



# THE UNIVERSITY *of* EDINBURGH

## Edinburgh Research Explorer

### The Significance of UNESCO's Universal Declaration on the Human Genome and Human Rights

**Citation for published version:**

Harmon, S 2005, 'The Significance of UNESCO's Universal Declaration on the Human Genome and Human Rights', *SCRIPTed*, vol. 2, no. 1, pp. 18-47. <https://doi.org/10.2966/scrip.020105.20>

**Digital Object Identifier (DOI):**

[10.2966/scrip.020105.20](https://doi.org/10.2966/scrip.020105.20)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Publisher's PDF, also known as Version of record

**Published In:**

SCRIPTed

**Publisher Rights Statement:**

© Harmon, S. (2005). The Significance of UNESCO's Universal Declaration on the Human Genome and Human Rights. *SCRIPTed*, 2(1), 18-47. 10.2966/scrip.020105.20

**General rights**

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

**Take down policy**

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact [openaccess@ed.ac.uk](mailto:openaccess@ed.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.



# SCRIPT-ed

*Volume 2, Issue 1, March 2005*

## **The Significance of UNESCO's Universal Declaration on the Human Genome & Human Rights**

*Shawn H.E. Harmon*<sup>\*</sup>

### **Abstract**

*Modern medical research, particularly genetic research, is changing the nature of medicine. Concerns surrounding these changes and their potential negative impact on human rights led UNESCO to spearhead collaboration by experts in the creation of an international instrument intended to provide guidance for the promotion of bioethics and the protection of human rights in the genetic context. The result was the Universal Declaration of the Human Genome and Human Rights. This article briefly highlights the scientific and social setting into which the Declaration was injected. This is followed by a consideration of the drafting body (the IBC) so as to assess whether UNESCO was the appropriate body to lead this project. The process by which the Declaration was created is also considered so as to assess whether it represents an example of ethical and democratic drafting. Finally, the substantive content of the Declaration is considered and measured against the pre-existing regime so as to assess whether it represents an intelligible and coherent response to the concerns raised capable of offering guidance now and into the future. By assessing these procedural and substantive matters, one can draw some tentative conclusions about the utility and significance of the Declaration.*

DOI: 10.2966/scrip.020105.20

© Shawn Harmon 2005. This work is licensed through [SCRIPT-ed Open Licence \(SOL\)](#).

---

<sup>\*</sup> Shawn H.E. Harmon, BA (1993), LLB (1996), LLM (2005), has clerked with the Federal Court of Canada and practiced extensively in Nova Scotia as a litigator, primarily in the fields of insurance and tort law. He received his LLM (with distinction) in international law from the University of Edinburgh, and has returned to the University of Edinburgh to both undertake research as a Research Fellow with INNOGEN and to pursue his PhD studies in genetic regulation.

*[Human] genetics ... is beginning to create a new generation of acute and subtle dilemmas that will in the new millennium transform the ways in which we think of ourselves and of society. It is genetics, bringing both a new understanding of what we are and almost daily developing new ways of enabling us to influence what we are, that is creating a revolution in thought, and not least in ethics.*<sup>1</sup>

## 1. Introduction

The inexorable advance of science is expanding the breadth and scope of human activity. Nowhere is its impact more acute than in the health and related fields, where it has contributed to a sea change in individual and community healthcare. It has made healthcare more predictive, increased treatment options, expanded healthcare programs and altered the social setting within which medicine is practiced.<sup>2</sup> It has huge potential to alleviate suffering and increase quality of life. The intimate interaction between scientific advances and health led to concerns about the pace of advances, the dearth of applicable legal standards, and the social consequences of the application of biotechnology within existing healthcare systems.

Unsurprisingly, genetic advances play an increasingly important role in the scientific advances that impact healthcare. Although genetics has the potential to increase healthcare options, it also gives rise to fears. It offers knowledge about humanity's vital mechanisms and the capability to influence and modify them, which prompts fears that attempts to control present health could injure future health.<sup>3</sup> It offers the capability to "design" the humans of the future, which, given past abusive eugenic practices,<sup>4</sup> excited anxiety over sex and genetic discrimination and the development of heretofore unheard of liability claims.<sup>5</sup> It offers the possibility of transforming the

---

<sup>1</sup> J. Harris, "Introduction: The Scope and Importance of Bioethics" in J. Harris (ed.), *Bioethics* (Oxford: OUP, 2001), at 20.

<sup>2</sup> D. Morgan, "Science, Medicine and Ethical Change" in A. Bainham *et al.* (eds.), *Body Lore and Laws* (Oxford: Hart Publishing, 2002) 329-342, at 329. For more on these, see N. Matsaniotis, "The Evolution of Technology, Genetics and Bioethics" in L. Sicilianos & M. Gavouneli (eds.), *Scientific and Technological Developments and Human Rights* (Athens: Sakkoulas Publishers, 2001) 161-170, at 164, V. Harpwood, "Gene Therapy Treatment for Parkinson's Disease" (2002) 9(11) M.L.M. 2-4, V. Harpwood, "Malaria Likely to be Conquered by Geneticists" (2002) 9(11) M.L.M. 5, and T. Beauchamp, "On Justifications for Coercive Genetic Control" in J. Humber & R. Almeder (eds.), *Biomedical Ethics and the Law* (London: Plenum Press, 1977) 361-374, at 363.

<sup>3</sup> We are only at the beginning of understanding. Research has not yet produced a single broadly applicable therapeutic treatment. Even if gene therapy were possible (it remains a dream), interventions could have unforeseen consequences. For example, upon discovery of the sickle cell anaemia gene, its link to resistance to malaria was discovered. See T. Caulfield, "Underwhelmed: Hyperbole, Regulatory Policy and the Genetic Revolution" (2000) 45 McGill L.J. 437-460, at 440-445, and E. Marden & D. Nelkin, "Displaced Agendas: Current Regulatory Strategies for Germline Gene Therapy" (2000) 45 McGill L.J. 461-481.

<sup>4</sup> A common example is that of the Nazis, but there are others: M. Kirby, *Through the World's Eye* (Sydney: The Federation Press, 2000), at 44-45.

<sup>5</sup> Examples include the emergence of (1) "informational claims" by individuals for whom biotechnology has altered the structure of human kinship, (2) "wrongful life" claims by "defective" individuals seeking compensation for their diminished ability to achieve the autonomy, interpersonal relationships and personal development as a result of improperly utilized biotechnology, and (3)

species, which, given certain healthcare shortfalls (i.e., the organ transplant crisis<sup>6</sup>), leads to distress over healthcarers being pushed precipitously toward genetic solutions.

Further, genetic research/knowledge and the distribution of new genetic biotechnologies are facilitated by a world in the throes of “globalization”,<sup>7</sup> which contributed to concerns about the Human Genome Project (HGP)<sup>8</sup> and the worldwide implications of its potential negative consequences. Some concerns were expressed as follows:

*[T]he interdependence of developments in the world is felt more acutely today than ever before. The HGP, ... which will lead to breakthroughs in the most intimate knowledge of the biology of*

---

“negligence claims” against genetic counselors. See N. Lenoir, “The Human Genome: From UNESCO to the UN” in L. Sicilianos & M. Gavouneli (eds.), *supra*, note 2, 171-178, L. Walters, “Reproductive Technologies and Genetics” in R. Veatch (ed.), *Medical Ethics*, 2d ed. (London: Jones & Bartlett, 1997) 209-233, at 212, and B. Knoppers *et al.*, “Physicians and Genetic Malpractice” (2002) 21 Med. Law 661-680.

<sup>6</sup> R. Vermot-Mangold (Rapporteur), *Trafficking in Organs in Europe* (2003) Doc. 9822, J. Montgomery, *Health Care Law*, 2d ed. (Oxford: OUP, 2003), and many more.

<sup>7</sup> Globalization is characterized by increasing (1) cross-border integration of political, economical and cultural practices and dissemination of values and information, (2) control of infrastructure (ie: transport, utilities, emergency services, banking, security) by computer; and (3) transnational mobility of people, disease, products/technology and capital. See R. Rogers, “Identity Revisited in the New Technological Culture” (2000) 19 Med. Law 381-387, at 382, and P. Bates, “Health, Law, Ethics and Policy: Challenges and New Avenues for the 21st Century and New Millennium” (1999) 18 Med. Law 13-46. For more on globalization, see D. Henwood, “Beyond Globophobia” (2003) at [www.globalpolicy.org/globaliz/define/2003/1113globophobia.htm](http://www.globalpolicy.org/globaliz/define/2003/1113globophobia.htm) (July 10/04), IMF, “Globalization: Threat or Opportunity?” (2002) at [www.imf.org/external/np/exr/ib/2000/041200.htm](http://www.imf.org/external/np/exr/ib/2000/041200.htm) (July 10/04), C. Norchi, “The Global Divide” (2000) at [www.globalpolicy.org/soecon/tncs/davos/davos10.htm](http://www.globalpolicy.org/soecon/tncs/davos/davos10.htm) (July 10/04), L. Sklair, “Competing Conceptions of Globalization” (1999) 5 J.W.S.R. 143, C. Chase-Dunn, “Globalization: A World-Systems Perspective” (1999) 5 J.W.S.R. 165, J. Breidenbach & I. Zukrigl, “The Dynamics of Cultural Globalization” (1998) at [www.inst.at/studies/collab/breidenb.htm](http://www.inst.at/studies/collab/breidenb.htm) (July 10/04), C. Sjolander, “The Rhetoric of Globalization: What’s in a Wor(l)d?” (1996) 51 Int’l J. 603, P. Cerny, “Globalization and Other Stories: The Search for a New Paradigm for International Relations” (1996) 51 Int’l J. 617, W. Reisman, “Sovereignty and Human Rights in Contemporary International Law” (1990) 84 A.J.I.L. 866. Both [www.emory.edu/soc/globalization/issues01.html](http://www.emory.edu/soc/globalization/issues01.html) and [www.globalization.about.com/cs/whatsit/a/whatsit.htm](http://www.globalization.about.com/cs/whatsit/a/whatsit.htm) (July 10/04), provide further links to a host of sources.

<sup>8</sup> The Human Genome Project (HGP) is a global collaborative scientific endeavour with the goal of mapping and sequencing the entire chain of human DNA and genes. Begun in the 1980s, it involves Canada, Denmark, France, Germany, Holland, Italy, Japan, Sweden, the UK, the US, regional organizations such as the EU, and non-governmental organizations (NGOs) such as the WHO. The Human Genome Organization (HUGO), an independent organization of international scientists, coordinates the research and fosters collaboration among scientists so as to avoid competition and duplication. The genome is now 99% mapped and researchers are moving into the functional analysis and genetic variation phases. It has been described positively as “one of the most ambitious scientific projects ever undertaken”, and negatively as a process “driven by an opportunistic technology, an avaricious lobby and misguided goals”. See A. Taylor, “Globalization and Biotechnology: UNESCO and an International Strategy to Advance Human Rights and Public Health” (1999) 25 A.J.L.M. 479-541, E. Ben-Asher *et al.*, “Harvesting the Human Genome: The Israeli Perspective” (2000) 2 I.M.A.J. 657-664, S. MacLean & D. Giesen, “Legal and Ethical Considerations of the Human Genome Project” (1994) 1 M.L.I. 159, and A. Lippman, “Led (Astray) by Genetic Maps: The Cartography of the Human Genome and Health Care” (1992) 25 Soc. Sci. & Med. 1496, for further background on the HGP.

*human beings, requires true international cooperation and an unrestricted exchange of information, firstly because of the returns this can have with relation to research and application and, secondly, because of the need for international analysis of the societal, ethical and ... legal implications this project could engender.*<sup>9</sup>

And:

*Scientific and technological progress [permits] increasing control of our environment and ... our living conditions. In the fields of biology and genetics especially, progress is all the more staggering since man, for the first time, has the power to transform living matter in a programmed and selective manner. ... It is above all in the biomedical field that progress has been the most spectacular and provokes the most questions, especially since it involves living human beings.*<sup>10</sup>

The “age of genetics”<sup>11</sup> was viewed as a “risk society”<sup>12</sup> with the potential for catastrophic harm.<sup>13</sup> It demanded “lengthened foresight” to “help disclose what is possibly at stake, what values and traditions we may pass up, what goals and opportunities we ought, in all conscience, to deny ourselves; what we must avoid ... [and] preserve at all cost.”<sup>14</sup>

This led Federico Mayor, Director-General of the United Nations Economic, Social and Cultural Organization (UNESCO),<sup>15</sup> to conclude that UNESCO needed to

---

<sup>9</sup> F. Mayor, “Statement at ‘Genetics, Ethics and Human Values: Human Genome Mapping, Genetic Screening and Gene Therapy’” 24th CIOMS Conference, Japan, 1990. An international response was also warranted because of the international awareness that globalization linkages was creating about scientific possibilities and issues. For more on these linkages and the evolving “global” awareness, see UN Secretary-General, *Report: An Agenda for Peace: Preventative Diplomacy, Peacemaking and Peacekeeping*, UN GAOR, 47th Sess., UN Doc. A/47/277-S/34111 (1992).

<sup>10</sup> N. Lenoir, “Annual Report of the IBC” in *Proceedings of the Second Session of the IBC*, vol. I (Paris: UNESCO, 1995), 1-9, at 1.

<sup>11</sup> R. Brownsword *et al.*, “Human Genetics and the Law: Regulating a Revolution” in R. Brownsword *et al.* (eds.), *Law and Human Genetics: Regulating a Revolution* (Oxford: OUP, 1999) 1-5, at 5.

<sup>12</sup> Wherein we look not at what nature can do but at what we can do, thereby circumventing “fate”: see D. Morgan, *supra*, note 2, at 331-332, and U. Beck, *Risk Society: Toward A New Modernity* (London: Sage, 1992), who coined the phrase “risk society”.

<sup>13</sup> Indeed, most initial responses to genetic breakthroughs were reactionary, emotive, precipitous and negative. For more on this, see M. Lupton, “To Clone or Not to Clone – Whither the Law?” (1999) 18 *Med. Law* 107-123.

<sup>14</sup> D. Morgan, *supra*, note 2, at 341, quoting Hans Jonas, a German philosopher. See also S. Murphy, “Biotechnology and International Law” (2001) 42 *Harv. I.L.J.* 47-139, and S. Benatar, “A Perspective from Africa on Human Rights and Genetic Engineering” in J. Burley (ed.), *The Genetic Revolution and Human Rights* (Oxford: OUP, 1999) 159-189, for a discussion of the science and its applications and the human rights concerns surrounding its use.

<sup>15</sup> UNESCO is a specialized agency formed pursuant to art. 57 of the United Nations Charter.

contribute “more fully to the construction of a common human destiny grounded on the essential values of mankind.”<sup>16</sup> He understood that, like developments on the scientific side, effective legal and ethical responses would have to be coordinated globally. An international initiative reliant on universal standards derived largely from the International Bill of Rights (IBR), which includes the Universal Declaration of Human Rights (UDHR),<sup>17</sup> the International Covenant on Civil and Political Rights (ICCPR),<sup>18</sup> and the International Covenant on Economical, Social and Cultural Rights (ICESCR),<sup>19</sup> could be coordinated through UNESCO.<sup>20</sup> Thus, in 1993, UNESCO’s newly created International Bioethics Committee (IBC) began drafting an international bioethics instrument specifically directed at human rights and genetics.<sup>21</sup>

<sup>16</sup> F. Mayor, “Preface” in *Proceedings of the First Session of the IBC* (Paris: UNESCO, 1994).

<sup>17</sup> Universal Declaration of Human Rights, GA Res. 217A(III), UN GAOR, 3d Sess., 67th Plen. Mtg., UN Doc. A/811 (1948).

<sup>18</sup> International Covenant on Civil and Political Rights, GA Res. 2200, UN GAOR, 21st Sess., Supp. No. 16, UN Doc. A/6316 (1966), 993 U.N.T.S. 171, and its Optional Protocol, GA Res. 2200, UN GAOR, 21st Sess., Supp. No. 16, UN Doc. A/6316 (1966).

<sup>19</sup> International Covenant on Economical, Social and Cultural Rights, GA Res. 2200, UN GAOR, 21st Sess., Supp. No. 16, UN Doc. A/6316 (1966), 993 U.N.T.S. 3.

<sup>20</sup> Authored by a broad cross-section of ideologically opposed states in the aftermath of WWII, and enjoying a high level of consensus in a variety of cultures, the IBR (or parts of it) is widely accepted as representative of universal standards. Its “universal” status is bolstered by the inclusion of its key principles in numerous international and regional instruments. For example, see the European Convention on Human Rights (1950), the American Convention on Human Rights (1969), the African Charter on Human and Peoples’ Rights (1981), the Arab Charter on Human Rights (1994), and many other Conventions and Declarations. Even the largely odious Bangkok Declaration (1993) evokes a common understanding of equality and non-discrimination. Otherwise it has been roundly and correctly criticized as a cynical and politically-motivated relativistic instrument intended to empower specific Asian regimes against opposition, both domestically and internationally: see H. Samuels, “Hong Kong on Women, Asian Values and the Law” (1999) 21 H.R. Quart. 707-734, and E. Lee, “Human Rights and Non-Western Values” in M. Davis (ed.), *Human Rights and Chinese Values* (Oxford: OUP, 1995) 72-90, at 87-88.

For more on the IBR, its history and universality, see A. Taylor, *supra*, note 8, at 502-505, K. Appiah, “Citizens of the World” in M. Gibney (ed.), *Globalizing Rights* (Oxford: OUP, 2003) 189-232, M. Glendon, “The Forgotten Crucible: The Latin American Influence on the Universal Human Rights Idea” (2003) 16 Harv. H.R.J. 27-40, at 27 and 31, R. Andorno, “Biomedicine and International Human Rights Law: In Search of a Global Consensus” (2002) 80(12) WHO Bulletin 959-963, R. Macklin, *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine* (Oxford: OUP, 1999), J. Mann *et al.*, “Human Rights and Public Health” in J. Mann *et al.* (eds.), *Health and Human Rights* (London: Routledge, 1999) 7-20, S. Goonesekere, “Nationality and Women’s Human Rights: The Asia/Pacific Experience” in A. Byrnes *et al.* (eds.), *Advancing the Human Rights of Women: Using International Human Rights Standards in Domestic Litigation* (London: Commonwealth Secretariat, 1996) 86-100, at 87-88, A. Cassese, *Human Rights in a Changing World* (Cambridge: Polity Press, 1990), T. Buergenthal, *International Human Rights in a Nutshell* (Minnesota: West Publishing Co., 1988), at 17-18.

<sup>21</sup> This overt linking was a predictable step in the evolution of both disciplines. Human rights, from the UDHR to the present, has been motivated by the desire to safeguard “human dignity” generally. Bioethics (often framed by autonomy, beneficence, non-maleficence and justice), although directed at enhancing the availability and quality of healthcare, often both draws and impacts on “human dignity”. For more on “human dignity”, see paras. 1 and 5 of the Preamble and art. 1 of the UDHR, R. Andorno, *ibid.*, at 960, O. Schachter, “Human Dignity as a Normative Concept” in H. Steiner & P. Alston (eds.), *International Human Rights in Context*, 2d ed. (London: Cambridge U. Press, 2000), 400-402, at 400-401, R. Dworkin, *Taking Rights Seriously* (Cambridge: Harvard U. Press, 1977), and others.

The offspring of UNESCO's efforts, the Universal Declaration on the Human Genome and Human Rights (the Declaration), was adopted by the General Conference in 1997,<sup>22</sup> and by the UN General Assembly in 1998.<sup>23</sup>

The following article assesses both the process of the Declaration's creation and the substance of its provisions, with a view to assessing its significance and determining whether the rationale for drafting it (as identified above) has been realized. Part 1 undertakes a "process examination". First, it considers the Declaration's authors (UNESCO/IBC) to determine whether they were entitled and best situated to act. Second, it highlights the drafting process to determine whether what was adopted was ethical or democratic and thereby in keeping with the spirit of the instrument itself. Part 2 undertakes a "substance examination". First, it reviews some of the pre-existing international human rights instruments that influenced the Declaration's creation to determine whether a new instrument was warranted. Second, it considers the content of the Declaration to determine whether it advances coherent foundational values supported by effective substantive rights and, in addition, fills any gaps left by the pre-existing regime. Having considered these issues, one may be able to draw some conclusions about the significance of the Declaration and its proper place in the international genetic and human rights regulatory pantheon.

## **2. Process Examination: The Authors & The Drafting Process**

### **2.1 Authorship: The role/remit of UNESCO and the IBC. Is their leadership in the genetics and human rights field appropriate?**

Pursuant to its Constitution,<sup>24</sup> UNESCO is comprised of a General Conference,<sup>25</sup> an Executive Board,<sup>26</sup> and a Secretariat.<sup>27</sup> It is further divided into five specialized

---

<sup>22</sup> UNESCO General Conference Resolution 29 C/17, UNESCO GC, 29th Sess. (1997).

<sup>23</sup> UN General Assembly Resolution A/RES/53/152, UN GAOR, 53rd Sess. (1998).

<sup>24</sup> Adopted in London on November 16, 1945, when representatives from 37 states signed it, it came into force on November 4, 1946, when 20 signatories ratified it. The Constitution can be viewed at [www.portal.unesco.org/en/ev.php-URL\\_ID=Constitution](http://www.portal.unesco.org/en/ev.php-URL_ID=Constitution) (May 5/04).

<sup>25</sup> The General Conference is the primary decision-making body of UNESCO (see art. IV). It is comprised of representatives of member states (each of which have one vote) and associate member states together with observers from non-member states, NGOs and intergovernmental organizations (IGOs). The General Conference meets every 2 years to elect Executive Board members, determine policy directions and assess programs, and make budgetary decisions. UNESCO derives its budget from member state assessments and extra-budgetary funding from NGOs, IGOs and other private sector sources. For more on the General Conference and budget/funding information, see [www.portal.unesco.org/en/ev.php-URL\\_ID=The Organization](http://www.portal.unesco.org/en/ev.php-URL_ID=The Organization) (May 10/04).

<sup>26</sup> The Executive Board is composed of representatives from 58 member states. Representatives are elected to reflect the cultural and geographic diversity of UNESCO. It meets twice per year to ensure that the decisions made by the General Conference are implemented and to prepare the work of the General Conference. Its tasks are defined by the Constitution (see art. V), the General Conference and agreements with the UN, various specialized UN agencies and other IGOs, and includes advising the UN. For more on this body, see [www.portal.unesco.org/en/ev.php-URL\\_ID=The Organization](http://www.portal.unesco.org/en/ev.php-URL_ID=The Organization) (May 10/04).

<sup>27</sup> The Secretariat, structured and governed by art. VI of the Constitution, consists of the Director-General and his or her staff. The Director-General is the executive head of UNESCO. His or her role is to formulate policies, proposals of action and budgetary recommendations for the General Conference. The staff, some 2,000 people from 160 states as of April 2003, implement existing and



Sectors, one of which is the Human & Social Sciences Sector.<sup>28</sup> The IBC, established within this Sector, was an *ad hoc* body comprised of 50 independent experts in anthropology, biology, genetics, law, medicine and philosophy, chosen by the Director-General to reflect the geographical and cultural diversity of UNESCO. It was approved by the General Conference<sup>29</sup> and eventually made permanent.<sup>30</sup> The IBC's general purposes are to:

- 1) Raise issues and promote reflection and the exchange of ideas regarding developments in the life sciences;
- 2) Make recommendations and encourage action among decision-makers (i.e., states, IGOs, NGOs and domestic bioethics committees); and
- 3) Disseminate the principles set out in the UDHR and apply them to new technologies.<sup>31</sup>

Its specific remit was to conduct a debate on the ethical, social, and human consequences of genetic developments and prepare an international instrument for the protection of the human genome.<sup>32</sup>

The Director-General opined that UNESCO must “play its full role in the world of the future [by conducting] a world-wide debate on the ethical, social and human consequences of the development of the life sciences.”<sup>33</sup> Insofar as the IBC's drafting process created a global and cross-cultural debate on genetics, bioethics and human rights, it fulfilled this goal and was in conformity with UNESCO's Constitutional purposes, which are, *inter alia*, to:

- 1) Develop and increase the means of communication between peoples and employ them to promote mutual understanding and a truer/better knowledge of each other's lives;<sup>34</sup>
- 2) Advance, through educational, scientific and cultural relations, the objectives of international peace and common welfare of mankind;<sup>35</sup> and

---

newly developed programs and maintain 53 field offices around the world. For more on this body, see [www.portal.unesco.org/en/ev.php-URL\\_ID=The Organization](http://www.portal.unesco.org/en/ev.php-URL_ID=The+Organization) (May 5/04).

<sup>28</sup> The HSS Sector is tasked with helping people understand and interpret the developing social, cultural and economic environment. It does this by: (1) studying what is (providing empirical research); (2) anticipating what could be (providing philosophical critiques); and (3) determining what should be (providing ethics and human rights-based analyses). Generally, it analyzes societal trends and tries to steer them in directions supportive of the UDHR and its own institutional goals of promoting education, discourse and peace. See [www.portal.unesco.org/en/ev.php-URL\\_ID=Social Sciences](http://www.portal.unesco.org/en/ev.php-URL_ID=Social+Sciences) (May 20/04).

<sup>29</sup> UNESCO General Conference Resolution 27 C/5.15, UNESCO GC, 27th Sess. (1993).

<sup>30</sup> UNESCO Executive Board Resolution, UNESCO EB, 154th Sess. (1998).

<sup>31</sup> See [www.portal.unesco.org/en/ev.php-URL\\_ID=Social Sciences/Ethics/Bioethics/IBC](http://www.portal.unesco.org/en/ev.php-URL_ID=Social+Sciences/Ethics/Bioethics/IBC) (May 21/04).

<sup>32</sup> Justice M. Kirby suggests that the impending completion of the HGP made the choice of acting on genetics self-evident: M. Kirby, “Inquiry re: Declaration” from [jsaleh@hcourt.gov.au](mailto:jsaleh@hcourt.gov.au) (May 20/04).

<sup>33</sup> H. Espiell, *Birth of the Universal Declaration on the Human Genome and Human Rights* (Paris: UNESCO, 1999), at 1.

<sup>34</sup> Preamble, para. 6.



- 3) Contribute to peace and security by promoting educational, scientific and cultural collaboration among states in order to further universal respect for justice, rule of law and human rights affirmed for all peoples without discrimination.<sup>36</sup>

These purposes are to be realized through constitutionally-sanctioned activities, including cooperation with other specialized agencies whose interests and activities are related to its own purposes,<sup>37</sup> and encouragement of cooperation and personnel exchanges among states in all branches of intellectual activity.<sup>38</sup> UNESCO is also empowered to collaborate in the preparation of international agreements to promote the free flow of ideas by word and image.<sup>39</sup> Indeed UNESCO collaboration in the preparation of international instruments is neither new nor novel:

*UNESCO, the premier international organization in the fields of science, culture, communications and education, has the legal authority to negotiate and sponsor the codification and implementation of international instruments advancing technology, public health and human rights.*<sup>40</sup>

Its initiative is also defended as being:

*... perfectly in line with the objectives of this international organization ... [which is] “to contribute to peace and security by promoting collaboration among the nations through education, science and culture in order to further universal respect for justice, for the rule of law and for human rights ...” because it is clear that the increasing access to the human genome has profound implications for human rights ...*<sup>41</sup>

Although UNESCO’s Constitution confers authority to develop “conventions” and “recommendations”,<sup>42</sup> not “declarations”, it is generally accepted that

---

<sup>35</sup> Preamble, para. 7.

<sup>36</sup> Article I(1).

<sup>37</sup> Article XI.

<sup>38</sup> Article I(2)(c).

<sup>39</sup> Article I(2)(a).

<sup>40</sup> A. Taylor, *supra*, note 8, at 481. In fact, UNESCO has served as the forum for the preparation of some 33 international conventions and a host of other instruments, including the Convention Against Discrimination in Education (1960), the Declaration of the Principles of International Cultural Cooperation (1966), the Recommendation Concerning the Status of Scientific Researchers (1974), the Convention Concerning the Protection of Natural and Cultural World Heritage (1972), and the Declaration on Race and Racial Prejudice (1978). See F. Mayor, Report of the Director-General, UNESCO, 29th Sess., Annex D, UNESCO Doc. 29C/3 (1997).

<sup>41</sup> R. Andorno, “Seeking Common Ground on Genetic Issues: The UNESCO Declaration on the Human Genome” in J. Sandor (ed.), *Society and Genetic Information: Codes and Laws in the Genetic Era* (Budapest: Central European University, 2003), 105-123, at 105. [hereinafter paginated 1-12]

<sup>42</sup> See art. IV(4).

recommendations and declarations, both of which are non-binding (or “soft law”), are substantively similar and the use of the latter does not invalidate the initiative.<sup>43</sup>

Although UNESCO was still rehabilitating its tarnished reputation,<sup>44</sup> its IBC was the only global forum for in-depth bioethical reflection.<sup>45</sup> Few other international organizations could claim the same level of experience and knowledge regarding science, its cross-cultural impact, and its significance for human rights.<sup>46</sup> Further, none of UNESCO’s competitors or compatriots in the human rights field represent any measurable improvement in representation or structure, nor do the instruments they have drafted represent any significant improvement in form or content.<sup>47</sup> Finally, it is not inappropriate for non-state entities like UNESCO to take the lead on emerging issues. This is an unavoidable symptom of the new global era where sovereignty has been re-conceptualized and such institutions (i.e., IMF, WIPO, WTO) take on international law-making functions.<sup>48</sup>

Given the above, UNESCO’s IBC was probably the body best suited to prepare the first international instrument on genetics. At the very least, it was within its broad remit to do so.

## **2.2 Process: The mechanics of drafting the Declaration and the deviations. Was the process ethical and democratic?**

It was recognized at the outset that the IBC’s task would be delicate because of the diversity of ethical positions founded on divergent value systems conditioned by disparate cultural and religious traditions and societal and economic standings.<sup>49</sup> The highlights of the drafting process, which was conducted by a multi-national group of experts conscious of the cultural, legal, philosophical, and religious milieu, are:

---

<sup>43</sup> See A. Taylor, *supra*, note 8, at 508, and the sources cited in his note 247. For more on the considerations which went into the choice of drafting a declaration as opposed to some other form of instrument, see H. Espiell, *supra*, note 33, at 27-31.

<sup>44</sup> A. Taylor, *ibid*, at 525-526. UNESCO’s turbulent history and controversial activities, which led to US (1985) and UK (1986) withdrawal, is well documented: see M. Allen, “UNESCO and the ILO: A Tale of Two Agencies” (1985) 1 J.L. Ethics & Pub. Pol. 391, and M. Finnemore, “International Organizations as Teachers of Norms: The UN Educational, Scientific and Cultural Organization and Science Policy” (1993) 47 Int’l Org. 565.

<sup>45</sup> See H. Espiell, *supra*, note 33, at 1, and [www.portal.unesco.org/en/ev.php-URL\\_ID=SocialSciences/Ethics/Bioethics/IBC](http://www.portal.unesco.org/en/ev.php-URL_ID=SocialSciences/Ethics/Bioethics/IBC) (May 21/04).

<sup>46</sup> A. Iles, “The Human Genome Project: A Challenge to the Human Rights Framework” (1996) 9 Harv. H.R.J. 27-60, at 43.

<sup>47</sup> The UN Commission on Human Rights represents an alternative drafting institution, but has remained largely inactive, appearing to adopt the view that the existing human rights framework is adequate. In any event, an examination discloses no obvious advantage (procedurally or otherwise) with respect to preparing an international instrument on genetics. The Council of Europe has drafted the more broadly applicable Biomedicine Convention (1998), but the Council of Europe is a regional body, its Convention reflects the Declaration in several respects, and it has not mandated significant departures from the existing member practices. See A. Iles, *ibid*, at 39-42.

<sup>48</sup> R. McCorquodale & R. Fairbrother, “Globalization and Human Rights” (1999) 21 H.R. Quart. 735-766, at 736-737.

<sup>49</sup> N. Lenoir, “Report to the Director General on the Human Genome” in *Proceedings of the First Session of the IBC* (Paris: UNESCO, 1994) 3-20, at 16.

- Drafting took 4 years. The IBC's Legal Commission conducted 8 meetings and the IBC held 4 sessions. These bodies debated some 9 drafts.<sup>50</sup> Although there was a body of key contributors, every member of the IBC took part in the drafting of one article or another, and most member states contributed.<sup>51</sup> The Declaration was finalized by a committee of government representatives from 81 member states.<sup>52</sup>
- The IBC used broad consultative procedures; it solicited learned papers and considered opinions from various domestic and international bodies, and circulated at least one draft and questionnaire to some 300 bodies—scientific, philosophical, legal, ethical, intergovernmental, and UN—for comments and suggestions.<sup>53</sup>
- Drafting was accompanied by a host of related activities, such as support of fledgling bioethics training programs, conduct of issue-specific genetic-related surveys, and sponsorship of various bioethics-related domestic statutes.<sup>54</sup> These fostered dialogue amongst public decision-makers, experts and others and thereby broadened mutual understanding and enhanced (bioethical) education with a view to promoting justice, human welfare, and human rights principles.<sup>55</sup>

It is claimed that the overall institutional framework emphasized the ethical elements of scientific development, and that the drafting procedure modeled an “ethical” drafting process based on the articulation of “consensus-based” principles and rights, and was free of political influence and vested interest pressures.<sup>56</sup> Although this is largely true, politics played some part, most noticeably in the late addition of specific prohibitions in arts. 11 and 24. Regarding the art. 11 cloning prohibition, it has been said:

*We know that the statement defining cloning as ‘contrary to human dignity’ was a late addition by UNESCO to the text originally produced by [the IBC]. Moreover, one of the [IBC] members ... has*

---

<sup>50</sup> H. Espiell, *supra*, note 33.

<sup>51</sup> See H. Espiell, *ibid.* F. Mayor (Spain), H. Espiell (Uruguay) and N. Lenoir (France) dominate the documentary background: see [www.portal.unesco.org/en/ev.php-URL\\_ID=Social\\_Sciences/Ethics/Bioethics/IBC\\_Documents](http://www.portal.unesco.org/en/ev.php-URL_ID=Social_Sciences/Ethics/Bioethics/IBC_Documents) (May4/04). Special contributions from B. Knoppers (Canada), S. Altman (USA), and Gonzalo Yanez (Chile) are noted within the documents: see H. Espiell, *ibid.*, at 53. N. Lenoir, B. Knoppers and M. Jean (Canada) are also singled out by subsequent IBC members: see M. Kirby, *supra*, note 32, Q-5.

<sup>52</sup> A. Taylor, *supra*, note 8, at 509.

<sup>53</sup> And the response resulted in a “wealth and diversity of contributions” which were discussed at the Fifth Meeting of the Legal Commission, September 25, 1995: see H. Espiell, *supra*, note 33, at 67-78, and Annex VII.

<sup>54</sup> F. Mayor, “Address by the Director General” in *Proceedings of the First Session of the IBC* (Paris: UNESCO, 1994) 63-67, at 63, and N. Lenoir, “Speech” in *Proceedings of the Third Session of the IBC*, vol. I (Paris: UNESCO, 1995), 111-114, at 113.

<sup>55</sup> H. Espiell, *supra*, note 33, at 2.

<sup>56</sup> N. Lenoir, *supra*, note 5, at 172, N. Lenoir, *supra*, note 49, at 16, and N. Lenoir, *supra*, note 54, at 113, wherein she described the process as “ethical” in that it was “transparent and interactive”.

*reported that ‘several delegations proposed not to rush in condemning any particular technique, including cloning’.*<sup>57</sup>

and:

*It is my belief that the inclusion of specific reference ... [to] banning reproductive cloning was added after the IBC itself had finished its work and as a consequence of initiatives of ... Professor Mayor.*<sup>58</sup>

Similarly, a prohibition of germ-line interventions was originally considered inappropriate,<sup>59</sup> but nevertheless found its way into art. 24, lending support to the allegation that the Declaration is a “dignitarian instrument” created by a “dignitarian alliance”:

*... ‘[D]ignitarian’ because its fundamental commitment is to the principle that human dignity should not be compromised; ... ‘[A]lliance’ because there is more than one pathway to this ethic – Kantian and communitarian as well as religious ... [and each are represented in the supporters to the Declaration]. ... [T]he dignitarian view gives voice to the interests of conservatism, constancy and stability ... [and] the concern that we should ... hang on to those parts of the human condition that are familiar and reassuringly ‘human’ [and it is exemplified by the reproductive cloning and germ-line intervention prohibitions].*<sup>60</sup>

Analysis of the drafting process permits only ambivalent conclusions. Certainly it was ethical in that it solicited the learned opinions of a swathe of experts, and the text was subject to extensive debate and numerous drafts. In short, and as suggested above, it was inclusive of culture- and rights-sensitive men and women from across the globe who attempted to articulate an instrument capable of addressing both science and rights. All told, a compelling argument could be made in support of the “commendable and largely ethical” process. However, the process suffered from at least a couple incidents of political wrangling and compromise. One might legitimately argue that compromise and negotiation/wrangling support the democratic aspect of the Declaration’s creation, and obviously trade-offs are a common feature in the democratic process. However, the trade-offs identified above appear to have been associated with tactics of questionable procedural merit in that they may have been achieved “out-of-process”. The resultant provisions are the most controversial and

---

<sup>57</sup> J. Harris, *supra*, note 1, at 64, who quotes M. Revel as disclosing the discord or lack of unanimity on this point.

<sup>58</sup> M. Kirby, *supra*, note 32, Q-6. For more on the politics that shaped the final version of the Declaration, see M. Revel, “Human Reproductive Cloning, Embryo Stem Cells and Germline Gene Intervention: An Israeli Perspective” (2003) 22 Med. Law 701-732.

<sup>59</sup> H. Espiell, *supra*, note 33, at 58, citing the comments at the 5th Meeting of the Legal Commission. In 1990, CIOMS concluded that the possibility of germ-line interventions should remain open: A. Taylor, *supra*, note 8, at 496.

<sup>60</sup> R. Brownsword *et al.*, *supra*, note 11, at 4-5. See also D. Dwyer, “Beyond Autonomy: The Role of Dignity in Biolaw” (2003) 23 Ox. J.L.S. 319.

generally viewed as the least justified.<sup>61</sup> Nonetheless, one cannot conclude that they detract from the propriety of UNESCO actions.

### 2.3 Summation

The Declaration was a response to the dramatic and alarming rate of scientific advances, particularly genetic ones. Its conception was marked by several themes: fear that science would irreversibly damage a fundamental aspect of humanity; hope that a just society is within human capabilities; and concern that we are far from that society and sliding in the wrong direction. Despite the negative triggers, it was a response by a body (UNESCO) entitled and reasonably well placed to act and to offer leadership in this field. UNESCO's decision to act signifies its view that international human rights standards can be transmogrified into subject-specific ethical rules that can guide biomedical practices regardless of geographic location or cultural prevalence, and its desire to push society in a "safe" direction with a specific and comprehensive instrument. Care was taken to ensure that the IBC was a representative international body reflective of UNESCO/global membership. Principles may have given way to the tactics of a specific philosophical/legal perspective,<sup>62</sup> with consequences that may arguably detract from the legitimacy of the drafting process and the acceptability of the Declaration, but the process was *largely* a model of how to ethically draft in an international forum.

### 3. Substance Examination: The Predecessor And The Provisions

Human dignity and the conviction that it should not be compromised play a dominant role in both the Declaration and the pre-existing international human rights regime (i.e., the IBR).<sup>63</sup> Although one might assess their value on how they advance this principle, "human dignity" on its own is not a useful analytical tool.<sup>64</sup> It is too vague and flexible,<sup>65</sup> capable of being defined both as:

- The idea that humans, regardless of status or capacity and by virtue of being "human", have intrinsic or inherent value and worth and are deserving of respect;<sup>66</sup> and

---

<sup>61</sup> See the discussions in Revel, *supra*, note 58, and J. Harris, "Clones, Genes and Human Rights" in J. Burley (ed.), *supra*, note 14, 61-94.

<sup>62</sup> Or to the natural rigours and pitfalls of the democratic process, depending on one's view.

<sup>63</sup> N. Lenoir, *supra*, note 10, at 16-17. "Dignity" is mentioned some 15 times: see Preamble and arts. 1, 2, 6, 10, 11, 12, 15, 21 and 24.

<sup>64</sup> S. Cowen, "Can Dignity Guide South Africa's Equality Jurisprudence?" (2001) 17 S.A.J.H.R. 34-58, at 37-40, states that dignity lacks clear meaning and must be supplemented by other values to usefully serve as a conceptual tool.

<sup>65</sup> R. Macklin, *supra*, note 20, at 220-221. M. Bedjaoui, *Proceedings of the Third Session of the IBC*, vol. 1 (Paris: UNESCO, 1995), at 144, stated that "human dignity" is "full of fragility".

<sup>66</sup> See D. Beylveeld & R. Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford: Oxford U. Press, 2001), at 15-17, and P. Walsh, "Principles and Pragmatism" (1995) 3 M.L.R. 237-250.

- The particular cultural understanding of the inner moral worth of the human “person” (which can include family, friends, foes, ancestors and successors) and his or her proper political relation with society.<sup>67</sup>

It is used both as an empowering force (grounding individual rights and freedom of choice) and as a constraining force (forbidding “instrumentalization” of the body).<sup>68</sup>

As such, both the pre-existing regime and the Declaration are more appropriately evaluated by assessing the extent to which they coherently define and further other dignity-related values, being, in no particular order, (1) autonomy, (2) equality, and (3) solidarity. Autonomy rests on the broad notion of valuing people as physical, psychological, economical and legal entities.<sup>69</sup> It affirms the human capacity for self-determination that entitles individuals to some level of self-rule, and it therefore grounds rights such as confidentiality and freedom from coercion.<sup>70</sup> Equality also rests on the worth/value of humans. It promotes justice by stipulating that all humans are equal before the law and deserving of equitable treatment by, and fair distribution of, the benefits of law. It grounds the right not to be discriminated against.<sup>71</sup> Solidarity, comprising elements of beneficence and non-maleficence, is the natural unity of humanity: the common cause with fellow man. It imposes on everyone duties of mercy, altruism, and charitableness and the duty to avoid doing harm.<sup>72</sup>

These three values are arguably more definable and measurable than “human dignity” standing alone. Also and importantly, they capture multiple conceptions of “human dignity”, which, I believe, increases their validity. Although they may not be completely free of the vagaries that limit the utility of “human dignity” as a measuring stick (i.e., a certain interpretive flexibility), they are more easily dealt with and therefore preferable.

### 3.1 Predecessor to the Declaration: The values and rights of the pre-existing regime. Was it adequate to address the “new genetics”?

The international human rights regime was and continues to be dominated by the IBR. Although not specifically directed at the potential negative consequences of genetic advances, the IBR may be relevant in that it promotes autonomy, equality and solidarity and their related rights, and it can be applied in a variety of contexts,

<sup>67</sup> See K. Pannikar, “Is the Notion of Human Rights a Western Concept?” 383-389, at 387, and R. Howard, “Dignity, Community and Human Rights” 398-400, at 399, both in H. Steiner & P. Alston (eds.), *supra*, note 21.

<sup>68</sup> D. Beyleveld & R. Brownsword, “Human Dignity, Rights and Genetics” in R. Brownsword *et al.* (eds.), *supra*, note 11, 69-88, at 88. R. Brownsword, “Regulating Human Genetics: New Dilemmas for a New Millenium” (2004) 12 M.L.R. 14, online at <http://web.lexis-nexis.com/professional>, [hereinafter paginated 1-19], at 4, describes the forces that oversaw the creation of the Declaration as a “dignitarian alliance” who uses “human dignity” as a constraining force.

<sup>69</sup> See S. Aksoy & A. Elmali, “The Core Concepts Of The ‘Four Principles’ Of Bioethics As Found In Islamic Tradition” (2002) 21 Med. Law 211-224, G. Dworkin, *The Theory and Practice of Autonomy* (UK: Cambridge University Press, 1988), at 6. T. Beauchamp & R. Faden, *The History and Theory of Informed Consent* (Oxford: OUP, 1986), at 7.

<sup>70</sup> O. O’Neill, *Autonomy and Trust in Bioethics* (UK: Cambridge University Press, 2002), at 23.

<sup>71</sup> T. Beauchamp & J. Childress, *Principles of Biomedical Ethics*, 4th ed. (Oxford: OUP, 1994), at 52.

<sup>72</sup> For more on these concepts, see S. Aksoy & A. Elmali, *supra*, note 69, at 53.

including the genetic context. Further, the IBR is supported and reaffirmed by subsequent instruments directed specifically at the interaction of science and human rights.

With reference to the touchstones identified above, the significance of this regime for genetics is as follows:

- Autonomy-related provisions erect rights (1) of access to healthcare advances, (2) of non-coercion of patients/subjects, and (3) to pursue research. Article 25 (UDHR) and art. 12 (ICESCR) confirm an individual right to healthcare. Article 27 (UDHR) states that everyone has the right to participate in cultural life and share in scientific advancement, thus supporting the right to undertake research. Article 7 (ICCPR) erects the necessity of participant consent. All of these rights are logically applicable to and exercisable in the genetic context, such as the right of access to genetic healthcare, the right to genetic research, and the requirement of consent to genetic treatment and research. The Tehran Declaration,<sup>73</sup> noting that scientific developments may endanger individual or group rights and human dignity, recommends that states study problems regarding the “protection of the human personality and its physical and intellectual integrity in view of the progress in biology, medicine and biochemistry.”
- Equality-related provisions erect rights of non-discrimination. Article 7 (UDHR) states that all are equal before the law and are entitled to equal protection of the law. This could be invoked to bar discrimination based on genetic disability or predisposition. Article 23 (UDHR) affirms the family as entitled to protection and could be used to prevent states from limiting choices about marriages or reproduction based on genetics. Articles 22 and 23 (UDHR) enshrine the rights of employment, choice of employment, favourable work conditions, and realization of the economic, social and cultural rights essential to human dignity. They are supportive of a requirement that states prevent alterations to social relations and practices that reduce the access of some groups to employment, healthcare, and insurance.<sup>74</sup>
- Solidarity provisions erect rights to share in genetic advances and duties to share these advances. Article 27 (UDHR) and art. 15 (ICESCR) state that *everyone* has the right to “share in” or “enjoy” the benefits of scientific advancement and resultant applications. Individuals or groups could use these to demand access to new treatments and to share in advances currently enjoyed unevenly. Article 12 (ICESCR) directs states to take steps for the prevention of occupational, endemic, and epidemic diseases. The UN General Assembly has called for states to take measures to ensure that the results of science and technology are used only for the benefit of humankind.<sup>75</sup> Although not directed at humans *per se*, the Convention on Biological

---

<sup>73</sup> Final Act of the International Conference on Human Rights, Tehran, UN Doc. A/CONF.32/41 (1968).

<sup>74</sup> A. Iles, *supra*, note 46, at 36.

<sup>75</sup> General Assembly Resolution 48/140, UN GAOR, 48th Sess., Supp. No. 49, UN Doc. A/48/49 (vol. 1) (1994).



Diversity<sup>76</sup> addresses the need to protect, *inter alia*, biological diversity, which includes genetic diversity.<sup>77</sup> It espouses sharing technology so as to exploit and preserve biological and genetic resources,<sup>78</sup> and it envisions sharing knowledge, research, and biotechnology with developing states.<sup>79</sup>

In addition, and on a more general note, the Scientific and Technological Progress Declaration<sup>80</sup> emphasizes the need to neutralize present and possible future harmful consequences of scientific developments, including their interference with individual and group human rights.

All told, the IBR and subsequent instruments create a matrix of values and rights evocable in the genetics context. They could be used by states, which must take statutory steps to secure their domestic realization, as touchstones for formulating ethical, human-rights-sensitive genetic policy.<sup>81</sup> Individuals or groups could also use them as support for human rights claims: the Optional Protocol to the ICCPR has enforcement provisions that can be invoked by individuals.<sup>82</sup> With respect to monitoring, the UN Commission on Human Rights has already invited states and NGOs to inform it of measures taken to ensure that science develops in a manner respectful of human rights.<sup>83</sup>

In short, although the IBR and related pre-existing instruments were not created with genetics in mind, they form a useful complex latticework of instruments. However, that latticework has gaps in its protection. For example, the pre-existing regime does not make explicitly clear that the genome needs protection. Further, it fails to address, much less answer, some of the dominant health and human rights related concerns and questions raised by the new genetics. For example:<sup>84</sup>

- 1) What criteria should be used for identifying permissible genetic research?
- 2) What type of consent is most appropriate in the genetic context?
- 3) How can we promote and realize the even distribution of benefits?

---

<sup>76</sup> (1992) 31 I.L.M. 818, signed by 157 states.

<sup>77</sup> See the Preamble.

<sup>78</sup> See arts 1, 2 and 7.

<sup>79</sup> See arts. 12, 15, 16, 17 and 18.

<sup>80</sup> Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind, GA Res. 3384, UN GAOR, 30th Sess., UN Doc. A/Res./3384 (1975).

<sup>81</sup> Such an approach is discussed in B. Knoppers, "Reflections: The Challenge of Biotechnology and Public Policy" (2000) 45 McGill L.J. 559-566.

<sup>82</sup> See arts. 1 to 6.

<sup>83</sup> CHR Resolution 91, UN GAOR, CHR, 49th Sess., 67th mtg., UN Doc. E/CN.4/1993/122 (1993). See also Resolution 71 (1997) (non-discrimination in the field of health) and Resolution 11 (1989) (human rights and bioethics).

<sup>84</sup> The field of genetics and human rights obviously raises many, many more questions than these. For example, see J. Legemaate, "Integrating Health Law and Health Policy: A European Perspective" (2002) 60 Health Policy 101-110, M. Latham & S. Leonard, "The European Convention on Biomedicine and the Human Rights Act 1998: Grasping the Nettle of Biomedicine?" in J. Tingle *et al.* (eds.), *Healthcare Law: The Impact of the Human Rights Act 1998* (London: Cavendish, 2001) 331-346, and more. However, these are the more obvious and regularly debated questions that the IBR leaves unanswered, and therefore grounds support for the creation of *additional* regulation.

- 4) Is the patenting of human genetic material appropriate and under what conditions?
- 5) How can we combat the rise of science-based determinism and discrimination?
- 6) What are the proper protection and disclosure mechanisms for genetic information?

Although this does not represent a comprehensive list of genetically related concerns, it represents some of the main questions left unanswered, and lends support to Prof. Mayor's view that something specific, modern, and proactive was necessary: a need existed and the Declaration was designed to respond to that need.<sup>85</sup>

### **3.2. Content of the Declaration: The values and rights in the Declaration. Is it a comprehensible and internally coherent instrument that fills the gaps?**

The Declaration contains a Preamble which recalls the ideals and remit of UNESCO, identifies the international instruments relied on and highlights the risks represented by genetic advances. Its seven Sections purport to lay down universal bioethical standards that will ensure genetic advances are not used in a manner contrary to human rights.<sup>86</sup> Conclusions can be drawn about the Declaration's significance and proper place in the international bioethical and human rights scene based on the extent to which the Declaration (1) gives the touchstone values of autonomy, equality and solidarity effect in the genetic context through the articulation of understandable and internally consistent substantive rights, and (2) answers the questions identified above which represent gaps in the pre-existing regime.

#### *3.2.1 Autonomy*

Although usually relating to individually exercisable choice, the international application of autonomy can be complicated by its occasional use with reference to the social unit.<sup>87</sup> This has implications when it comes to autonomy-based rights such as confidentiality and freedom from coercion. The Declaration appears to acknowledge this tension, but fails to deal with it, never consistently articulating its concept of the value or rationally supporting its patchwork support for autonomy's concomitant rights.

---

<sup>85</sup> H. Espiell, *supra*, note 33.

<sup>86</sup> Section A, "Human Dignity and the Human Genome" (arts. 1-4), is directed at protecting the human genome itself. Section B, "Rights of the Persons Concerned" (arts. 5-9), deals with procedures relating to the genome, which are likely to have physical, psychological, economic, social or other consequences for the individual or the group to which she or he belongs. Section C, "Research on the Human Genome" (arts. 10-12), addresses limitations on the right of research. Section D, "Conditions for the Exercise of Scientific Activity" (arts. 13-16), enunciates state and individual responsibilities regarding research. Section E, "Solidarity and International Cooperation" (arts. 17-19), espouses solidarity and international cooperation with the hope that it will result in all humanity benefiting from genetic advances. Section F, "Promotion of the Principles Set Out in the Declaration" (arts. 20-21), is aimed at promotion of the Declaration core principles and the establishment of bioethics as part of the culture of the future. Section G, "Implementation of the Declaration" (arts. 22-25), unique to a non-binding instrument, suggests that states take all appropriate measures and makes implementation recommendations, including the outline of UNESCO activities.

<sup>87</sup> See A. Taylor, *supra*, note 8, at 491 and his note 98.

Article 4 constitutes an outright autonomy limitation. It prohibits individuals from gaining financially from the genome “in its natural state”. The absence of this prohibition from the Preliminary Outline, and the debate over its content and impact on existing intellectual property rights, suggest that it was a matter of controversy and that the Declaration represents a compromise position:

*[S]hould there be a reference in the preamble to the international instruments concerning the protection of intellectual property rights? [S]hould a new article be added ... for the prohibition of all forms of appropriation or marketing of the results of genome research? Any prohibition ... of patenting the results of [genetic] research ... would have a significant impact on research itself, since prohibiting all possibility of gaining commercial benefits would be liable to discourage research ... .*

*It would be difficult to address the ... patenting of human genetic sequences in the UNESCO context alone, particularly in view of the economic interests at stake. The need for balance between the imperative of free access to the results of genome research and the investment essential for developing that research must be borne in mind. ...*

*The Chairperson ... was of the opinion that UNESCO could not go any further in the declaration with regard to the question of patentability, in view of the many interests at stake.*<sup>88</sup>

Given the ability of third parties to gain financially from the human genome through the patenting of genes and gene sequences,<sup>89</sup> the ethical soundness of a prohibition limited to individual gene originators is questionable.<sup>90</sup> Indeed, the IBC subsequently issued an Advice<sup>91</sup> alleging strong ethical grounds for excluding the human genome from patentability, and recommending that the WTO clarify that patenting the human genome is contrary to the public interest. The prevalence of cross-national/cultural opposition to patenting,<sup>92</sup> and the potential for industry/economic concerns to drive genetic policy (particularly in developing states trying to close the economic gap with

---

<sup>88</sup> H. Espiell, *supra*, note 33, at 58-59.

<sup>89</sup> In America, Australia, Europe and Japan. In South Africa, the courts have endorsed the idea that patents create useful incentives for pharmaceutical companies to supply healthcare providers and invest in research: see *Syntheta (Pty) Ltd. v. Janssen Pharmaceutical NV et al.*, [1999] 1 S.A. 85 (C.A.).

<sup>90</sup> See R. Brownsword, “Dolly, Dignity and the Genetics Debate” (1998) 148 New L.J. 413, and D. Beylerveld & R. Brownsword, “Patenting Human Genes: Legality, Morality and Human Rights” in J. Harris (ed.), *Property Problems: From Genes to Pension Funds* (London: Kluwer, 1998) 9-24.

<sup>91</sup> Advice of the IBC on the Patentability of the Human Genome, UNESCO IBC, 8th Sess., Paris, September 12-14, 2001.

<sup>92</sup> See C. Leng, “Human Genome and Population Genetics Research and the Third World: Some Points for Consideration” in *Proceedings of the Third Session of the IBC*, vol. II (Paris: UNESCO, 1995) 37-45, at 39-40, who identifies a host of organizations mobilizing against patenting, including NGOs, IGOs, religious and indigenous groups.

industrialized states),<sup>93</sup> further suggest that the Declaration's failure to squarely address patenting is a serious *lacunae*.<sup>94</sup>

Article 5, although not as philosophically confused as the Declaration's stance on gene ownership and financial gain, nonetheless triggers concerns. It stipulates, *inter alia*, that all patients/subjects:

- a) Are entitled to full disclosure of the potential risks and benefits of the treatment/research;
- b) Must be competent and provide free and informed consent, or authorization must be otherwise obtained according to law; and
- c) Have the right to decide whether to be informed of results.

On its face, the article seems beneficial and obviously addresses concerns about autonomy. However, the utility of its stipulations in practice are unclear, a fact which reduces the Declaration's comprehensibility and, by implication, its significance.

For example, stipulation (a) offers little guidance as to the meaning of "full disclosure".<sup>95</sup> In the genetic context, physicians and counselors ought to communicate the (i) objective, type and reliability of tests; (ii) risk of tests; (iii) possibility of unexpected results; and (iv) possible psychophysical repercussions. Post-testing, physicians and counselors ought to (i) verify that all information has been understood; (ii) inquire regarding consequences; and (iii) provide or direct patients or subjects to support.<sup>96</sup> No such criteria are provided.

Stipulation (b) offers no guidance as to the components of or participants in ethical "consent" in the genetic context. Should it in all circumstances be exercised by the subject/patient alone or jointly with others? Can it be exercised entirely by others? Under what conditions? Inclusion of the requirements that consent be "obtained in the manner prescribed by law" and "guided by the person's best interests" were allegedly added to accommodate those jurisdictions where the family or community play a role in consent decisions.<sup>97</sup> Many argue that it is never proper to dispense with first-person consent.<sup>98</sup> Even if it can be, the Declaration fails to recognize that

<sup>93</sup> See S. Pepa *et al.*, "Research and Trade in Genetics: How Countries Should Structure for the Future" (1998) 17 *Med. Law* 437-454.

<sup>94</sup> For more on gene patenting generally, see M. Kirby, *supra*, note 4, at 45-46, G. Laurie, "Patenting Stem Cells of Human Origin" [2004] 2 *E.I.P.R.* 59-66, R. Gold, "Biomedical Patents and Ethics: A Canadian Solution" (2000) 45 *McGill L.J.* 413-435, R. Ford, "The Morality of Biotech Patents: Differing Legal Obligations in Europe" [1997] *E.I.P.R.* 315-318, and L. Bently & B. Sherman, "The Ethics of Patenting: Towards a Transgenic Patent System" (1995) 3 *Med. Law* 275-291.

<sup>95</sup> An issue that is discussed in J. Kegley, "Genetics Decision Making: A Template for Problems with Informed Consent" (2002) 21 *Med. Law* 459-471, and J. Kegley, "An Ethical Imperative: Genetics Education for Physicians and Patients" (2003) 22 *Med. Law* 275-284.

<sup>96</sup> A. Conti *et al.*, "Informed Consent When Taking Genetic Decisions" (2004) 23 *Med. Law* 337-355, at 344.

<sup>97</sup> H. Espiell, *supra*, note 33, at 76.

<sup>98</sup> See C. Ijsselmuiden & R. Faden, *supra*, note 58. A. Iles, *supra*, note 46, at 28, points out that, ultimately, human rights centre on the individual's life and experience and seek to alleviate unfairness and avoid injury starting with the individual. R. McCorquodale & R. Fairbrother, *supra*, note 48, at 766, quote Eleanor Roosevelt as follows: "Where after all do universal human rights begin? In the small places close to home ... Yet they are the world of the individual person: the neighbourhood he lives in; the school or college he attends; the factory, farms or office where he works. Such are the

consent is not an event but a process the participants of which may develop but which must *start* with the individual,<sup>99</sup> and it fails to grapple with the implications for the patient/subject's art. 7 privacy rights when first-person consent is dispensed with (i.e., who properly receives information, how much information, etc.).

The permissiveness of stipulation (c) has been described as contrary to solidarity with family members,<sup>100</sup> but is defended as an important autonomy-based right because it empowers the affected patient/subject to determine his or her exposure to information that may have severe repercussions for their psychological well being.<sup>101</sup>

Article 5(d) deals with research protocols, but fails to enunciate any clear or precise rules, and has been criticized for its vagueness.<sup>102</sup>

The one unambiguous autonomy-based provision is art. 8, which erects the individual right to reparation for damage sustained as a result of genomic interventions. The IBC oscillated between the word "reparation" and "compensation" but settled on the former, which offers states greater latitude to fashion such remedies as best suits their legal and cultural traditions.<sup>103</sup> Inclusion of the word "direct" was intended to bar actions by descendants.<sup>104</sup>

Overall, autonomy is not defined, support for autonomy (as defined above) is equivocal, and its related rights are left very much to the vagaries of domestic lawmakers, a fact which is further emphasized by art. 9, a provision which ultimately abdicates the very function of the Declaration, which is to establish universal thresholds. More damaging than its failure to deal clearly or cohesively with autonomy as a value (i.e., what is it and is it essential in the genetics and rights settings), is its failure to offer sound guidance as to the minimum internationally acceptable ethical requirements for (1) observing consent and (2) protecting confidentiality where consent is not first-person. Even if individual self-rule is assumed, it fails to address how existing social, economic and political pressures may circumscribe or distort the choices individuals make in the genetic context.<sup>105</sup>

### 3.2.2 Equality

A common fear is that genetic information—which is increasingly specific, accurate and voluminous—will be used to define and classify people according to race, ethnicity, or other markers such as existence of deficiencies or physical/mental potentialities, and will generally become a tool by which to perpetuate existing or

---

places where every man, woman or child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere."

<sup>99</sup> K. Berger, "Informed Consent: Information or Knowledge?" (2003) 22 Med. Law 743-750.

<sup>100</sup> See J. Harris & K. Keywood, "Ignorance, Information and Autonomy" (2001) 22 T.M.B. 415-436.

<sup>101</sup> See R. Andorno, *supra*, note 41, at 6, where he notes that, in any event, the right is not absolute; physicians can override this aspect of confidentiality *per* art. 9 when treatment is available for others who may be affected.

<sup>102</sup> See A. Taylor, *supra*, note 8, at 510.

<sup>103</sup> H. Espiell, *supra*, note 33, at 59.

<sup>104</sup> H. Espiell, *ibid*, at 5.

<sup>105</sup> A. Iles, *supra*, note 46, at 44.

create new social, economic or power divisions and inequalities.<sup>106</sup> Thus, equality is a cornerstone value of the Declaration.<sup>107</sup>

Article 2 stipulates that everyone is equal in dignity regardless of their genetic make-up (i.e., even if new technology discloses genetic illness or predisposition). Together with art. 3, which claims that the genome evolves and is influenced by natural and social environments, it rejects genetic determinism, which tries to explain all human personality and behaviour on the basis of genes.<sup>108</sup> They “attempt to avoid the division of human society into ‘genetically valid’ and ‘genetically non-valid’ members, which would constitute a disastrous effect of scientific knowledge [and] ... would weaken the proper foundation of democracy.”<sup>109</sup>

Article 6 reflects the anti-discrimination policy common to many international instruments,<sup>110</sup> extending the prohibited grounds to genetic characteristics. However, this right never becomes “concrete” because the article offers no guidance as to what practices diminish an individual’s or group’s right to human dignity. For example, it does not address:<sup>111</sup>

- 1) The use of genetic markers to delineate groups;<sup>112</sup>
- 2) The significance of unequal access to genetic testing and treatment or the use of testing to determine access to treatment (i.e., surgeries, transplants, etc.); or
- 3) The use of genetic criteria to determine access to insurance, social benefits, employment, promotion, or property.

Further, it offers no insight as to what international law demands for equal treatment in light of one’s genetic circumstances—there are no samples of conduct that is unacceptable to underline the scope of the right). Finally, it makes no suggestions as to the appropriate consequences to states, other entities or individuals of infringing equality rights.<sup>113</sup>

---

<sup>106</sup> See A. Caplan, “Handle With Care: Race, Class and Genetics” in T. Murphy & M. Lappe (eds.), *Justice and the Human Genome Project* (Berkeley: U. of al. Press, 1994), and many more.

<sup>107</sup> See Preamble, paras. 1, 4 and 6.

<sup>108</sup> Genetic determinists try to explain all human personality/behaviour on the basis of genes. They draw teleological sustenance from behavioural geneticists, who try to isolate and identify genes relevant to specific behavioural traits and discover modes of intervention. For more on this, see D. Glick & H. Soreg, “Ethics, Public Policy and Behavioural Genetics” (2003) 5 I.M.A.J. 83-86, and National Research Council, “Human Rights and Human Genetic Variation Research” in M. Mann *et al.* (eds.), *supra*, note 56, 380-394.

<sup>109</sup> R. Andorno, *supra*, note 41, at 4

<sup>110</sup> For example, see the UDHR, the European Convention on Human Rights (1950), the Convention Concerning Discrimination in Respect of Employment and Occupation (1958), the Convention Against Discrimination in Education (1960), the International Convention on the Elimination on All Forms of Racial Discrimination (1965), the American Convention on Human Rights (1969), the Declaration on Race and Racial Prejudice (1978), the Convention on the Elimination of All Forms of Discrimination Against Women (1979).

<sup>111</sup> A. Iles, *supra*, note 46, at 47.

<sup>112</sup> On this point, N. Papadimitrou & A. Ryan, “Chief Scientist Bob May Lambasts Human Genetics Panel (2001) 7 Sci. Soc. 9, report that research continues to seek “intelligence genes”, “pleasant traits genes” and “gay genes”.

<sup>113</sup> Probably because there is no enforcement mechanism and thus no reason to develop sanctions

Article 7 ties into art. 6 by addressing equality in relation to genetic information; it aims to avoid discrimination by keeping such information confidential.<sup>114</sup> Specific protection was desired because genetic information:<sup>115</sup>

- Has implications for the current and future health of the patient or subject, asymptomatic blood relations, and future (unborn) relatives;
- Does not change from *in utero* to post-death, and offers some certainty in determining who will be affected by genetic disease;
- Is unique in the continued existence of massive shortfalls between conditions that can be identified and those that can be treated or cured; and
- Documented instances already exist of genetic discrimination in the insurance and employment contexts.<sup>116</sup>

However, art. 7 fails to address the circumstances when confidentiality may be breached or the criteria for doing so.<sup>117</sup>

Overall, although obviously supportive of equality, the Declaration is vague and equivocal and leaves much to domestic lawmakers with respect to defining what infringes this right. It also fails to address control over the activities of private corporations.<sup>118</sup>

### 3.2.3 Solidarity

The Declaration addresses solidarity both philosophically and practically. Philosophically, art. 1 affirms the “fundamental unity” of the human species and the value of preserving it. Art. 1 also stresses our inter-relatedness, common genetic blueprint and shared future by stating that the human genome is, symbolically, “the heritage of humanity”.<sup>119</sup> This notion is intended to convey the idea that the human genome engages a responsibility from and for all of humanity and:<sup>120</sup>

---

or remedies, although a provision akin to art. 8 might have been added to punctuate the right.

<sup>114</sup> The Declaration does not specify what constitutes a violation of the right to genetic privacy, but UNESCO has since adopted the International Declaration on Human Genetic Data (2003).

<sup>115</sup> H. Espiell, *supra*, note 33, at 4, R. Andorno, *supra*, note 41, at 6, I. Ellis *et al.*, “Retained Human Tissue: A Molecular Genetic Goldmine or Modern Grave Robbing? A Legal Approach to Obtaining and Using Stored Human Samples” (2003) 22 Med. Law 357-372, G. Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambridge U. Press, 2002), at 92-105, K. Mason *et al.*, *Law and Medical Ethics*, 6<sup>th</sup> ed. (London: Butterworths, 2002), at 207-212, T. Murray, “Genetic Exceptionalism and ‘Future Diaries’: Is Genetic Information Different from Other Medical Information?” in M. Rothstein (ed.), *Genetic Secrets* (London: Yale U. Press, 1997), 60-76. See also House of Lords Select Committee of Science & Technology, “Fourth Report: Human Genetic Databases” (2000) at [www.publications.parliament.uk/pa/Id200001/Idselect/Idscitech/57/5701.htm](http://www.publications.parliament.uk/pa/Id200001/Idselect/Idscitech/57/5701.htm) (Mar. 4/04).

<sup>116</sup> N. Holtzman & D. Shapiro, “The New Genetics: Genetic Testing and Public Policy” (1998) 316 B.M.J. 852-856, at 854. See also T. Lemmons, “Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws?” (2000) 45 McGill L.J. 347-412.

<sup>117</sup> A. Black, “Confidentiality and Drivers License Authorities” (2003) 22 Med. Law 333-343.

<sup>118</sup> A. Iles, *supra*, note 46, at 49. The issue of cross-border transfers of medical information and the desperate need for universal regulation of same is addressed in H. Abbing, “Medical Confidentiality and Electronic Patient Files” (2000) 19 Med. Law 107-112.

<sup>119</sup> A phrase modified from the “common heritage of humanity”, which was coined by A. Pardo



- 1) Is not suitable for appropriation by any state or private entity;
- 2) Requires a management system in which all users have rights and benefits are shared; and
- 3) Is reserved for peaceful purposes and preserved for future generations.

Unfortunately, this premise is weakened by the Declaration's failure to address or condemn gene patenting, which represents the greatest risk of "appropriation" and which is currently "managed" through a "system" widely criticized as inappropriate to medicine, genetics, and the protection of human rights (the latter of which is not even a patentability factor).

On the practical level, although accepting that the right to pursue research, necessary for the progress of knowledge and freedom of thought, is a human right,<sup>121</sup> the Declaration's conception of solidarity is linked with state/group and individual duties rather than rights. With respect to states, the Declaration directs that they:

- Foster conditions favourable for ethical research, (2) ensure that research is not used for non-peaceful purposes, and (3) recognize the value of establishing multidisciplinary ethics committees independent from political, economic, scientific and medical authorities;<sup>122</sup>
- Ensure solidarity towards genetically vulnerable individuals, families and populations by fostering research on the identification, prevention and treatment of genetically-based and influenced diseases, both rare and endemic;<sup>123</sup>
- Practice international solidarity toward developing states by disseminating scientific knowledge so that advances can be enjoyed by everyone, and the rich/poor and developed/developing gap does not widen;<sup>124</sup>
- Encourage measures that will enable developing states to benefit from scientific and technological research.<sup>125</sup>

---

(Malta) and used in various instruments such as the European Convention on Human Rights (1950), the UNESCO Declaration of the Principles of International Cultural Cooperation (1966), the Declaration of Principles Governing the Seabed and Ocean Floor (1970), and the Convention on the Law of the Sea (1982). Although used in the Preliminary Outline, it was dropped in favour of the modified form because of fears that it might be interpreted in commercial terms or used to dilute individual rights in favour of eugenic policies: see H. Espiell, *supra*, note 33, at 3, and R. Ida, "Human Genome as Common Heritage of Humankind" in N. Fujiki & D. Macer (eds.), *Bioethics in Asia* (Tsukuba: Eubios Ethics Institute, 1998) 59-63.

<sup>120</sup> R. Andorno, *supra*, note 41, at 3.

<sup>121</sup> See art. 12, as well as the ICESCR, the UNESCO Recommendation on the Status of Scientific Researchers (1974), and Y. Dinstein, "Technological Development, Equality and Non-Discrimination" in L. Sicilianos & M. Gavouneli (eds.), *supra*, note 2, 215-222, at 216. See also *Huvig v. France* (1990), 12 E.H.R.R. 528 (E.C.H.R.), and *Niemietz v. Germany* (1992), 16 E.H.R.R. 97 (E.C.H.R.), in the European context.

<sup>122</sup> See arts. 14, 15 and 16.

<sup>123</sup> See art. 17. D. Resnik, "The Distribution of Biomedical Research Resources and International Justice" (2004) 4 D.W.B. 42-57, reports that less than 10% of research funds are directed at addressing the problems responsible for 90% of the world's burden of disease.

<sup>124</sup> See art. 18. See also the discussion in R. Andorno, *supra*, note 41, at 9.

However, it offers no guidance or concrete recommendations as to how solidarity between nations might be manifested (i.e., no models of global assistance to ensure access to genetic advances are identified).<sup>126</sup>

With respect to individuals, art. 10 stipulates that human rights must take precedence over research. Article 12 stipulates that the benefits of research and advances should be made available to all, and that research shall be directed to the improvement of health and relief from suffering. Article 13 identifies the ethical duties incumbent on every researcher (i.e., meticulousness, caution, intellectual honesty, and integrity). The Declaration also contains research prohibitions identified as contrary to human dignity; namely (1) human reproductive cloning (art. 11),<sup>127</sup> and (2) germ-line interventions (art. 24).<sup>128</sup>

These prohibitions belie claims that (1) the IBC is merely a forum for exchanging ideas and facilitating understanding that does not pass judgment on specific practices,<sup>129</sup> and (2) the Declaration enunciates principles, not regulates scientific or medical practice.<sup>130</sup> Although they are defended, in part, on the basis that domestic and international prohibitions already exist,<sup>131</sup> there is no indication how the processes are contrary to human dignity.<sup>132</sup> Indeed, the ethical basis of these blanket claims/bans is questionable, particularly when used to restrict practices which may pass ethical muster on a case-by-case basis as technology progresses and understanding increases.<sup>133</sup> Their inclusion has led to allegations that the Declaration ignores the fact that entirely beneficial consequences should be a factor in determining the propriety of practices.<sup>134</sup> In addition, they create certain internal inconsistencies:

*It is difficult to reconcile these different viewpoints, one saying that human dignity “makes it imperative not to reduce individuals to their genetic characteristics” and the other that “deliberate*

---

<sup>125</sup> See art. 19.

<sup>126</sup> As noted by A. Taylor, *supra*, note 8, at 510.

<sup>127</sup> Very generally, human reproductive cloning is a means of producing a human chromosomally and genetically identical to another. For more on the process, see M. Lupton, *supra*, note 13, and M. Revel, *supra*, note 58.

<sup>128</sup> Very generally, germline gene therapy is a means of producing a human using reproductive cells that have undergone a permanent genetic modification. For more on the process, see M. Revel, *ibid.*

<sup>129</sup> See F. Mayor, *supra*, note 54, at 66, and [www.portal.unesco.org/en/ev.php-URL\\_ID=SocialSciences/Ethics/Bioethics](http://www.portal.unesco.org/en/ev.php-URL_ID=SocialSciences/Ethics/Bioethics) (May 21/04).

<sup>130</sup> H. Espiell, *supra*, note 33, at 58, citing the comments at the 5th Meeting of the Legal Commission.

<sup>131</sup> R. Andorno, *supra*, note 41, at 7-9.

<sup>132</sup> Failure to ethically substantiate these claims is common among the cloning bans: see M. Lupton, *supra*, note 13, at 110-114.

<sup>133</sup> See the sound and incisive critique of the reproductive cloning ban by J. Harris, *supra*, note 61. Both D. Beylerveld & R. Brownsword, *supra*, note 66, at 155, and L. Ulrich, “Reproductive Rights and Genetic Disease” in J. Humber & R. Almeder (eds.), *supra*, note 2, 351-360, at 359, identify some ethical arguments supportive of cloning or “infant design” rights.

<sup>134</sup> R. Brownsword, *supra*, note 68, at 4-5.

*creation of genetically identical human beings is contrary to human dignity.*<sup>135</sup>

A more balanced approach providing reasonable criteria for consideration of practices currently viewed as questionable was inexplicably eschewed.

Overall, although the Declaration espouses solidarity (*via* researcher responsibilities and state sharing of biotechnological advances so everyone can benefit from emerging medical techniques), its position is not entirely coherent. With reference to the definition above, although the Declaration certainly seeks to avoid harm through certain of its provisions, it may be over-inclusive by banning practices which may help patients and ultimately promote beneficence and justice by expanding treatment options.

### 3.3 Summation

The above demonstrates that the Declaration addresses the values of autonomy, equality, and solidarity and their concomitant rights (consent, confidentiality, non-discrimination) and duties (information sharing, avoiding “dangerous” practices) in the genetic context in a broad manner only. It is claimed that the Declaration is:

- 1) An attempt to “get things moving on the international level [and] to stimulate further international and regional activity;”<sup>136</sup>
- 2) “[A] call to attention” to states to make them aware of the ethical issues that genomic research presents;<sup>137</sup>
- 3) “[N]ot ... a final expression of international consensus and policy on advances in genetic science [but] a first step toward stimulating international debate and cooperation,”<sup>138</sup> and
- 4) “[J]ust the first step towards the elaboration of an international biomedical law.”<sup>139</sup>

Viewed as such, and appreciating the need to accommodate diverse social, cultural, political, and socioeconomic backgrounds and the futility of seeking dramatic change, the Declaration is useful; an understandably cautious approach that distilled a few basic rules from harmonized principles.<sup>140</sup> So characterized, it has been described as “the most thorough global initiative to date addressing the need to protect human rights with respect to genetic advances.”<sup>141</sup> Further, the inclusion of implementation

---

<sup>135</sup> M. Revel, *supra*, note 58, at 710, who highlights the irreconcilability of arts. 2, 3 and 11.

<sup>136</sup> M. Kirby, *supra*, note 32, Q-1 and Q-3.

<sup>137</sup> R. Andorno, *supra*, note 41, at 10, cites an E. Benda (Germany), interview in the *Frankfurter Rundschau*, given on November 1, 1997.

<sup>138</sup> A. Taylor, *supra*, note 8, at 511.

<sup>139</sup> R. Andorno, *supra*, note 20, at 959.

<sup>140</sup> R. Andorno, *ibid*, at 962.

<sup>141</sup> A. Taylor, *supra*, note 8, at 509.

mechanisms could, in the long run, improve the continued life and relevance of the Declaration.<sup>142</sup>

Insofar as the above is true, the criticisms leveled against it may be overly specific/rigorous and unfair. However, this is an instrument that claims to offer guiding principles. As such, it should be expected to guide, but it fails to do so in many important respects (i.e., the core values were not addressed in a comprehensive, coherent or internally consistent manner, no new rights were articulated to match the new scientific reality, paradigmatic and systemic issues were ignored).<sup>143</sup> In addition:

*[T]he Declaration ... overlooks a wide variety of issues ... . For example, the Declaration does not discuss human embryo research, genetic techniques to choose the sex of children or the permissible uses of therapeutic abortion for genetic disorders, including the nature and extent of reproductive autonomy and the limitations on government interventions in reproductive decision-making.*<sup>144</sup>

Its failures may stem from its origins as a reaction to genetic advances (specifically cloning), its self-imposed time pressure,<sup>145</sup> or the political limitations under which the IBC worked.<sup>146</sup> Regardless, its “ cursory treatment of the most intricate problems ”<sup>147</sup> means that it only minimally advances the understanding of the interaction between genetics and the values and rights addressed.

Further, and more importantly, it suffers from the same weaknesses identified with respect to the pre-existing regime in that it fails to answer the questions important in the medical context that it left unanswered. Although identifying “ inappropriate ” research, it fails to defend its position (Q-1). It addresses consent, but not really in a manner wholly relevant to situations with genetic implications (Q-2). Although reiterating that benefits must be shared, it elaborates no mechanisms for even distribution (Q-3). It takes no stand on the patentability of human genetic material (Q-4). It certainly makes clear its position on determinism and discrimination, but offers no positive response when they raise their ugly head (Q-5). It identifies no disclosure mechanisms for genetic information (Q-6). By its frequent deference to domestic lawmakers, it fails to provide a universal response that will guard against

---

<sup>142</sup> M. Gavouneli, “ Binding Character and Implementation Control of International Instruments on Biomedicine ” in L. Sicilianos & M. Gavouneli (eds.), *supra*, note 2, 197-211, at 202-204. However, M. Wadman & D. Butler, “ UNESCO Declaration Lacks Legal Teeth ” (1998) 391 *Nature* 219, note that international supervision of state responses to non-binding Declarations is minimal. Further, UNESCO has had difficulty establishing itself as a centre for implementation: see A. Taylor, *supra*, note 8, at 528, and the sources cited in his note 405.

<sup>143</sup> For example, the public-private divide (all the more important in the new global reality) and the resultant gaps in protection were ignored. For more on this, see H. Undersmith & C. Chinkin, “ The Gender of *Jus Cogens* ” (1993) 15 *H.R. Quart.* 63-73.

<sup>144</sup> A. Taylor, *supra*, note 8, at 510-511.

<sup>145</sup> Given the rapidity with which scientific advances were proceeding, the IBC was encouraged to conclude its work with all due haste and, in any event, by 1998, the jubilee of the UDHR: see H. Espiell, *supra*, note 33, at 43-44.

<sup>146</sup> R. Andorno, *supra*, note 41, at 2, notes that “ the drafters ... were clearly aware of the fact that if they had decided to prepare a binding instrument, [it] would never have been approved. ”

<sup>147</sup> See A. Iles, *supra*, note 46, at 43. M. Gavouneli, *supra*, note 142, 197-211, also notes that the Declaration contains only vague normative content.

piecemeal legislation and a “race to the bottom”. As such, it comes under just criticism.

All told, the Declaration is not a failure, but an equivocal success; perhaps a better example of “knee-jerk reaction” than “lengthened foresight”. One could reasonably describe it as an exercise in pragmatic ethics that embodies a *reiteration* of *existing general* human rights principles in the genetic context. It *underlines* the importance of autonomy, equality and solidarity to genetics and *emphasizes* the need to ensure that advances reflect human rights standards, but it does little to articulate how this might be done “on the ground”. Ultimately, massive gaps remain, permitting dramatically varying practices. Although the issues are more clearly articulated in the genetic context by the Declaration, it fails to respond fully to those issues, and so the need that existed continues.

#### 4. Conclusion

The stunning genetic achievements of the late 20th and early 21st centuries necessitate “lengthened foresight”, not only because of the consequences they can have for future generations, but because the forms of oppression permitted by them are non-traditional (i.e., relating more to the often-invisible distribution of life opportunities).<sup>148</sup>

Globalization combined with the nature of genetics itself demands a cooperative and universalist regulatory approach. The pre-existing regime was neither cohesive nor specific enough to address the concerns raised by the new genetics. Thus, UNESCO and its IBC tried to improve matters and exercise this “lengthened foresight” through the Declaration.

The drafting process, which identified short- and long-term genetic issues, was perhaps UNESCO’s greatest success. The debate, the formation of an epistemic community,<sup>149</sup> and the simple existence of a genetics-specific instrument fostered further debate and prompted manifold bioethical activities that are ongoing.<sup>150</sup> These are unequivocal pluses.

---

<sup>148</sup> A. Iles, *ibid*, at 57.

<sup>149</sup> Which was considered necessary to the coordination and augmentation of biomedical treaties: see S. Murphy, *supra*, note 14, at 49.

<sup>150</sup> It was intended to “get things moving” and to “stimulate further regional and international activity”, and it has informed the work of many national bioethics committees: M. Kirby, *supra*, note 32, Q-14. Many genetics-related conferences, meetings, symposia and workshops have discussed the Declaration and it has informed the thinking of stakeholders in the genetic field: Secretariat, *Report and Evaluation of the Implementation of the Universal Declaration on the Human Genome and Human Rights*, UNESCO, 32nd Sess. of the Gen. Conf., UNESCO Doc. 32 C/23 (2003). In the UK, a non-UNESCO member, it was drawn on by the Human Genetics Advisory Commission and the Human Fertility and Embryology Authority, *Cloning Issues in Reproduction, Science and Medicine* (UK: HGAC/HFEA, 1998), and by the Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (UK: HGC, 2002): see R. Brownsword, *supra*, note 90, and M. Bale, “Inquiry re: Declaration” at [mark.bale@doh.gsi.gov.uk](mailto:mark.bale@doh.gsi.gov.uk) (May 14/04). See also G. Berlinguer & L. De Castro, *Report of the IBC on the Possibility of Elaborating a Universal Instrument on Bioethics*, UNESCO, 32d Sess. of the Gen. Conf., UNESCO Doc. SHS/EST/02/CIB-9/5, as well as [www.unesco.org](http://www.unesco.org) and [www.who.int](http://www.who.int) for further international activities, which include further UNESCO-sponsored ethical discussions, lectures and training programs.

For many reasons including vagueness and internal inconsistencies, the significance of the Declaration itself is more equivocal. Reliant on a great variety of cultural and political divisions, it manifests as an instrument of “limited ambition” (i.e., it fails to elucidate a readily comprehensible goal capable of pressuring responses and clearly guiding policy-making).<sup>151</sup> It thus fails to adequately provide the reasoned “lengthened foresight” that was considered so vital. Nonetheless, the Declaration, with its quiet and intermittent influence, must be considered a limited success.<sup>152</sup> Despite being an additional non-binding instrument in a field littered with unenforceable instruments, the Declaration is not irrelevant.<sup>153</sup> Indeed, time and state practice may eventually transform the Declaration from soft law into something more binding.<sup>154</sup>

A jurisdiction-by-jurisdiction analysis would be necessary to determine whether the Declaration’s primary values and concomitant rights have been recognized and given legal effect at the domestic level “out in the world”, and such is not within the scope of this article. From the practical advancement of these values and rights in the post-Declaration, one might draw some conclusions as to the “universality” of the Declaration. Similarly, the “universalizing dynamic” engendered by the Declaration is another question of interest which may warrant further consideration.

---

<sup>151</sup> A. Iles, *supra*, note 46, at 59.

<sup>152</sup> Based on a survey conducted in 2003, UNESCO claims that the Declaration is widely known and its principles have played a part in genetic or bioethical legislation or regulations in a number of member states: Secretariat, *supra*, note 150.

<sup>153</sup> For a discussion on non-compliance with international instruments, see J. Moore, “Enhancing Compliance with International Law: A Neglected Remedy” (1999) 39 Va. J.I.L. 881-1016.

<sup>154</sup> For more on the transformation of soft law into binding law, see M. Olivier, “The Relevance of ‘Soft Law’ as a Source of International Human Rights” (2002) 35 C.I.L.J.S.A. 289-307, at 294-301, who states that soft law is useful in the transitional stage of development when the content of international norms are vague and imprecise.