

injury control, and epidemics. A few entries examine even more specific topics, such as the public health ethics issues surrounding AIDS, the disposal of toxic wastes, and the responsibilities of health officials. Several articles examine warfare in terms of the moral responsibility to take care of the public's health in consideration of the vast global morbidity and mortality rates that it causes, comparable to illness and death caused in times past by epidemics.

What are the objectives of the Encyclopedia? In Reich's words, they are:

"to present, in integrated fashion, what is known about the scientific and clinical state of the art; to synthesise, analyze, and compare a full range of ethical positions taken on the problems of bioethics, as well as the social, legal and policy options in matters dealing with the life sciences and health care; to establish and explore the scope and methods of the field; to identify new and emerging issues and voices; to supply the reader with additional resources, especially bibliographies and important documents included in the Appendix; and to indicate where our knowledge of the ethics of the life sciences and health care is deficient and requires deeper exploration".

Reich points out that there are now 464 articles - all original, signed and previously unpublished - by 437 contributors (compared to 315 articles by 285 contributors in the original edition).

The Encyclopedia (whose price seems eminently reasonable in comparison with other contemporary publications) is beautifully bound and presented and is in a format that will withstand constant use by the purchaser (and, no doubt, her/his colleagues). It should be on the bookshelf of every reader of this newsletter.

Sev S. Fluss

The author, based in Geneva, was formerly Chief, Health Legislation, WHO. The views expressed are his own.

LINKS: NETWORKS OF IAB

FEMINIST APPROACHES TO BIOETHICS

Co-ordinator: Anne Donchin

Conference on Feminist Approaches to Bioethics, 24 - 25 November 1996

The above conference will be held in conjunction with the Third World Congress of the International Association of Bioethics. Sessions will cover the following issues:

1. Feminism, Disability and Genetics
2. Reflections on Autonomy, Agency, and Resistance
3. Integrating Justice and Care: A Feminist Approach to Bioethical Theory
4. Reproduction, Race and Class
5. Women's Health Issues in Emerging Economies
6. Collaborative Reproduction
7. Mindful Bodies
8. Fertility and Genetic Interventions
9. Justice in an Unjust World
10. Reconstructing Bioethics Discourse: Centering the Marginalised
11. Women and the Power/Right to Consent

NEWS FROM AROUND THE WORLD

The Bioethics Debate in Brazil

There are diverse pressing bioethical dilemmas in contemporary medicine: among others, germ-line gene therapy; patenting life; genetics and medically assisted procreation; the use of tissue from aborted fetuses; the ethics of research with human subjects.

Currently, the regulation of bioethics is a challenge in many countries, which raises simultaneously philosophical, technical, cultural and political issues. Bioethics needs to be approached in a more meaningful way. Besides embracing the judgements of health professionals and the theological viewpoint, it should also contemplate the distinctive attitudes of societies and groups.

In Brazil, the bioethical challenge is monumental because, as we know in advance, the broad participation of society in such a gigantic process will confront the barriers imposed by the cultural and social exclusion of large amounts of people among the nearly 160 million inhabitants.

In 1988 the Brazilian National Health Council (NHC) introduced the first guidelines for biomedical research involving human beings. In November 1995, pressed by the new bioethical dilemmas, the NHC decided to launch an open-minded scrutiny of the contents of its previous decree. The call for this assignment introduced the entire country in the discussion on the limits of public policy and the role of government on thorny bioethical issues.

These limits vary from one country to another, the differences expressing the cultural tradition of each nation. Thus, while the French government regulates bioethical issues at the federal level, in other European countries the model of professional self-regulation predominates. The United States regulatory model, although envisioning public funded research, has its rules broadly respected both in the public and private sectors.

Currently, most developed countries recognise the need for a national commission. Nevertheless, the question is whether a government should legislate on bioethical issues, including applicable punishments or, on the contrary, whether its main role should be to interpret and to implement bioethical principles to the myriad of controversies.

Many assert that legislation on bioethics risks the minimisation of some complex problems, threatens the research freedom in medicine and will induce negative impacts on the current vogue of paradigmatic changes in the

biomedical field. Lastly, to submit bioethics to Law, will necessarily discharge scientific facts to the domain of Justice, which often is not prepared to deal with Science.

A controversial aspect is related to the process of choice of the members of a national bioethical commission. This point sustains the polemic on elitism and legitimacy. Albeit qualified to assess the complex network of causes binded to ethical issues, the expert components of a commission will not invariably represent the values and the interests of all the social sectors, so as to accomplish moral judgements on behalf of society. This debate enlightens that, to be fully successful, the legitimacy of a national bioethics commission should be noticeable.

Also important are the dilemmas surrounding biomedical research with human subjects associated to some essential features of market economies. Currently, the regulation of biomedical research merges scientific and economic breakthroughs and limits between science and industrial interests are blurred. For this reason, bioethics legislators are frequently pressed by scientists, physicians and entrepreneurs fighting in a common arena of interests.

The regulation of bioethics for research involving drugs and medical equipment and devices does not focus on a disinterested field, where scientific information circulates freely between scientists exclusively aspiring to benefit humankind. Unfortunately, the rhetoric of solidarity frequently only masks vested interest existing in the international health market.

In this field saturated of economic interest, citizens/human subjects will be morally authorised, according to the ethical precept, to submit their bodies and minds to the advance of science, provided they give their informed consent. Under the guard of the civilian rights, the regulation of bioethics inherently has a liberal viewpoint of the human body submitted to scientific research.

We agree with the belief that the contemporary dominant bioethics approach, focusing on the edge of science and technology and resting almost exclusively in the reverence of individual autonomy, should

receive, in Brazil, a new approach to enclose those ethical issues imposed by social inequalities and by the right to the sustainable development of the country.

Finally, considering all the current bioethical complexity, we do believe that reviewing the bioethical guidelines in Brazil, in order to succeed, should be taken as a challenge by the entire society.

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HUGO Statement on the Principled Conduct of Genetic Research

The following statement has been issued by the HUGO Ethics Committee (Chair: Professor Bartha M. Knoppers, Faculty of Law, University of Montréal)

The HUGO Ethics Committee recommends:

That scientific competence is an essential prerequisite for ethical research. It includes appropriate training, planning, pilot and field testing, and quality control.

That communication not only be scientifically accurate but understandable to the populations, families, and individuals concerned and sensitive to their social and cultural context. Communication is a reciprocal process; researchers must strive to understand as well as to be understood.

That consultation should precede recruitment of possible participants and should continue throughout the research. Cultural norms vary, as do perceptions of health, disease and disability; of family and of the place and importance of the individual.

That informed decisions to consent to participate can be individual, familial, or at the

level of communities and populations. An understanding of the nature of the research, the risks and benefits, and any alternatives is crucial. Such consent should be free from coercion by scientific, medical or other authorities. Under certain conditions and with proper authority, anonymous testing for epidemiological purposes and surveillance could be an exception to consent requirements.

That any choices made by participants with regard to storage or other uses of materials or information taken or derived from them be respected. Such choices bind other researchers and laboratories. In this way, personal, cultural and community values can be respected.

That the recognition of privacy and protection against unauthorized access be ensured by the confidentiality of genetic information. Coding of such information, procedures for controlled access, and policies for the transfer and conservation of samples and information should be developed and put into place before sampling. Special consideration should be given to the actual or potential interests of family members.

That collaboration between individuals, populations and researchers and between programs in the free flow, access and exchange of information is essential not only to scientific progress, but also for the present or future benefit of all participants. Cooperation and co-ordination between industrialized and developing countries should be facilitated. An integrated approach and standardization of conditions and consents is essential to ensure viable collaboration and comparison of results.

That any actual or potential conflict of interest be revealed at the time information is communicated and before agreement is reached. Such actual or potential conflicts should also be reviewed by an ethical review committee before any research begins. Honesty and impartiality are cornerstones of ethical research.

That undue inducement through compensation for individual participants, families and populations should be prohibited. This prohibition, however, does not include agreements with individuals, families, groups,