

THE QUEST FOR UNIVERSALITY: REFLECTIONS ON THE *UNIVERSAL DRAFT DECLARATION ON BIOETHICS AND HUMAN RIGHTS*

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ABSTRACT

This essay focuses on two underlying presumptions that impinge on the effort of UNESCO to engender universal agreement on a set of bioethical norms: the conception of universality that pervades much of the document, and its disregard of structural inequalities that significantly impact health. Drawing on other UN system documents and recent feminist bioethics scholarship, we argue that the formulation of universal principles should not rely solely on shared ethical values, as the draft document affirms, but also on differences in ethical values that obtain across cultures. UNESCO's earlier work on gender mainstreaming illustrates the necessity of thinking from multiple perspectives in generating universal norms. The declaration asserts the 'fundamental equality of all human beings in dignity and rights'¹ and insists that 'the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition'² yet it does not explicitly recognize disparities of power and wealth that deny equal dignity and rights to many. Without attention to structural (as opposed to merely accidental) inequities, UNESCO's invocation of rights is so abstract as to be incompatible with its avowed intention.

Experience within the bioethics community has shown that it is far easier to reach common ground at the level of practice (on

¹ United Nations Educational, Scientific and Cultural Organization (UNESCO). 2005. *Universal Draft Declaration on Bioethics and Human Rights*. SHS/EST/05/CONF.204/3REV. Paris, 24 June 2005. UNESCO. Article 10.

² *Ibid.* Article 14, paragraph (b).

the basis of ‘incompletely theorized agreements’) than moral principle.³ An important advantage of the international human rights framework alluded to in the opening paragraphs of the United Nations Educational, Scientific and Cultural Organization’s (UNESCO) *Universal Draft Declaration on Bioethics and Human Rights (UDBHR)*⁴ is its refusal to derive human rights from metaphysical first principles. The consensus reached in these earlier agreements, such as the *European Convention on Bioethics*,⁵ the *Bioethics Declaration* approved by the World Conference of Bioethics in Gijón,⁶ and the UNESCO document on the human genome,⁷ was possible only by focusing on concrete goals and bypassing any single overarching grand theory. Accordingly, the drafters of UNESCO’s *UDBHR* are to be commended for their attempt to forge a consensus around such practical goals as defining the moral conditions of scientific research and clinical trials. Yet, beneath the surface of the UNESCO document are theoretical presuppositions that undermine that intention. Here we focus on two underlying presumptions that impinge on the effort to engender universal agreement on a set of bioethical norms: the conception of universality that pervades much of the document, and its insufficient attention to structural inequalities that have a significant impact on health

CONCEPTS OF UNIVERSALITY

In proposing to draft ‘universal principles’ for bioethics, UNESCO has assumed the awesome responsibility of speaking across human differences in the name of global health. The task requires a critically formulated concept of universality.

³ This expression is borrowed from C. Sunstein. 2001. *Designing Democracy: What Constitutions Do*. New York. Oxford University Press.

⁴ UNESCO, *op. cit.* note 1.

⁵ Council of Europe. 1997. *Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine*. Oviedo, 4 Apr 1997. Spain. Council of Europe. Available at: <http://conventions.coe.int/treaty/en/treaties/html/164.htm> [accessed 11 July 2005].

⁶ International Society of Bioethics (SIBI). 2000. *Bioethics declaration of Gijon*. Gijon. SIBI. Available at: <http://www.sibi.org/ingles/ddc/bio.htm> [accessed 11 July 2005].

⁷ United Nations Educational, Scientific and Cultural Organization (UNESCO). 1997. *Universal Declaration on the Human Genome and Human Rights*. Paris, UNESCO. Available at: http://portal.unesco.org/shs/en/ev.php-URL_ID=1881&URL_DO=DO_TOPIC&URL_SECTION=201.html [accessed 11 July 2005].

Unfortunately, UNESCO's draft document simply relies on concepts of universality, rights, persons, and equality that derive from the logic of fraternity and Enlightenment philosophies of 'man's' common sense. As feminist philosophers have demonstrated, these concepts are not innocent and inevitably reflect a certain history of power.⁸ In this philosophical tradition, moral agency has been marked explicitly as male, white, and European in descent. Within this conceptual history women have been defined not as agents but as property, the medium of exchange through which bonds of brotherhood are elaborated. From Aristotle's account of her as a 'nutritive medium' to Hegel's sequestering of her apart from public life in the family where she tends the body, this tradition renders 'woman' a supplement to 'man's' agency, lacking the self-consciousness and rational capacities necessary for autonomous, self-directed activity. Moreover, as Irigaray has argued, this subjection of 'woman' through the denial of women's agency is reflected in other forms of subjection and hierarchies of power based on race, class, and ethnicity.⁹ The formidable task of articulating 'universal principles' requires a critical recognition of the implication of Enlightenment concepts of persons, rights, and equality in the hegemony of particular racial, cultural, and sexual identities.

By distancing itself from this conceptual history, the UNESCO project relies on abstract concepts of equality that obscure the real inequities that characterize contemporary ethical urgencies, and it fails to articulate a sense of universality ample enough to address the actual inequalities of power and resources that prevail across the globe. Figures of universality ought to call for and sustain solidarity without reducing the specificities of experience to any single generic form. Twice the draft document articulates respect for cultural diversity, only to qualify it by the injunction that such diversity may not be 'invoked to infringe upon human dignity, human rights and fundamental freedoms nor upon the principles set out in this Declaration'.¹⁰ What the document fails to recognize is that the diversity of human traditions and experiences, rather than being a threat to the project, is itself a crucial

⁸ See, e.g. L. Irigaray. 2000. A Two Subject Culture. In *Democracy Begins Between Two*. (trans by K. Anderson). London. The Athlone Press, p. 71, where Irigaray discusses this problem specifically in relation to the *Universal Declaration of Human Rights*.

⁹ *Ibid.* p. 152.

¹⁰ UNESCO, *op. cit.* note 1, Article 12.

resource for generating adequate universal norms.¹¹ Differences in human experience produce different images of the good, justice, and society, and genuinely universal norms can be reached only by thinking from these multiple perspectives. Such a strategy would contribute new figures through which to address persistent problems of moral and political life without which our thought will be too impoverished and too subject to legacies of power to respond to the real ethical urgencies before us.¹² Thus, it will be necessary to formulate ‘universal *Principles*,’ not only by considering ‘*shared* ethical values, (our emphasis)’ but also the differences in ethical values that obtain across cultures. UNESCO’s own work on ‘gender mainstreaming’ illustrates the necessity of thinking from multiple perspectives in generating ‘universal norms’.¹³ Moreover, the final draft of UNESCO’s declaration on bioethics contains a recognition that attention to ‘the position of women in society,’¹⁴ so often considered a special case in the Enlightenment tradition, constitutes, in fact, an important general approach to questions of justice and ‘social reality’.

Feminist bioethicists have taken the initiative in reframing bioethical norms in ways that are responsive to the disparity of social conditions that structure the lives of women and other marginalized social groups across multiple cultural traditions. They have sought to supplant the abstract individualistic bias that permeates the Western Enlightenment tradition with a contextualized understanding of social relations. Much effort to date has focused on reconstructing the conception of autonomy within bioethics to incorporate a relational perspective that recognizes

¹¹ United Nations Educational, Scientific and Cultural Organization (UNESCO). *Results of the Written Consultation on the Third Outline of the Text of a Declaration on Universal Norms on Bioethics (27 Aug 2004)*. Paris, 10 January 2005. UNESCO. Available at: http://portal.unesco.org/shs/en/file_download.php/e9d8dfce8497c221c4e620d11952dde1Consultation_en.pdf [accessed 11 July 2005]. The World Health Organization’s analysis of the final document also notes a ‘lack of clarity’ that derives from this ‘unresolved tension’ between ‘declaring universal norms’ and ‘wanting to accept local differences.’

¹² See M.C. Rawlinson. The Concept of a Feminist Bioethics. *J Med Philos* 2001; 26: 405–416.

¹³ Note S. Walby. 2003. *Genetic Mainstreaming: Productive Tensions in Theory and Practice*. Paris. UNESCO. Available at: http://portal.unesco.org/shs/fr/ev.php-URL_ID=7057&URL_DO=DO_TOPIC&URL_SECTION=201.html [accessed 8 July 2005].

¹⁴ UNESCO, *op. cit.* note 1, Preamble.

how networks such as family and social group ground and sustain individual identity. This work has major implications for reconsidering the full complement of bioethical norms specified in the UNESCO document.¹⁵ However, *Article 5* of the *UDDBHR* on 'autonomy and individual responsibility' continues the Enlightenment tradition of focusing on individual decision-making and conflicts among individuals, failing to recognize the sociality of ethical identity.

STRUCTURAL INEQUALITIES

An important theme in recent feminist bioethics scholarship is recognition that contemporary ethical urgencies tend to arise in relations that are *unequal*: doctor/patient, teacher/student, parent/child, boss/worker, or between the politically and economically powerful and those who are poorer, weaker, and disenfranchised. The UNESCO document asserts the 'fundamental equality of all human beings in dignity and rights'¹⁶ and insists that 'the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition';¹⁷ yet it does not explicitly recognize structural inequities of power and wealth that deny equal dignity and rights to many. For example, a person who cannot vote or drive in her own country or who is condemned by her village council to be raped in order to settle a dispute among men or whose children die of dysentery in the twenty-first century is not 'fundamentally equal'. Nor are the many women around the world whose lives are disrupted when multinational companies and technically oriented development projects irresponsibly impose changes that deprive their local economies of traditional markets and other resources required to meet subsistence needs and sustain their culture.

Without recognition of structural (as opposed to merely accidental) inequity, UNESCO's invocation of rights is so abstract as to be incompatible with its avowed intention. Its injunction 'to promote equitable access to medical, scientific, and technological developments, particularly in [developing countries]',¹⁸ is

¹⁵ Examples of this work include articles by S. Dodds, A. Donchin, and C. McLeod and S. Sherwin in C. MacKenzie and N. Stoljar, eds. 2000. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press.

¹⁶ UNESCO, *op. cit.* note 1, Article 10.

¹⁷ *Ibid.* Article 14, paragraph (b).

¹⁸ *Ibid.* Article 2, paragraph (vi).

painfully vacuous without recognition of interconnections between health and wealth in both the global North and global South. For instance, when comparisons are made between the living conditions of poor women in developed and developing countries, disparities between economies diminish considerably. Though the severity of their poverty may be greater in poorer countries, patterns of discrimination in developed countries are very similar, particularly within family units. Moreover, though imbalances in access to health care among economic groups and disparities in maternal/infant morbidity and mortality may not be as severe in richer countries, their injustice is all the more striking, as the resources needed to rectify such imbalances are more readily available. An analogous point can be made about violence against women. Data indicate that women are the victims of both public and private violence in similar proportions in both developed and developing countries.¹⁹

Article 14 on 'social responsibility and health' which defines health as a 'social and human good'²⁰ implies connections among health, poverty, political status, and education. But because they are presented as abstract goals, their urgency is not recognizable. Who could object to 'the reduction of poverty and illiteracy'²¹ or 'improvement of living conditions and the environment'?²² It has been amply demonstrated that, with a few notable exceptions (HIV/AIDS and inoculations), infrastructure development has a far greater impact on health than specific medical interventions. Women in the global South have questioned the effectiveness of large scale centralized programs and recommended that development assistance be adapted to local institutional structures and cultural environments.²³

More pertinent to the development of a global bioethics than the invocation of abstract norms, would be attention to the controversy between those who wish to limit bioethics and the scope

¹⁹ Cited by S. Moller Okin 1995. *Inequalities between the Sexes in Different Cultural Contexts*. In *Women, Culture and Development: A Study of Human Capabilities*. M. Nussbaum and J. Glover, eds. New York, Oxford University Press: 274–297.

²⁰ UNESCO, *op. cit.* note 1, Article 14, paragraph (b) (i).

²¹ *Ibid.* Article 14, paragraph (b) (v).

²² *Ibid.* Article 14, paragraph (b) (iii).

²³ N. Nzegwu. 1995. *Recovering Igbo Traditions: A Case for Indigenous Women's Organizations*. In *Women, Culture and Development: A Study of Human Capabilities*. M. Nussbaum and J. Glover, eds. New York, Oxford University Press: 444–465.

of the UNESCO document to 'emerging' issues in medicine and the life sciences linked to new knowledge and new technologies, such as the regulation of genetic research, and those who feel 'that the social dimension of bioethics should be at the heart of the future declarations.'²⁴ Taking a global perspective, even one limited to Anglo-European societies alone, 'persistent' issues of poverty, access to health care, education, and sustainable environmental resources have far more immediate bearing on health and bioethics than does the regulation of esoteric research. The social responsibilities enumerated in *Article 14* should be far more fully integrated throughout the document to emphasize the impact of structural inequalities on the health of populations, as well as the necessity of social transformations and redistributions of power in addressing them.

Implementation of health promotion programs that incorporate structural change and sustainable development will require recognition of culturally diverse social institutions and practices, as well as individual rights to bodily integrity. Struggles to insure women's reproductive rights have shown how easily bodily integrity can be sacrificed to state interests such as population goals. (Notably, in this draft in *Article 14*, which articulates 'access to quality health care' as a goal, an explicit mention of 'reproductive health' has been replaced by a generic reference to the 'health of women'²⁵). Prior international instruments, including the World Health Organization (WHO) definition of health and documents based on it, all extend the conception of health promotion to both groups and individuals.²⁶ Moreover, many rights proclaimed by the United Nations (UN), including the right to development, entitle individuals to goods which can only be satisfied through participation in specific communities or groups. Thus, while the preamble of the *UDDBHR* refers in passing to 'groups and communities,' a clearer recognition of the positive connection between cultural diversity and human rights is both practically and conceptually necessary.

²⁴ United Nations Educational, Scientific and Cultural Organization (UNESCO). 2005. *First Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics*. SHS/EST/05/CONF.203/5. Paris, 6 April 2005. UNESCO. Preamble. Available at: <http://unesdoc.unesco.org/images/0013/001395/139593e.pdf> [accessed 7 July 2005].

²⁵ UNESCO, *op. cit.* note 1, Article 14, paragraph (b) (i).

²⁶ J. Mann *et al.* 1999. Health and Human Rights. In *Health and Human Rights*. In J. Mann *et al.*, eds. London. Routledge: 7–20.

CONCLUDING REMARKS

One can only applaud the *UDDBHR*'s call for 'transparency'²⁷ and 'informed and pluralistic debate,'²⁸ but we fear that in failing to articulate the reality of ethical urgencies its effect will be to make them more opaque and further subject to the voices of partisan pressure groups and privileged elites. For what is implicit in the abstract language? Many readers may wonder whether this draft's emphasis on 'respect for the life of human beings'²⁹ in the discussion of human dignity and human rights is not an intervention on behalf of the antiabortion movement, rather than an expression of concern about capital punishment or state-sanctioned torture and executions. Similarly, can the statement on 'the freedom of scientific research'³⁰ and the need to ensure that it 'respect human dignity and protect human rights and fundamental freedoms'³¹ be read apart from recent debates on stem-cell research? And, can the injunctions on 'human solidarity' in *Article 13* or the statement on protecting the environment and future generations, or *Article 29* on the assessment and management of risk be read apart from the vast inequities of wealth and power that obtain within and across societies or apart from the way in which global development in the form of dams, power plants, conversion of arable land, industrial pollution, and the trafficking in women and children are integral features of our current historical situation and significantly influence human health?

One of us attended the January discussion of the draft document that was open to observers. We can only hope that the enormous amount of intelligent good will that has been invested in this project will be matched by the courage to give voice to the concrete ethical urgencies that beset us, as well as the creativity and imagination needed to reformulate rights and equalities so as to more adequately capture the morally significant diversity of human experience. Other UN documents such as the *Convention on the Elimination of All Forms of Discrimination Against Women*³² and

²⁷ UNESCO, *op. cit.* note 1, Article 18, paragraph (a).

²⁸ *Ibid.* Article 18, paragraph (c).

²⁹ *Ibid.* Article 2, paragraph (iii).

³⁰ *Ibid.* Article 2, paragraph (iv).

³¹ *Ibid.* Article 2, paragraph (iv).

³² United Nations (UN). 1979. *Convention on the Elimination of All Forms of Discrimination Against Women*. New York. UN. Available at: <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm> [accessed 11 July 2005].

the *Beijing Platform of Action*³³ provide good guidance in this effort.³⁴ Along with previous bioethics declarations and other recent UN documents, they advance international policies beyond their initial preoccupation with Western masculinist formulations of ethical norms by invoking a broad diversity of human voices.

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³³ United Nations (UN). 1995. *Beijing Declaration and Platform for Action*. New York. UN. Available at: <http://www.un.org/womenwatch/daw/beijing/platform/declar.htm> [accessed 11 July 2005].

³⁴ For further discussion of relevant documents see R. Petchesky. 2003. *Global Prescriptions: Gendering Health and Human Rights*. New York. Zed Books; A. Donchin. Converging Concerns: Feminist Bioethics, Development Theory and Human Rights. *Signs: Journal of Women in Culture and Society* 2004; 29: 299–324.