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Social responsibility in a human rights context: the right to health and the right to enjoy the benefits of scientific progress

Donders, Y.

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United Nations
Educational, Scientific and
Cultural Organization

International Bioethics Committee (IBC)

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SHS/EST/08/CIB/WG-soc.resp./1
Paris, 30 July 2008
Original: English

MEETING OF THE WORKING GROUP OF IBC ON SOCIAL RESPONSIBILITY AND HEALTH

UNESCO Headquarters, Paris, 2 – 4 July 2008
Room XVI (Bonvin building)

REPORT OF THE MEETING

Division of Ethics of Science and Technology

I. INTRODUCTION

1. At its meeting of January 2008, the Bureau of IBC finalized the work programme of IBC for 2008-2009 and decided that IBC will continue its work on social responsibility and health in order to complete and finalize the report on this subject.

2. The IBC Working Group on Social Responsibility and Health established to this end (hereafter: the Working Group) met therefore at UNESCO Headquarters in Paris from 2 to 4 July 2009 (see the Agenda and Timetable of the meeting in Annex I). In regards to the composition of the working group, the renewal of the membership of IBC beginning 2008 allowed for the reconsideration of the composition of the group involving new as well as old members of the Committee (see the list of participants in Annex II). The Working Group could be further expanded to meet emerging technical or expert needs during the elaboration of the report.

3. As agreed upon by the Bureau of IBC, two experts, Prof. (Mr) Søren Holm and Dr (Mrs) Yvonne Donders, were invited to attend the meeting and provide in advance two extensive background documents: one focusing on the ethical implications of article 14 of the Universal Declaration on Bioethics and Human Rights (hereafter "the Declaration"), the other on the legal context and the link with human rights, i.e. the right to health and the right to benefit from scientific progress and its applications. Moreover, in order to ensure the inclusiveness of deliberation on this topic, Dr (Ms) Marie-Charlotte Bouësseau, Ethics, Equity, Trade and Human Rights, World Health Organization (WHO), was also invited to take part in the discussions of the Working Group.

4. The documents provided to participants included the Preliminary Draft Report on Social Responsibility and Health (Ref. SHS/EST/CIB-14/07/CONF.507/3) drawn up by the working group set up in 2006-2007, the two background documents (see par. 4 of this report), a historical overview of the work done since 2005 by UNESCO and IBC on the principle of social responsibility and health and the Compilation of comments made by IGBC on the Preliminary Draft Report (Re. SHS/EST/IGBC-5/07/CONF.204/9).

II. PRESENTATION OF THE BACKGROUND AND CONTEXT OF THE WORK OF THE GROUP AND PRELIMINARY EXCHANGE OF VIEWS ON THE STATUS OF THE PRELIMINARY DRAFT REPORT AND THE WORK METHODS FOR ITS FINALIZATION

5. After the welcome from Mr Adolfo Martinez Palomo, Chairperson of IBC and Chairperson of the Working Group, the Secretary-General of IBC, Mr Henk ten Have, presented the history of the engagement of IBC in the issue of social responsibility and health that led to the preparation of the Preliminary Draft Report. Mr ten Have recalled that, within the framework of IGBC, all Member States that expressed their opinion accorded great importance to the topic of social responsibility and health; however, while the current preliminary draft includes descriptive information and empirical health data, further reflection on ethical and legal dimensions of the principle are needed: the document should be reorientated, making it more concise and focusing on the bioethical aspects of social responsibility and health, which should constitute the core of the report.

6. The members of the Working Group agreed that the report should aim at facilitating the implementation of the principle of social responsibility and health as stated in the Declaration: it needs to be practically orientated, so as to support the responsibility of governments and all the members of society in solving health related problems, but at the same time academically rigorous in order to stand up to criticism. From this perspective, the sections of the preliminary draft report on the international framework and global health conditions, which indeed provide valuable data, should be shortened and/or moved as annexes to the report.

7. A lively discussion occurred around the issue of definitions. The Working Group considered definitions useful for a reader to better understand the Declaration and its principles, but a note of caution was sounded in respect to political and cultural sensibilities of defining certain terms.

III. PRESENTATION BY DR (MS) MARIE-CHARLOTTE BOUËSSEAU, WHO

8. The presentation by Ms Bouësseau of WHO focused on the importance given to the principle of social responsibility and health by her Organization, the history of the WHO's work towards this end, and the ways that WHO would benefit from the IBC report (see powerpoint presentation in Annex III).

9. From a WHO perspective, the report could greatly advance the principle of social responsibility and health if it could point to the ways to translate the principle articulated in article 14 of the Declaration, which enjoys universal consensus, into concrete policy options for its domestic implementation. In order to implement article 14 of the Declaration, Member States need to establish concrete mechanisms that address specific responsibilities in health, and the IBC report has a potential to assist States in conceiving such mechanisms.

10. As an example of existing WHO publications that would be enhanced by the IBC report by clarifying the principle of social responsibility and health, Ms Bouësseau mentioned the *Guidance on ethics and equitable access to HIV treatment and care* – a publication that stresses the role of national bioethics committees in promoting social responsibility and health, and *Pandemic preparedness* - a publication that analyzes national plans that deal with emergencies, including how to give priorities during emergency situations to vulnerable groups.

11. The discussion turned towards the possibilities of synergy between the work of UNESCO and WHO in the area of social responsibility and health. Towards this end, it was noted that both organizations emphasized the importance of national bioethics committees in providing guidance and policy advice to policy makers on the meaning of the concept and on moral and ethical obligations that the concept engenders. Further reflection was deemed necessary on the potential role and specific responsibilities of such committees in promoting awareness about the principle articulated in Article 14 of the Declaration among the various policy-making and societal levels.

12. It was also pointed out that research ethics in developing countries is an area missing in the preliminary draft report and the Group agreed that this is an issue for which the report could formulate concrete recommendations.

IV. PRESENTATION BY DR (MS) YVONNE DONDERS ON THE BACKGROUND DOCUMENT "SOCIAL RESPONSIBILITY IN A HUMAN RIGHTS CONTEXT: THE RIGHT TO HEALTH AND THE RIGHT TO ENJOY THE BENEFITS OF SCIENTIFIC PROGRESS"

13. Dr (Ms) Yvonne Donders, Deputy Director of the Amsterdam Center for International Law, University of Amsterdam, the Netherlands, presented the background paper drafted in order to enrich the deliberations of the IBC Working Group (see Annex IV) and focused on two human rights relevant to the Declaration – the right to health and the right to enjoy the benefits of scientific progress – and their link with the principle of social responsibility.

14. Ms Donders noted from the very outset that legally speaking social responsibility is, in principle, voluntary. It concerns going above and beyond what is called for by the law, which is referred to as legal responsibility. However, the idea of social responsibility, namely to eliminate irresponsible or unethical behaviour that might bring harm to the community, its people or the environment, is closely related to the idea of human rights. The presentation drew the attention of the Working Group members on the tripartite typology of State

obligations “to respect, protect and fulfil”, which are based not on specific treaty provisions, but rather result from all human rights, whether civil, political, economic, social or cultural in nature.

15. During the discussion, some members of the Working Group underlined the importance to refer to “the right to the highest attainable standard of health,” as it is formulated in Article 14 of the Declaration, instead of referring to the “right to health”, which is a general and highly contentious issue from a legal standpoint.

16. It was agreed that while justiciability is a key criteria for distinguishing between legal and ethical principles, it cannot be considered as a static and absolute criteria, since several rights of social and economic nature that used to be non-justiciable have recently been used in the courts of law to effectuate human rights-based claims. Moreover, since the focus of the report will be on moral responsibilities of concerned stakeholders, it should not be constrained with the principle of justiciability. A clear distinction should be made in the report between the legal, moral and social obligations and responsibilities: a special attention should be paid to focus on social responsibility within the human rights framework, while finding a balance between moral and legal considerations.

17. Much of the ensuing discussion focused on the dichotomy between domestic responsibility and international responsibility. It was mentioned that while human rights are of universal nature, the obligations are overwhelmingly domestic – States have obligations towards their citizens. Yet, great disparities in access to health exist not only within States, but between States, especially across the North-South divide, raising the question of international moral responsibility of developed countries towards developing countries. A suggestion was made to include in the report a principle of “double maximum” – the domestic obligation of States to maximize the equality of its citizens in access to health care, and the international responsibility of States to maximize solidarity and cooperation for assisting developing countries to build their health systems.

V. PRESENTATION BY DR (MR) SOREN HOLM ON THE BACKGROUND DOCUMENT ON ARTICLE 14 FROM A PHILOSOPHICAL PERSPECTIVE

18. Dr (Mr) Søren Holm, Professorial Fellow in Bioethics, Cardiff Law School, Cardiff University, United Kingdom, presented the paper on philosophical perspectives on social responsibility and health (see Annex V) by primarily focusing on moral obligations. The statement of Article 14 of the Declaration that “the promotion of health and social development for their people is a central purpose of governments that all sectors of society share” implies that health should be one of the most important purposes of governments; at the same time, promoting health and social responsibility is an obligation shared by all societal actors, private and public.

19. The presentation also urged participants to think about the scope of Article 14 in relation to other relevant articles of the Declaration, in particular Article 10 on equality, justice and equity; Article 13 on solidarity and cooperation; Article 15 on sharing of benefits; and Article 21 on transnational practices.

20. Members of the Working Group underlined the need for the report to address the role and moral obligations of all stakeholders, not only governments and to focus specifically on aspects of education, ethics committees, and the monitoring health and social development impacts. In this context, at least three of the existing activities carried out by the Division of Ethics and Science and Technology were mentioned as mechanisms already in place – the Ethics Education Programme (EEP), the Assisting Bioethics Committees (ABC) project and the Global Ethics Observatory (GEObs).

VI. FOLLOW-UP DISCUSSION AND THE STEPS FORWARD

21. The Working Group agreed on the following draft structure of the report recapturing the different points raised during the meeting:

I. Introduction
- a. Why UNESCO should engage in this topic, and why should it do so now?
- b. Article 14: the ethical and legal dimensions of social responsibility and health
- c. Relationship of Article 14 with other articles of the Declaration.

II. Social determinants of health/Constraints to healthcare access

III. Moral obligations and responsibilities of various stakeholders (from States to individuals)

IV. Special areas of focus
- a. Education
- b. Research
- c. Industry
- d. Healthcare
- e. Other

V. Recommendations
- a. National Bioethics Committees
- b. Other

VI. Conclusions

Annex I Historical overview of international initiatives in promoting the principle of Social Responsibility and Health

Annex II Global health conditions – an overview.

22. Whilst Professor Martinez Palomo and Professor Evans will be in charge of drawing up a first draft, the responsibility for written contributions was divided between the members of the Working Group, the Secretariat and the invited guests. Mr ten Have will contribute to the drafting of the introduction, Professor Gracia and Professor Semplici will contribute to the section on the concept of social responsibility and its ethical dimensions, while Dr Touré will write on constraints to healthcare access. Dr Wasunna and Dr Chandra committed to contribute to the section on research, Professor D'Empaire agreed to write on social responsibility and healthcare and Mr Solbakk to elaborate on the role of national bioethics committees in promoting social responsibility and health. The Secretariat will ensure the revision and up-dating of the two annexes if necessary and, as usual, will coordinate the exchanges between members of the group and the finalization of the draft report.

23. IBC will examine the draft report at its fifteenth (ordinary) session in October 2008 and will also have the opportunity to get comments and opinions from members of the Intergovernmental Bioethics Committee (IGBC) at the joint session of IBC and IGBC. Moreover, the draft report could also be circulated within the UN Inter-agency Committee on Bioethics to receive feedback from a broad range of UN agencies and other relevant intergovernmental organizations.

ANNEX I

Paris, 29 May 2008
Original: English/French

MEETING OF THE WORKING GROUP OF IBC ON SOCIAL RESPONSIBILITY AND HEALTH

UNESCO HEADQUARTERS, PARIS, 2 – 4 JULY 2008
ROOM XVI (BONVIN BUILDING)

AGENDA AND TIMETABLE

Wednesday 2 July 2008

10:00 a.m. – 1:00 p.m.

- **WORDS OF WELCOME FROM *MR ADOLFO MARTINEZ PALOMO*, CHAIRPERSON OF IBC**
- **PRESENTATION BY *MR HENK TEN HAVE,* SECRETARY-GENERAL OF IBC, OF THE BACKGROUND AND CONTEXT OF THE WORK OF THE GROUP**
- Preliminary exchange of views on the status of the preliminary draft report and the work methods for its finalization

Lunch ***Offered by UNESCO (UNESCO Restaurant – Fontenoy building)***

2:30 p.m. – 5:30 p.m.

- Introduction by the Chairperson
- Presentation by *Dr (Mrs) Marie-Charlotte Bouësseau*, Ethics, Equity, Trade and Human Rights, World Health Organization
- General debate and discussion on the related chapter(s) of the draft report

Thursday 3 July 2008

10:00 a.m. – 1:00 p.m.

- Introduction by the Chairperson
- Presentation by *Dr (Mrs) Yvonne Donders*, Deputy Director of the Amsterdam Center for International Law, University of Amsterdam, the Netherlands, on the background document "Social Responsibility in a Human Rights Context: The Right to Health and the Right to Enjoy the Benefits of Scientific Progress"
- General debate and discussion on the related chapter(s) of the draft report

2:30 p.m. – 5:30 p.m.

- Introduction by the Chairperson
- Presentation by *Dr (Mr) Soren Holm*, Professorial Fellow in Bioethics, Cardiff Law School, Cardiff University, United Kingdom, on the background paper "Article 14 of the Universal Declaration on Bioethics and Human Rights from a philosophical perspective"
- General debate and discussion on the related chapter(s) of the draft report

Friday 4 July 2008

10:00 a.m. – 1:00 p.m.

- Continuation of the discussion and definition of the timetable and tasks for the finalization of the draft report to be submitted to the fifteenth session of IBC (October 2008)

2:30 p.m. – 5:30 p.m.

- Continuation *(if necessary)*

ANNEX II

Paris, 23 juin / June 2008
Original : English/français

REUNION DU GROUPE DE TRAVAIL DU CIB
SUR LA RESPONSABILITE SOCIALE ET LA SANTE

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MEETING OF THE WORKING GROUP OF IBC
ON SOCIAL RESPONSIBILITY AND HEALTH

PARIS, 2 – 4 JUILLET / JULY 2008

LISTE PROVISOIRE DES PARTICIPANTS / PROVISIONAL LIST OF PARTICIPANTS

I. PRESIDENT DU GROUPE DE TRAVAIL / CHAIRPERSON OF THE WORKING GROUP

Prof. (Mr) Adolfo *MARTÍNEZ-PALOMO* (Mexique / Mexico)
Professeur émérite au Centre pour la recherche et les études avancées (CINVESTAV) /
Emeritus Professor Centre for Research and Advanced Studies (CINVESTAV)
Coordinateur du Conseil des sciences et des technologies de la présidence du Mexique /
Coordinator of the Council of Science and Technology of the Presidency of Mexico
Membre du Conseil national de bioéthique /
Member of the National Bioethics Council
Membre de l'Académie des sciences du tiers monde /
Member of the Third World Academy of Science (TWAS)

II. MEMBRES DU GROUPE DE TRAVAIL / MEMBERS OF THE WORKING GROUP

Prof. (Mr) Sharat H. *CHANDRA* (Inde / India)
Professeur émérite, Département de microbiologie et de biologie cellulaire de l'Institut indien des sciences (Bangalore) / Emeritus Professor, Department of Microbiology and Cell Biology, Indian Institute of Science, Bangalore
Directeur du Centre de génétique humaine (Bangalore) /
Director of the Centre for Human Genetics, Bangalore
Membre du Comité national de bioéthique /
Member of the National Bioethics Committee

Prof. (Mr) Gabriel *D'EMPAIRE* (Venezuela)
Professeur de bioéthique, Université centrale du Venezuela /
Professor of Bioethics, Central University of Venezuela
Directeur de l'Unité de cardiologie et de soins intensifs, Hôpital Clínicas Caracas /
Director of Coronary and Intensive Care Unit, Clínicas Caracas Hospital
Président de l'Association clinique de bioéthique du Venezuela /
President of the Bioethics Clinical Association of Venezuela
Membre invité de l'Académie nationale de médecine du Venezuela /
Guest Member of the National Academy of Medicine of Venezuela

Prof. (Mr) Donald *EVANS* (Nouvelle Zélande / New Zealand)
Professeur de philosophie / Professor of Philosophy
Directeur du Centre de bioéthique, Université d'Otago /
Director of the Bioethics Centre, University of Otago
Ancien membre du Comité consultatif national d'éthique de Nouvelle Zélande /
Former member of the National Ethics Advisory Committee of New Zealand

Prof. (Mr) Diego *GRACIA* (Espagne / Spain)
Professeur d'histoire de la médecine et de bioéthique à la Faculté de médecine, Université Complutense de Madrid / Professor of History of Medicine and Bioethics, Medical Faculty, Complutense University of Madrid
Directeur de l'Institut de bioéthique de la Fondation pour les sciences de la santé (Madrid) /
Director, Institute of Bioethics of the Foundation for the Health Sciences, Madrid
Professeur honoraire à l'Université du Chili, l'Université de Lima (Pérou) et l'Université de Cordoba (Argentine) / Honorary Professor at the University of Chile, University of Lima, Peru, and University of Cordoba, Argentina
Membre de l'Académie royale de médecine d'Espagne /
Member of the Royal National Academy of Medicine of Spain

Prof. (Mr) Stefano *SEMPLICI* (Italie / Italy)
Professeur d'éthique sociale à la Faculté de lettres et philosophie de l'Université de Rome Tor Vergata /
Professor of Social Ethics, Faculty of Philosophy, University of Rome Tor Vergata
Directeur de la revue internationale *Archives of Philosophy* /
Editor of the international journal *Archives of Philosophy*
Directeur scientifique du Collège « *Lamaro Pozzani* » (Rome) /
Scientific Director, "*Lamaro Pozzani* " College, Rome
Membre du Comité scientifique du Centre d'éthique générale et appliquée du Collège Borromeo (Pavia) / Member of the Scientific Board, Institute for General and Applied Ethics, Borromeo College, Pavia

Dr (Mrs) Aïssatou *TOURE* (Sénégal / Senegal)
Immunologiste et Chercheur à l'Institut Pasteur de Dakar /
Immunologist and Researcher, Pasteur Institute, Dakar
Membre du Conseil national de la recherche en santé /
Member of the National Health Research Council

Prof. (Mrs) Monique K. Ajilong *WASUNNA* (Kenya)
Médecin consultant, spécialiste en médecine tropicale et maladies infectieuses /
Consultant Physician and Specialist in Tropical Medicine and Infectious Disease
Directeur par intérim du *Kenya Medical Research Institute* (KEMRI) /
Acting Director of the Kenya Medical Research Institute (KEMRI)
Chercheur principal en médecine tropicale et maladies infectieuses du KEMRI /
Chief Research Officer in Tropical Medicine and Infectious Disease (KEMRI)
Membre du Comité consultative scientifique de l'Organisation mondiale de la santé sur les diagnostiques accessibles et de qualité / Scientific Advisory Committee member for the World Health Organization on Accessible Quality-Assured Diagnostics
Membre du Comité éthique et scientifique, Université de Nairobi et Hôpital national Kenyatta/
Member of the University of Nairobi and Kenyatta Hospital Scientific and Ethics Committee
Membre du Conseil de l'Institut de médecine tropicale et des maladies infectieuses de l'Université de Nairobi / Board member of the University of Nairobi, Institute of Tropical Medicine and Infectious Diseases

Excusé(e)s / Apologies from

Prof. (Mr) Abdallah *DAAR* (Oman)
Professeur de santé publique et Professeur de chirurgie, Université de Toronto (Canada) /
Professor of Public Health Sciences and Professor of Surgery, University of Toronto, Canada
Co-directeur du Programme en sciences de la vie, éthique et politique du Centre McLaughlin pour la santé mondiale, Réseau universitaire de la santé et Université de Toronto /
Co-Director, Programme in Life Sciences, Ethics and Policy, McLaughlin-Rotman Centre for Global Health, University Health Network and University of Toronto
Membre de l'Académie des sciences du tiers monde /
Fellow of the Third World Academy of Science (TWAS)
Prix Avicenne pour l'éthique scientifique de l'UNESCO, 2005 /
UNESCO Avicenna Prize for Ethics in science, 2005

Prof. (Ms) Olga *KUBAR* (Fédération de Russie / Russian Federation)
Chef du Département clinique de l'Institut Pasteur de Saint-Pétersbourg /
Head of the Clinical Department, Saint-Petersburg Pasteur Institute
Ancienne présidente du Forum pour les comités d'éthique dans la Communauté d'États indépendants /
Former Chair, Forum for Ethics Committees in the Commonwealth of Independent States

Prof. (Mr) Carter IV *SNEAD* (Etats-Unis d'Amérique / United States of America)
Professeur associé, Notre Dame Law School (Indiana) /
Associate Professor, Notre Dame Law School, Indiana
Ancien conseiller général du *President's Council on Bioethics* /
Former General Counsel of the President's Council on Bioethics

Prof. (Mrs) Sissel ROGNE (Norvège / Norway)
Professeur de biotechnologie à la Faculté de Médecine, Université de Bergen /
Professor of Biotechnology, Faculty of Medicine, University of Bergen
Directeur général du Comité consultatif norvégien des biotechnologies /
Director-General of the Norwegian Biotechnology Advisory Board
Membre du comité d'éthique du Fonds d'investissement Biotech NORFUND (Inde) /
Member of the ethics committee in the NORFUND Biotech Investment Fund, India

III. EXPERTS INVITÉ(E)S / INVITED EXPERTS

Dr (Mrs) Yvonne M. *DONDERS*
Directeur adjoint du Amsterdam Center for International Law, Université d'Amsterdam /
Deputy Director, Amsterdam Center for International Law, University of Amsterdam

Prof. (Mr) Soren *HOLM*
Professeur de bioéthique, Faculté de droit, Université de Cardiff (Royaume-Uni)/
Professor of Bioethics, Cardiff Law School, uniterd Kingdom

Dr (Mrs) Marie-Charlotte *BOUËSSEAU*
Ethique, Equité, Commerce et Droits de l'homme, Organisation mondiale de la santé (OMS) /
Ethics, Equity, Trade and Human Rights, World Health Organization (WHO)

IV. UNESCO SECRETARIAT

M. / Mr Henk TEN HAVE
Secrétaire général du CIB /
Secretary-General of IBC
Directeur, Division de l'éthique des sciences et des technologies /
Director, Division of Ethics of Science and Technology

M. / Mr Jan Helge SOLBAKK
Chef de Section bioéthique /
Chief, Bioethics Section
Division de l'éthique des sciences et des technologies /
Division of Ethics of Science and Technology

Mme / Mrs Sabina COLOMBO
Secrétariat du CIB / IBC Secretariat
Spécialiste du programme, Section de bioéthique /
Programme Specialist, Bioethics Section
Division de l'éthique des sciences et des technologies /
Division of Ethics of Science and Technology

M. / Mr Irakli KHODELI
Spécialiste adjointe du programme, Section de bioéthique /
Assistant Programme Specialist, Bioethics Section
Division de l'éthique des sciences et des technologies /
Division of Ethics of Science and Technology

Mme / Mrs Leonie TREGUER
Secrétariat et Administration, Section de bioéthique/
Secretariat and Documentation, Bioethics Section
Division de l'éthique des sciences et des technologies /
Division of Ethics of Science and Technology

IBC working group on social responsibility and health

UNESCO, July 08

Dr Marie-Charlotte Bouësseau
Ethics, Equity, Trade and Human Rights

World Health Organization

Overview

- Contribution of ethical approach
  - focus on analysis of dilemmas
  - methodology: multidisciplinary, multisectoral
- Application of article 14 in health policies: examples
  - HIV
  - Pandemic preparedness
  - Research for health
- Practical suggestions
  - The role of NEC
  - The role of other sectors (education)

World Health Organization

Contribution of ethical approach

a) Analysis of dilemmas (part IV of the report)

World Health Organization

Priority setting

How to choose between two vulnerable groups?

Ethical analysis must differentiate general questions such as "*the challenges of medicine in the XXI century*" from specific questions related to the application of universal ethical principles

e.g. justice / right to health applied to access to new vaccines in limited resources setting

World Health Organization

How to address the tension between principles / values?

- Rights to confidentiality / need to share information useful for the community
- Risk for individual participants to clinical trial / new product available for the community
- Security of the community / individual rights e.g. quarantine or isolation

World Health Organization

Human Rights framework

Ethical analysis is done in the framework of Human Rights in particular the right to health established in a number of legal instruments different from access to care and treatment established in many health policies.

World Health Organization

Contribution of ethical approach (2)

b) Multidisciplinary approach

World Health Organization

Formulation of an ethical dilemma

- Scientific approach (evidence)
- Legal context (Human Rights)
- Social and economical determinants
- Cultural, philosophical aspects
- Tension between
  - ethical principles (universal)
  - cultural values (particular)
  - Context (singular - individual or community)

World Health Organization

Responses are transectoral and must include all stake holders

- Health care
- Environment
- Education
- Global and national political commitment

World Health Organization

Validity of the process

- Inclusive
- Transparent
- Interests in conflict should be identified

Application of article 14 in health policies

In order to implement article 14 of the Declaration Member States need to establish concrete mechanisms addressing specific responsibilities in health

Guidance on ethics and equitable access to HIV treatment and care

9 recommendations (2004)

– Establish national ethics advisory bodies
to plan, promote and monitor equity

– Create opportunities
for public dialogue on
equitable access
to HIV treatment and care

– Identify vulnerable populations

Pandemic preparedness

- Swiss National Advisory Commission on Biomedical Ethics

drafted a document on
ethical questions in pandemic plan

- Maori in pandemic planning

Maori Reference Group
is part of the health sector branch
of the New Zealand's
pandemic planning process

Research for Health

Promoting the highest ethical standards in research

⇨ Level of care and treatment for trial participants to be defined before the trial e.g. matrix for negotiation process in vaccine trials

Research for Health

⇨ Sharing responsibilities in research

Guidance point 14

"prior to initiation of a trial, all research stakeholders should come to agreement through participatory processes on mechanisms to provide and sustain such HIV related care and treatment"

Research for Health

Setting up a research agenda addressing health priorities (10/90 gap)

⇨ e.g. Bamako ministerial forum on research for health

Justice in health

- universal access is the ultimate goal (justice)
- at a first stage health strategies must focus on vulnerable groups /situations (equity)

  e.g.
  – access to care in rural areas
  – access to relevant information including testing (HIV status)
  – cultural barriers against pain treatment (morphine)

Role of education

Equitable access to education, health promotion, prevention and treatment in the context of

– Food crisis
– Climate change
– Geographical inequity (urban / rural)
– Violence and insecurity

Conclusion

- A number of practical guidance points related to art.14 are established
- NEC should be prepared to apply ethical principles established in art.14, into specific health programmes
- Education as a key role to play in preparing health professional to share responsibilities promoting equitable access to care and treatment. Other stakeholders in the civil society should benefit from these educational programmes
- More knowledge is needed in order to identify cultural barriers/synergies in sharing responsibilities

SOCIAL RESPONSIBILITY IN A HUMAN RIGHTS CONTEXT: THE RIGHT TO HEALTH AND THE RIGHT TO ENJOY THE BENEFITS OF SCIENTIFIC PROGRESS

Yvonne Donders[♣]

1. INTRODUCTION

As suggested by its title, the Universal Declaration on Bioethics and Human Rights (the Declaration) places the topic of bioethics within a human rights framework. Human rights form the foundation of the Declaration, as is reflected in its Preamble referring to many human rights instruments, as well as in Article 3 that identifies human rights and human dignity as core principles of the Declaration. References to specific human rights can further be found throughout the text.

In order to enhance the application of the Declaration, it is important to further clarify its principles and provisions. International norms often have a general character and need to be further elaborated in order to be (better) implemented at the national level. This paper will deal with two human rights explicitly included in the Declaration – the right to health and the right to share the benefits of science – and their link with social responsibility. These issues are analyzed from a legal perspective, in particular the framework of international human rights law.

The concept of social responsibility refers to the ethical theory that an entity, which could be a government, corporation, organization or individual, has a certain responsibility to society. This responsibility can be 'negative' in that it is a responsibility to refrain from acting, or it can be 'positive' meaning there is a responsibility to act. While primarily associated with governmental practices and business (corporate social responsibility), other actors such as NGOs and local communities can also be associated with social responsibility, whereby different entities may have different responsibilities.

It is important to note that social responsibility is, in principle, voluntary. It concerns going above and beyond what is called for by the law, which is referred to as legal responsibility. Bearing in mind the different meaning of these two notions, it is difficult to speak about social responsibility in a legal context. However, the idea of social responsibility, namely to eliminate irresponsible or unethical behavior that might bring harm to the community, its people or the environment, is closely related to the idea of human rights. The paper will therefore try to outline some elements of the legal responsibility related to the human rights to health and science, bearing in mind the social responsibility context.

In the first part of the paper, the general human rights framework will be addressed. The right to health and the right to enjoy the benefits of scientific progress are incorporated in several international human rights instruments, most prominently in the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966). They form part of the so-called category of economic, social and cultural rights. As opposed to civil and political rights, economic, social and cultural rights are sometimes considered as less important rights. In fact, some argue that these rights do not have any legal character, but are more policy goals. Another firm distinction between the two sets of rights is the idea that civil and political rights demand primarily State abstention, while economic, social and cultural rights demand mainly State action, including financial resources. The paper will try to show that the distinction between the two sets of rights is not that strict and that it is generally agreed that economic, social and cultural rights are also true human rights that protect important aspects of human dignity.

[♣] Dr. Y.M. Donders is Deputy Director of the Amsterdam Center for International Law of the University of Amsterdam, The Netherlands.

The second part of the paper will address the right to health and the right to enjoy the benefits of scientific progress in more detail. The meaning and scope of these rights will be elaborated on the basis of the object or normative content of the right and the corresponding State obligations. As most human rights are formulated in rather general terms, clarification of these elements is needed so that individuals and communities are aware what they are entitled to and States know what kind of obligations they have in relation to the implementation of these rights. The principle of social responsibility, however, suggests that apart from States, other actors, such as individuals or companies, also take part in the process. Although the international human rights instruments are primarily addressed to States, the role of other actors in the promotion and protection of human rights will also be touched upon.

The final part of the paper merges the right to health and the right to science and tries to elaborate on some principles and activities that could be respected and undertaken by States in order to enhance them, which are also relevant to the advancement of the Universal Declaration on Bioethics and Human Rights.

2. THE HUMAN RIGHTS FRAMEWORK OF THE RIGHTS TO HEALTH AND SCIENCE

2.1 ECONOMIC, SOCIAL AND CULTURAL RIGHTS

The development of international human rights law was boosted by the horrors of the Second World War. The Universal Declaration of Human Rights (UDHR), adopted in 1948, is still the cornerstone human rights instrument. At the time of its adoption, the Universal Declaration contained a set of human rights principles that reflected a 'common standard of achievement'. In other words, the Declaration was not legally binding, but included norms that States wished to achieve.[1]

The norms in the UDHR were then transformed into binding legal norms through the adoption of two international treaties: the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). The different categories of human rights – civil, political, economic, social and cultural – were laid down in two different instruments to point out their different character, particularly with regard to the means of implementation. The ICCPR enumerates a number of civil and political rights or 'classic freedom rights', which are supposed to be immediately guaranteed by States.[2] Examples of these rights are the right to life, the right to respect for private life, the right not to be tortured, freedom of expression, freedom of religion and freedom of assembly and association. It was argued that the enforcement of civil and political rights mainly demanded States *not* to interfere; in other words, they should refrain from action in these areas. The ICCPR further provides for rather extensive means of review and supervision: a reporting procedure (Article 40), a State complaint procedure (Article 41, optional) and an individual complaint procedure (Optional Protocol to the ICCPR).[3]

The ICESCR contains economic, social and cultural rights to be 'recognized' by States.[4] Examples of such rights are the right to social security, the right to an adequate standard of living, including food and housing, the right to health, the right to work and the right to education. These rights were considered to require a proactive role of the State involving financial and material resources. Since these resources might not necessarily be directly available, the implementation of economic, social and cultural rights could only be undertaken progressively. The provisions of the ICESCR were formulated in a programme-

[1] Nowadays, most of the provisions of the Universal Declaration of Human Rights are considered to be binding upon all States as international customary law.

[2] In Article 2 ICCPR, it is stated that States Parties undertake to respect the rights in the ICCPR and to undertake to take the necessary steps in the field of legislation and policy measures.

[3] The State complaints procedure and the individual complaints procedure are not obligatory. States can, separately from ratifying the treaty, opt to accept these procedures.

[4] In Article 2 of the ICESCR, it is stated that States Parties will undertake to take steps, "…to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognised in the present Covenant…"

type manner. States should promote and protect these rights, but national circumstances may be taken into account. The supervisory mechanism is more modest and consists only of a reporting procedure (Article 16).[5]

The legal character of economic, social and cultural rights has sometimes been questioned. Can economic, social and cultural rights truly be called human rights, or should they merely be considered as policy goals? It is argued that economic, social and cultural rights are formulated in a broad and vague manner, leaving their content and corresponding State obligations unclear. This is the main reason that some consider these rights to be non-justiciable, in other words not suitable for handling by a court or another judicial or quasi-judicial body.

However, presently, there is general consensus that economic, social and cultural rights are 'real rights', as they have been included in legally-binding human rights instruments. As far as their vagueness is concerned, it is noted that some civil and political rights may also be called 'vague', for example the right to respect for private life or privacy. Moreover, much interpretative work on economic, social and cultural rights has been done by the UN Committee on Economic, Social and Cultural Rights, the independent experts' body supervising the implementation of the ICESCR. Through so-called General Comments[6] the Committee has elaborated on the normative content and State obligations of many of these rights. Although these rights may not (yet) be fully justiciable at the international level, as individuals do not (yet) have a possibility of complaining directly to the Committee, economic, social and cultural rights are regularly invoked in national and regional human rights procedures.[7]

2.2 CLARIFYING RIGHTS AND OBLIGATIONS

The content and scope of human rights are usually clarified by elaborating the three-term structure of its object, subject and addressee. The *object* concerns the normative content of a right, in other words what one is entitled to when invoking a certain right. The *subject* refers to the beneficiary of the right, which may be individuals, groups of individuals or collectivities. Most human rights are formulated in individual terms, implying that the subject is the individual. However, it is also acknowledged that most human rights have a strong collective dimension.[8] The *addressee* relates to the obligations that correspond to a right, as all rights imply duties for somebody else. The addressee of human rights is first and foremost the State. However, in the case of the rights under review here, the role of other actors, such as companies, is also relevant. In short: rights imply a claim (object) by the beneficiary or holder (subject) of a right towards the addressee to do something or to refrain from doing something (State obligations). The issue of State obligations will be further explored below.

2.2.1 STATE OBLIGATIONS

Positive and Negative Obligations

[5] A draft Optional Protocol containing a communications procedure for individuals was drafted by the open ended working group on the Optional Protocol to the ICESCR was on 4 April 2008 and sent to the Human Rights Council for adoption, after which it will be submitted to the General Assembly.

[6] General Comments or General Recommendations are adopted by the UN treaty monitoring bodies to clarify the normative content of provisions of the treaties. They are based on the experience of these bodies in addressing State reports and individual complaints (if applicable). General Comments are not legally binding upon States, but they provide an authoritative interpretation of the treaties.

[7] See, for a recent study on this topic, International Commission of Jurists, *Courts and Legal Enforcement of Economic, Social and Cultural Rights – Comparative Experiences of Justiciability*, Geneva, 2008.

[8] Although strictly formulated as rights of every individual, the rights to, for example, freedom of assembly, freedom of expression, freedom of religion, the right to enjoy culture, the right to education and many other human rights are often enjoyed collectively. This, however, is not the same as collective rights that belong to communities as such.

Generally, State obligations can be divided into negative and positive obligations. Negative obligations imply that the State should refrain from action, whereas positive obligations require State action.

As stated above, a distinction used to be made between civil and political rights that demanded State abstention or negative obligations, and economic, social and cultural rights that required an active State policy or positive obligations. However, this firm distinction has been disputed and it is nowadays accepted that all categories of human rights may imply positive as well as negative State obligations. Civil and political rights are not only freedom rights demanding State respect and abstention. For example, the classic right to freedom of expression may require, apart from the negative obligation to respect the prohibition of censorship, also a positive obligation to create the conditions necessary for the freedom to demonstrate, for example, police escort and protection. Other examples are the right to vote and the right to a fair trial, which imply that the State should organize elections and institute a proper judicial system. Similarly, economic, social and cultural rights may also require *non*-interference by the State. Examples of economic, social and cultural rights that imply negative State obligations are the right to form and join trade unions, scientific freedoms and the freedom of parents to choose the education for their children.

Progressive Realization

As the rights to health and science are laid down in the ICESCR, the State obligations can be deducted from the specific treaty regime of the ICESCR. The key provision in the ICESCR with regard to State obligations is Article 2(1), which lays down the principle of progressive achievement conditioned by the availability of resources. It says that States should undertake to take steps to the maximum of their available resources, "…with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including, in particular, the adoption of legislative measures."

What does such a 'progressive realization' mean? To what are States obliged when implementing the rights in the ICESCR? To what extent can States postpone their obligations by claiming, for example, lack of resources? An important interpretation of the obligations of States under the ICESCR is laid down in the General Comment on Article 2 ICESCR, adopted by the Committee on Economic, Social and Cultural Rights in 1990.[9] Although General Comments are not legally-binding, they form an important source of interpretation.

In its General Comment on Article 2, the Committee stated *inter alia* that the obligation to take steps or measures as laid down in Article 2(1) has an immediate character. States should take steps "…within a reasonable, short period of time…" after the Covenant has entered into force.[10] Furthermore, taking the appropriate measures implies not only legislative measures, but also administrative, financial, educational, social and other measures, including judicial remedies.[11] States are free to determine which measures they consider best to implement the material provisions of the ICESCR, whereby the Committee,

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[9] UN Committee on Economic, Social and Cultural Rights, General Comment 3 on the nature of States parties' obligations (Art. 2, § 1 of the Covenant), fifth session, December 1990. The General Comment reflects many ideas of another important document on the provisions and obligations of the ICESCR, which is the 'Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights'. These Limburg Principles were the outcome of a conference of experts organized in Maastricht in 1986. As the outcome of an academic conference, they have no legally binding character. See "The Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights", *Human Rights Quarterly*, Vol. 9 (1987), pp. 122-135, also published as UN Doc. E/CN.4/1987/17; See, further, one of the working papers of the Conference by Alston and Quinn, "The Nature and Scope of States Parties' Obligations under the International Covenant on Economic, Social and Cultural Rights", *Human Rights Quarterly*, Vol. 9 (1987), pp. 156-229.

[10] General Comment No. 3, 1990, pp. 83-87, § 2. The Limburg Principles use a stricter regime and determine that States should take steps immediately; see the Limburg Principles, 1987, No. 16.

[11] General Comment No. 3, 1990, § 5.

as supervisory body, finally determines whether the State has, in fact, taken the appropriate measures.[12]

The Committee further states in its General Comment that the duty to 'progressively realize' is closely related to the availability of financial and economic resources. According to the Committee, the States should start the implementation immediately and should move as fast as possible towards the end of total realization.[13] States should, regardless of their level of economic development, do the maximum possible to ensure the enjoyment of economic, social and cultural rights. The Committee also determined in its General Comment that retrogressive measures need to be fully justified by reference to the totality of the rights in the ICESCR and in the context of the full use of the maximum of available resources.[14]

Article 2(2) of the ICESCR contains a provision that obliges States to take measures to immediately ban *de jure* discrimination in the enjoyment of the rights in the Covenant. The idea of progressive realization is not applicable here, since the term 'to ensure' is used. Forms of passive discrimination caused, for example, by a lack of resources, should be banned as soon as possible. This guarantee of non-discrimination based on Article 2(2) implies a firm legal obligation that is immediately applicable and justiciable for a national court.[15]

The Tripartite Typology: Obligations to Respect, Protect and Fulfill

An important theory with regard to State obligations is the tripartite typology of State obligations. This theory is not based on specific treaty provisions, but instead claims that three types of State obligations, namely, to respect, protect and fulfill, can in principle result from all human rights, whether civil, political, economic, social or cultural in nature.

The *obligation to respect* means that States should refrain from "…anything that violates the integrity of the individual or infringes on his or her freedom, including the freedom to use the material resources available to that individual in the way he or she finds best to satisfy the basic needs."[16]

The *obligation to protect* means that the State should take the necessary measures "…to prevent other individuals or groups from violating the integrity, freedom of action, or other human rights of the individual – including the prevention of infringement of the enjoyment of his material resources."[17]

The *obligation to fulfill* means that the State should take measures "…to ensure for each person within its jurisdiction has opportunities to obtain satisfaction of those needs, recognized in the human rights instruments, which cannot be secured by personal efforts."[18] The obligation to fulfill is sometimes divided into the obligation to facilitate and the obligation to provide.

The tripartite typology is a functional way of clarifying State obligations in relation to human rights. Especially in relation to economic, social and cultural rights, it demonstrates that States do not just have positive obligations that may have financial implications. States may also have the negative duty to respect and to refrain from action, which does not have financial consequences. The typology has gained international recognition. It has been used by the Committee on Economic, Social and Cultural Rights in its General Comments and can be found in many scholarly publications on human rights.

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[12] General Comment No. 3, 1990, § 4 and 7; Limburg Principles, 1987, no. 17, 18 and 20.
[13] General Comment No. 3, 1990, § 9; Limburg Principles, 1987, no. 21.
[14] General Comment No. 3, 1990, § 9.
[15] Limburg Principles, no. 35-39; General Comment No. 9 on the domestic application of the Covenant, December 1998, § 9.
[16] UN Doc. E/CN.4/Sub.2/1987/23, 1987, *The Right to Adequate Food as a Human Right*, report prepared by Mr. A. Eide, 1987, § 67.
[17] Eide, UN Doc. E/CN.4/Sub.2/1987/23, 1987, § 68.
[18] Eide, UN Doc. E/CN.4/Sub.2/1987/23, 1987, § 69.

The Core Content of Human Rights

As stated above economic, social and cultural rights are often described in a programmatic way, requiring States to take measures. However, the obligations are usually vague and open-ended, which leaves it unclear how and to what extent these rights should be realized. The principle of 'progressive realization' to the maximum of available State resources adds to the obscurity. The definition of a 'core content' of a right can make clear what States should immediately realize, irrespective of their available resources. The ICESCR Committee refers to core content in its General Comment on Article 2(1) ICESCR, in which it states that States have, regardless of their level of economic development, a "…minimum core obligation…" to guarantee at least the "…minimum essential levels…" of economic, social and cultural rights.[19]

The ICESCR Committee has since tried to define the core content of specific human rights provisions.[20] It should be noted that the concept of core content should be dealt with carefully. Whereas the concept of core content may be interesting from an academic point of view, it can also be dangerous. Identifying the core content of a right brings the risk that the remainder of the right is considered unimportant and therefore to be denied. It should be made clear that States should also take measures concerning the aspects that are not part of the core content. The core content is a minimum that States should guarantee, but they are obliged to do as much as possible to do more than just the minimum.

3. RIGHTS IN FOCUS: THE RIGHT TO HEALTH AND THE RIGHT TO ENJOY THE BENEFITS OF SCIENTIFIC PROGRESS

3.1 THE RIGHT TO HEALTH

It is generally recognized that health is a precondition for the enjoyment of human rights. Accordingly, the right to health[21] is considered a fundamental right indispensable for the enjoyment of other human rights. It has been included in many human rights instruments, at universal, regional and national level, and much elaborative work on its normative content and State obligations has been done.[22]

3.1.1 The Definition of "Health"

The first international legal recognition of the right to health can be found in the founding documents of the World Health Organization (WHO). In the preamble of its Constitution, adopted in 1946 and in force since April 1948, a definition of health is given as being "…a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." While it is generally agreed that health goes beyond the mere absence of disease and disability, this definition has been criticized as being too broad and vague, because it almost equates health with human well-being. Moreover, some argue that this definition for mistakenly implies that good health is an end rather than a limited means to a meaningful life. It would imply that States should guarantee a complete physical, mental and

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[19] See General Comment No. 3, 1990, § 10 and 11; Limburg Principles, 1987, no. 25.

[20] The ICESCR Committee has used the concept of core content and core obligations in several General Comments: see General Comment no. 3 (1990) on the Nature of State Parties Obligations, § 10; General Comment No. 12 (1999) on The Right to Adequate Food, § 8; General Comment No. 13 (1999) on the Right to Education, § 57; General Comment no. 14 (2000) on the Right to the Highest Attainable Standard of Health, § 43-45.

[21] Formally, this right refers to "the right of everyone to the enjoyment of the highest attainable standard of health", but in this paper it will be mainly referred to as the right to health.

[22] See, for detailed elaborative work on the right to health, *inter alia*, B. Toebes, *The Right to Health as a Human Right in International Law*, School of Human Rights Research Series, No. 1, Intersentia/Hart, 1999; A. Chapman, "Core Obligations related to the Right to Health", in: A. Chapman and S. Russell (eds.), *Core Obligations: Building a Framework for Economic, Social and Cultural Rights*, Intersentia, 2002. See, also the work of the UN Special Rapporteur on the Right to Health at www.ohchr.org as well as the work done by the World Health Organization (WHO) at www.who.org.

social well-being for all, which would be an impossible goal. Despite these critical remarks, however, the WHO definition is still one that is often used and referred to.[23]

3.1.2 The Right to Health in Universal Human Rights Instruments

The preamble of the WHO Constitution recognizes the right to the highest attainable standard of health as "…one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition." States further agreed that health cannot be improved merely by providing health care services. It was therefore included in the Constitution that governments should take adequate health *and* social measures (emphasis added). The Constitution of an international organization such as the WHO is a multilateral treaty that is binding upon the 193 States that are a party to the WHO.

The right to health has found its place in many universal human rights instruments. In the UDHR, the right to health was included as part of a standard of living. In Article 25(1) UDHR it is laid down that "[e]veryone has the right to a standard of living adequate for the health of himself and of his family, including …medical care."

The most comprehensive provision on the right to health is included in Article 12 ICESCR. This provision reads as follows:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
    (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
    (b) The improvement of all aspects of environmental and industrial hygiene;
    (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
    (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

The right to health is further included in Article 12 of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), adopted in 1979 and in force since 1981. This provision charges States to eliminate discrimination of women in the field of health care and to provide equal access of men and women to health care services. It further pays specific attention to the provision of adequate services related to pre- and post-natal care.

A very comprehensive provision on health is included in the Convention on the Rights of the Child, adopted in 1989 and in force since 1990. In Article 24 on the right to the highest attainable standard of health for children, reference is not only made to the right to access to health care facilities, but also to food, drinking water, environmental health, access to information and the prohibition of traditional harmful practices.

There are many other international and regional human rights instruments that include a provision on health, including the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (1990, Article 28), the European Social Charter (1996, Article 11), the Convention on Human Rights and Biomedicine (1996, Article 3), the American Declaration of the Rights and Duties of Man (1948, Article XI), The Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador, 1988, Article 10), and the African Charter on Human and Peoples' Rights (1981, Article 16).

Another international source to be mentioned is the Millennium Development Goals, adopted in 2000. The eight Millennium Development Goals (MDGs) represent commitments to reduce poverty and hunger and to tackle ill-health, gender inequality, lack of education, lack of

[23] The definition of "health" has been object of extensive academic debate. For an overview, see Toebes, 1999, pp. 20-25 and Chapman, 2003, pp. 187-188.

access to clean water and environmental degradation. Three of the MDGs specifically address health issues: Goal 4 to reduce child mortality; Goal 5 to improve maternal health and Goal 6 to combat HIV/AIDS, malaria and other diseases. These areas provide clear priorities that States have agreed on.

In short, the right to health is firmly embedded in international human rights law. Most of these provisions not only include the right to health care services, but address a number of related issues such as safe drinking water and adequate sanitation, as well as environmental and occupational health. However, this broad scope leads to the question of what is precisely the normative content of the right to health and which concrete State obligations it entails.

3.1.3 Interpretation of the Normative Content and State Obligations

Much elaborative work on Article 12 ICESCR has been done by the Special Rapporteur[24] on the Right to Health, the Committee on Economic, Social and Cultural Rights and other treaty bodies supervising the respective treaties, the WHO, as well as academics and civil society organizations. It shows the broad interest and involvement of different actors in the promotion and protection of the right to health. From the abundance of documents on the right to health, some general lines can be deducted.

First of all, the right to health does not mean the right to be healthy. There are evidently non-medical factors and/or factors beyond the control of the State that influence one's health, including natural factors, education and income, as well as one's own behavior. The right to health mainly means that States should create conditions in which everyone can be as healthy as possible. Such conditions may vary from ensuring the availability of health services, to healthy and safe working conditions, adequate housing and nutritious food.

The right to health contains generally two aspects: the *freedom aspect*, for example the freedom from non-consensual treatment and non-consensual participation in clinical trials; and the *entitlement aspect*, for example to a system of health care and protection. For the most part, freedoms do not have budgetary implications, while entitlements do.[25]

The Committee on Economic, Social and Cultural Rights distinguished in its General Comment on the right to health (Article 12) several elements to evaluate the realization of this right. It determined that all health services, goods and facilities should be:

- *available* in sufficient quantity;
- *accessible*, which includes non-discrimination, physical accessibility (within safe reach), economic accessibility (being affordable) and information accessibility (being transparent);
- *acceptable*, meaning respectful of medical ethics and culturally appropriate;
- *of good quality*, scientifically and medically.[26]

As regards the State obligations corresponding to the implementation of this right, it should be noted that, since the right to health is included in the ICESCR, the system of progressive realization applies. It is generally recognized that the right to health is subject to resource constraints. Nonetheless, there are several obligations arising from the right to health that are subject to neither progressive realization nor resource constraints, but are of immediate effect, for instance the obligation to avoid *de jure* and *de facto* discrimination.

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[24] Special Rapporteurs form part of the so-called 'special procedures' established by the Commission on Human Rights and assumed by the Human Rights Council to address either specific country situations or thematic issues in all parts of the world. These persons are independent experts serving in their personal capacity to examine, monitor, advise and publicly report on human rights situations in specific countries or territories, known as country mandates, or on major phenomena of human rights violations worldwide, known as thematic mandates.

[25] See a recent document of the Special Rapporteur called draft Guidelines for consultation for Pharmaceutical Companies in relation to Access to Medicines, currently under discussion, para I. See http://www2.ohchr.org/english/issues/health/right/index.htm (last accessed 12 May 2008).

[26] UN Doc. E/C.12/2000/4, General Comment No. 14 on the Right to the Highest Attainable Standard of Health, Article 12 of the International Covenant on Economic, Social and Cultural Rights, 11 August 2000, § 12.

The Committee has identified in its General Comment different State obligations to respect, protect and fulfill, whereby the last includes obligations to facilitate, provide and promote. The *obligations to respect* prohibit, for example, the denial of equal access to health care services to all persons (including prisoners, minorities, asylum seekers and illegal immigrants), marketing unsafe drugs, application of coercive medical treatment, limiting access to contraceptives, or unlawfully polluting air, water and soil. The *obligations to protect* include, for instance, ensuring equal access to health care services provided by third parties and controlling the marketing of medical equipment and medicines by third parties. The *obligations to fulfill* include, for example, the adoption of a national health policy, providing immunization programmes against major infectious diseases, providing sexual and reproductive health services, providing a public, private or mixed health insurance system that is affordable for all, and promoting health education.[27]

The *core obligations* of the right to health include the following: to ensure the right of access to health facilities, goods and services on a non-discriminatory basis; to ensure equitable distribution of all health facilities, goods and services; to ensure access to the minimum essential food and freedom from hunger; to ensure access to basic shelter, housing and sanitation and an adequate supply of safe and potable water; to provide essential drugs; and to adopt and implement a national public health strategy addressing the health concerns of the whole population.[28]

The Committee further identified several other key obligations of the right to health: to ensure reproductive, maternal and child health care; to provide immunization against the major infectious diseases occurring in the community; to take measures to prevent, treat and control epidemic end endemic diseases; to provide education and access to information concerning the main health problems in the community; and to provide appropriate training for health personnel, including education on health and human rights.[29]

States parties also have responsibilities towards each other through international cooperation. While developing countries have a responsibility to seek international assistance and cooperation, developed States have some responsibilities towards the realization of the right to health in developing countries.[30]

Women are considered a vulnerable group for which the right to health is of special importance, in particular concerning reproductive health. At several UN Conferences, such as the International Conference on Population and Development (Cairo, 1994) and the World Conference on Women (Beijing, 1995), the issue of reproductive rights was discussed and States were urged to take special measures to protect these rights. The Committee on the Elimination of Discrimination against Women, supervising the implementation of the CEDAW, adopted a General Recommendation – which is comparable to a General Comment – on women and health. It urges States to integrate e gender perspective in their health policies and to promote women's right to health.[31]

The above shows that the right to health includes a variety of elements. Most of these are closely linked to other human rights, including economic, social and cultural rights, such as the right to food, housing, work and education, but also civil and political rights, such as the right to life, privacy, information, and the freedoms of association and assembly. The prohibition of torture, as laid down in Article 7 ICCPR, has a specific link with health and includes that "no one shall be subjected without his free consent to medical or scientific experimentation".

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[27] General Comment on the Right to Health, § 34-37. An extensive discussion of these obligations falls outside the scope of this paper. An overview of violations of the obligations to respect, protect and fulfill is given in § 50-52 and discussed in Chapman, 2002, pp. 205-214.
[28] General Comment on the Right to Health, § 43.
[29] General Comment on the Right to Health, § 44.
[30] General Comment on the Right to Health, § 38.
[31] General Recommendation No. 24 on Article 12: Women and Health, 1999, § 29-31.

3.1.4 The Right to Health in the Universal Declaration on Bioethics and Human Rights

The Universal Declaration on Bioethics and Human Rights includes in Article 14:

Social responsibility and health

1. The promotion of health and social development for their people is a central purpose of governments that all sectors of society share.
2. Taking into account that the enjoyment of 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, progress in science and technology should advance:
    (a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good;
    (b) access to adequate nutrition and water;
    (c) improvement of living conditions and the environment;
    (d) elimination of the marginalization and the exclusion of persons on the basis of any grounds;
    (e) reduction of poverty and illiteracy.

The Declaration reflects the holistic approach of the right to health described above. It reaffirms that health is more than the absence of disease or disability and that the right to health implies not only access to health care and medicine, but also to other social and economic issues, including safe food and drinking water and education. For the advancement of this provision, ideas and suggestions could be drawn from the work done on the right to health in the framework of international human rights law, notably the scheme of availability, accessibility, acceptability and quality and the core obligations as outlined above.

3.2 THE RIGHT TO ENJOY THE BENEFITS OF SCIENTIFIC PROGRESS

One of the human rights least known is the right to enjoy the benefits of scientific progress and its applications. Although it is included in the UDHR and the ICESCR – be it at the very end of both documents – it has hardly received any attention from States, UN bodies and programmes and academics. The role of science in societies and its benefits and potential danger have been discussed in many international fora, but hardly ever in a human rights context.[32]

3.2.1 The Definition of "Science"

The *Recommendation on the Status of Scientific Researchers*, adopted by the Member States of UNESCO in 1974, defines 'science' as:

> "…the enterprise whereby mankind, acting individually or in small or large groups, makes an organized attempt, by means of the objective study of observed phenomena, to discover and master the chain of causalities; brings together in a coordinated form the resultant sub-systems of knowledge by means of systematic reflection and conceptualization, often largely expressed in the symbols of mathematics; and thereby furnishes itself with the opportunity of using, to its own advantage, understanding of the processes and phenomena occurring in nature and society."

It is further stated that "[t]he expression 'scientific research' signifies those processes of study, experiment, conceptualization and theory-testing involved in the generation of scientific knowledge…" These definitions are relevant in relation to the right to enjoy the benefits of scientific progress.

[32] William A. Schabas, "Study of the Right to Enjoy the Benefits of Scientific and Technological Progress and Its Applications", in: Yvonne Donders and Vladimir Volodin (eds.), *Human Rights in Education, Science and Culture – Legal Developments and Challenges*, Paris, UNESCO/Ashgate Publishing, Paris, 2007, pp. 273-308; C.G. Weeramantry (ed.), *Human Rights and Scientific and Technological Development*, United Nations University Press, Tokyo, 1990, pp. 11-12.

3.2.2 UN Instruments on Science: Benefits versus Abuse

In the 1970s – just before the ICESCR came into force in 1976 – States adopted several international documents focusing on the duties of States and scientists to promote, conduct and use science in a responsible way.

For example, the *Charter of Economic Rights and Duties of States*, adopted by the General Assembly in 1974, contains a right of States – not of individuals – to benefit from scientific advancement and developments in science and technology. It also includes that States should promote international scientific and technological co-operation and the transfer of technology to developing countries, as well as facilitate access of developing countries to the achievements of modern science and technology.[33]

In 1975, the General Assembly adopted the *Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind*. This document concentrates on the possible abusive use of science contrary to human rights. It is acknowledged in the preamble that scientific and technological achievements could on the one hand improve the conditions of peoples and nations, but they could, on the other hand, cause social problems or threaten human rights and fundamental freedoms. Other issues in this document include non-discrimination and international cooperation to ensure that the results of science and technology are used in the interest of peace and security and for the economic and social development of peoples. It is further laid down that States should prevent the use of scientific and technological development to limit the enjoyment of human rights and protect the population from possible harmful effects of the misuse of science and technology.[34]

Another international instrument that contains a reference to science is the *Universal Declaration on the Human Genome and Human Rights*, adopted by the UNESCO General Conference in 1997 and endorsed by the UN General Assembly in 1998. This Declaration also focuses on the potential abuse of science, not so much on its potential benefits. It is, for instance, stated that researchers have special responsibilities in carrying out their research, including meticulousness, caution, intellectual honesty and integrity (Article 13). The Declaration also urges States to promote the international dissemination of knowledge, in particular between industrialized and developing countries (Article 18).

This idea of sharing the benefits of science is more clearly present in the *International Declaration on Human Genetic Data*, adopted by the Member States of UNESCO in October 2003. Article 19 concerns the sharing of the benefits of science with the society as a whole and with the international community. Benefits specifically mentioned include access to medical care, the provision of new diagnostics, facilities for new treatments or drugs deriving from research and support for health services.

It should be noted that most of these instruments are not legally binding upon States. They reflect principles or political norms to be respected by States. Although these instruments do not always explicitly address the human rights dimension of scientific progress, they reflect many issues, such as the prevention of harm and the equal sharing of benefits, which are directly relevant in relation to the right to enjoy the benefits of scientific progress.

3.2.3 Science in Universal Human Rights Instruments

The right to enjoy the benefits of scientific progress and its applications is included in the UDHR (Article 27) as the right to share in scientific advancement and its benefits. In the ICESCR it is included in Article 15(1)(b). The full provision reads as follows:

1. The States Parties to the present Covenant recognize the right of everyone:
    (a) To take part in cultural life;
    (b) To enjoy the benefits of scientific progress and its applications;

[33] UN Doc. A/RES/29/3281, *Charter on Economic Rights and Duties of States*, 12 December 1974, Article 13.
[34] UN Doc. A/RES/30/3384, *Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind*, 10 November 1975, Article 2.

(c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for the conservation, the development and the diffusion of science and culture.
3. The States Parties to the present Covenant undertake to respect the freedom indispensable for scientific research and creative activity.
4. The States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields.

The paragraphs of this provision address the two components of this right: the right of individuals to enjoy the benefits of scientific advancement[35] and the rights of scientists to freely conduct science and to have the results of their work protected. This last issue concerns intellectual property rights, a topic which falls outside the scope of this paper.[36] This paper focuses on the legal obligations of States to ensure the two other elements: to conduct and to enjoy.

3.2.4 Interpretation of the Normative Content and State Obligations

The right to freely *conduct* science seems to involve an interesting dichotomy. On the one hand, freedom to conduct research and scientific freedom have been driving forces behind technological advancement and economic growth. On the other hand, it is widely acknowledged that freedom to conduct science can be misused resulting in harmful science, as was the main topic of many of the documents discussed above.

As far as the *enjoyment* of scientific advancement is concerned, a similar dichotomy comes to mind. While on the one hand, technological advancement is more widely spread than ever through information and communication technologies, at the same time, progress is made at such high speed that the gap between the developed and the developing countries seems to widen. Many developing countries do not enjoy the benefits of scientific advancement, because too little of the knowledge and technology is accessible or applicable in these countries.

Both these issues have led to an increasing awareness for the need to reinforce the link between science and human rights. There are generally three sorts of human rights related to science: 1. the right to *protection* from possible harmful effects of science; 2. the right of *access* to scientific and technological advancement; and 3. the right or *freedom to assess and choose* the preferred path of scientific and technological development.[37]

The Committee on Economic, Social and Cultural Rights has not adopted a General Comment on this provision. Consequently, no concrete State obligations to respect, protect and fulfill, nor the core content of this right, have been identified by the Committee. However, the following elements could be distinguished:

Firstly, States should protect and promote scientific freedom to conduct research and disseminate its results, avoiding and preventing political or economic pressures. Academic freedom is closely linked to other human rights, such as the rights to freedom of expression and opinion, freedom of information and association and freedom of movement.

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[35] The ICESCR does not speak of "to share" in scientific advancement as the UDHR does. This was found to be too ambiguous and not leading to concrete State obligations. See, Richard P. Claude, "Scientists' Rights and the Human Right to the Benefits of Science", in: A. Chapman and S. Russell (eds.), *Core Obligations: Building a Framework for Economic, Social and Cultural Rights*, Intersentia, 2002, p. 254.

[36] In a statement on intellectual property and human rights, adopted in 2002, the Committee on Economic, Social and Cultural Rights stated that intellectual property rights must be balanced with the right to enjoy the benefits of scientific progress and encouraged the development of intellectual property systems and the use of intellectual property rights in a balanced manner that would provide protection for the moral and material interests of authors, and at the same time promote the enjoyment of these and other human rights. See UN Doc. E/C.12/2001/15, Human Rights and Intellectual Property, Statement by the Committee on Economic, Social and Cultural Rights, 14 December 2001. The Committee on Economic, Social and Cultural Rights has adopted General Comment No. 17 on Article 15(1)(c), UN Doc. E/C.12/GC/17, 12 January 2006.

[37] Weeramantry, 1990, pp. 13-14.

Secondly, States should promote the development of science and its beneficial applications in such a way that it includes safeguards from misuse or harmful applications of science. This is closely related to the right to education and the right to information.

Thirdly, the fact that everyone should enjoy this right presupposes equality. Access to and participation in science should be equal for all, based only on ability and competence. This is closely related to the general equality and non-discrimination principles of human rights treaties, but more specifically to Article 3 ICESCR which concerns the promotion of equality between men and women in the enjoyment of economic, social and cultural rights. Gender inequality is still very present in the field of science.

Fourthly, the right implies international cooperation, not only to increase the benefits of science, but also to support countries less developed in the field of science. This is linked to Article 2 ICESCR, which concerns a general provision on the need for international cooperation in the advancement of economic, social and cultural rights.[38]

Some ideas can further be drawn from another document of the Committee on Economic, Social and Cultural Rights, namely the reporting guidelines. These are meant to assist States in their reporting obligations by outlining the topics that need to be addressed when discussing Article 15(1)(b). States are, for instance, asked to describe measures taken to ensure the application of scientific progress for the benefit of everyone, including measures at promoting a healthy and pure environment and information on the institutional infrastructures established for that purpose. States should also report on the measures taken to prevent the use of scientific and technical progress for purposes which are contrary to the enjoyment of all human rights, including the rights to life, health, personal freedom, privacy and the like. The Committee also wants to know whether any restrictions are placed upon the exercise of this right and requests details of the legal provisions prescribing such restrictions.[39] The different elements of this right, including equal sharing, prevention of harm, as well as the promotion of information and the creation of a healthy environment, are clearly reflected here.

The prevention of harm in relation to scientific progress has been addressed by States during both World Conferences on Human Rights in Tehran in 1968 and in Vienna in 1993. The Proclamation of Tehran includes in paragraph 18 that scientific advancement may encourage progress, but it may also endanger the rights and freedoms of individuals. It directly after refers to the importance of disarmament.[40] The World Conference in Vienna in 1993 refers more directly to the right to enjoy the benefits of scientific progress. In paragraph 11 it is stated that “Everyone has the right to enjoy the benefits of scientific progress and its applications. The World Conference on Human Rights notes that certain advances, notably in the biomedical and life sciences as well as in information technology, may have potentially adverse consequences for the integrity, dignity and human rights of the individual, and calls for international cooperation to ensure that human rights and dignity are fully respected in this area of universal concern.”[41] It should be noted that again the different elements are present. The focus however has shifted from disarmament to issues of biotechnology.[42]

Despite the provisions on scientific progress included in international human rights instruments, it should be noted that scientific research and progress are not always inspired by human rights concerns. Investments in research are often determined by commercial interest, rather than by development needs. For example, enormous amounts of money are devoted to research to developing drugs for ‘erectile dysfunction’ and similar real or

[38] Claude, 2002, pp. 254-255, p. 259.
[39] UN Doc. E/C.12/1991/1, Revised general guidelines regarding the form and contents of reports to be submitted by states parties under articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights, 17 June 1991.
[40] Proclamation of Tehran, proclaimed by the International Conference on Human Rights at Teheran on 13 May 1968.
[41] Vienna Declaration and Programme of Action, adopted at the World Conference on Human Rights, Vienna, 25 June 1993 (See UN Doc. A/CONF.157/23, 12 July 1993).
[42] Schabas, 2007, p. 279.

imagined illnesses of the rich. Much less is spent on eliminating the scourge of malaria, tuberculosis or other diseases among the world's poor. Scientific research with respect to food suffers from the same problems as medical and pharmaceutical research. It is often driven by profit, neglecting those who are the hungriest, for example by not investing in the most important crops for the poor, because they are commercially not attractive.[43]

3.2.5 The Right to Enjoy the Benefits of Scientific Progress in the Universal Declaration on Bioethics and Human Rights

Article 15 of the Universal Declaration on Bioethics and Human Rights reads as follows:

Sharing of benefits

1. Benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, in particular with developing countries. In giving effect to this principle, benefits may take any of the following forms:
    (a) special and sustainable assistance to, and acknowledgement of, the persons and groups that have taken part in the research;
    (b) access to quality health care;
    (c) provision of new diagnostic and therapeutic modalities or products stemming from research;
    (d) support for health services;
    (e) access to scientific and technological knowledge;
    (f) capacity-building facilities for research purposes;
    (g) other forms of benefit consistent with the principles set out in this Declaration.
2. Benefits should not constitute improper inducements to participate in research.

This provision focuses on the sharing of the results of science and less on the advancement of science or the freedom to conduct science. However, some of the elements of the human right to enjoy the benefits of scientific progress, as outlined above, could be useful in the further elaboration of this provision. It is interesting to see that the Declaration identifies some concrete benefits that States are supposed to share. Most of these concern health, which shows the link between the two issues.

4. HEALTH AND SCIENTIFIC PROGRESS: A RIGHTS-BASED APPROACH

The above shows that health and science are clearly embedded in the international human rights framework and that there is a clear link between the two. In fact, health is an important area of science. The various dimensions of the right to health as identified in Article 12(2) ICESCR, including the reduction of the stillbirth-rate and of infant mortality, improvement of environmental and industrial hygiene, and prevention and treatment of diseases, involve science and technology.

In order to try and merge the different elements of the rights to health and science and to enhance the human rights framework of scientific progress in the field of health, the so-called rights-based approach could be useful. The theory of a rights-based approach has been elaborated within the UN system and is now widely used among UN bodies, programmes and agencies.[44] While it started as the human rights-based approach to development, nowadays it is more widely applied. For example, the WHO promotes the rights-based approach to health.

A rights-based approach generally refers to a "…conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights".[45]

In a common understanding adopted in 2003, UN bodies, programmes and agencies agreed on three aspects of the human rights-based approach to development:

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[43] Schabas, 2007, p. 296-298; Chapman, 2007, pp. 23-26.
[44] For an overview and analysis of how UN bodies, programmes and agencies have worked with this concept see André Frankovits, *The Human Rights Based Approach and the United Nations System*, desk study prepared for UNESCO, Sector of Social and Human Sciences, 2006 (also available in French and Spanish).
[45] See: *Frequently asked questions on a human rights-based approach to development cooperation*, Office of the High Commissioner for Human Rights, 2006, p. 15.

> "1. All programmes of development cooperation, policies and technical assistance should further the realization of human rights as laid down in the Universal Declaration of Human Rights and other international human rights instruments.
>
> 2. Human rights standards contained in, and principles derived from, the Universal Declaration of Human Rights and other international human rights instruments guide all development cooperation and programming in all sectors and in all phases of the programming process.
>
> 3. Programmes of development cooperation contribute to the development of the capacities of duty-bearers to meet their obligations and of rights-holders to claim their rights."[46]

In other words, a rights-based approach integrates the norms, standards and principles of the international human rights system into the plans, policies and processes related to the topic in question, be it development, health or science. Special attention is thereby paid to the enhancement of the capacities of the holders (or subjects) of the rights to claim these rights and of the duty-bearers (or addressees, mostly States) to respect and fulfill their obligations. The norms and standards referred to above are those contained in the international treaties and declarations, including the right to health and the right to enjoy the benefits of scientific progress. The principles mentioned include the following: universality, inalienability, interrelatedness and interdependence of all human rights; equality and equity; accountability and rule of law; participation and inclusion.

In a study for UNESCO, Professor Audrey Chapman has applied the human rights-based approach to the right to benefit from scientific progress in relation to the right to health.[47] She argues that: "a rights based approach requires that both the process of doing the science and the products that are developed are consistent with fundamental human rights principles..."[48]

These principles include (emphases added):

- *human dignity*, which means placing the interest of the person above the interest of society or science;
- *non-discrimination and equal treatment*, as basic principles of human rights laid down in all human rights instruments;
- *focus on the disadvantaged or marginalized*, not on the interests of the economically advanced or otherwise privileged, which, as described above, is presently often the case;
- *availability, accessibility, acceptability and quality*, as elaborated by the Committee on Economic, Social and Cultural Rights in its General Comment on the right to health, as outlined above;
- *participation* of all members of society, although this is not easy bearing in mind the advanced knowledge needed to understand and evaluate options related to science;
- *free and informed consent* to participate in scientific research, especially the testing of medicine or treatment.[49]

Combining the possible State obligations of the rights to health and science, the following could be, *inter alia*, identified:

- establishing an educational infrastructure and encourage scientific learning at all levels, in order to overcome the enormous shortage of health professionals;

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[46] *The Human Rights Based Approach to Development Cooperation: Towards a Common Understanding among UN Agencies*, UN Development Group, May 2003.
[47] Audrey R. Chapman, *The Interrelationship between the Human Right to the Benefits of Scientific Progress and the Human Right to Health*, Study for UNESCO's Sector of Social and Human Sciences, Division of Human Rights, Human Security and Philosophy, Paris, August 2007.
[48] Chapman, 2007, p. 4.
[49] Chapman, 2007, pp. 4-14.

- setting priorities for health research that balance the opportunities for scientific advancement and the benefits for society, in particular disadvantaged and marginalized groups in that society;
- developing laws, institutions and policies conducive to the regulation of medical science and technology, which would enable to assess the quality, efficacy and appropriateness of research in order to protect the public from harmful science.[50]

These various principles and actions related to the rights to health and to enjoy the benefits of scientific progress are also relevant to the enhancement of Article 14 and 15 of the Universal Declaration on Bioethics and Human Rights. States could use the elements elaborated in the field of human rights promotion and protection to develop policies and take measures to advance the Declaration.

One of the major challenges in doing so lies in the area of the privatization and commercialization of health and science. Economic globalization has boosted the role and power of multinational corporations, which has in certain cases weakened the power of States, especially that of less developed countries. Major pharmaceutical companies have more financial resources than some governments. Consequently, as noted above, scientific research and progress are often more directed by commercial interest than by human rights concerns. Medical and pharmaceutical research is expensive and increasingly depends upon investments from multinational companies. Consequently, scientific progress in the field of health is often driven and controlled by private corporations, which may be more interested in the financial potential of a certain drug or treatment than in its social benefits. This is precisely the area where social responsibility plays a role, going beyond the legal responsibility of the State. Social responsibility implies that not only States, but all actors in the field of health should try to act for the benefit of society. These actions go beyond the strict legal responsibility that States may have.

In other words, States should first of all respect their legal responsibilities, in terms of implementing human rights treaties and respecting their obligations in this regard. With regard to health, the main obligations have been clearly elaborated and provide all States, regardless of their level of development, sufficient tools to develop health strategies and policies. The right to enjoy the benefits of scientific progress and its applications has not been much elaborated, but this right too implies some basic principles that should be respected. Apart from obligations to respect and to fulfill, State obligations in relation to health and science include the obligation to protect individuals from harmful actions by third parties, including companies.

Corporations and businesses themselves may not be bound directly by international human rights standards, but they too have responsibilities in relation to the advancement of human rights, at least to respect them.[51] Moreover, even if there is no concrete legal responsibility for these actors to positively implement human rights norms and standards, their social responsibility goes beyond such legal barriers. More and more companies are aware of this responsibility and try to integrate human rights norms, as well as others, for instance environmental norms, into their business policies and strategies.[52]

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[50] Chapman, 2007, pp. 14-18.

[51] The issue of the responsibilities or obligations of multinational corporations in relation to human rights is the subject of extensive debate among human rights scholars and UN bodies and agencies. See, inter alia, Ph. Alston (ed.), *Non-State Actors and Human Rights*, Oxford University Press, Oxford, June 2005; A. Clapham (ed.), *Human Rights Obligations of Non-State Actors*, Oxford University Press, Oxford, April 2006. See, also, UN Doc. E/CN.4/Sub.2/2003/12/Rev.2, Norms on the responsibilities of transnational corporations and other business enterprises with regard to human rights, adopted by the Sub-Commission on the Promotion and Protection of Human Rights, 26 August 2003.
There is also a Special Representative of the Secretary-General on human rights and transnational corporations and other business enterprises, Mr John Ruggie (USA).

[52] One can also think of the Global Compact, the ten UN principles in the field of human rights, the environment, labor and anti-corruption, to which companies and businesses can, voluntarily, adhere. Many transnational corporations nowadays include sections on human rights and other norms in their year reports. These corporations may not have a *legal* responsibility to do so: it reflects a sense of *social* responsibility.

The human rights to health and to enjoy the benefits of scientific progress, including the elaboration of their normative content, State obligations and underlying principles, could provide useful guidelines for the application of Articles 14 and 15 on health and science in the Universal Declaration on Bioethics and Human Rights. In general, States should apply a human rights-based approach to their health and science policies and try as much as possible to take into account human rights norms and principles when applying the Universal Declaration on Bioethics and Human Rights. After all, it is those human rights norms and principles that form the foundation of the Declaration.

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Background paper on Article 14 of the Universal Declaration on Bioethics and Human Rights from a philosophical perspective

Professor Søren Holm, BA, MA, MD, PhD, DrMedSci
Professorial Fellow in Bioethics, Cardiff Law School, Cardiff University, Cardiff, UK[53]
&
Professor of Medical Ethics II, Section for Medical Ethics, University of Oslo, Oslo, Norway

1. BACKGROUND AND INTRODUCTION

The purpose of this paper is to provide a philosophical explication and discussion of Article 14 of the Bioethics Declaration[54]. This will draw on current work in ethics and political philosophy.

The focus is therefore philosophical and not legal. This means that when words like duty, obligation, ought or must are used in relation to states or societal actors they are used in their philosophical sense and not in their legal sense and carry no direct legal implications[55].

Because of the linguistic limitations of the author the discussion is only based on the English language version of the Bioethics Declaration and may therefore not take into account any subtle differences in emphasis between the different official versions.

The text of Article 14 is as follows:

> **Article 14 – Social responsibility and health**
>
> 1. The promotion of health and social development for their people is a central purpose of governments that all sectors of society share.
>
> 2. Taking into account that the enjoyment of 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, progress in science and technology should advance:
>
> (a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good;
>
> (b) access to adequate nutrition and water;
>
> (c) improvement of living conditions and the environment;
>
> (d) elimination of the marginalization and the exclusion of persons on the basis of any grounds;
>
> (e) reduction of poverty and illiteracy."

This paper will, in Section 2 provide a general explication of the Article in relation to other articles in the Declaration and will then proceed to explicate the specific relevance in relation to **health** and in relation to **social development.** In Section 3 it will then relate Article 14 to recent philosophical work in relation to justice, equality and legitimate decision-making

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[53] Correspondence address:

Professor Søren Holm, Cardiff Law School, Museum Avenue, CF10 3AX Cardiff, UK

holms@cardiff.ac.uk

[54] Universal Declaration on Bioethics and Human Rights, adopted by acclamation 19 October 2005.

[55] It is, as always important to remember that there is no one to one relation between ethical and legal obligation or prohibition. There are many ethically problematic actions that are not, and should not be legally prohibited (e.g. telling your friends the truth about themselves), and there are on the other hand also many actions that are legally prohibited but not ethically problematic (e.g. blasphemy).

concerning societal resource allocation. In Section 4, which is the most tentative of the sections in the paper it will then briefly consider the practical implications of the analysis for possible further actions in relation to Article 22.1 and Article 25

2. INITIAL EXPLICATION AND INTERPRETATION OF ARTICLE 14 FROM A PHILOSOPHICAL POINT OF VIEW

2.1 The context of interpretation

Although this paper provides a philosophical interpretation of Article 14 the Article cannot be interpreted as an isolated text fragment. Any interpretation must take account of the whole of the Declaration in particular the other articles[56]. These provide both constraints on the possible interpretations and guidance concerning the fundamental values underlying the Declaration.

Of particular relevance to the interpretation of Article 14 are Articles 1.2, 3, 10-13 and 15. Article 1.2 makes clear that although the primary addressees of the Declaration are states, the Declaration is also intended to guide a range of other societal actors in their decision making. Article 3 establishes the fundamental importance of human dignity and individual human rights and does, in 3.2 constrain possible interpretations of other articles by establishing the primacy of individual rights and interests over the sole interests of science or society[57]. Whether this also establishes the primacy of individual rights over group rights is beyond the scope of this background paper because promotion of most and possibly all of the substantive areas covered by Article 14 can be achieved at the individual level or without reference to group membership[58]. Even though solidarity as explicated below in section 3.2 of this paper is a group concept it does not establish any particular rights for the group in relation to society or other groups, although it may establish obligations within the group. Article 10-13 further establishes a set of core principles and values that must shape any interpretation of Article 14[59], and the extensive explication of the concept of benefit sharing in scientific research in Article 15 entails that this specific aspect of obligations related to health and social development falls outside the scope of Article 14.

With these preliminaries in place we are now in a position to provide an analysis of the subsections of Article 14.

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[56] This is made clear in Article 26:
"Article 26 – Interrelation and complementarity of the principles
This Declaration is to be understood as a whole and the principles are to be understood as complementary and interrelated. Each principle is to be considered in the context of the other principles, as appropriate and relevant in the circumstances."

[57] Here we might note that although we may not follow Margaret Thatcher in believing that "There is no such thing as society" there are philosophical difficulties in conceptualising an "interest of society" which does not have some relation to the interests of at least some members of that society. It is thus questionable whether there can be a "sole interest of society".

[58] For recent discussions of group rights see: Griffin 2008, Raz 1986, Kymlicka 1989.

[59] "Article 10 – Equality, justice and equity
The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.
Article 11 – Non-discrimination and non-stigmatization
No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.
Article 12 – Respect for cultural diversity and pluralism
The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope.
Article 13 – Solidarity and cooperation
Solidarity among human beings and international cooperation towards that end are to be encouraged."

2.2 Article 14.1

Article 14.1 is of crucial importance to a proper understanding of the wide ranging scope of the Article as a whole. It states that:

> "14.1. The promotion of health and social development for their people is a central purpose of governments that all sectors of society share."

There are three important items to note in this succinct phrasing: 1) the obligation that is described is related to the promotion of health **and** the promotion of social development, 2) this is identified as a **central** purpose of government and 3) it is stated that it is a purpose that **all sectors** of society share.

Below in Section 2.2.1 and elsewhere we will discuss the philosophical and ethical issues surrounding promotion of health and social development in more detail. So here we will focus on the two other parts of Article 14.1.

This sub-section of the Article clearly entails that the promotion of health and social development must be given special importance. It is not only "a purpose of government" but "a **central** purpose of government". This entails by implication that there are other more peripheral purposes of government that must yield if there is a conflict between them and the promotion of health and social development. Article 14 is silent on what these more peripheral purposes might be and it would be inappropriate to try to develop a list in this paper, partly because such a list is likely to be context dependent[60].

How can the centrality of promotion of health and social development as a government purpose be justified. One perhaps surprising line of argument finds justification in a neo-Hobbesian analysis of the obligations of the sovereign[61]. Hobbes famously held in the Leviathan that life outside the state was "solitary, nasty, brutish and short" and that the only obligation of the sovereign to his subjects was to ensure their security against external and internal threats of violence. But in modern welfare states and even in many resource poor countries the threat of war or violence is no longer the main threat facing citizens and the legitimation of sovereignty must therefore be located elsewhere in the ability to protect citizens from current threats. Among these threats is the risk of death due to (untreated) disease and this gives the modern state a reason to make the promotion of health, and the protection against health threats a central purpose of government. Similarly states have neo-Hobbesian obligations to protect citizens from social threats like poverty or severe environmental degradation.

Other more familiar lines of argument would justify the centrality of these purposes in the importance of health as a general precondition for successful agency and participation in society. Health is thus an important part of any persons capability set (Sen 1992) and a basic good (Rawls 1971 & 1999, Daniels 1995), and because health contributes significantly to welfare or preference satisfaction it becomes of interest to consequentialist theories. Similarly it is obvious that individual wellbeing and welfare is intimately connected with social development.

The other very important issue that Article 14 makes clear is that **all sectors of society** share in the purpose of promotion of health and social development. This is a normative and not a descriptive statement, and is perhaps the normatively most important statement of the whole Article. Why is the statement so important?

It is clearly possible for a sector in society not to feel any responsibility for health and social development and not to act in a way that promotes health and social development. Furthermore it is possible to mount arguments based on some strands of moral and political

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[60] Possible candidates for less central governmental purposes could be national pride, military development beyond what is needed for national defence....

[61] This line of argument is developed more or less independently by Ashcroft 2005, Erin & Harris 1993 and Holm 1999.

philosophy (e.g. libertarianism) that certain sectors in society are justified in ignoring such a responsibility (Nozick 1977), or perhaps even that it would be wrong for them to try to pursue such a responsibility. It has for instance been argued that the only responsibility and only legitimate goal of a firm that is traded publicly on the stock market is to aim to maximise long term shareholder value (Sternberg 2000)[62]. This is equivalent to saying that the only legitimate stakeholders in a listed company are the shareholders and that the whole idea of wider stakeholder influence is not only incoherent, but ethically problematic.

But Article 14 clearly denies the legitimacy of these arguments. No sector in society can legitimately isolate itself from responsibility for the promotion of health and social development. A corollary to this is that it is a valid criticism of a sector in society if it does not take this responsibility seriously, whether this is a criticism mounted by government or by civil society organisations. The exact addressee of such a criticism can, however be difficult to fix because even if we have an intuitive grasp of what "a sector of society" is, there is rarely any natural or elected representative of such a sector we can address. We may, for instance believe that parts of the food industry does not take its responsibility for preventing childhood obesity seriously or seriously enough but there may not be one easily identifiable representative of that industry to whom we can address our criticism or who would be able to act on it (Butland et al 2007).

2.2.1 What is health and what is social development?

Both the concept of "health" and the concept of "social development" are contested. In the philosophical literature on the concept of health there is only agreement on two things: 1) health is not the opposite of disease, and 2) the WHO definition of health as "Complete physical, psychological and social well being" may define some human state, but it does not define health[63].

Accepting the WHO definition as a definition of health would also entail that all areas of societal policy became areas of health policy since all areas of policy influence psychological and social well being.

The two leading contenders for a philosophical conception of health are:

Health as a state of species typical functioning
Health as an ability to pursue your chosen goals

The bio-statistical conception of health sees health as an objective biological state that can be defined in terms of species typical functioning in relation to an age and sex matched reference class (Boorse 1975)[64]. A healthy organ is thus an organ with species typical functioning, and a healthy organism is an organism where all parts are functioning at their species typical level. The attraction of this conception of health is that it is seemingly objective, value free and linked to biology only. This conception has been criticised for hiding

[62] Even for those who hold this rather extreme view the emphasis is on **long term** shareholder value and it thus rules out at least some kinds of business behaviour.

[63] Some have jokingly referred to the WHO definition as the orgasmic definition of health implying that it only occurs at the moment of orgasm (Skrabanek 1994).

[64] More formally Boorse defines health disease in the following way:
1. The reference class is a natural class of organisms of uniform functional design; specifically, an age group of a sex of a species.
2. A normal function of a part or a process within members of the reference class is a statistically typical contribution by it to their individual survival and reproduction.
3. Health in a member of the reference class is normal functional ability; the readiness of each internal part to perform all its normal functions on typical occasions with at least typical efficiency.
4. A disease is a type of internal state which impairs health, i.e. reduces one or more functional abilities below typical efficiency.

the value judgements in the choice of reference class, and for having difficulty in dealing with mental illness and any subjective elements of illness and disease.

The action theoretic conception of health sees health as the set of biological and mental properties that enables an agent to pursue his or her reasonable goals (Nordenfeldt 1995). The healthy agent is thus the agent who is not restricted by biology in pursuing his or her reasonable goals. This conception is avowedly value-laden in the sense that what counts as health for you may not count as health for me if we have different reasonable life goals. Values also enter in discussing what counts as "reasonable goals". The attraction of this conception of health is that it inherently links health with the main reasons why we value health. It has been criticised for on the one hand allowing too many states to be classed as healthy (for persons who have limited life goals) and on the other hand allowing too many states to be classed as unhealthy (for persons who have expansive and ambitious life goals).

It is plausible that the action theoretic conception is closer to the conception of health and the value of health embodied in the Declaration in Article 14.2a "... health is essential to life itself and must be considered to be a social and human good" which is clearly not a purely biological conception.

In many policy decisions (e.g. in relation to public health interventions) it will not matter what conception of health the policy maker adopts. There is a large overlap between the states classed as healthy (or unhealthy) by the two conceptions, and most people who are affected by the policy decision will be unhealthy and in need of health promotion according to both.

Fixing the content of the concept of "social development" is more complicated partly because the reference of "social" is vague, partly because the concept of "development" is itself contested[65].

It should be uncontroversial that a change in material social conditions within a given society that is actually Pareto optimal, i.e. it benefits some and harms no one is an instance of social development, at least if the number benefited is sufficiently large. But actually Pareto optimal social changes are few and far between. Most social changes are only potentially Pareto optimal, i.e. there are winners and losers and the situation can be converted to an actually Pareto optimal situation if the winners compensate the losers (Culyer 2005). But potentially Pareto optimal changes are only ethically uncontroversial if the compensation happens! In assessing whether a change is a truly beneficial social change we therefore need to guard against any rhetoric that hides the fact that there are losers or relies solely on an unspecified future "trickle down" effect from those who gain to those who lose.

Positive social changes can occur across the whole range of societal sectors and activities but they are not all equally important social developments and it would, for instance be strange to define an improved ability of teenagers to sing in tune and keep rhythm as a social development that government should promote as a central purpose even though it would undoubtedly be a beneficial social change.

We therefore need to ask what kind of social developments that are covered by the obligations outlined in Article 14. A help in this task is the partial explication provided by article 14.2a-e:

> "(a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good;
>
> (b) access to adequate nutrition and water;
>
> (c) improvement of living conditions and the environment;

[65] Any social change is trivially a social development in the sense of development that does not imply progress or positive change. The decline of the Roman Empire was a social development in this sense, but at least for the citizens of Rome not a positive social development. This trivial sense of development is clearly not the sense used in the Declaration.

(d) elimination of the marginalization and the exclusion of persons on the basis of any grounds;

(e) reduction of poverty and illiteracy."

Any social change that improves one of the areas mentioned here is *eo ipse* a social development that should be promoted by government and all sectors in society. This is so whether or not it can be shown to improve health since the obligations relating to health and social development in Article 14 are separable. This must be so despite the interpretive problem that arises because the first part of Article 14.2 is phrased solely in terms of health.

It is important that the social developments that should be promoted are both developments in material conditions (e.g. access to water), in formal and cultural structures (e.g. elimination of marginalisation and exclusion) and in education (e.g. reduction in illiteracy). This indicates that the scope of promotion of social development is quite wide and must involve most sectors in society.

It is again straightforwardly possible to link the areas listed in the Declaration as primary targets for social development to Sen's capability approach or Rawls' conception of basic goods.

There is nothing in the Article suggesting that 14.2a-e is intended to provide a definitive and exhaustive list of important areas of social development and there may well be a number of other areas that ought to be promoted by states and other societal actors. It would, however be natural to see the areas mentioned in 14.2a-e as areas of primary interest for social development.

The promotion of social development and the promotion of health are contingently linked since the areas of social development are at the same time the social determinants of health. By achieving social development we therefore in most cases also achieve a positive change in the determinants of health and health promotion[66].

2.2.2 The concept of "access"

The term access is used in Article 14.2a and 14.2b and since this term is ambiguous it is necessary to explicate what concept of access that is implied.

In general we can distinguish between formal access and real or realistic access. In a completely free market system everyone has formal access to any good that is traded in the market, but only those who can afford to pay for the good has real or realistic access. This distinction is along the same lines as Berlin's distinction between negative and positive liberty (Berlin 1969). Formal access is equivalent to the negative liberty not to be stopped from obtaining the good in question by societal actors.

But having a negative liberty is not the same as having effective freedom or access. As already Anatole France remarked both the rich and the poor man is free (i.e. has negative liberty) to sleep under the bridges of Paris. But whereas they both have this negative liberty and the negative liberty to stay in the Ritz Hotel, only the rich man has effective freedom to do the latter because only the rich man possesses the resources to act effectively and exploit his liberty.

[66] There may be cases where a positive social development changes one of the social determinants of health in a negative way. It is, for instance arguable that the current rise in obesity in affluent countries is at least partially a side-effect of these countries being affluent and of the removal of any kind of food insecurity. The achievement of affluence and food security are in themselves positive social developments, but may have had negative side-effects.

A purely formal conception of access is compatible with most citizens not having real access[67]. The formal conception is thus extremely impoverished and cannot be the one intended in the Declaration.

But fixing the exact scope of the conception of real access is not unproblematic if the good in question can be delivered at varying levels of quality. This may not affect water (Article 14.2b) because clean water is clean water, but it does affect both health care and nutrition (see more below in Section 3).

2.3 The possible transnational scope of Article 14 in the light of Articles 15 and 21

Does Article 14 have transnational scope, i.e. do the obligations it allocates to governments and other societal actors go beyond the borders of any particular nation state? The following article, Article 15 on benefit sharing clearly has transnational scope, but Article 14 may initially seem not to carry any transnational implications and the use of the term "for their people" might even indicate an explicit restriction to the people in the particular state. Furthermore, all the actions Article 14 describes are within the scope of normal governmental activities. In this context it is, however important to remember that all articles in the Declaration have to be interpreted so as to comply with Article 21.1.[68] Article 21.1 is not restricted to research activities, as Article 15 and the following sub-sections of Article 21 but covers all transnational activities.

In so far as the governmental activities or activities of other social actors are pursued in different states the full set of obligations imposed by Article 14 must therefore also be observed in the other states that are affected by the activities. One example of this would be that a firm that is engaged in activities in a different country than the country in which it is incorporated cannot absolve itself from its obligations by the argument that it only has these obligations in "its own country"[69].

Another possible transnational aspect of Article 14 is in relation to establishing rules for intellectual property. Establishing rules for the legal recognition and exploitation of intellectual property in all its different forms is one of the ways in which a state can try to ensure that "…progress in science and technology …" (Article 14.2) advances health and social development in the areas mentioned in 14.2a-e but modern intellectual property regimes reach far beyond the borders of individual states. In so far as the intellectual property regime of one state has implications elsewhere or in relation to negotiations concerning international intellectual property rules state and societal actors have a plausible obligation to consider what the effects of the rules will be in other states, especially whether health and social development will be promoted.

Although the argument has not to my knowledge been made directly, a substantial amount of the criticism of the effects of the World Trade Organisation's TRIPS agreement on access to pharmaceutical products in resource poor countries could be made in terms of lack of reflection concerning the Article 14 implications of the intellectual property rules[70].

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[67] A society would, for instance fulfil the criteria for formal access to quality health care and essential medicines even if all hospitals are private and the majority of the population so poor that they cannot afford to go there.

[68] "Article 21 – Transnational practices

1. States, public and private institutions, and professionals associated with transnational activities should endeavour to ensure that any activity within the scope of this Declaration, undertaken, funded or otherwise pursued in whole or in part in different States, is consistent with the principles set out in this Declaration."

[69] Another possible, slightly more contentious example would be a country subsiding the export of tobacco products.

[70] On this critique of the implications of the WTO intellectual property framework see for instance Holm 2000 and Pogge 2005. Pogge also has extensive proposals for a fundamental re-orientation of the international intellectual property framework.

3. ARTICLE 14 AND CURRENT PHILOSOPHICAL WORK ON JUSTICE, EQUALITY AND LEGITIMATE DECISION-MAKING

This section of the paper will relate Article 14 to current philosophical work in areas such as justice, equality and legitimate decision-making. It will first look at the status of health as a good and the public / private good distinction and extend this to social development.

It will then discuss the relation between justice, solidarity and equality in health and social development and the importance of legitimate decision making processes.

3.1 The status of health and aspects social development as "a good"

Article 14.2a states that "... health is essential to life itself and must be considered to be a social and human good" but exactly what kind of good is health?

As mentioned above many theories in political philosophy acknowledge health as a basic good, either on its own or because of the strong links between health and welfare and health and social participation. These arguments are not affected by the observation that there may be individuals who do not value health or for whom health is not important.

There is also little doubt that having healthy citizens is a benefit to society and that health is a social or public good in that sense. The health of individuals contributes positively to general social conditions.

There is, however another economic sense of "public good" in which it more doubtful whether health qualifies as a public good (Culyer 2005). Economists distinguish between private goods that are characterised by being "rival and excludable" and public goods that are "non-rivalrous and non-excludable". A non-rivalrous good is a good where my consumption does not affect your consumption of the same good and a non-excludable good is a good where it is impossible effectively to exclude some but not others from consumption (e.g. exclude non-payers but still allow payers to consume). Classic examples of economic public goods are clean air, effective national defence and street lighting. Economic theory predicts that there will be undersupply of public goods because their non-excludable nature means that it will be impossible to extract market value payment from all consumers of the goods. This entails that there is an economic argument for state intervention in the market and possible state provision of the good or taxation to make up for the market failure. If health was an economic public good there would thus be a purely economic argument for providing health (in reality, providing health promotion and care since health cannot be provided directly). This would be a desirable outcome because it would reduce the need for appeal to moral or even prudential obligations to secure health care for those who cannot pay for themselves (Kaul et al. 1999, Chen et al. 1999).

The "health is a public good" argument does, however face significant obstacles. It is clearly not the case that most forms of health care are non-rivalrous or non-excludable. Physical and manpower resources are finite leading to rivalry between consumers and it is very easy to exclude people from health care or the benefits of health care. Health care knowledge is non-rivalrous[71], but it is not non-excludable and therefore still falls outside of the definition of an economic public good. The increasing tendency to patent university based inventions in the health care area clearly indicates that exclusion is possible in the area of health care knowledge, and that it is seen as economically desirable by some.

There are areas where it is more plausible to see health as an economic public good, especially in relation to the prevention of infectious disease and in relation to treatment of infectious disease which significantly reduces the spread of the disease. I am benefited by the fact that other people have immunisations and this general benefit of "herd immunity" is

[71] In reality even this is complicated because the exploitation of health care knowledge may involve rivalry, for instance between producers of the same pharmaceutical product.

non-ri'valrous and non-excludable. But similar arguments cannot be made for health care in general. My appendectomy does not in any appreciable way benefit you. In an economic sense health (care) is a private good.

But acknowledging that health is a private good in an economic sense does not negate the fact that health is a public good in the much more straightforward sense outlined above that a society with healthy citizens is a better society than one with much illness. This can still be an excellent reason to promote health.

Certain areas of social development more clearly involve economic public goods than the health area. Many improvements of living conditions and the environment are of the nature of an economic public good and there are thus good reasons drawn from economic theory for involving states in ensuring that these public goods are efficiently produced at the appropriate level.

Other social development goods are like health contested. There is for instance an economic public good aspect to basic education in modern complex societies, because I benefit from everyone having a generally adequate level of education. But more than adequate education is in an economic sense a clearly private good.

3.2 The relation between justice, solidarity and equality

Current discussions about justice, solidarity and equality are relevant for a proper understanding of the justification for and scope of the obligations imposed by Article 14, especially because all of these concepts are mentioned in the preceding articles of the convention.

The concept of solidarity is probably the most contested of the three concepts. There is a common shared understanding of what justice and equality is, although there is profound disagreement concerning what justice requires of us and whether equality is a goal that should be pursued. But for solidarity both the content and the normative importance of the concept is contested.

It is not the aim here to give a full analysis of solidarity in its manifold possible forms but to provide a brief outline of a fairly common understanding of social solidarity where solidarity is seen essentially as a group concept.[72] This will show how considerations of solidarity may differ from considerations of justice (ten Have and Keasberry 1992). According to the group conception of social solidarity it is the case that without existence of a definable group of which one can feel a member, solidarity has no meaning.

In most groups there will be some tendency to prefer or be benevolent towards other members of the group, but solidarity requires more than that. It requires an idea of shared life or destiny. It also requires a sense of belonging, integration or rootedness of each individual member within the group.

This sense of belonging is the underlying motivation which changes the passive understanding of a common destiny to active work for common goals.

The classical example of social solidarity is the labour unions in the late 19th century and the beginning of the 20th century. Whereas the old guilds had been pursuing a policy of exclusion and protection, the new labour unions worked for improvement of workers conditions, the liberation of workers and, at least in some countries, unification of the working class. The labour union movement was built on explicit ideas about a common life experience, a common goal and a common destiny for all workers. This was forcefully argued by Karl Marx, but was also a part of the ideology of the more revisionist social democratic parties. The labour union movement was one of the leading forces behind the establishment of comprehensive public health care systems in Europe, and Marxist analysts

[72] The analysis here follows Holm 1993 and Hasman and Holm 2005.

have presented interesting interpretations of the connection between international differences in the strength of the working classes and their unions and the type of health care system chosen (Navarro 1989).

The expression of underlying solidarity, however, actually predates the labour movement in Northern Europe by at least half a century. In 1820 the Danish priest N.F.S. Grundtvig for instance wrote the following lines in a song about Denmark, at a time when Denmark was still an absolute monarchy:

> *"... and in prosperity we will have reached far when few have too much and fewer too little"* (Grundtvig 1820, my translation)

Grundtvig thereby expressed the ideal of a national solidarity. This almost Rawlsian conception of community and solidarity has had a lasting impact in Northern Europe countries, and has permeated the political ideologies and political rhetoric to such an extent, that even far right wing parties pay homage to this ideal.

Both the labour movement and the national movements saw solidarity not as a goal in itself but as a means to the realization of a final goal, which can perhaps best be described as "a better world". This utopian "better world" is not construed along utilitarian lines, as a world where utility is maximized, but instead as a world in which the group achieves its destiny and lives a group-life to the best of its abilities.

Because solidarity is essentially a group concept, it restricts the scope of our usual notions of justice. Within the group justice may be a fully operative concept, but in comparing treatment of persons in the group and persons outside of the group justice concepts may not be applicable. Even though the formal principles of justice tell us to treat similar cases similarly, the cases are just not similar. One of these persons is someone with whom we share a common goal, a common destiny and perhaps even a common idea of the good life, the other is an outsider who just happens to be in my neighbourhood, so to speak. We may have compassion with the outsider, or show mercy towards him, but neither of these reactions is likely to lead to the kind of assistance we (the group) would offer to a person within the group.

If solidarity can be harnessed to goals such as the promotion of health and social development it can be a powerful motivating force.

3.3 Justice and equality – some further complications

Article 10 of the Declaration re-affirms "The fundamental equality of all human beings in dignity and rights" but a plausible interpretation of Article 14 supports the view that with regard to the promotion of health and social development the needs of those who have the greatest need, or are most vulnerable should be given priority. Article 14.2a mentions "women and children" and 14.2e "poverty and illiteracy". What philosophical accounts of social justice can support such an "option for the poor"[73]?

The perhaps most obvious candidate is Rawls' so-called "Difference Principle" as expounded in "A Theory of Justice" (Rawls 1971 & 1999). According to Rawls social and economic inequalities are to be arranged so that they are of the greatest benefit to the least-advantaged members of society. It is plausible that the poor and the illiterate, as well as women and children will count as the least-advantaged or the worst off in many of the decisions a government has to make which have distributive implications. However, there is a potential problem in that someone who is worst off in respect to one parameter may not be worst off in respect to other parameters. Someone who is rich and powerful may be very ill and worst off on the health scale, while still being very advantaged in relation to resources and power. This means that it becomes unclear what the implications of the difference

[73] To use a very appropriate term from liberation theology.

principle are in situations where someone or a group is worst off on one relevant parameter, but not worst off on another.

A significant amount of philosophical work on issues of relevance to social justice has also taken place within the consequentialist or utilitarian school of moral philosophy. It is a well known problem for the classical account of consequentialism that it does not contain and cannot accommodate any substantial account of distributive justice. Pursuing consequentialist maximisation can lead to end states with very large disparities between persons in welfare and resources, and even introducing the idea of a decreasing marginal return of utility does not remove the underlying problem. It was however only when Derek Parfit showed that standard consequentialism was open to the so-called "repugnant conclusion" that consequentialists became seriously interested in distributive issues (Parfit 1986). One current strand of consequentialist theory, usually called "prioritarianism" or "the priority view" argues for the proposition that "benefits to the worse off count for more, in terms of overall utility, than comparable benefits to the better off" (Rabinowicz 2001, Parfit 1991). Here the best and the worse off are defined in terms of their prior levels of utility, levels that at least in theory can be explained as a single number and the approach is thus immune against the criticism often raised against Rawlsian approaches that it is impossible to define who is worst off (see above).

Prioritarianism can also justify giving priority to the poor and the illiterate, although it has greater difficulty in justifying prioritising women and/or children as distinct groups, since at least some women and children already possess high levels of utility.

Neither the Rawlsian nor the prioritarian approach implies strict equality, but many people clearly have strong egalitarian intuitions in relation to basic goods or more generally in relation to the distribution of resources globally and in specific societies. The pursuit of strict distributive equality is, however fraught with theoretical and practical difficulties[74]. At a theoretical level most egalitarian approaches are vulnerable to the so-called "levelling down objection". The point of the objection is that one way of achieving equality (or just reducing differentials) is not by making the disadvantaged better off, but by making the better off worse off. We can make the distribution of health more equal by making the healthy ill. And levelling down will sometimes be the only way of achieving strict equality in situation where it is impossible to improve the status of the worst off to the level of the best off (e.g. if some have such severe health problems that they cannot be made healthy).

Other difficulties arise for the egalitarian because Temkin's work has shown that there is no non-arbitrary way to perform trade-offs between equality and welfare (Temkin 1993). There are many situations where the welfare of the worst off can be improved, but only if the welfare of the better off is improved as well. In some of these situations this will lead to greater equality, but in some it will lead to greater inequality. Egalitarianism has a clear answer to give with regard to the first set of situations where inequality is reduced, but no clear answer with regard to the second set of situations.

All of this leads to the tentative conclusion that whereas Article 14 in conjunction with Article 10 and Article 13 leads to an obligation to pay special attention to the interests of those who are worst off with regard to social status and health or otherwise vulnerable (e.g. children) when contemplating activities to promote health and social development, it is more difficult to argue that these Articles imply an obligation to seek strict distributive equality.

3.4 The importance of legitimate decision-making procedures

It is evident that pursuing the goals of promoting health and social development is not without cost and that few societies, if any have the resources to actively pursue all the goals mentioned in Article 14 to a sufficient degree and concurrently. This entails that societies will

[74] The following section is only concerned with distributive equality. The same kinds of problems do not affect considerations of formal equality, e.g. equality before the law or equality in voting.

have to prioritise between and within goals. Recent work on priority setting in health care and on societal priority setting more generally has shown that there is no uncontroversial algorithm that can provide definite answers to how such priorities should be set. Drawing on ideas from discussion in political philosophy on the characteristics of deliberative democracy, and the use of deliberative processes to confer legitimacy on decisions various deliberative accounts of priority setting have been developed[75].

The most thoroughly worked out procedure for priority setting is the so-called "Accountability for Reasonableness" (or "A4R") framework developed by Daniels and Sabin (Daniels & Sabin 2002). The essential features of A4R are outlined by Daniels in the following quote:

> "In pluralist societies we are likely to find reasonable disagreement about principles that should govern priority setting…In the absence of consensus on principles, a fair process allows us to agree on what is legitimate and fair. Key elements of fair process will involve transparency about the grounds for decisions; appeals to rationales that all can accept as relevant to meeting health needs fairly; and procedures for revising decisions in light of challenges to them. Together these elements assure 'accountability for reasonableness'." (Daniels 2000)

The A4R framework thus has four distinct components: *publicity*, *relevance*, *appeals* and *enforcement*[76].

In conjunction these four components emphasise reason-giving and create successive opportunities for all interested parties to challenge priority decisions. The basic notion behind the process is that it will increase the likelihood of priority decisions being based on reasons that reflect a commitment to fairness.

Publicity is a call for explicitness. That is, it is a requirement that decisions are made by a group of decision-makers and that the rationales for priority decisions be made accessible to the wider public and are open for scrutiny, not just to the members of the decision-making group, but to all those affected.

Relevance entails a requirement for reasonableness in priority setting. That is, priority decisions must be made in accordance with reasons that "people who in principle seek to cooperate with others on terms that are mutually justifiable" (Daniels and Sabin, 1998) will agree are relevant and adequate.

The *Appeals* component is an institutional mechanism that provides patients with an opportunity to dispute and challenge decisions that have gone against them. It also offers organisations an option to revise funding decisions in the light of further arguments. Establishing internal institutional dispute resolution procedures will give those who have been affected by a priority decision an opportunity to reopen deliberation. Appeals processes may also engage a broader segment of society in the process of deliberation including those who are not empowered to take part in the actual decision process. An appeals process is also thought to enrich decision-making because initial agreement on reasons can be reassessed in light of new evidence and priority decisions can be compared with past decisions to ensure consistency in decision-making.

Finally, *enforcement* entails public or voluntary regulation of the decision process to ensure the three other components are maintained. Proper enforcement of the decisions which are made through agreement on fairness will ensure that reasoning is decisive in priority setting and not merely a theoretical exercise.

It could be argued that any societal priority setting within and between goals outlined in Article 14 would have to follow a legitimate process and that A4R or some other account of the deliberative component of deliberative democracy would be a good candidate for specifying the necessary elements of that process. This is not a line of argument that will be

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[75] For general accounts of deliberative democracy see Gutmann 1993, Gutmann and Thompson 1993, Habermas 1992 & 1995, Rawls 1996.
For a theoretical account of the issued in applying deliberative democracy in bioethics see Holm 2006.

[76] This exposition relies on Hasman and Holm 2005.

pursued further here, except in the context of the reasons that can be given for a given priority decision.

Within a framework where decisions receive part of their normative force through the process by which they have been made and part of their force from the reasonableness of the reasons that have featured in the process Article 14 is relevant because it establishes the *prima facie* reasonableness of a set of reasons related to the goals enumerated in sub-section 2 of the article. The mere fact that an activity, for instance aims at relieving poverty is a reasonable, though not sufficient reason to pursue the activity. And conversely, the mere fact that an activity would increase poverty is a reasonable, though not sufficient reason not to pursue the activity.

More generally a decision maker who is contemplating a decision with implications for the promotion of health and/or social development ought to ensure that the effect of the contemplated activity on all the goals mentioned in Article 14 are considered. Otherwise there is a significant possibility that reasonable and important reasons have not featured in the decision making process. Article 14 can thus be the basis for a rough checklist for the reasonableness of reasons given by policy makers to justify decisions in the areas covered by the Article.

4. PRACTICAL IMPLICATIONS FOR FURTHER ACTIONS IN RELATION TO ARTICLE 22.1 AND ARTICLE 25

The discussion so far has shown that although the analysis of Article 14 leaves considerable scope for disagreement about the most plausible interpretation, the article has specifiable and normatively significant content. It excludes certain views and arguments and allocates an at least partly specifiable set of obligations to governments and other societal actors.

This entails that governments are obligated to take the types of actions that are mentioned in Article 22.1[77] in relation to the Article 14 obligations of both the governments themselves and of important sectors of society.

This would minimally entail that a state must ensure that Article 14 relevant reasons are taken into account in all decisions with significant effect on health and social development. And furthermore that it must be actively engaged in making other societal sectors aware of their obligations.

There is undoubtedly a significant task for UNESCO in supporting and facilitating the educational aspects of this task in relation to its obligations specified in Article 25.

More ambitiously the specifiable content in Article 14 makes it possible to monitor the progress of states in fulfilling their obligations. One example would be through the introduction of Health Impact Assessment (HIA) as a part of government decision making at all levels. HIA is essentially a methodology to ensure that the health impact of government decisions are assessed before the decisions are made and the initial development of HIA was modelled on the already existing frameworks for environmental impact assessment. Through a structured process it ensures that both the direct health effects and the effects on the determinants of health are identified and as far as possible estimated (Lock 2000).

Similarly one could envisage the gradual development of Social Development Impact Assessment methodologies measuring government policies against the social development obligations laid out in Article 14.

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[77] "**Article 22 – Role of States**

1. States should take all appropriate measures, whether of a legislative, administrative or other character, to give effect to the principles set out in this Declaration in accordance with international human rights law. Such measures should be supported by action in the spheres of education, training and public information."

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