

# HEALTH FROM A HUMAN RIGHTS PERSPECTIVE<sup>1</sup>

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## I. Introduction

Human rights constitute a set of norms governing the treatment by states and non-state actors of individuals and groups on the basis of ethical principles incorporated into national and international legal systems. Because the subject matter of the norms in question relates to the treatment of human beings, human rights overlap to a considerable degree with ethics but should not be confused with ethics. Similarly, because human rights include the right to health and refer to essential social determinants of health and well-being of people, they overlap with many principles and norms of bioethics. However, human rights and bioethics differ in scope, sources, legal nature, and the mechanisms of monitoring and applying the norms.

The *scope* of bioethics is the ethical issues arising from health care and biomedical sciences, whereas that of human rights embraces the claims individuals and groups can legitimately make against states and non-state actors to respect their dignity, integrity, autonomy and freedom of action as defined in an officially endorsed set of standards or norms. Bioethics regulates clinical encounters with patients on the basis of principles such as beneficence, non-maleficence, confidentiality, autonomy and informed consent; whereas human rights are the special rules agreed upon in a given society to achieve justice and well-being and overcome the pain and suffering that result from repression (somatic violence) and oppression (systemic violence).

The *source* of human rights is the norm-creating process of national and international legal systems, whereas that of bioethics is the deliberations and published opinions of leading thinkers, constituted review boards and professional associations on the ethical issues they address. 'Source' is used here as the formal validation of normative positions rather than an abstract grounding of ethical reasoning in moral philosophy or a biological assessment of empathy or altruism. Bioethics and human rights share this deeper distal grounding but have recourse to different proximate sources. The proximate source of human rights is typically an international human rights treaty or declaration and of bioethics is a professional code or review board guidelines. Exceptionally, the proximate source is identical when an instrument of international law

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<sup>1</sup> A condensed version of this text will appear as the entry on "Human Rights" in the *Encyclopedia of Bioethics*, 3rd edition.

addresses directly an issue of bioethics and human rights, such as UNESCO's Universal Declaration on the Human Genome and Human Rights or the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, both of 1997.

The *legal nature* of human rights norms ranges from merely aspirational claims to the justiciable and enforceable legally binding obligations. The former include non-binding norms through which advocates of various causes (GLBT rights, abolition of the death penalty, Tibetan self-determination, for example) draw upon human rights discourse to seek social change. The latter refer to legally binding rules of domestic (normally constitutional) and international law requiring governments to respect, ensure, promote and fulfill certain norms, with opportunities for persons denied their rights, nongovernmental organizations and various international agencies to obtain redress or change policy consistent with those norms. Insofar as those norms concern health and medicine, they contribute to the tasks of bioethics, although the legal nature of bioethical standards is less a matter of constitutional and international law than a field of inquiry, and reasoned philosophical discourse that may be used in law reform and litigation takes on a legal form through codes of conduct formally adopted by professional bodies with authority over the conduct of their members.

An important distinction may clarify further the difference between human rights and bioethics, namely that between "rights" and "human rights." In ethics a right refers to any entitlement, the moral validity or legitimacy of which depends on the mode of moral reasoning the ethicist is using. In law, a right is any legally protected interest. In human rights discourse, a human right is a higher-order right authoritatively defined using the expression "human rights" with the expectation that it carries a preemptory character similar to Rawls's idea of the "priority of liberty"<sup>2</sup> or Dworkin's "rights as trumps"<sup>3</sup>. In other words, in case of conflict human rights prevail over other (ordinary) rights. This distinction is relevant to both the natural law and positive law foundations of human rights.

As defined in natural law, a human right is usually considered inalienable, immutable and absolute, whereas in positive law it is dependent upon a political and legal process that results in a declaration, law, treaty or other normative instrument and may vary over time and be subject to derogations or limitations designed to optimize respect for human rights rather than impose an absolute standard. Although much confusion arises regarding moral and legal bases of human rights, the relationship between the two may be understood by considering that human rights emerge from claims of people suffering injustice, based on moral sentiment, but become part of the social order when they are proclaimed by an authoritative body, through a process that is law-based. During the process from moral sentiment to legal entrenchment, claims not yet formally recognized as human rights may nevertheless be legitimate and have consequences without being incorporated into binding law. However, the most solid basis for asserting

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<sup>2</sup> John Rawls, *Justice as Fairness: A Restatement*, Harvard University Press, 2001, pp. 104-106.

<sup>3</sup> Ronald Dworkin, *Taking Rights Seriously*, Harvard University Press, 1977, pp. 91-92 and 184-205; Ronald Dworkin, "Rights as Trumps," *Oxford Journal of Legal Studies*, vol. 1, pp. 177-212 (1981).

that an act or omission is or is not in conformity with human rights standards is positive law. That is why the International Bill of Human Rights,<sup>4</sup> along with the other human rights treaties of the UN and of regional organizations, constitutes the primary source and reference point for what properly belongs in the category of human rights.

The moral or natural law basis of human rights is essential to challenging abusive power and advancing human rights, but its universality may be questioned because it is culturally determined by contextualized moral and religious belief systems. The consensual or positive law basis of human rights reflects compromise and historical shifts but attains a higher degree of universality by virtue of the participation of representatives of virtually every nation in the norm-creating process.

The *methods of monitoring compliance* with human rights include moral judgments made with reference to recognized human rights, quasi-judicial procedures of investigation and fact-finding leading to official pronouncements of political bodies regarding compliance, and enforceable judicial decisions. Those of bioethics also include moral judgments made with reference to principles or codes of bioethics and official pronouncements of professional bodies that may result in altering research design or the behavior or liability of health professionals in their relations with patients or in policies affecting the health of populations.

The overlap of human rights and bioethical discourse and differences between the two will become clearer as one clarifies the emergence of human rights in political and legal discourse, the content of the right to health as defined in human rights instruments, the other human rights as they relate to health and well being, and the role and responsibility of health professionals, governments, international organizations and non-governmental organizations to respect, protect, promote and provide for these rights.

## **II. Emergence of human rights**

The early formulation of norms we characterize today as human rights is inseparable from historical and philosophical manifestations of human striving for justice. The deepest origin of human rights no doubt derives from basic human instincts of survival of the species and manifestations of empathy and altruism that evolutionary biology is only beginning to explain.<sup>5</sup> Since human evolution is driven by reproductive selfishness, one could wonder why the human species would develop any ethical system, like that of human rights, according to which individuals manifest feeling for the suffering of others (empathy) and—even more surprising—act in self-sacrificing ways for the benefit of others without achieving any noticeable reproductive advantage. And yet, as Paul Ehrlich notes in *Human Natures*, “empathy and altruism often exist where the chances for any return for the altruist

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<sup>4</sup> The International Bill of Human Rights consists of the Universal Declaration of Human Rights of 1948 (UDHR) and the two International Covenants of 1966—one on civil and political rights, the other on economic, social and cultural rights.

<sup>5</sup> Paul R. Ehrlich, *Human Natures: Genes, Cultures, and the Human Prospect*, Washington, D.C.: Island Press/Shearwater Books, 2000, pp. 305-331.

are nil.”<sup>6</sup> Natural selection does not provide the answer to moral behavior as “there aren’t enough genes to code the various required behaviors” but rather “cultural evolution is the source of ethics”<sup>7</sup> and therefore of human rights.

In legend, literature, religion and political thought, justice and eventually the concept of human rights became socially constructed over time into complex webs of social interaction striving toward a social order in which human beings are treated fairly as individuals and collectivities. The best-known histories of the human rights movement<sup>8</sup> tend to begin with the ancient religions and societies.

Religion and law have an ambiguous role in this historical process. The history of religions is replete with advances in the moral principles of behavior—many of which directly influenced the drafting of human rights texts—but also in crimes committed in the name of a Supreme Being. Similarly, the emergence of the rule of law has been critical to the advance of justice and human rights against the arbitrary usurpation of power in most societies but also in preserving the impunity of oppressors.

Scholars trace the current configuration of international human rights norms and procedures to the revolutions of freedom and equality that transformed governments across Europe and North American in the 18<sup>th</sup> century and liberated subjugated people from slavery and colonial domination in the 19<sup>th</sup> and 20<sup>th</sup> centuries. Enlightenment philosophers derived the centrality of the individual from their theories of the state of nature. Social contractarians, especially Jean-Jacques Rousseau, predicated the authority of the state on its capacity to achieve the optimum enjoyment of natural rights, that is, of rights inherent in each individual irrespective of birth or status. He wrote in *Essay on the Origin on Inequality among Men* that “it is plainly contrary to the law of nature...that the privileged few should gorge themselves with superfluities, while the starving multitude are in want of the bare necessities of life.”<sup>9</sup> Equally important was the concept of the universalized individual (“the rights of Man”), reflected in the political thinking of Immanuel Kant, John Locke, Thomas Paine and the authors of the French and American Declarations. Much of this natural law tradition is secularized in contemporary human rights.

World War II was the defining event for the internationalization of human rights. In 1940, H.G. Wells wrote *The Rights of Man or What are We Fighting For?*; Roosevelt’s four freedoms speech was given in 1941; the UN Charter established in 1945 an obligation of all members to respect and observe human rights and created a permanent commission to promote their realization; and the trial of Nazi doctors defined principles that were codified in the Nuremberg Code in 1946. In the war’s immediate aftermath, bedrock human rights texts were adopted: the Genocide Convention and the Universal Declaration of Human Rights in 1948, the Geneva Conventions in 1949, followed in 1966 by the International

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<sup>6</sup> *Id.*, p. 312.

<sup>7</sup> *Id.*, p. 317.

<sup>8</sup> See Paul Gordon Lauren, *The Evolution of International Human Rights: Visions Seen*, University of Pennsylvania Press, 1998, and Hersch Lauterpacht, *International Law and Human Rights*, Frederick A. Praeger, Inc., 1950, reprinted by Garland Publishing, 1973.

<sup>9</sup> Jean-Jacques Rousseau, *The Social Contract and Discourses* (1762), tr. by G.D.H. Cole, rev. and augmented by J.H. Brumfitt and John C. Hall, updated by P.D. Jimack (1973), p. 117.

Covenants on Human Rights. NGOs played a role in all of these developments and in subsequent drafting of treaties on the rights of the child, discrimination against women, and the International Criminal Court, as well as in the creation of investigative and accountability procedures at the intergovernmental level. William Korey describes how human rights NGOs not only contributed to the drafting of the Universal Declaration of Human Rights but also in bringing down Apartheid,<sup>10</sup> transforming the political and legal configuration of East-Central Europe<sup>11</sup> and restoring democracy in Latin America.<sup>12</sup> Amnesty International (founded in 1961), the Moscow Human Rights Committee (founded in 1970), and Helsinki Watch (founded in 1978 and expanded into Human Rights Watch in 1988) were among the more effective NGOs. Latin American, Africa and Asia saw the creation of an extraordinary array of human rights groups in the 1980s and 1990s, enumerated in the web sites linked to <http://www1.umn.edu/humanrts/links/links.htm>, which also includes links to human rights relevant web sites of the UN, other inter-governmental organization, centers for human rights research and training, and centers for rehabilitation of torture survivors.<sup>13</sup>

Drawing heavily on the debates in the Third Committee of the General Assembly in 1948, Johannes Morsink finds that the philosophy of the Universal Declaration was linked to that of the French Declaration of 1789 but that 18<sup>th</sup> century deism had been replaced by 20<sup>th</sup> century secular humanism, as evidenced by the rejection of the explicit reference to “nature.”<sup>14</sup> This is not only true for the legislative history of the Universal Declaration but is also an accurate characterization of the understanding more governments, scholars and activists have of the grounding of international human rights in the 21<sup>st</sup> century.

The valuation of every individual through natural rights was a break with the earlier determination of rights and duties on the basis of hierarchy and status. Commenting on the French Revolution’s break with the past, Jürgen Habermas wrote that this “revolutionary consciousness gave birth to a new mentality, which was shaped by a new time consciousness, a new concept of political practice, and a new notion of legitimization.”<sup>15</sup> Although it took more than a century for this new mentality to include women and slaves, the awareness that the “rights of man” should extend to all human beings was forcefully argued in the same period by Mary Wollstonecraft<sup>16</sup> and by the Society for the Abolition of the Slave Trade, founded in 1783. The movement to abolish slavery was the precursor of today’s vast array of human rights non-governmental

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<sup>10</sup> William Korey, *NGOs and the Universal Declaration of Human Rights: A Curious Grapevine*, St. Martin’s Press, 1998, pp. 7-8.

<sup>11</sup> *Id.*, pp. 95-116.

<sup>12</sup> *Id.*, pp. 229-247.

<sup>13</sup> For a searchable database of human rights websites recorded by site content, features, geographical focus, keywords, issues, see The Internet Directory at <http://www.hri.ca/coldfusion/cfidir/>. Groups that focus on Health and Human Rights at listed [www1.umn.edu/humanrts/links/health.html](http://www1.umn.edu/humanrts/links/health.html).

<sup>14</sup> Johannes Morsink, "The Philosophy of the Universal Declaration," *Human Rights Quarterly*, vol. 6, 1984, p. 333.

<sup>15</sup> Jürgen Habermas, *Between Facts and Norms: A Contribution to a Discourse Theory of Law and Democracy*, The MIT Press, Cambridge, MA, 1996, p. 467.

<sup>16</sup> *A Vindication of the Rights of Woman* (1792).

organizations (NGOs). Another significant historical moment for this form of social mobilization at the national level was the response to the unjust condemnation of Captain Dreyfus in 1894 as a spy for the Germans, which led Emile Zola to proclaim, in his famous “J’accuse,” an impassioned call to action that led to the creation of the Ligue française des droits de l’homme in 1897, and numerous similar leagues, which became federated in 1922 into the International Federation of Leagues for the Rights of Man (now International Federation for Human Rights), which spawned its counterpart in the U.S., the International League for the Rights of Man in 1942, now functioning in New York as the International League for Human Rights.

The secular tradition of human rights over the past three centuries has reflected a certain tension between political liberalism and democratic egalitarianism, between Locke and Rousseau, between liberty and equality, between civil and political rights and economic, social and cultural rights. Marx and much of socialist thinking questioned the “bourgeois” character of a limited interpretation of individual human rights. Community interest and egalitarian values are not the sole prerogative of Marxists and socialists; they are reflected in the Universal Declaration’s balancing of “bourgeois” liberal rights with duties to the community and social, economic and cultural rights as correctives to abuses of property rights. Significantly, the Declaration acknowledges that “Everyone has duties to the community in which alone the free and full development of his personality is possible.”<sup>17</sup> While socialist thought and positions taken by Soviet bloc countries supported concepts of duties and economic, social and cultural rights, these are also deeply imbedded in other cultural and political traditions, including European social democracy and Roosevelt’s proposal for an economic bill of rights. The emphasis on community and duties is also found in conservative elements of American society, as well as in Islamic, Hindu and other Asian societies. The simultaneous affirmation of rights and duties, of protecting individual freedoms and meeting social and economic needs, and of group rights and individual rights is part and parcel of human rights, adding complexity and depth to the norms, but also ambiguity and tension.

Notwithstanding this balancing, the debate over the “universality” of human rights continues. The matter was not settled by the compromised language of the World Conference on Human Rights (Vienna, June 1993), according to which:

All human rights are universal, indivisible and interdependent and interrelated. The international community must treat human rights globally in a fair and equal manner, on the same footing, and with the same emphasis. While the significance of national and regional particularities and various historical, cultural and religious backgrounds must be borne in mind, it is the duty of States, regardless of their political, economic and cultural systems, to promote and protect all human rights and fundamental freedoms.<sup>18</sup>

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<sup>17</sup> UDHR, Art. 29.

<sup>18</sup> *World Conference on Human Rights. The Vienna Declaration and Programme of Action, June 1993*, para. 5.

This statement nevertheless captures an important feature of human rights today, namely, the claim that they are universal and the reality of geocultural diversity. To understand fully the challenge this feature represents requires an understanding of the normative content of the current catalogue of human rights.

### **III. The normative content of human rights: The right to health**

The current catalogue of human rights consists of some fifty normative propositions enumerated in the international bill of human rights, extended by a score of specialized UN treaties, a half-dozen regional human rights treaties, and hundreds of international norms elaborated in the fields of labor, refugees, armed conflict, and criminal law. This corpus of human rights law, enriched by declarations, programs of action and other formulations of human rights in the process of becoming legally binding, is the source of the norms that properly fall with the category of international human rights.

The human rights framework takes on particular relevance for bioethics when the meaning, scope and practical significance of the right to health are considered. The right to health as understood in international human rights law is defined in Article 25 of the 1948 Universal Declaration of Human Rights (UDHR) ("Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services") and Article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) ("the right of everyone to the enjoyment of the highest attainable standard of physical and mental health").

Variations on this definition are found in Article 5 (e) (iv) of the International Convention on the Elimination of All Forms of Racial Discrimination of 1965 ("The right to public health, medical care, social security and social services"), in Articles 11.1 (f) and 12 of the Convention on the Elimination of All Forms of Discrimination against Women of 1979 (CEDAW) ("the right to protection of health and to safety in working conditions, including the safeguarding of the function of reproduction...[and] to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning [and] ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation") and in Article 24 of the Convention on the Rights of the Child of 1989 (CRC) ("the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health..."). Regional human rights treaties also define the right, as in Article 11 of the European Social Charter of 1961 as revised in 1996, (states' obligation to take measures "to remove as far as possible the causes of ill-health; to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health; to prevent as far as possible epidemic, endemic and other diseases, as well as accidents" and the duty "to ensure that any person who is without adequate resources and who is unable to secure

such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition”); Article 16 of the African Charter on Human and Peoples' Rights of 1981 (“...the right to enjoy the best attainable state of physical and mental health [and the obligation of the state to] take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick”); and Article 10 the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights of 1988 (“enjoyment of the highest level of physical, mental and social well-being” and measures to ensure “a. Primary health care, that is, essential health care made available to all individuals and families in the community; b. Extension of the benefits of health services to all individuals subject to the State's jurisdiction; c. Universal immunization against the principal infectious diseases; d. Prevention and treatment of endemic, occupational and other diseases; e. Education of the population on the prevention and treatment of health problems; and f. Satisfaction of the health needs of the highest risk groups and of those whose poverty makes them the most vulnerable”).

In a General Comment on the Right to Health, the Committee on Economic, Social and Cultural Rights (CESCR) (created to monitor the ICESCR) analyzed the normative content of the right in terms of accessibility, affordability, appropriateness and of quality of care, and specified the duties of the state to respect, protect and provide this right.<sup>19</sup> It also listed the following 14 human rights as “integral components of the right to health: the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement.”<sup>20</sup> In other words, these related rights defined to a large extent the determinants of health.

The right to health does not mean the right to be healthy, since being healthy is determined in part by health care, but also by genetic predisposition and social factors. What is of greater significance for the realization of healthy lives is the extent to which respect for other human rights has a direct bearing on the right to health or on the social factors that contribute to healthy lives. The field of social epidemiology has excelled at establishing correlations between discrimination based on race, class or gender, denial of education and of decent working conditions, as well as other factors that contribute directly to increased rates of mortality and morbidity.<sup>21</sup> These social determinants may also be defined in human rights terms as deprivation of these health-related rights. The rapid survey which follows seeks to underscore the function of human rights as determinants of health by highlighting the normative content and their relation to health.

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<sup>19</sup> CESCR, *General Comment 14: The right to the highest attainable standard of health*, UN Doc. E/C.12/2000/4, 4 July 2000, paras. 34-37.

<sup>20</sup> *Id.*, para. 3.

<sup>21</sup> Lisa F. Berkman and Ichiro Kawachi (eds.), *Social Epidemiology*, Oxford University Press, 2000.

#### **IV. Health-related human rights**

Human rights have been categorized in various ways, such as economic, social and cultural or civil and political rights; as first, second, and third generation rights; as positive and negative rights; as procedural and substantive rights, and so on. For the purposes of relating the core internationally recognized human rights to the realization of health and well-being, it is proposed here to group human rights into three categories, those that relate to the physical and mental existence of humans (“rights of existence”); those that relate to autonomy of thought and action of individuals (“rights of autonomous action”); and those that involve social interactions of individuals and groups from the family to the political, cultural and international communities (“rights of social interaction”).

##### **a. Rights of Existence**

Foremost among the human rights relating to physical and mental integrity is the right not to be arbitrarily deprived of life. As defined internationally the right to life does not ban death resulting from lawful acts of warfare nor capital punishment, although international humanitarian law limits the former, and newer protocols and regional conventions, supported by UN resolutions and social movements, define the latter as a violation of human rights. The right to death with dignity is sometimes claimed as the human rights grounding for domestic legislation on the subject. Although there is no explicit international human right to death, some scholars construe this right from various recognized rights, such as the rights to dignity and freedom from cruel, inhuman, or degrading treatment.

Another controversial aspect of the right to life is the tension between the claim that it includes the right to life of the fetus from the moment of conception and the claim that reproductive rights of the pregnant women include the right to voluntary termination of her pregnancy. The right to an abortion is recognized in various national legal systems but not explicitly in international human rights due in large part to opposition by Catholic and Islamic countries.

Physical integrity is protected in various ways. Special standards, developed in the context of the UN’s work on crime prevention and treatment of offenders, apply to the treatment of detainees, rights and responsibilities of lawyers, prosecutors, judges, and law enforcement officers. More recent standard-setting activity has focused on impunity, accountability of high government officials, and compensation for victims of human rights violations. Special treaties and procedures exist for torture, disappearance, and summary and extra-judicial execution.

Political violence resulting in massive harm to populations entails a wide range of human rights violations. Certain acts of grievous harm to physical and mental integrity, when “part of a widespread or systematic attack directed against any civilian population,” may constitute crimes against humanity, punishable under international law. The Rome Statute of the International Criminal Court of 17 July 1998 lists the following acts as falling within this particular violation of human rights:

(a) Murder; (b) Extermination; (c) Enslavement; (d) Deportation or forcible transfer of population; (e) Imprisonment or other severe deprivation of physical liberty in violation of fundamental rules of international law; (f) Torture; (g) Rape, sexual slavery, enforced prostitution, forced pregnancy, enforced sterilization, or any other form of sexual violence of comparable gravity; (h) Persecution against any identifiable group or collectivity on political, racial, national, ethnic, cultural, religious, gender ..., or other grounds that are universally recognized as impermissible under international law, in connection with any act referred to in this paragraph or any crime within the jurisdiction of the Court; (i) Enforced disappearance of persons; (j) The crime of apartheid; (k) Other inhuman acts of a similar character intentionally causing great suffering, or serious injury to body or to mental or physical health.<sup>22</sup>

Special treaties and procedures for prevention and repression of certain human rights violations considered as international crimes—such as genocide, torture, slavery, racial discrimination and various forms of terrorism—are part of human rights law, as well as of international criminal law and international humanitarian law. International humanitarian law, established to protect victims of armed conflict (injured and shipwrecked combatants, prisoners of war and civilian populations notably under occupation) was codified in the four Geneva Conventions of 12 August 1949 and the Additional Protocols of 1977 and is sometimes referred to as “human rights in time of armed conflict.”

Disability rights were not included in the International Bill of Human Rights, but specific human rights standards have been developed for persons with disabilities and mental illness, such as the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted in 1993.<sup>23</sup> These rules are monitored by the United Nations Special Rapporteur on the Standard Rules for the Equalization of Opportunities of Persons with Disabilities (Bengt Lindqvist), who was appointed by the Commission for Social Development. However, the norms and procedures that have been invoked on behalf of persons with disabilities range much farther and wider than the Standard Rules. A recent study of some 300 pages on *Human Rights and Disability* reviews how a human rights framework has been applied to issues of disability by each of the six main UN human rights treaties and civil society, national institutions, and UN machinery.<sup>24</sup> It also provides the background for the proposed comprehensive and integral international convention to protect and promote the rights

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<sup>22</sup> Rome Statute of the International Criminal Court, circulated as document A/CONF.183/9 of 17 July 1998 and corrected by procès-verbaux of 10 November 1998, 12 July 1999, 30 November 1999, 8 May 2000, 17 January 2001 and 16 January 2002, Article 7. The Statute entered into force on 1 July 2002.

<sup>23</sup> Adopted by the General Assembly in Resolution 48/96 of 20 December 1993.

<sup>24</sup> Gerard Quinn and Theresia Degener with others, *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability*, United Nations, 2002.

and dignity of persons with disabilities, which the General Assembly requested the High Commission to consider.<sup>25</sup>

The right to “a standard of living adequate for the health and well-being” of oneself and one’s family was defined in the Universal Declaration of Human Rights as including “food, clothing, housing and medical care and necessary social services” as well as “the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond [one’s] control.” Subsequently, the rights to health, work, safe and healthy working conditions (occupational health), adequate food and protection from malnutrition and famine, adequate housing, and social security (that is a regime covering long-term disability, old age, unemployment and other conditions) have been further elaborated. The rights to work and to decent conditions of work have been the responsibility of the International Labour Organisation since 1919, and specific rules have been developed through some 200 ILO conventions and recommendations, constituting a highly developed sub-field of human rights. The other rights relating to an adequate living standard have also been expanded upon by treaties, international conferences and summits, and the work of special rapporteurs and treaty bodies.

During the Cold War, these economic, social and cultural rights were enumerated in instruments separate from those that listed civil and political rights. Thus, the International Covenant on Economic, Social and Cultural Rights was adopted in the UN, the Europe Social Charter in the Council of Europe, and the Protocol on Certain Aspects of Economic, Social and Cultural Rights in the Organization of American States, separately from the main human rights treaties, which focused primarily on civil and political rights. Earlier distinctions among these two categories of rights on grounds of intrinsic nature, method of implementation, need for resources and other factors have dissipated and the current trend in human rights thinking—notwithstanding the official position taken by the government of the United States, which stands virtually alone in this respect—is to regard civil, cultural, economic, political and social rights as universal, interdependent, interrelated and of equal importance.

#### b. Rights of Autonomous Action

Several human rights fall within the category of rights that preserve and protect the human value of each person and his or her autonomy and freedom of action. Dignity tends to be mentioned as both the basis for all human rights and a right per se. If dignity means the worth and honor due to any human being in accordance with the social context in which failure to respect dignity results in humiliation, then the right requires both acts and omissions, such as discrimination, mistreatment, or lack of an adequate standard of living, and a psychological outcome. However, some courts have applied an objective concept of dignity, according to which certain acts (such as making a spectacle of a disability) violate the right to dignity even if consented to by the alleged victim.

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<sup>25</sup> General Assembly Resolution 56/269.

The human right to identity may have a broad philosophical meaning but in positive human rights law tends to be limited to the civil status of registration of birth and acquisition of a nationality.

The great civil liberties—freedom of oral and written expression, freedom of conscience, opinion, religion or belief—as well as rights to a fair hearing and an effective remedy for violations of human rights, and protection of privacy in domicile and correspondence all support the autonomy of individuals to act without interference from the state or others. The implications for mental health of these freedoms are easy to identify. Similarly, freedom from arbitrary detention or arrest, from torture or other forms of cruel, inhuman or degrading punishment or treatment, and humane conditions of detention for those legally deprived of their liberty have obvious implications for physical and mental health. Human rights standards in UN and regional texts provide the definitions and means of redress for these rights. A separate but related human right is that of informed consent to medical experimentation, which was included in post-1945 enumerations of rights due to the abhorrent abuse of that right during World War II.

Equality and non-discrimination are human rights that are at the same time principles for the application of all other human rights, since they require that all persons be treated equally in the enjoyment of their human rights and that measures be taken to remove discriminatory practices on prohibited grounds.

Related to freedom of expression is the right to what is called the “moral and material interests” in any literary, artistic or scientific creation. Thus copyright, patents and other intellectual property rights fall into the category of human rights to the extent that they relate to an individual’s creative energies and products; intellectual property rights are less justified as “human rights” when owned by corporations and utilized to market products for return on investment. The distinction made earlier between rights as any legally protected interest and human rights as higher-order rights aiming at preserving and protecting the worth of human persons justifying limiting the human rights significance of intellectual property to avoiding unjust enrichment from the creative output of individuals.

Freedom of movement means the right to reside where one pleases and to leave any country, including one’s own, and to return to one’s country. The right to seek and enjoy asylum from persecution is also a human right, which has been developed and expanded by international refugee law, the practice of the UN High Commissioner for Refugees and recent codes relating to internally displaced persons. This right, like many others, is not absolute; limitations may be imposed, for example, in time of epidemic, as long as certain safeguards, defined in human rights law, are observed.

### c. Rights of Social Interaction

The third set of rights that are also determinants of health relate to the participation of individuals in their society. Social well-being—an element of health—relates to group rights, education, family, culture, political and cultural participation,

gender and reproductive rights, scientific activity, the environment and development, all of which are the subject of specific human rights.

The basic human rights texts affirm a limited number of group rights, notably the rights of “peoples” to self-determination, that is, to “determine their political status and freely pursue their economic, social and cultural development” and to permanent sovereignty over natural resources.<sup>26</sup> They also enumerate the rights of persons belonging to minorities to practice their religion, enjoy their culture and use their language.<sup>27</sup> Indigenous peoples have defined rights that take into account their culture and special relation to the land.

The right to education includes compulsory primary education, availability and accessibility of secondary education and equal access to higher education, and the role of parents in choosing their child’s educational institution. Several instruments relating to discrimination in education, technical aspects and content of education have been adopted by UNESCO. In addition to the right to education, rights of the child have been codified in several instruments, primarily the 1989 Convention on the Rights of the Child (CRC), which has been ratified by every country except the U.S. Defining a child as anyone under 18, the CRC makes “the best interest of the child” the primary consideration and defines rights relating to the child’s identity, health and access to health care, expression of opinion, conditions of adoption, and protection from abuse, torture, capital punishment, and traditional practices prejudicial to the child’s health.

Participation takes at least three forms in international human rights. Political participation includes the right to run for office and to vote in genuine and periodic elections. Cultural participation means primarily the right to participate in the cultural life of the community, whether through access to visual and performance art or through artistic creation and the protection of writers, artists and performers. The third meaning of participation is participation in efforts to realize human rights whether through the exercise of freedom of association or protection of human rights defenders in accordance with a 1998 declaration, officially entitled Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms.

Health issues loom large in human rights standard-setting and policy determination regarding gender, sexual rights, and reproductive rights. The basic human rights texts have been supplemented by a specialized Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) of 1979. Considerable advances in mainstreaming women’s rights as human rights were made at the international conferences in Vienna (human rights, 1993), Cairo (population, 1994), and Beijing (women, 1995). Further developments have been made to deal with violence against women (through a 1993 Declaration and a Special Representative to study the problem) and traditional practices harmful to health, such as female genital cutting or mutilation,

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<sup>26</sup> ICCPR and ICESCR, Article 1.

<sup>27</sup> ICCPR, Article 27.

about which the World Health Organization, UN Children's Fund (UNICEF) and the UN Fund for Population Activities issued a statement in 1996.

Reproductive rights begin with "The right of men and women of marriageable age to marry and to found a family...",<sup>28</sup> which is closely related to the right of "men and women . . . to decide freely and responsibly on the number and spacing of their children" (CEDAW, Article 16(1)(e)), and "to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice."<sup>29</sup> Various internationally approved programs and plans of action have set out in considerable detail the specific ways in which this right can be realized.

Bioethical concerns overlap with human rights with respect to the right to enjoy the benefits of scientific progress and the right to scientific research.<sup>30</sup> The former refers to the positive and equitable use of scientific advances while the latter protects freedom to conduct research and disseminate results and the requirement of informed consent of human subjects.

In the same way that the distinction between civil and political and economic, social and cultural rights is losing its relevance in the post-Cold War, so too is the third category of solidarity or third generation rights less helpful than it was twenty years ago.<sup>31</sup> It referred to certain global values such as peace, a healthy environment, development, communication, humanitarian intervention or assistance and the like, which were raised to the level of human rights, notwithstanding the complex matter of defining the rights- and duty-holders and the precise obligations involved. While the literature continues to refer occasionally to all these values as constituting human rights, and some support exists in the literature and declarations of political bodies, two have become more systematically developed and enshrined in authoritative texts, namely the right to a healthy environment and the right to development.

The right to a healthy environment (or a related formulation such as "to live in an environment adequate for their health and well being"<sup>32</sup>) has been recognized in some 90 national constitutions, including most national constitutions enacted since the 1992 Rio Conference on Environment and Development. South Africa's Constitution is exemplary in this regard:

Everyone has the right (a) to an environment that is not harmful to their health or well being; and (b) to have the environment protected, for the benefit of present and future generations, through reasonable legislative and other measures that (i) prevent pollution and ecological degradation;

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<sup>28</sup> ICCPR, Article 23 (2).

<sup>29</sup> Report of the International Conference on Population and Development, U.N. Doc A/CONF.171/13, Oct. 18, 1994.

<sup>30</sup> ICESCR, Article 15.

<sup>31</sup> See Stephen Marks, "Emerging Human Rights: A New Generation for the 1980's?" *Rutgers Law Review*, vol. 33, no. 2, 1981, pp. 435-452; Philip Alston, "Peoples' Rights: Their Rise and Fall," in Alston, *Peoples' Rights*, Oxford University Press, 2001, pp. 259-293.

<sup>32</sup> UN General Assembly Resolution 45 /94 of 14 Dec. 1990.

(ii) promote conservation; and (iii) secure ecologically sustainable development and use of natural resources while promoting justifiable economic and social development.<sup>33</sup>

Environmental protections appear in several human rights conventions, such as the Convention on the Rights of the Child and ILO Convention 169 concerning Indigenous and Tribal Peoples in Independent Countries, and are included in regional human rights treaties, particularly the African Charter on Human and Peoples' Rights and the Protocol of San Salvador to the American Convention on Human Rights.<sup>34</sup> Specific aspects of environmental rights are covered by the 1998 Aarhus Convention on Access to Information, Public Participation and Access to Justice in Environmental Matters, and in the European case law supporting the right to know whether pollution is likely to affect a particular individual or community.

The right to development has been recognized in numerous UN resolutions and specifically in the 1986 Declaration on the Right to Development,<sup>35</sup> as well as in the African Charter on Human and Peoples' Rights. The Declaration defines this right as “an inalienable human right by virtue of which every human person and all peoples are entitled to participate in, contribute to, and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realized.”<sup>36</sup> The right implies that development policies of governments and partner agencies should “aim at the constant improvement of the well-being of the entire population and of all individuals, on the basis of their active, free and meaningful participation in development and in the fair distribution of the benefits resulting therefrom.”<sup>37</sup>

Finally, the Universal Declaration proclaims the right of everyone to “a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.”<sup>38</sup> This right is perhaps the broadest but also the most significant in making human rights the ordering criterion for national societies and international relations. The required social order suggests a democratic constitutional regime in which human rights of all categories are recognized in law and effectively observed in practice. It also suggests that international relations provide support for global efforts to further human rights and establish means of accountability for persons and groups to obtain redress from countries that fail to fulfill their human rights obligations.

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<sup>33</sup> Constitution of the Republic of South Africa, as adopted on 8 May 1996 and amended on 11 October 1996 by the Constitutional Assembly, Article 12.

<sup>34</sup> African Charter of Human and Peoples' Rights, Article 24; Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, Article 11 (1).

<sup>35</sup> The Declaration on the Right to Development was adopted by the General Assembly in its resolution 41/128 of 4 December 1986.

<sup>36</sup> *Id.*, Article 1.

<sup>37</sup> *Id.*, Article 3.

<sup>38</sup> UDHR, Article 28.

## V. The enforcement and application of human rights

In the domestic system, law is binding and the courts and the police are available to use force to compel compliances. In the international human rights regime the term “enforcement” refers to coerced compliance, while “implementation” refers to supervision, monitoring and general effort to hold duty-holders accountable. Implementation is further subdivided into promotion—preventive measures to ensure respect for human rights in the future—and protection—responses to violations that have occurred in the past. The means and methods of implementation may be summarized in three forms of promotion and five forms of protection.

*Promotion* of human rights is achieved through developing awareness, standard-setting and interpretation, and creation of national institutions. Awareness of human rights is a precondition to acting on them and is advanced through dissemination of knowledge (publications, information campaigns) and human rights education at all levels, for which the UN proclaimed a decade of action for the period 1995-2004.<sup>39</sup> By standard-setting is meant the drafting of human rights texts, for which the UN Commission on Human Rights, established in 1946, plays a central role, including drafting the International Bill of Human Rights and most declarations and conventions that were eventually adopted by the General Assembly. Numerous other bodies in the UN, such as the Commission on the Status of Women, and UN Specialized Agencies such as the ILO and UNESCO, as well as the regional organizations (Council of Europe, Organization of American States, Organization of African Unity-now the African Union) draft numerous international human rights standards. These norms are interpreted by various international courts and treaty-monitoring bodies, such as the CESCR which adopted the General Comment on the right to health. The third preventive or promotional means of implementation is national institution-building, which includes improvements in the judiciary and law enforcement institutions and the creation of specialized bodies, such as national commissions for human rights and offices of an ombudsman.<sup>40</sup>

The *protection* of human rights involves a complex web of national and international mechanisms to monitor, judge, denounce, and coerce states, as well as providing relief to victims.<sup>41</sup> Monitoring compliance with international standards is carried out through the reporting and complaints procedures of the UN treaty bodies and regional human rights commissions and courts. States are required to submit reports and the monitoring body—often guided by information provided by NGOs—examines progress and problems with a view to guiding the reporting country to do better. Several optional procedures allow individual and groups (and sometimes other states) to petition

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<sup>39</sup> General Assembly Resolution 49/184, adopted on 23 December 1994.

<sup>40</sup> In October 1991 a group of representatives of national institutions, States, the United Nations, its specialized agencies, intergovernmental and non-governmental organizations adopted in Paris a set of Principles relating to the status and functioning of national institutions for protection and promotion of human rights, which were endorsed by the Commission on Human Rights in Resolution 1992/54 of March 1992 and by the General Assembly in its Resolution A/RES/48/134 of 20 December 1993.

<sup>41</sup> More on these procedures may be found in Stephen P. Marks, “The United Nations and Human Rights: The Promise of Multilateral Diplomacy and Action,” in Weston and Marks (eds.), *The Future of International Human Rights* (New York: Transnational Publishers, 1999), pp. 291-350.

these bodies for a determination of violations. The quasi-judicial bodies (such as the Human Rights Committee or the African Commission on Human and Peoples' Rights) utilize various forms of fact-finding and investigation and then issue their views.

Special procedures have been established in the UN through which working groups and special rapporteurs are mandated to study countries or issues, including taking on cases of alleged violations. The special rapporteurs report back on their findings and the political bodies to which they report often adopt resolutions calling for redress from governments. Among the "thematic" rapporteurs, one is specifically mandated to study the right to health, and others deal with health-related issues, such as food, housing, and toxic waste. The second means of protection is adjudication of cases by fully empowered human rights courts, the main ones being the European Court of Human Rights, which has contentious jurisdiction over cases brought by persons within the 44 member states of the Council of Europe; the Inter-American Court of Human Rights, which has both contentious and advisory jurisdiction and is open to the 25 states parties to the American Convention on Human Rights; and soon an African Court of Human and Peoples' Rights.

Political supervision refers to the authority of bodies made up of representatives of states to adopt resolutions judging the policies and practices of states. The Commission on Human Rights, the UN General Assembly, the Committee of Ministers of the Council of Europe, and the Assembly of OAS have all adopted politically significant resolutions denouncing governments for violations of human rights and demanding that they redress the situation and often that they provide compensation to the victims. This form of sanction may appear toothless since it is not backed up with coercive force; however, in practice many governments take quite seriously such political naming and shaming and go to considerable lengths to avoid it, including improving their human rights performance.

The use of coercion is available only to the Security Council, which can use its powers under Chapter VII of the UN Charter to impose sanctions, cut off communications, create ad hoc criminal tribunals, and authorize the use of force by member states or deploy UN troops to put an end to a threat to international peace and security, which it has on occasion interpreted to include human rights violations. Human rights considerations were part of the use of Chapter VII in Haiti, Somalia, Bosnia, Iraq and other locations. This forceful means of protecting human rights is complex and dangerous and can have harmful health consequences, as has been the case with sanctions imposed on Haiti and Iraq. If used properly it can be a modern and legitimate form of the 19<sup>th</sup> century doctrine of humanitarian intervention, according to which states use armed force to halt atrocities committed in another state while respecting the principles of necessity, proportionality, disinterestedness and collective action. NATO sought to employ such a doctrine in Kosovo in 1999, but without the necessary authorization from the Security Council engaged in a legitimate but illegal use of force. Each case of action (e.g., no-fly zones over Iraq since 1991) or inaction (e.g., Rwanda in 1994) regarding the use of armed force for human rights purposes has ethical and legal difficulties. Nevertheless, the legitimacy and legality of authorized force in response to a human rights crisis is now well-established.

The final means of responding to human rights violations is through humanitarian relief or assistance. Provision of food, blankets, tents, medical and sanitary assistance, and other forms of aid saves lives and health of persons forcibly displaced often as a result of large-scale human rights violations. Refugees and internationally displaced persons come under the protection of the UN High Commissioner for Refugees (UNHCR), which deploys massive amounts of aid, along with the International Committee of the Red Cross, UNICEF, WFP, UNDP, the UN Office for the Coordination of Humanitarian Affairs and other agencies, as well as major NGOs like Oxfam, Care, and the International Rescue Committee.

## **VI. Conclusion**

Every country in the world has accepted that human rights are universal but all are challenged, in one way or another, to achieve progress with respect to those rights they neglect, however proud they may be of achievements with respect to other rights. Thus Cuba may be rightfully proud of its record on rights to health and education but is challenged to do more for political and civil rights; the U.S. may pride itself on the degree to which freedom of expression or civil rights are guaranteed but is challenged to take seriously economic, social, and cultural rights. The normative content of the corpus of human rights standards is probably the most complete catalogue of the determinants of physical, mental and social well-being. The methods of implementation or intervention to ensure compliance are not directly linked to medical and health practice as is the case with bioethics. They nevertheless constitute a potentially rich framework for the improvement of health, which is the objective of the emerging sub-field of health and human rights.