. on Human Rights, Teheran, 22 Apr.-13 May, 1968, U.N. Doc. A/CONF.32/41 [hereinafter Teheran Declaration]. The Conference later passed a resolution recommending analysis of the "protection of the human personality and its physical and intellectual integrity." *Id.*, Res. 11, at 12. In 1975, the United Nations issued the Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and For the Benefit of Mankind, G.A. Res. 3384, U.N. GAOR, 30th Sess., U.N. Doc. A/Res.3384 (1975) [hereinafter 1975 Declaration], which recognizes the possible dangers of scientific advancement in more detail. *Id.* at 1. The Conference Resolution and the 1975 Declaration notably recognize the importance of group rights to the biotechnology discussion, unlike the IBHR, which emphasizes individual rights. *Id.* at 3 (recognizing that genetic research may "infringe on the rights . . . of the group"); Teheran Declaration, *supra*, Res. 11, at 12 (acknowledging that scientific advancement "may entail certain dangers for . . . the group and for human dignity").

crimination may arise.¹²⁹ Moreover, they do not define or reject a legal status for people with genetic conditions and their unborn children.¹³⁰

The language that human rights movements traditionally employ does not function well within a biotechnology framework.¹³¹ Traditional human rights law was based on the assertion of individual rights against the state.¹³² Genetic technology upsets this presumption by pitting the rights of existing individuals against those of future individuals.¹³³ By adding new players to the human rights game,¹³⁴ genetic technology defies the concepts underlying the existing model and reveals the need for a revised language.¹³⁵

B. TRADITIONAL CONCEPTS

Most human rights scenarios typecast the state¹³⁶ as the human rights violator.¹³⁷ They portray governments as awesome, centralized monsters that actively

129. *Accord Iles, supra* note 4, at 38 (describing the 1975 Declaration as isolated and undeveloped).

130. 1975 Declaration, *supra* note 128, at 3.

131. *Cf. Kingston, supra* note 109, at 467-68 (arguing that because either pro-choice or anti-abortion activists may invoke human rights arguments, the existing human rights framework is not helpful to the abortion debate).

132. See ANDREW CLAPHAM, *HUMAN RIGHTS IN THE PRIVATE SPHERE* 91 (1993) (arguing that individuals traditionally viewed their rights as protected against state action); Irwin Cotler, *Human Rights as the Modern Tool of Revolution*, in *HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE*, *supra* note 72, at 11 (explaining that the individual is the subject of post-World War II human rights law). For further background on individualism as a basis of international human rights law, compare DEL RUSSO, *supra* note 86, at 255 (arguing that individuals are still the focus of human rights), and Iles, *supra* note 4 at 51-52 (arguing that the existing human rights framework has a bias towards individualism), with Espiell, *supra* note 97, at 43-51 (arguing that the individualist concept of human rights was obsolete by 1948).

133. See BRODY, *supra* note 32, at 36 (arguing that individuals may limit the rights of their progeny by fully exercising their own rights).

134. See Hendricks & Nowak, *supra* note 96, at 266 (stating that genetic technology implicates the rights of posterity).

135. See Eichler, *supra* note 79, at 887 (advocating an expanded human rights approach that addresses global as well as individual interests).

136. Although the words "state" and "government" have distinct definitions in international law, this Comment uses them interchangeably to refer to the governing authority of each nation.

137. See, e.g., Nani Palkhivala, *Economic, Social and Cultural Rights*, in *HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE*, *supra* note 72, at 442 (explaining that the focus of human rights is the assertion of rights against the government); Bossuyt, *supra* note 72, at 50 (arguing that states are the primary human rights violators); Cotler, *supra* note 132, at 12 (listing nine recommendations for the human rights movement, five of which are directed at states); Iles, *supra* note 4, at 52 (arguing that traditional liberalism calls upon people to enforce their rights against the state). But see Johannes Morsink, *The Philosophy of the Universal Declaration*, 6 *HUM. RTS. Q.* 309, 333 (arguing that human

abuse their people.¹³⁸ Because of the state's leading role, traditional scenarios limit human rights issues to the public sphere, where individuals clash with state agents.¹³⁹ As a result, claims of abuse by private actors fall outside the scope of the human rights framework.¹⁴⁰

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.¹⁴¹ In most cases, the members of this group are distinguishable by physical features such as race or gender, or by natural affiliation with an ethnic, national, linguistic or religious group.¹⁴²

The Convention on the Prevention and Punishment of the Crime of Genocide clearly illustrates this "contained" image of the human rights victim.¹⁴³ The Convention defines genocide as an act performed "with intent to destroy, in whole or in part, a national, ethnic, racial or religious group"¹⁴⁴ by any of the following means:

- (a) Killing members of the group;
- (b) Causing serious bodily or mental harm to members of the group;
- (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part;
- (d) Imposing measures intended to prevent births within the group;

rights in the UDHR are based on natural rights that transcend the state).

138. See Van Bueren, *supra* note 87, at 598 (explaining that traditional interpretations of human rights focus on a state's power to subject its people); DEL RUSSO, *supra* note 86, at 62 (stressing the role of the state as the perpetrator of genocide).

139. CLAPHAM, *supra* note 132, at 91 n.10 (articulating the traditional assumption that only states carry human rights responsibilities).

140. See *id.* at 126 (stating that traditional human rights law excludes actions of private actors); Dinah Shelton, *Private Violence, Public Wrongs, and the Responsibility of States*, 13 FORDHAM INT'L L.J. 1, 20 (1990) (stating that international human rights standards generally do not apply to acts of private persons).

141. See Richard Falk, *Preface* to EDITH B. WEISS, IN FAIRNESS TO FUTURE GENERATIONS: INTERNATIONAL LAW, COMMON PATRIMONY, AND INTERGENERATIONAL EQUITY, at xxi-ii (1989) (explaining that in traditional international law, problems of justice involve people living on "distinct territorial units" surrounded by "discernible boundaries").

142. See Malcolm N. Shaw, *The Definition of Minorities in International Law*, 1990 ISRAEL Y.B. HUM. RTS. 13, 29 (stating that some scholars distinguish between race as a hereditary physical characteristic and ethnicity as a cultural, linguistic and religious characteristic); Asbjorn Eide, *Minority Protection and World Order: Towards a Framework for Law and Policy*, in UNIVERSAL MINORITY RIGHTS 87, 88 (Alan Phillips & Allan Rosas eds., 1995) (explaining the traditional assumption that minority groups exist naturally and immutably).

143. The Convention on the Prevention and Punishment of the Crime of Genocide, Dec. 9, 1948, 78 U.N.T.S. 277, reprinted in CARTER & TRIMBLE, *supra* note 87, at 419 [hereinafter Genocide Convention]; see also Eide, *supra* note 142, at 106-07 (discussing measures to accommodate minority groups based on their territorial location).

144. Genocide Convention, *supra* note 143, art. II.

(e) Forcibly transferring children of one group to another group.¹⁴⁵

The Convention limits eligibility for group status to race—which is physically distinguishable—and nationality, ethnicity and religion—which arrange individuals into easily recognizable categories.¹⁴⁶ The condemnation of killing, bodily harm, and physical destruction implies that the human rights victim is necessarily a living being whose physical integrity must exist in order to be threatened.¹⁴⁷

In this manner, the traditional human rights framework paints both the victim and the state as discrete and cohesive.¹⁴⁸ Moreover, it forces human rights organizations to act as reactionary bodies.¹⁴⁹ Because violation requires action by the state, human rights groups can address violations only after they occur.¹⁵⁰ Consequently, the role of human rights organizations is limited to treatment rather than prevention.¹⁵¹

II. ANALYSIS: FORMING NEW DEFINITIONS

A. SOCIETY AS VIOLATOR

1. Privatization of Power

Biotechnology challenges the human rights status quo by usurping the state's power to violate and by placing that power in the hands of private actors throughout society.¹⁵² Doctors, attracted by the opportunity to lower their liability insurance, may offer these innovations to their patients.¹⁵³ Insurance companies and

145. *Id.*

146. (protecting national, ethnic, racial, and religious groups); see also Eide, *supra* note 142, at 90 (quoting scholar Clifford Geertz, who argues that collective identity emerges from "immediate contiguity," kinship and birth into particular religious or linguistic community).

147. *Id.* art. II (a)-(c) (discussing killing, bodily harm, and physical destruction); see also DEL RUSSO, *supra* note 86, at 59 (comparing genocide to homicide).

148. See *supra* notes 141-42 and accompanying text (describing both the state and human rights victims as insular); BUERGENTHAL, *supra* note 16, at 8-9 (discussing international protection of "pockets" of ethnic, religious, and linguistic minorities under the League of Nations system).

149. See Cotler, *supra* note 132, at 19 (stating that non-governmental organizations addressing human rights issues have traditionally been "crisis-oriented").

150. *Id.*

151. *Id.* (stating that crisis management is the traditional objective of human rights nongovernmental organizations).

152. See Iles, *supra* note 4, at 33-34 (arguing that regulation of genetic technology should focus on the actions of doctors, scientists, employers, insurers, biomedical corporations, and clinics).

153. See HUBBARD & WALD, *supra* note 4, at 27 (arguing that doctors will recommend tests to their patients to avoid malpractice suits, even when there is no discernible health

employers may implement these innovations to stream-line their operations.¹⁵⁴ Patients, pressured to discover their own health potential and that of their children, may demand them as well.¹⁵⁵

Biotech corporations, sensing a huge pot of gold at the end of a research and development rainbow,¹⁵⁶ will aggressively market genetic technology to meet this demand.¹⁵⁷ Because of its specialized nature,¹⁵⁸ widespread availability of biotechnology may transform biotech companies into mini-technocracies that can influence the personal decisions of broad sectors of society, usurping power traditionally in the hands of the state.¹⁵⁹ If the application of biotechnology breeds discrimination or causes harmful mutations in future generations, state responsibility will arise from authorizing the violations rather than authoring them.¹⁶⁰

Ultimately, human rights abuses resulting from scientific advancement will originate in the private sphere of society, rather than the public sphere of government. This privatization of human rights abuses will occur as part of a growing trend of privatization of services.¹⁶¹ Whereas people once viewed the state as the only source of authority,¹⁶² they now view themselves as "subjects" of private po-

problem); Paul, *supra* note 72, at 76-77 (arguing that genetic screening will provide doctors with protection against malpractice suits).

154. See *supra* notes 53-59 and accompanying text (explaining how genetic screening can reduce operating costs for employers and insurance companies).

155. See Hendricks & Nowak, *supra* note 96, at 283-84 (arguing that an individual's stake in test results increases as more non-medical actors begin to require testing); see also Paul, *supra* note 72, at 77 (predicting that increased use of genetic tests will make parents feel as if they have no reasonable alternative to testing or aborting their fetus); *supra* note 73 and accompanying text (projecting high public demand for genetic technology).

156. See HUBBARD & WALD, *supra* note 4, at 35 (quoting physicians Benjamin Wilfond and Norman Frost, who argue that biotechnology companies will "reap enormous profits" from genetic test sales); see also *supra* note 72 and accompanying text (discussing the large profit opportunities for biotechnology companies).

157. See HUBBARD & WALD, *supra* note 4, at 35-36 (arguing that biotechnology producers will go to great lengths to market their products, particularly since they are expensive to produce).

158. See WILKIE, *supra* note 46, at 162 (discussing the high level of technical expertise that genetic surgeons must have).

159. See *id.* at 162 (arguing that a "small elite technocracy" of genetic surgeons will have technical control over the future of human genetic resources); see also Iles, *supra* note 4, at 34 (recommending regulation to prevent biomedical companies and clinics from recommending certain genetic tests).

160. See Shelton, *supra* note 140, at 21-24 (1990) (arguing that international law requires states to exercise due diligence to prevent human rights violations by private actors); see also CLAPHAM, *supra* note 132, at 91-92 (asserting that states may be responsible for private violations that they do not address in legislation).

161. See Van Bueren, *supra* note 87, at 596-97 (discussing the continuing privatization of institutions and personnel); CLAPHAM, *supra* note 132, at 126 (stating that privatization of services is the current trend in Europe).

162. CLAPHAM, *supra* note 132, at 126.

lice, hospitals, corporations, and religious institutions.¹⁶³ As a result, the privatization of human rights will obscure the boundaries of the public and private spheres.¹⁶⁴ Where private actors develop authority similar to a state,¹⁶⁵ they will qualify for scrutiny under international human rights standards.¹⁶⁵

Although regional international human rights courts have recognized the responsibility of private actors,¹⁶⁷ the international community has not acted upon this idea in practice.¹⁶⁸ At any rate, privatization makes clear that the sources of human rights abuse will outgrow their legal infrastructure.¹⁶⁹ This prompts many scholars to argue for a redefinition of human rights that includes accountability of private actors who assume a quasi-public role.¹⁷⁰

163. *Id.* (suggesting that such institutions are not typically considered "organs" of the state).

164. Van Bueren, *supra* note 87, at 597.

165. It is interesting that several scholars use political language to describe the conduct of private commercial actors. See, e.g., Ursula Franklin, *New Threats to Human Rights Through Science and Technology—The Need for Standards*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 733-34 (contending that scientific advances have "increased the machinery of dominance and oppression" and may create a "headless tyranny"); HUBBARD & WALD, *supra* note 4, at 116 (referring to geneticists as "self-appointed arbiters of human excellence"); WILKIE, *supra* note 46, at 162 (referring to genetic surgeons as a "small, elite technocracy"); Paul, *supra* note 72, at 77 (referring to the private health care industry as "quasi-public").

166. CLAPHAM, *supra* note 132, at 126 (arguing that quasi-public actors should have to adhere to international human rights law as well as national statutory law); Nigel S. Rodley, *Can Armed Opposition Groups Violate Human Rights?*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 300 (redefining human rights law to include relationships between individuals and entities exercising state-like power).

167. See Velasquez Rodriguez v. Honduras, Inter-Am. C.H.R. OAS/ser. L/V/III.19, doc. 13 (1988) (holding that states must prevent human rights violations by public authorities and private actors assuming an authoritative role); *X & Y v. Netherlands*, 91 Eur. Ct. H.R. (ser. A) (1985) (suggesting that state responsibility extends to interactions between private individuals).

168. Kathleen E. Mahoney & Paul Mahoney, *Introduction, Section III(b): Non-State Actors and Violence*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 295.

169. See CLAPHAM, *supra* note 132, at 126 (arguing that human rights violations by quasi-public actors fall outside the scope of traditional human rights law).

170. See, e.g., Mahoney & Mahoney, *supra* note 168, at 295 (arguing that human rights law must extend to private actors in practice); UNESCO Secretariat, *UNESCO and the Challenges of Today and Tomorrow: Universal Affirmation of Human Rights*, in HUMAN RIGHTS: THIRTY YEARS AFTER THE UNIVERSAL DECLARATION, *supra* note 84, at 208 (advocating the use of human rights concepts to combat violations by corporations and other private actors); CLAPHAM, *supra* note 132, at 126 (arguing that a new definition of the public sphere must incorporate private actors and actions); Van Bueren, *supra* note 87, at 601 (arguing for complete extension of international human rights law into the private sphere); Iles, *supra* note 4, at 35 (promoting a human rights framework that confronts abuses by private social institutions); Shelton, *supra* note 140, at 34 (recommending the ratification of ACHR to require the United States to exercise due diligence to prevent human rights violations by

2. Diffusion of Power

The expanding role of private actors in human rights analyses also reveals a diffusion of power from a centralized state to individuals dispersed throughout society.¹⁷¹ Strong public demand and aggressive commercial supply can transform the nature of eugenics from a state-managed program to a grass-roots movement.¹⁷² Ursula Franklin, a Professor Emeritus at the University of Toronto, argues that technology produces a power diffusion by masking principled decisions in non-human structures.¹⁷³ These structures ultimately control larger numbers of people by more invisible means.¹⁷⁴ 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.¹⁷⁵ By per-

private actors); cf. Alan W. Schefflin, *The Use of Medicine and Psychiatry to Commit Human Rights Violations: The Mind Control Experiments*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 843 (argues for recognition of mind control practices by state and private actors as human rights abuse). Some scholars do not specifically address privatization in their writings but devote equal attention to public and private actors as sources of human rights violations. See *id.* at 832-39 (addressing the use of mind control by state and private actors as a human rights violation); Hendricks & Nowak, *supra* note 96, at 281-86 (addressing the use of genetic technology by both state and private actors).

171. See HUBBARD & WALD, *supra* note 4, at 160-62 (arguing that laws must restrain the broad power that genetic technology confers upon geneticists, physicians, and society in general); HENDRICKS AND NOWAK, *supra* note 96, at 272 (criticizing the aesthetic discretion that GLM gives parents).

172. See Paul, *supra* note 72, at 70 (observing the rise of a "new eugenics" rooted in a multitude of individual decisions to undergo genetic testing and therapy); JONATHAN MARKS, HUMAN BIODIVERSITY: GENES, RACE AND HISTORY 150 (1995) (identifying the family as the source of contemporary eugenics); McKusick, *supra* note 4, at 633 (arguing that prenatal diagnosis requirements by insurance companies would result in defacto eugenics); Iles, *supra* note 4, at 54 (arguing that individual decisions may produce a eugenic effect when aggregated); Groves, *supra* note 9, at B1 (referring to parents' use of GLM to enhance their children's physical characteristics as "commercial eugenics"); see also Highfield, *supra* note 68, at 12 (quoting Professor Steve Jones of the University College London, who observes that the public is more open to GLM use than policymakers).

173. Franklin, *supra* note 165, at 734-35. To illustrate this point, Franklin contrasts a security guard with a magnetic card reader. While people may question the authority of a guard who prevents them from entering a building, they are much less likely to question a card-reader that controls the lock on the door. *Id.* This example represents a trend in human behavior to question the fruits of government but not those of science. See Somerville, *supra* note 74, at 871 (explaining the traditional assumption that medicine is motivated by altruism and therefore cannot be a source of human rights violations).

174. Franklin, *supra* note 165, at 734-35. Revisiting her example, Franklin notes that after people enter the building and pass the guard, they are free from "human control." Yet other card-readers may track and document where and when they move about the building. *Id.*

175. See McKusick, *supra* note 4, at 633 (arguing that insurance policies that require

forming GLM on individual embryos or sex cells, physicians can produce snowballing genetic alterations that may subject entire families to harmful mutations or societal prejudice.¹⁷⁶

To address this problem, Franklin proposes a conceptual framework for human rights encompassing both micro-situations, which affect small, discrete groups of people, and macro-situations, which affect large segments of society.¹⁷⁷ She concludes that the current human rights regime can only address micro-situations and must be rebuilt to confront macro-situations as well.¹⁷⁸ Franklin's conceptual framework is particularly useful in the genetics context because it acknowledges that governments need a broadened definition of "violation" in order to regulate the potential "headless tyranny" of science.¹⁷⁹

B. HUMANITY AS VICTIM

Privatization of abusive power alters the nature of the human rights victim.¹⁸⁰ When the power to violate human rights diffuses throughout society through testing and therapy applications, the effects of abuse become large-scale.¹⁸¹ Discrimination transcends racial, ethnic, or other conventional classifications to affect large cross-sections of society.¹⁸² Moreover, by extending this discrimination to future generations, GLM and embryo diagnosis add a temporal dimension to human rights infringement.¹⁸³ Given this potential for violations-of-scale, the conventional image of the discrete human rights victim becomes inadequate.¹⁸⁴ Technological

prenatal diagnosis would, in effect, create eugenics programs).

176. See *supra* notes 32-49 and accompanying text (discussing the potential biological and social consequences of GLM).

177. Franklin, *supra* note 165, at 736. Franklin offers torture and kidnapping as examples of micro-violations and chemical and nuclear warfare as examples of macro-violations. *Id.*

178. *Id.*

179. *Id.* at 735.

180. See Somerville, *supra* note 74, at 873-74 (arguing that human rights breaches in health care create societal harms).

181. See Edward W. Ploman, *Foreword* to EDITH B. WEISS, IN FAIRNESS TO FUTURE GENERATIONS: INTERNATIONAL LAW, COMMON PATRIMONY, AND INTERGENERATIONAL EQUITY at xxvi (1989) (recognizing that technology allows people unprecedented control over their environment, producing a wide spatial effect); Proctor, *supra* note 14, at 70 (arguing that the effects of gene therapy and genetic testing will be populational); Paul, *supra* note 72, at 70 (arguing that the decisions of private individuals can have populational effects).

182. Ploman, *supra* note 181, at xxvi (arguing that technology gives people broad power that transcends territorial boundaries).

183. *Id.* at xxvi; K. Nolan & S. Swenson, *New Tools, New Dilemmas: Genetic Frontiers*, HASTINGS CTR. REP., Oct./Nov. 1988, at 42 (predicting "renewed commitment to intergenerational relatedness").

184. See Eichler, *supra* note 79, at 887 (arguing that the effects of new reproductive technologies are not limited to small groups of people and supporting the expansion of hu-

innovations that cross social and generational boundaries¹⁸⁵ enlarge the victim pool from specific groups of humans to humanity in general.¹⁸⁶ Thus, the paradigm of human rights analysis shifts from the individual incident to the ongoing condition.¹⁸⁷

The juxtaposition of spatial and temporal forces defies conventional definitions of many human rights violations.¹⁸⁸ This particularly applies to genocide, which relies conceptually on state aggression, conspicuous conduct, and a demarcated group victim.¹⁸⁹ Biotechnology provides a new image of victimhood which invites exploration into the definitional frontiers of genocide.

1. Gene-ocide

Broad application of GLM or embryo diagnosis for selective pregnancy is arguably comparable to genocide, as defined by the Genocide Convention.¹⁹⁰ Applications involve intentional acts by parents, doctors or commercial actors to destroy all or part of groups sharing certain genetic traits.¹⁹¹ Scientists design these techniques in a calculated attempt to destroy the physical integrity of these groups, implicating Article II(c) of the Convention.¹⁹² Health care professionals implement these techniques in order to prevent births within genetic groups, implicating Article II(d).¹⁹³ These similarities raise the question whether the definition of genocide can or should include social repression of genetic traits. Does genocide apply to expressions of life as well as life itself? Or is biotechnology fostering a separate crime of gene-ocide?

man rights analysis to encompass issues with global repercussions).

185. *But see* Iles, *supra* note 4, at 46 (arguing that genetic discrimination reinforces traditional social divisions).

186. *See* Ploman, *supra* note 181, at xxvii (arguing that all of humanity holds intergenerational rights); Lenoir, *supra* note 70, at 1255 (condemning cosmetic gene therapy as a threat to the integrity of the human species).

187. *See* BRODY, *supra* note 32, at 36 (asserting that reproductive rights operate in a continuum that mediates the freedoms of existing and future generations).

188. *See* Ploman, *supra* note 181, at xxvi (explaining the complimentary nature of spatial and temporal factors in international law).

189. *See* DEL RUSSO, *supra* note 86, at 62 (arguing that a plan by the United States government to destroy all or part of the black race would be genocide, but that private lynchings would not); *see also supra* note 145 and accompanying text (providing the conventional definition of genocide).

190. Genocide Convention, *supra* note 143, art. II.

191. *Id.* (requiring intent to destroy a group).

192. *Id.* art. II(c) (prohibiting actions calculated to bring about the physical destruction of all or part of a group).

193. *Id.* art. II(d) (prohibiting "measures intended to prevent births within the group"). However, these arguments assume that people prone to "undesirable" genetic conditions are worthy of group status. The Genocide Convention applies only to racial, national, ethnic, and religious groups. *Id.* art. II.

Several scholars propose broadened definitions of genocide.¹⁹⁴ Sociologist Helen Fein offers a definition particularly well-suited to the genetics debate. Fein defines genocide as: "sustained purposeful action by a perpetrator to physically destroy a collectivity, directly or indirectly, through interdiction of the biological and social reproduction of group members, sustained regardless of the surrender or lack of threat offered by the victim."¹⁹⁵

Fein's definition recognizes that the calculated conduct of social institutions and private individuals can create discrimination against groups of people without malicious intent.¹⁹⁶ Thus, even if scientists develop GLM strictly to combat disease,¹⁹⁷ they may still be culpable if they know that people will use GLM to eliminate socially undesirable traits.¹⁹⁸ Fein's definition does not typecast the state as the hu-

194. Frank Chalk, *Redefining Genocide*, in *GENOCIDE: CONCEPTUAL AND HISTORICAL DIMENSIONS* at 47 (George J. Andreopoulos ed., 1994). For example, Pieter Drost argues that the Genocide Convention definition should prohibit the intentional destruction of the physical life of individuals based on their membership in any human collectivity. *Id.* at 48. While this definition recognizes that discrimination can arise against groups not enumerated in the Convention, it fails to specify whether destruction of physical life encompasses alteration of life in its prenatal form. *Id.* Irving Louis Horowitz proposes that the Convention recognize genocide as state-sponsored destruction of innocent people using structural and systemic means. See Chalk, *supra*, at 48-49. This definition acknowledges that technology can violate human rights through structure and function rather than decree. *Id.* at 49. Yet it does not apply to biotechnology issues because it assumes the state's active role in the violation. *Id.* Isidor Wallimann and Michael Dobkowski build on Horowitz's definition by arguing that a definition of genocide that requires intent ignores violations that are so widespread and systemic that both the perpetrators and the victims are unaware of them. *Id.* Isidor Wallimann & Michael N. Dobkowski, *Introduction to GENOCIDE AND THE MODERN AGE: ETIOLOGY AND CASE STUDIES OF MASS DEATH* xvi (Isidor Wallimann & Michael N. Dobkowski eds., 1987). This definition, like that of Horowitz, is relevant to the genetics debate because it acknowledges that human rights violations can be rooted in societal forces. *Id.* Yet it mistakenly equates intentionality with malicious acts rather than deliberate acts. Helen Fein, *Genocide, Terror, Life Integrity, and War Crimes: The Case for Discrimination*, in *GENOCIDE: CONCEPTUAL AND HISTORICAL DIMENSIONS*, *supra*, at 95, 97 (defining intent as 'purposeful action' rather than motive); Roger W. Smith, *Human Destructiveness and Politics: The Twentieth Century as an Age of Genocide*, in *GENOCIDE AND THE MODERN AGE: ETIOLOGY AND CASE STUDIES OF MASS DEATH*, *supra*, at 21, 23 (asserting that an act is intentional when the actor persists in the action despite knowledge of its consequences).

195. Chalk, *supra* note 194, at 49.

196. See Fein, *supra* note 194, at 97 (arguing that purposeful action, not motive, fulfills the intent requirement of genocide); Chalk, *supra* note 194, at 53 (discussing the concept of a "genocidal society," where a state and its citizens exhibit the intent element of genocide by continually pursuing policies that they know will result in the destruction of an indigenous group).

197. Ward, *supra* note 2, at 63 (stating that researchers are developing gene therapy to treat illnesses such as heart disease, diabetes, AIDS, and susceptibility to cancer). But see Elias & Annas, *supra* note 31, at 149 (arguing that the distinction between disease and enhancement is "inherently fuzzy" and that it may be impossible to prevent cosmetic uses of GLM once the technique is available).

198. Likewise, surgeons who alter a genetic defect in an individual embryo do not in-

man rights violator, but refers more generally to a perpetrator.¹⁹⁹ Moreover, by focusing generally on the collectivity, Fein's definition acknowledges that groups face discrimination based on factors other than race, religion, nationality, or ethnicity.²⁰⁰ Finally, by addressing reproductive intervention and the vulnerability of the victim, the definition confronts the ethical problems of gene manipulation without the informed consent of the patient.²⁰¹

Frank Chalk argues that expanding the definition of genocide to include structural mechanisms or private acts would debase government conduct that threatens the existence of whole peoples.²⁰² Chalk bases his argument on two faulty assumptions, however. First, he assumes that only states act in ways that threaten large populations.²⁰³ Institutional practices often inflict more harm by disguising human rights violations in standard operating procedures.²⁰⁴ Social admiration of science and skepticism of government reinforces this invisibility.²⁰⁵ Furthermore, because individuals interact with employers, schools, and insurance companies on a daily basis, social institutions can cause them more direct harm than a distant government.²⁰⁶

Chalk also assumes that expanding the definition of genocide beyond the scope of state activity will trivialize state-sponsored atrocities.²⁰⁷ In doing so, he imposes

tend to eradicate the defect from the entire human species. Ward, *supra* note 2, at 63. Yet genetic surgeons know that their individual actions, when aggregated, form broad medical practices that may reduce genetic diversity. *Id.*

199. See *supra* notes 137-38 and accompanying text (discussing the traditional role of the state as human rights violator).

200. See Genocide Convention, *supra* note 143, art. II (limiting the scope of genocide to "national, ethnical, racial or religious groups").

201. See *supra* notes 75-76 and accompanying text (discussing the ethical implications of GLM for future generations).

202. Chalk, *supra* note 194, at 56-57. Chalk criticizes the emphasis on structural sources of violation, arguing that people, not systems, kill. *Id.* He insists that genocide must be perpetrated by an agent of the state because only the state has the power to stop genocide. *Id.* at 59. But see Rodley, *supra* note 166, at 310 (stating that because genocide involves large-scale assault on a population, it may be an exception to the state nexus requirement for private-actor liability).

203. Chalk, *supra* note 194, at 59 (asserting that the role of the state as the perpetrator of genocide distinguishes genocide from homicide).

204. See Franklin, *supra* note 165, at 734-35 (illustrating the imperceptible nature of discriminatory policies that are implemented by technological innovations).

205. See Somerville, *supra* note 74, at 871 (criticizing the assumption that medicine is always motivated by altruism).

206. See *supra* note 60 and accompanying text (describing the use of genetic tests by schools to establish students' scholastic aptitude); CLAPHAM, *supra* note 132, at 137 (describing the emergence of state-like authority in social institutions such as associations, corporations, and interest groups).

207. Chalk, *supra* note 194, at 57. To illustrate this point, Chalk distinguishes the Nazi Holocaust as a unique example of genocide in part because it involved intent to destroy a biologically-defined group. *Id.* at 58. Biotech companies arguably develop tests and therapy

a moral hierarchy onto a definitional debate.²⁰³ International organizations must form a definition for genocide (or any crime, for that matter) based on criteria and apply the definition to all acts that satisfy them.²⁰⁹ Although moral considerations help establish criteria, they alone do not determine whether a definition applies.²¹⁰

Despite broadened definitions, genetic expression does not conform well to the physical aspects of genocide. Although the language of Article II(c) and (d) of the Genocide Convention arguably applies to the gene-ocide model,²¹¹ there is a strong scholarly consensus that genocide applies only to the physical destruction of existing lives.²¹² For this reason, human rights organizations should analyze GLM as a potential derivative of genocide called "gene-ocide." Although gene-ocide is technically distinct from genocide, it is arguably underpinned and sustained by similar social prejudices that seek to prevent rather than address deviation.²¹³

to accomplish the same result. See *infra* notes 250-76 and accompanying text (debating whether people with genetic conditions deserve international protection as a protected group).

208. See Fein, *supra* note 194, at 100 (criticizing Israel Charny for similar moral judgment).

209. See WEBSTER, *supra* note 1, at 356 (defining "definition" as a delineation or outline of the limits of a concept).

210. For instance, the fact that a racially-segregated lunch counter is less morally repugnant than slavery does not make it a weaker example of racial discrimination, nor does it make slavery less atrocious. Torture is torture whether the victim is an adult or a child.

211. Genocide Convention, *supra* note 143, arts. II(c)-(d) (discussing the physical destruction of and prevention of births within a group).

212. See Israel W. Charny, *Toward a Generic Definition of Genocide*, in GENOCIDE: CONCEPTUAL AND HISTORICAL DIMENSIONS, *supra* note 194, at 84 (restricting the concept of genocide to mass murders that end existing lives).

213. See Chalk, *supra* note 194, at 58 (citing Sir Isiah Berlin, *On the Pursuit of the Ideal*, N.Y. REV. OF BOOKS, Mar. 17, 1988 at 11-18 (discussing genocides aimed at maintaining the superiority of a race)). The Draft Declaration of Rights of Indigenous Peoples, adopted in August 1994, prohibits cultural genocide. Draft United Nations Declaration on the Rights of Indigenous Peoples, art. 7, U.N. Doc. E/CN.4/1995/2, Aug. 26, 1994, reprinted in, 34 I.L.M. 541 (1995) [hereinafter Indigenous Peoples Declaration]. In doing so, it recognizes a derivative of genocide that does not require the physical destruction of existing lives. See Charny, *supra* note 212, at 84 (distinguishing cultural genocide because it does not involve mass murder). The definition of cultural genocide in Article 7 includes acts that deny cultural values, dispossession of land or resources, forced assimilation, and propaganda. Indigenous Peoples Declaration, *supra*, art. 7. Culture, like genetics, is a form of expression. See WEBSTER, *supra* note 1, at 335 (defining "culture" as "style of social and artistic expression peculiar to a class or society"). Genetics deals with physical and behavioral expression, while culture deals with artistic and interpersonal expression. *Id.* at 335, 525. By integrating the concepts of culture and genocide, the Draft Declaration arguably recognizes an international interest in protecting expressions of life. See Elias & Annas, *supra* note 31, at 147 (quoting author Robert Morison who states that humans must safeguard the "richness and variety of their heritage—their human gene pool and their common culture").

2. Freedom of Genetic Expression: the Biodiversity Argument

The temporal implications²¹⁴ of genetic technology will require international human rights organizations to revisit issues surrounding the rights of the unborn that persist despite the abortion debate.²¹⁵ Unlike abortion, GLM and genetic testing can affect both existing and future fetuses.²¹⁶ Like environmental conditions, genetic technology can affect future generations as a collective.²¹⁷ Consequently, international law should address the rights of posterity from both an individual and a collective perspective,²¹⁸ using international environmental law as a conceptual guide.²¹⁹

Recent scholarly discussion focuses on the right of the individual fetus to be free from genetic manipulation.²²⁰ Some scholars point out that GLM essentially

214. See *supra* notes 44-46 and accompanying text (discussing the transgenerational effects of individual reproductive decisions involving the use of genetic tests or GLM).

215. See Hendricks & Nowak, *supra* note 96, at 275 (calling upon the Council of Europe to draft definitions of rights of posterity); *supra* note 124 (explaining several failed international attempts to extend the right to life to the fetus).

216. See *supra* note 44-46 and accompanying text (explaining that the effects of GLM pass on to the patient's offspring).

217. See Hendricks & Nowak, *supra* note 96, at 266 (recognizing the threats that gene therapy poses to rights of posterity); cf. Douglas-Scott, *supra* note 77, at 434 (recognizing the temporal nature of environmental rights).

218. See Maleiha Malik, *Communal Goods as Human Rights*, in UNDERSTANDING HUMAN RIGHTS, *supra* note 77, at 139 (pointing out examples of group rights such as the right to development, peace and security, existence, and self-determination). Groups, rather than individuals, exercise collective rights. *Id.* at 142. Collective rights presume that the welfare of an individual is inseparable from the welfare of his group. *Id.* Threats to collective rights ordinarily entail many relatively small actions that produce an aggregate effect. Douglas-Scott, *supra* note 77, at 430. Collective rights in a genetic context imply that individuals do not have separate interests in human biodiversity. *Id.* Their interests hinge on membership and interaction within a larger human community. *Id.* These rights are infringed by the cumulative effect of individual applications of genetic technology. *Id.*

219. See Douglas-Scott, *supra* note 77, at 430 (arguing that the right to environment, if it exists, should exist as a peoples' right). For further discussion on the development of international environmental law and the right to environment, see Alexandre Kiss, *Concept and Possible Implications of the Right to Environment*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 551; Maguelonne Dejeant-Pons, *The Right to Environment in Regional Human Rights Systems*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 595; GREENING INTERNATIONAL LAW (Philippe Sands ed., 1993).

220. See Hendricks & Nowak, *supra* note 96, at 272 (asserting that GLM imposes current aesthetic values on later generations); *Recommendation 934*, *supra* note 98, at 303 (acknowledging the "right to inherit a genetic pattern that has not been artificially changed"). Some courts in the United States recognized some form of this right, awarding damages to individuals suing their parents for wrongful birth or negligent conduct during pregnancy. See BRODY, *supra* note 32, at 79 (describing wrongful life lawsuits in the United States where parents sued laboratories for inaccurate genetic diagnoses, and children sued parents for failing to abort); Proctor, *supra* note 14, at 71 (stating that doctors who fail to counsel

subjects descendants to medical procedures without their informed consent.²²¹ They also argue that posterity should be free of the potential harms of therapies performed by a medical community that does not fully understand how genes interact.²²² Although communal concerns seem to underpin these arguments, they actually promote the right of *individuals* to enter the world unaffected by their predecessors' genetic priorities.²²³ In effect, this right is a "descendant" of the right to security of person guaranteed to individuals in the UDHR and ICCPR.²²⁴

The technology debate has not addressed whether humans, both present and future, have a collective right to live in a world that is genetically diverse. This argument imports policy concerns from international environmental law and applies them to human genetics.²²⁵ The basis of this argument is that GLM, aided by embryo diagnosis, may jeopardize human genetic diversity²²⁶ and that international organizations should respond by recognizing that human genetic diversity is intrinsically valuable.²²⁷ Essentially, the biodiversity argument reconceptualizes the right

parents about the likelihood of giving birth to a child with genetic conditions may be liable for wrongful birth); HUBBARD & WALD, *supra* note 4, at 25-26 (quoting physician and attorney Margery Shaw, who introduces "prenatal torts" as parental liability for carrying to term a fetus with a genetic defect); Dawn E. Johnsen, Note, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 YALE L.J. 599, 601-02 (1986) (stating that American common law has historically recognized rights in fetuses contingent upon birth). In addition, concern for the welfare of future generations is the impetus behind several international agreements addressing environmental and cultural sustenance. See, e.g., Stockholm Declaration, Prin. 1, U.N. Doc. A/CONF. 48/14 (1972) (stating humanity's responsibility to "protect and improve the environment for present and future generations"); Convention on Biological Diversity, preamble, June 5, 1992, 31 I.L.M. 818 (1992) (advocating conservation of biological diversity "for the benefit of present and future generations") [hereinafter Rio Convention]; Indigenous Peoples Declaration, *supra* note 213, art. 25 (stating that indigenous peoples have responsibilities to their descendants to sustain and fortify their natural resources).

221. See WILKIE, *supra* note 46, at 161 (explaining that GLM requires parents to give consent on behalf of their future child); Hendricks & Nowak, *supra* note 96, at 274 (arguing that there is no informed consent when the patient is an embryo).

222. See HUBBARD & WALD, *supra* note 4, at 114 (opposing GLM because mistakes that occur in its application enter the family's hereditary line); Hendricks & Nowak, *supra* note 96, at 266 (recognizing that GLM can cause disease in future generations).

223. See Hendricks & Nowak, *supra* note 96, at 272 (discussing parental use of GLM to impose aesthetic values on their children).

224. UDHR, *supra* note 86, art. 3; ICCPR, *supra* note 87, art. 9.

225. For an introduction to international environmental law, see PHILIPPE SANDS, *PRINCIPLES OF INTERNATIONAL ENVIRONMENTAL LAW I: FRAMEWORKS, STANDARDS AND IMPLEMENTATION* 368 (1995) (discussing the purposes of and international instruments addressing biological diversity).

226. See Lenoir, *supra* note 70, at 1261 (explaining that advances in genetic research raise questions about the human role in biological diversity).

227. See SANDS, *supra* note 225, at 369 (explaining that international environmental law protects biodiversity for non-scientific and aesthetic reasons); CHRISTOPHER STONE, *SHOULD TREES HAVE STANDING?* (1974) (arguing for intrinsic rights in natural objects).

to life in terms of the genetic diversity expressed throughout the human species.²²⁸

Biodiversity receives international protection for three main reasons.²²⁹ First, it provides humans with a continual source of nutritional, pharmaceutical, and agricultural resources.²³⁰ It gives them the raw materials they need to stay healthy and achieve social, cultural, economic, and scientific goals that improve the quality of human life.²³¹ Similarly, diversity in human genetic expression endows people with physical and behavioral differences that enrich social interactions, political debates, literary works, and music.²³² In this manner, conservation of human diversity functions like copyright law, providing protection to original works in order to generate a diverse pool of knowledge and creativity for people to tap.²³³

Biodiversity also helps maintain atmospheric conditions that are favorable to humans and other species.²³⁴ Genetic diversity serves a similar purpose for humans, producing a genetic pool that is more fit for reproduction²³⁵ and a social atmosphere that cultivates tolerance and appreciation of cultural differences.²³⁶

Finally, biodiversity receives protection for non-scientific ethical and aesthetic purposes.²³⁷ This purpose, unlike the first two, focuses on the intrinsic rather than the utilitarian value of diversity.²³⁸ It assumes that natural diversity has value separate from that which humans assign it.²³⁹ Following this reasoning, human genetic diversity deserves protection because it enriches the world.²⁴⁰

228. Rio Convention, *supra* note 220, art. 2 (defining "biodiversity" as the variability among living organisms).

229. SANDS, *supra* note 225, at 368.

230. *Id.*

231. *Id.* (discussing rapid species and habitat loss).

232. *Cf.* Rio Declaration, *supra* note 220, preamble (recognizing the social, economic, scientific, educational, and cultural value of biological diversity); DEL RUSSO, *supra* note 86, at 59 (presenting genocide as a loss of cultural contributions).

233. COPYRIGHT LAW § 1.04 (Joyce et al. eds., 3d ed., 1994) (stating that copyright encourages the creation of knowledge to promote the public welfare).

234. SANDS, *supra* note 225, at 369.

235. *See* MARKS, *supra* note 172, at 173-74 (explaining that genetically diverse populations are better equipped for survival).

236. *See* Elias & Annas, *supra* note 31, at 147 (quoting author Robert Morison, who states that people's survival and welfare depends both on their genetic composition and cultural exchange with others); *supra* note 81 and accompanying text (arguing that genetic technology may generate intolerance toward people who fall short of technically achievable ideals).

237. SANDS, *supra* note 225, at 369.

238. Rio Convention, *supra* note 220, preamble (recognizing the intrinsic value of biological diversity).

239. Douglas-Scott, *supra* note 77, at 441 (analyzing the intrinsic value argument for a right to environment).

240. *Id.* at 444. By analogy, Jeremy Waldron argues that killing a tree is bad not because it denies humans use of a resource, but because the world is impoverished by the tree's absence. *Id.* For a comprehensive discussion on the rights of natural objects, see generally STONE, *supra* note 227.

The human biodiversity argument warrants several criticisms. Environmental instruments may not apply to the genetics debate because GLM cannot realistically jeopardize genetic diversity to the same degree as environmental destruction.²⁴¹ Unlike GLM, environmental damage caused by human activity seriously threatens the existence of several species and can substantially alter the living conditions that future organisms must endure.²⁴² Although many scientists do not consider GLM an immense threat to the human gene pool,²⁴³ they concur that it jeopardizes the manner in which humans view and value one another.²⁴⁴ Like slavery and segregation, human and non-human biodiversity imply unequal threats but originate in the same social attitudes.²⁴⁵

It is also conceptually difficult to grant rights to non-living objects or humans who are not yet in existence.²⁴⁶ The concept of rights as a whole seems to imply the ability to demand, exercise, and enforce those rights.²⁴⁷ This cannot occur when the victim, whether by nature or timing, is not a part of human society.²⁴⁸ For this reason, some scholars assert that vesting rights in the unborn or the inanimate would render existing rights unenforceable.²⁴⁹

C. GENETIC GROUPS AS A PROTECTED CLASS

The potential for discrimination against genetic groups increases dramatically as genetic testing and GLM techniques become less expensive, more reliable, and more widely available.²⁵⁰ For this reason, genetic groups arguably deserve recog-

241. See Rio Convention, *supra* note 220, preamble (noting that human activities cause significant reductions of biological diversity).

242. See SANDS, *supra* note 225, at 369 (discussing 1992 estimates that if species and habitat loss continues at the current rate, fifteen percent of the earth's species will die out over twenty-five years).

243. See *supra* note 46 and accompanying text (arguing that GLM cannot eliminate genetic traits from the entire human gene pool).

244. See *supra* notes 79-80 and accompanying text (arguing that broad use of genetic technology can create genetically-defined standards of physical and behavioral normality).

245. See *supra* note 210 and accompanying text (arguing that moral repugnancy alone does not determine whether a definition is applicable).

246. Douglas-Scott, *supra* note 77, at 446-47.

247. See *id.* at 443 (discussing the theory that holders of rights must understand moral principles, possess critical capacities, and have self-awareness).

248. *Id.* at 447 (arguing that rights are man-made and should not be applied outside of human society).

249. See, e.g., Mike Radford, *Can Rights Extend to Animals?*, in UNDERSTANDING HUMAN RIGHTS, *supra* note 77, at 411-18 (discussing the historical tradition excluding animals from a "rights" framework); Douglas-Scott, *supra* note 77, at 447 (arguing that application of rights to natural objects damages their value in human contexts); Palkhivala, *supra* note 137, at 442 (arguing against the devaluation of human rights by overexpansion); Johnsen, *supra* note 220, at 614-15 (asserting that the expansion of fetal rights may intrude on women's autonomy rights).

250. See HUBBARD & WALD, *supra* note 4, at 134 (predicting a sharp rise in the use of genetic tests as they become cheaper to develop and purchase).

dition as a protected class under international human rights law.²⁵¹

Traditionally, human rights law protects groups of individuals who exhibit certain characteristics.²⁵² Groups worthy of legal status exist naturally, often based on characteristics beyond their members' control.²⁵³ The individuals in the group share more than common interests or discriminatory experiences;²⁵⁴ they share identity.²⁵⁵ Their welfare as individuals is determined in part by the welfare of the group.²⁵⁶ Historical and cultural ties unify them and distinguish them from others.²⁵⁷ Thus, group status arises from a sense of belonging among group members and recognition from the international community.²⁵⁸

Genetic groups clearly exhibit the objective factors of group identity.²⁵⁹ They face discrimination based on biological factors which, like race and ethnicity, are beyond their control.²⁶⁰ Thus, their common interest is naturally, not voluntarily, created.²⁶¹ Yet ironically, gene testing and GLM provoke discrimination based on genetic status²⁶² while simultaneously providing the means to alter that status.²⁶³ At

251. See Iles, *supra* note 4, at 45 (noting that genetic information may create a new source of group identity).

252. See *supra* note 125 (discussing groups protected against discrimination by the International Bill of Human Rights).

253. NATAN LERNER, GROUP RIGHTS AND DISCRIMINATION IN INTERNATIONAL LAW 29 (1991). Race and ethnicity are good examples. *Id.* at 30-31. By contrast, organizations and clubs cannot be protected groups because their members voluntarily establish them. *Id.* (arguing that artificial or planned groups do not earn protected status); see also Aviam Soifer, *On Being Overly Discrete and Insular: Involuntary Groups and the Anglo-American Judicial Tradition*, 1990 ISRAEL Y.B. HUM. RTS. 243, 245 (distinguishing voluntary associations from groups exhibiting innate, immutable traits).

254. See LERNER, *supra* note 253, at 32 (arguing that homosexuals do not earn group status because their group identification arises from experiences of discrimination rather than historical affiliation).

255. See Shaw, *supra* note 142, at 40-41 (discussing the minority as a mechanism to preserve identity).

256. See LERNER, *supra* note 253, at 29 (quoting author Owen Fiss who states that group members define their individual well-being partly in terms of their group's well-being).

257. *Id.* at 33; see also Shaw, *supra* note 142, at 35 (arguing that minorities must be objectively distinct from other groups within a state).

258. See Shaw, *supra* note 142, at 39 (requiring that group members intend to exist as a group); LERNER, *supra* note 253, at 34 (naming the decisive indicators of group identity as self-perception and perception of surrounding communities).

259. See Shaw, *supra* note 142, at 27 (recognizing objective and subjective criteria for minorities).

260. See *supra* note 253 and accompanying text (explaining that group status can arise from factors beyond the control of its members).

261. See *id.* (explaining that voluntary associations cannot earn group protection).

262. See *supra* notes 53-68 and accompanying text (describing discriminatory practices that can result from widespread use of genetic technology).

263. See *supra* notes 44-46 and accompanying text (explaining that GLM allows people to permanently alter the genetic make-up of their descendants).

the very least, gene manipulation can create the social perception that genetic conditions are within human control, weakening the argument for protected status.²⁶⁴

Genetic groups do not exhibit the subjective indicators of group status.²⁶⁵ Their members do not identify themselves by their genetic composition.²⁶⁵ People with genetic conditions worry about the welfare of their families and descendants rather than a larger genetic community.²⁶⁷ They do not exist as transnational units, but as dispersed aggregates protected to varying degrees by national and local laws.²⁶³ Self-perceptions can change as discriminatory practices become widespread, however.²⁶⁹ Growing acceptance of genetic reductionism, reinforced by exclusion from employment and insurance opportunities, may unify genetic groups on a global level.²⁷⁰ Discrimination may create the group identification that currently does not exist.²⁷¹

Perceptions should not determine group status in the technology context by assuming that victims can perceive discrimination.²⁷² Biotechnology widens the scope of people vulnerable to discrimination because it cloaks discriminatory attitudes in the prestige and procedure of science.²⁷³ Because genetic discrimination is invisible, its victims often do not notice it and therefore do not identify with other victims.²⁷⁴ Consequently, victims of genetic discrimination are *more* vulnerable

264. See *supra* note 79 and accompanying text (arguing that GLM can create societal assumptions that genetic conditions are avoidable).

265. Cf. Hendricks & Nowak, *supra* note 96, at 251 (arguing that, in theory, illness does not affect a person's legal status).

266. See Eide, *supra* note 142, at 89 (indicating several separate levels at which group identification can occur).

267. See Billings Surveys, *supra* note 2, at 640-42 (describing the situations of families who risk losing their health insurance by testing for or giving birth to a child with a genetic condition); *supra* notes 32-46 and accompanying text (explaining that the purpose of GLM is to prevent or alter genetic conditions in descendants).

268. See Knoppers & LeBris, *supra* note 70 (discussing various national regulatory schemes for biotechnology issues). By contrast, racial characteristics often bind people in a manner that transcends national borders. *Id.*

269. See Eide, *supra* note 142, at 89-90 (recognizing that group identification is a dynamic process of shifting alliances).

270. See *supra* note 78 and accompanying text (explaining that genetic technology may foster genetic determinism).

271. See Eide, *supra* note 142, at 90, 97 (recognizing that discriminatory attitudes from a dominant society can activate group identification). But see LERNER, *supra* note 253, at 32 (arguing that discriminatory treatment does not create group identity).

272. Darison M. Douglas, *Constitutional Law: The Quest for Freedom in the Post-Brown South: Desegregation and White Self-Interest*, 70 CHL-KENT L. REV. 639, 714 (noting that black Americans who entered "White Only" lunch counters in early 1960s confronted obvious discrimination in the form of signs and brutal treatment).

273. See Franklin, *supra* note 165, at 735 (describing how technology makes discrimination go unnoticed by replacing human supervision with mechanical supervision); Somerville, *supra* note 74 (explaining traditional assumptions that medicine is motivated by philanthropy and, therefore, cannot be a source of human rights violations).

274. For example, employers can discriminate against job applicants by using genetic

than others who face more obvious forms of discrimination.²⁷⁵ The invisibility of genetic discrimination arguably reinforces the need for international protection of genetic groups.²⁷⁶

III. CREATING A DICTIONARY

No international instrument currently in force addresses the human rights implications of genetic testing and gene therapy. As scientific progress accelerates,²⁷⁷ more scholars call upon international human rights organizations to reopen discussions on genetic technology and promulgate a set of principles representing the collective view of the international community.²⁷⁸

Two organizations accepted the challenge. In June 1996, the Council of Europe Steering Committee on Bioethics²⁷⁹ (CDBI) issued its second Draft Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (Bioethics Convention).²⁸⁰ In March

tests to weed out potentially unproductive employees. HUBBARD & WALD, *supra* note 4, at 139. Because employers are not accountable to applicants, however, applicants often do not perceive the discrimination and therefore have no impetus to unite. *Id.*

275. Cf. Schefflin, *supra* note 170, at 842 n.42 (arguing that mind control is more dangerous than homelessness, torture, or imprisonment because it is less visible and concrete).

276. See Douglas-Scott, *supra* note 77, at 443 (acknowledging that the groups most vulnerable to abuse are most deserving of legal protection).

277. See Elias & Annas, *supra* note 31, at 145 (stating that GLM research is advancing quickly).

278. See *id.* at 151 (advocating continuing public debate about GLM application); Thomas H. Murray, *Speaking Unsmooth Things about the Human Genome Project*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 253 (calling for public discussion and criticism of emerging genetic innovations); LeRoy Walters, *A National Advisory Committee on Genetic Testing and Screening*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, *supra* note 3, at 261 (advocating creation of National Advisory Committee on Genetic Testing and Screening to debate ethical ramifications of emerging technologies).

279. The Council of Europe, established in 1949 with thirty-four member states, is a pioneer of the bioethics debate. Iles, *supra* note 4, at 38. The Council's Parliamentary Assembly, which has 239 members from the national parliaments of the member states, has issued recommendations to guide the advancement of genetic research since 1976. ROGERS & DE BOUSINGEN, *supra* note 14, at 209. The Council created the Steering Committee on Bioethics (CDBI) in order to draft a bioethics convention and accompanying protocols. *Id.* The CDBI comprises sixty appointed experts, representatives of the Parliamentary Assembly and European Commission, and observers from non-member states and international organizations. *Id.*

280. Eur. Parl. Ass. Doc. No. 7622 (visited Apr. 7, 1997) <<http://stars.coe.fr/doc/adoc0496/adoc7622/htm>> [hereinafter Bioethics Convention]. CDBI plans to rename the draft the "Convention on Human Rights and Biomedicine" at some point in the future. Provisional Report to the Bioethics Convention (visited Apr. 7, 1997) <<http://stars.coe.fr/doc/adoc0496/adoc7622/htm>> [hereinafter Provisional Report].

1996, the UNESCO International Bioethics Committee²⁸¹ issued the most recent version of its Preliminary Draft of a Universal Declaration on the Human Genome and Human Rights²⁸² (UNESCO Declaration) which it hopes to adopt in 1998.²⁸³ Both documents use human rights language and themes to establish the moral guidelines of scientific research.²⁸⁴

To varying degrees, the UNESCO Declaration and the Bioethics Convention recognize and address the challenges that biotechnology presents for traditional human rights analyses. Both instruments emanate from the right of human dignity embodied in the UDHR²⁸⁵ and implicitly recognize the broad effects of genetic technology by acknowledging the importance of the human being as a member of the human species.²⁸⁶ Both instruments recognize that health care professionals and researchers can initiate human rights violations,²⁸⁷ yet neither specifically addresses the potential for discrimination by employers, insurers, and other private actors outside the scientific community.²⁸⁸ Although both recognize the right of

281. The United Nations formed UNESCO to promote human rights in the educational, scientific, and cultural arenas. UNESCO Secretariat, *UNESCO and the Challenges of Today and Tomorrow: Universal Affirmation of Human Rights*, in HUMAN RIGHTS: THIRTY YEARS AFTER THE UNIVERSAL DECLARATION, *supra* note 84, at 207. UNESCO formed the International Bioethics Committee in 1992 to draft an international instrument to protect the human genome based on human rights principles and multiculturalism. Lenoir, *supra* note 70, at 1263. The Committee comprises fifty members from forty states. *Id.*

282. CIP/BIO/96/COMJUR.6/2 (Prov. 5), Mar. 4, 1996 [hereinafter UNESCO Declaration].

283. Lenoir, *supra* note 70, at 1264.

284. See UNESCO Declaration, *supra* note 282, preamble (referring to UNESCO's Constitution which documents the importance of human rights principles and international human rights instruments); Bioethics Convention, *supra* note 280, preamble (acknowledging the need to safeguard human dignity).

285. UDHR, *supra* note 86, preamble; UNESCO Declaration, *supra* note 282, preamble; Bioethics Convention, *supra* note 280, preamble.

286. See Bioethics Convention, *supra* note 280, preamble (promoting respect for human beings as members of human species); UNESCO Declaration, *supra* note 282, at 4 (protecting individuals in order to preserve the integrity of the human species).

287. The Bioethics Convention requires health care professionals to apply genetic technology in accordance with professional standards. Bioethics Convention, *supra* note 280, art. 4; Draft Explanatory Report to the 1994 Draft Bioethics Convention [hereinafter Draft Report], reprinted in ROGERS & DE BOUSINGEN, *supra* note 14, at 261. The UNESCO Declaration emphasizes the special responsibilities of the research and development community and limits the conduct of health care professionals administering genetic interventions. UNESCO Declaration, *supra* note 282, arts. 7, 13 (stressing the duty of researchers to display "meticulousness, caution and intellectual honesty").

288. See UNESCO Declaration, *supra* note 282, art. 9 (calling for the protection of personal genetic information from "third parties" without identifying the "third parties" or the threats that they pose); Bioethics Convention, *supra* note 280, art. 12 (restricting the use of predictive genetic tests to "health purposes" without specifying to whom the restrictions apply or why).

every individual to be free of harm caused by genetic technology,²⁸⁹ neither explicitly recognizes the collective right of humanity to an unmanipulated genome.

Like the International Bill of Rights, the UNESCO Declaration and the Bioethics Convention fail to define the basic concept of personhood.²⁹⁰ The instruments refer to human beings, individuals, and persons repeatedly²⁹¹ but do not specify whether these classifications extend to embryos.²⁹² In particular, neither instrument addresses whether performing GLM on embryos violates the doctrine of informed consent.²⁹³ Neither instrument addresses the rights of the embryo in relation to the rights of its parents to control its upbringing.²⁹⁴

The Bioethics Convention more clearly recognizes the temporal implications of genetic testing and GLM. The preamble recognizes the interests of present and future generations.²⁹⁵ Article 13 of the Convention prohibits GLM but does not indicate a reason.²⁹⁶ A draft report issued by CDBI to facilitate the application of the Convention reveals the drafters' concern that scientific knowledge about GLM is presently so limited that applications would pose unknown dangers to future generations.²⁹⁷ Thus, although the Convention does not stipulate that posterity has a collective right to a GLM-free genome, concern for future generations underlies these provisions.²⁹⁸ The only temporal reference in the UNESCO Declaration is a description of the human genome as part of humanity's "common heritage."²⁹⁹ Far from acknowledging collective rights in future generations, the reference to "heritage" merely recognizes posterity as an interested party in biotechnological issues.

The UNESCO Declaration more thoroughly addresses the diffusive effects of gene testing and GLM. Besides recognizing the individual as a member of the

289. See UNESCO Declaration, *supra* note 282, preamble (stating that individuals have a right to reparation for injuries resulting from applications of genetic technology); Bioethics Convention, *supra* note 280, art. 24 (entitling persons who suffer from the harmful effects of genetic technology to compensation).

290. Draft Report, *supra* note 287, at 268 (acknowledging that the Bioethics Convention fails to define "everyone" or "human being").

291. See UNESCO Declaration, *supra* note 282, art. 2 (referring to "individuals" and "everyone"); Bioethics Convention, *supra* note 280, arts. 1, 2, 5, 7 (referring to "human beings," "persons" and "individuals").

292. See Draft Report, *supra* note 287, at 268. (acknowledging that human dignity must be respected when life begins).

293. Bioethics Convention, *supra* note 280, arts. 5-9. The Convention, which provides detailed guidance on the issue of consent, does not specify whether an embryo is a person "not able to consent." *Id.* art. 6. It addresses incapacitation of adults and children only. *Id.*

294. See *supra* note 133 and accompanying text (arguing that genetic technology, like abortion, implicates the rights of individuals against each other rather than the state).

295. Bioethics Convention, *supra* note 280, preamble (asserting that scientific advances must benefit present and future generations).

296. *Id.* art. 13 (prohibiting the manipulation of germ cells).

297. Draft Report, *supra* note 287, at 285.

298. *Id.* (projecting that the Council of Europe ethics committees may not approve therapies that affect subsequent generations).

299. UNESCO Declaration, *supra* note 282, preamble.

human species, the Declaration, in several articles, emphasizes that genetic technology has implications for all humanity.³⁰⁰ Unlike the Convention, it identifies the biodiversity parallel by recognizing the relevance of the United Nations Convention on Biological Diversity and emphasizing the importance of human biodiversity.³⁰¹ In doing so, it implicitly recognizes the broad impact of individual decisions and alludes to an intrinsic right of human biodiversity.³⁰² Neither instrument expressly acknowledges the aggregate effect of individual decisions.³⁰³

Both instruments explicitly prohibit discrimination based on genetic traits, thus granting legal protection to genetic groups.³⁰⁴ Surprisingly, however, the Bioethics Convention does not address the dangers of genetic reductionism and eugenics. As a result, it loses much of its definitional value, like a dictionary with missing pages. Article One, which articulates the purpose of the Convention, vaguely guarantees respect for integrity without discrimination.³⁰⁵ Article 12 limits the use of genetic testing to health-related purposes but does not identify the actors that it limits.³⁰⁶ Although the Provisional Report to the Bioethics Convention clearly recognizes the dangers of genetic determinism, eugenics, and discrimination by employers and insurers,³⁰⁷ the drafters do not incorporate this recognition into the text of the Convention where it would be most effectual. The Convention, therefore, identifies the *effects* of genetic discrimination, but fails to explain its sources and implications.³⁰⁸

By contrast, the UNESCO Declaration does address the social forces underlying genetic testing and GLM. The Declaration responds to genetic reductionism by stating that environmental, social, health, and economic factors all contribute to the development of the human personality.³⁰⁹ Recognizing the potential for a eugenics revival, it prohibits any eugenic practice that "runs counter to human dignity and human rights."³¹⁰ Although the Declaration does not enumerate which practices are

300. See *id.* (recognizing the benefits of scientific research to humankind); *id.* art. 4 (acknowledging the potential threat of genetic technology to the integrity of the human species); *id.* art. 11 (calling upon states to support research efforts to improve the health of humankind).

301. *Id.* (emphasizing the importance of human biodiversity).

302. *Id.* (recognizing that social or political attitudes may threaten human diversity and the dignity of the human family).

303. *Iles, supra* note 4, at 42-43.

304. Bioethics Convention, *supra* note 280, art. 11; UNESCO Declaration, *supra* note 282, art. 8. Article 2(c) of the UNESCO Declaration reinforces the Article 8 prohibition, guaranteeing respect for human dignity and rights "regardless of [genetic] characteristics." *Id.* art. 2(c).

305. Bioethics Convention, *supra* note 280, art. 1.

306. *Id.* art. 12.

307. Provisional Report, *supra* note 280, at paras. 16, 18.

308. *Id.* The drafters' failure to address these fundamental concerns undermines their attempt to "give a clear signal on this subject." *Id.* at para. 17.

309. *Id.* art. 2(c), 3 (stating that the human personality is not the product of a genetic formula).

310. *Id.* art. 1.

acceptable,³¹¹ its specific language creates a strong moral response to the threat of genetic discrimination. The UNESCO Declaration is superior in this regard because it more effectively confronts the social apathy that allows genetic discrimination to occur.

IV. RECOMMENDATIONS

Genetic technology is coming. Governments continue to postpone regulation on the assumption that it is a distant reality.³¹² Yet the recent development of the DNA Chip³¹³ and non-traditional cloning methods³¹⁴ brings this reality into clear view. As scientists overcome technical problems and the futuristic looms nearer, governments will have to reconsider the ethical implications of genetic technology and re-regulate its availability.

A. PROPOSED DEFINITIONS

Regulation requires language, language requires definitions, and definitions change with technological capability. Genetic testing and GLM magnify human rights violations conceptually: they shift power from few hands to many,³¹⁵ raise stakes from an individual to a collective level,³¹⁶ and affect the health of families for centuries to come.³¹⁷ Whether governments employ human rights principles to restrict or widen the availability of genetic technology, they need a human rights

311. *Id.*

312. See Elias & Annas, *supra* note 31, at 151 (discussing the de facto moratorium on GLM); Draft Report, *supra* note 287, at 285 (stating that the drafters of the Bioethics Convention did not provide exceptions to the GLM ban because GLM techniques remain undeveloped).

313. The DNA Chip is a glass microchip covered by a layered carpet of DNA fibers programmed to recognize and display specific gene sequences with the aid of a fluorescent solution. Nicholas Wade, *Meeting of Computers and Biology: The DNA Chip*, N.Y. TIMES, Apr. 8, 1997, at C1, C6. Scientists select the DNA sequences they want to test from a worldwide genetic database accessed through the Internet. *Id.* at C6. The chip measures gene expression and detects mutations that may foster predispositions toward certain diseases. *Id.* Experts are currently creating more powerful versions of the chip that will allow scientists to predict a person's susceptibility to diseases much more quickly than current methods allow. *Id.*

314. See Sharon Begley, *Little Lamb, Who Made Thee?*, NEWSWEEK, Mar. 10, 1997, at 53, 56-57 (detailing the process by which Scottish scientists created a lamb from the udder cell of a sheep); John Travis, *Two Monkeys 'Cloned' From Embryo Cells*, SCI. NEWS, Mar. 8, 1997, at 142 (discussing "nuclear transfer," a procedure similar to cloning, which enabled the creation of two rhesus monkeys from the cells of a developing monkey embryo).

315. See *supra* notes 152-57 and accompanying text (discussing the transfer of human rights violations from states to social institutions).

316. See *supra* notes 181-87 and accompanying text (explaining how technological innovations affect larger numbers of people).

317. See *supra* notes 44-46 and accompanying text (discussing the effects of GLM on subsequent generations).

language that is as state-of-the-art and progressive as the technology itself.³¹⁸ Accordingly, this Comment proposes the following definitions in order to integrate spatial and temporal considerations into the human rights analysis:

Violator: a government, or a private institution or company exerting specialized authority that is analogous to a government, that fails to comply with or ensure international human rights obligations.³¹⁹

Victim: a group, discrete or dispersed throughout society, or a private individual, existing currently or in the future, who either knowingly or unknowingly suffer(s) a human rights violation.³²⁰

This Comment also proposes the revision of the anti-discrimination clauses in the IBHR to condemn discrimination based on *genetic disposition*.³²¹

The development of reliable insertion techniques may reveal a need for international recognition of gene-ocide and a right to genetic expression.³²² If international human rights organizations choose to permit GLM in certain circumstances, they should incorporate a cost-benefit analysis into the definition of gene-ocide³²³ as proposed in the following definition:

Gene-ocide: the application of GLM techniques by a health care professional in order to alter an embryo or sex cell genetically, where the danger of harm to the developing fetus exceeds the seriousness of the disease under treatment.³²⁴

By weighing the harmful effects of the disease with those of the therapy, this definition discourages the use of genetic technology to effectuate social prejudice,³²⁵ while preserving a collective right to human genetic diversity that should be limited only in cases of severe pain or impairment.³²⁶ In the interim, interna-

318. See Rodley, *supra* note 166, at 299 (promoting evolving definitions of human rights).

319. *Id.* at 300 (redefining human rights to incorporate quasi-public actors).

320. See *supra* note 186 and accompanying text (discussing how technology expands the pool of human rights victims); WEBSTER, *supra* note 1, at 1286 (defining "victim" as "one harmed by or made to suffer from an act, circumstance, agency or condition").

321. See *supra* note 125 and accompanying text (discussing anti-discrimination clauses of the IBHR).

322. See *supra* note 33 (discussing research efforts to develop accurate methods of gene insertion).

323. See Proctor, *supra* note 14, at 67 (suggesting that gene manipulation is acceptable in certain circumstances).

324. It is illogical to fault researchers for the development of genetic technology but simultaneously allow its application in certain situations. See *Policy Issues*, *supra* note 78, at 16 (discussing the need for social policy input prior to the use of genetic technology in order to minimize the harms of technology). Consequently, this definition places liability on physicians and their agents, who are in a better position to weigh the potential benefit and harm of GLM application. Elias & Annas, *supra* note 31, at 271.

325. See *supra* notes 78-83 and accompanying text (explaining that applications of genetic technology may lead to genetic discrimination and idealized notions of health and normality).

326. See *supra* note 67 (distinguishing between serious and mild disabilities); Proctor,

tional human rights organizations should adopt these analogies as models for discussion.

Ultimately, the value of the biodiversity and gene-ocide models will depend on the overall objective of the international human rights system. If its purpose is to classify wrongs according to moral repugnancy or enforcement capability, the analogies are inadequate. They are instrumental, however, in addressing the attitudes and assumptions behind human rights violations. Because the international human rights framework has no efficient method of enforcement,³²⁷ it must rely on the power of its language as its most effective tool to frame the debate of policy-making.³²⁸ By providing human rights organizations with the opportunity to build an effective language, scientific advancement invites them to do what they do best—set a moral agenda.

B. EDITING THE DICTIONARY

The human rights debate on genetic technology is necessarily international.³²⁹ As a matter of principle, the level of control that existing humans assert over future humans and each other should not hinge on jurisdiction. The instruments proposed by UNESCO and the Council of Europe will serve a crucial function as dictionaries of human rights principles, providing state policymakers with moral and definitional guidance.³³⁰ For this reason, their language must be specific and strong enough to convey a moral message. To serve effectively as reference materials, the UNESCO Declaration and the Bioethics Convention must do more than address the effects of human rights violations; they must specifically recognize the causes.³³¹

To this end, the Bioethics Convention and the UNESCO Declaration should amend their preambles to explicitly recognize the social perceptions that underlie human rights violations, including genetic reductionism, eugenic philosophies, and prejudices against the disabled and socially deviant. Both instruments should ex-

supra note 14, at 67 (arguing that permitting disease does not enhance human diversity).

327. See Bilder, *supra* note 16, at 900 (explaining that there is no international police force to compel state compliance with judgments from international human rights courts).

328. See Iles, *supra* note 4, at 59 (recommending the drafting of a detailed international instrument to guide policy-making in individual countries).

329. See Somerville, *supra* note 74, at 874 (arguing that because biotechnology is "transnational, transcultural and transdisciplinary," human rights responses to biotechnology must be as well).

330. *Recommendation 1160 on the Preparation of a Convention on Bioethics*, Eur. Parl. Ass. Doc. No. 6449 (1991), reprinted in ROGERS & DE BOUSINGEN, *supra* note 14, at 320-21 (recommending the drafting of a bioethics convention as an international source of general principles and protocols).

331. See Theo van Boven, *Prevention of Human Rights Violations, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE*, *supra* note 72, at 940 (asserting that international organizations should address human rights violations by confronting their causes rather than their symptoms).

plicitly recognize the power of private actors such as employers, insurers, schools, and adoption agencies to foster discrimination through screening practices. Finally, both instruments should recognize that genetic technology produces far-reaching power by aggregating the effects of many individual actions and influencing subsequent generations.

C. PREVENTIVE MEDICINE

The genetics debate illustrates the symbiotic relationship between human rights and scientific progress.³³² Human rights language keeps human experience at the forefront of research agendas, reminding scientists that their power can harm as well as help people.³³³ In return, science gives the human rights framework tools to remain responsive to the needs of human rights victims. First, science provides international human rights organizations with an upgraded language that enables them to adapt to technological change and evolving definitions of human rights violations.³³⁴ By assuming the role of the human rights violator, the scientific community can also make states open to the human rights agenda. Marc Bossuyt³³⁵ argues that the "inherent weakness" of the traditional human rights system is that it requires states to condemn their own violations.³³⁶ Scientific issues allow states to protect their citizens from violations by social actors.³³⁷ As a result, human rights become the tool rather than the enemy of state policy, encouraging state cooperation with human rights organizations.

Genetic technology, in particular, allows human rights organizations to play an active role in preventing human rights violations. Because scientists can predict the development of techniques years in advance,³³⁸ human rights organizations have time to reassess and update their language, organize themselves, and promote their agenda before human rights violations occur. Rather than reacting to violations after they happen, organizations can use this lag-time to help states formulate poli-

332. See Lenoir, *supra* note 70, at 1264 (stating that human history goes hand-in-hand with scientific advancement).

333. Iles, *supra* note 4, at 28. But see Kingston, *supra* note 109, at 476 (arguing that the human rights framework oversimplifies complex issues).

334. See *supra* notes 319-20 and accompanying text (proposing new definitions of "violation" and "victim").

335. Mr. Bossuyt is a professor of international law at the University of Antwerp and Former Chairman of the U.N. Commission on Human Rights. Bossuyt, *supra* note 72, at 47.

336. *Id.* at 50.

337. See *supra* notes 159-60 and accompanying text (discussing the reactive role of the state within the context of technological advancement).

338. See *id.* at 1 (calling genetic research "predictive medicine" because it warns society about coming developments); Culliton, *supra* note 37, at (quoting Senator (now Vice-President) Albert Gore, who states that the predictability of scientific advances permits consideration of their ethical implications); Andy Coghlan, *Time to Reopen the Germ-Line File?*, *NEW SCIENTIST*, Nov. 27, 1993, at 4-5 (quoting LeRoy Walters and Doris Zallen, who argue that the time required to develop GLM permits discussion of ethical concerns).

cies that prevent violations from occurring. Predictive medicine³³⁹ may bring about the "rebirth" of the human rights organization by transforming it into an active player in the policy-making process.³⁴⁰ Through science, human rights organizations can learn some preventive medicine of their own.³⁴¹

D. TEACHING THE LANGUAGE

To make the most of this opportunity, human rights organizations should upgrade their role as well as their language.³⁴² They should do more than draft international dictionaries, since dictionaries are only useful when people pull them off a shelf.³⁴³ Although human rights principles are defined at the international level, they are implemented at the state level.³⁴⁴ Thus, human rights organizations must focus their efforts on the state policy-making arena.

Groups like the International Bioethics Committee and CDBI should function like consulting firms, sending out teams of experts³⁴⁵ to market the upgraded human rights language in state regulatory proceedings.³⁴⁶ Groups should implement this advisory function on two levels. First, teams should testify or lobby at regulatory proceedings as representatives of the international community to ensure that human rights concerns frame the debate. Second, teams should collaborate with local human rights groups in each state to teach them how to translate human rights arguments into legislation. Thus, human rights organizations can maximize their influential power by approaching state leaders from both outside and inside state

339. Powledge, *supra* note 22, at 1 (referring to fields of science where researchers can predict upcoming technologies).

340. See Franklin, *supra* note 165, at 735 (arguing that human rights organizations must intervene at the planning stage of human rights violations).

341. See van Boven, *supra* note 331, at 938 (arguing that human rights, like medicine, should focus on prevention rather than treatment).

342. See *id.* at 608 (arguing that the international community should prepare itself for progress so that it can function effectively in the coming century).

343. See Bilder, *supra* note 16, at 900 (stating that international human rights law ultimately relies on the voluntary compliance of states).

344. *Id.* (stating that international human rights law centers on international rules and bodies to formulate policy and domestic law to implement policy).

345. Ideally, the teams would consist of scientists, human rights experts, and political analysts from every region of the world. See Somerville, *supra* note 74, at 874 (stating that human rights responses to biotechnology must be transnational and transcultural). Nationally diverse teams would be well-equipped to address differences in culture and regulatory procedure among nations. See Jan Martenson, *The United Nations and Human Rights Today and Tomorrow*, in HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE, *supra* note 72, at 929 (recommending increased participation of people from various states in issues affecting their lives).

346. See Van Bueren, *supra* note 87, at 605-06 (advocating an advisory role for human rights organizations in order to prevent or ameliorate violations). Cf. BUERGENTHAL, *supra* note 16, at 250 (discussing the significant contributions of non-governmental organizations as international human rights consultants). Essentially, this role represents a human rights application of the "Think Globally, Act Locally" slogan.

regulatory structures.

CONCLUSION

Scholars often compare geneticists to astronauts who bravely explore the unknown frontiers of outer space.³⁴⁷ Ironically, the genetics race is more dangerous because it is local. 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.

347. *Policy Issues*, *supra* note 78, at 4; ROGERS & DE BOUSINGEN, *supra* note 16, at 15 (calling the human genome a "new cosmos"); *see also* HUBBARD & WALD, *supra* note 4, at vii (quoting James Watson: "We used to think our fate was in the stars. Now we know, in large measure, our fate is in our genes.").