## SHS/EST/ABC/REP/03



United Nations Educational, Scientific and Cultural Organization

•

# <u>UNESCO ASSISTING BIOETHICS COMMITTEES PROJECT</u> <u>2007</u>

# 1<sup>st</sup> Preparatory Meeting on the Establishment of a National Bioethics Committee on Jamaica, Kingston, Jamaica, 6-7 June 2007

## Background

The mission to Jamaica was undertaken to realise the objectives of the ABC Project ('Assisting Bioethics Committees'). Jamaica is one of the six first countries having indicated the wish to participate in this project. The objectives of this project are: To create a national bioethics committee in 12 Member States (Objective 1); to enhance the functioning of the committees established (Objective 2); and, to train members of established committees (Objective 3).

#### Participants in the meeting on June 6-7:

Dr. Harald Schmidth, Assistant Director, Nuffield Council on Bioethics, UK and Jan Helge Solbakk, Chief of Bioethics Section, EST/SHS, UNESCO. Due to delay of visa, the third member of the UNESCO team, Dr. Abdulaziz Al-Swailem, President of King Abdulaziz City for Science and Technology, Saudi Arabia, was not able to attend the mission. Participants in the meeting from Jamaica were:

- Mr. Everton Hannam, Secretary-General, Jamaica National Commission for UNESCO
- Hon. Maxine Henry-Wilson, Minister of Education & Youth, Chairperson of Jamaica National Commission for UNESCO
- Ms. Gloria Creary, Acting Director, Investigation & Enforcement Dept., Ministry of Health
- Mrs. Marcia Henry, representing the Executive Director, Scientific Research Council
- Dr. Derrick Aaarons, Consultant Bioethicist/Family and Palliative Care Physician, President of The Bioethics Society of the English-Speaking Caribbean (BSEC), Honorary Lecturer, Dept. of Community Health & Psychiatry, UWI
- Prof. Ralph Robinson, Professor of Parasitology, Dept. of Life Sciences, UWI, Honorary Secretary of BSEC
- Dr. Eileen Boxill, Attorney-at-Law & Director of Legal Reform, Ministry of Justice
- Dr. Anthony Mullings, Senior Lecturer, Department of Obstetrics, Gynaecology and Child Health, UWI, BSEC and CREI

- John Tunde Bewaji, Senior Lecturer and Coordinator, Philosophy Section, Dept. of Language, Linguistics and Philosophy, UWI
- Cheryl Brown, Attorney of law and Manager, Office of Sponored Research, UWI, BSEC and CREI

# Day 1 Morning Session

## Meeting June 6:

The meeting took place at the Jamaica National Commission for UNESCO and was chaired by Mr. Everton Hannam, Secretary-General of the National Commission for UNESCO. After Mr. Hannam's welcome remarks followed a presentation of the team from UNESCO and of the participants from Jamaica.

The chair then asked Jan Helge Solbakk to introduce the audience to the subject matter. Mr. Solbakk thanked the secretary general for having taken the initiative to realize this meeting and start an ethics cooperation with the Division of Ethics of Science and Technology of UNESCO. In his short introduction Solbakk drew attention to the fact that the last normative instrument adopted by UNESCO, i.e. the Universal Declaration on Bioethics and Human Rights, encourages member states to establish bioethics committees. He continued his introduction by informing about the different bioethics programmes of the Division, including the GEO-databases.

After Solbakk's introduction followed a short presentation of The Bioethics Society of the English Speaking Caribbean (BSEC):

- 6 of its members were present in the meeting
- First Bioethics Forum held on May 5<sup>th</sup> 2007: Presentation of different bioethics issues, ranging from teaching bioethics to clinical ethics and research ethics.
- The Newsletter of BSEC
- The website of BSEC

The formal opening of the meeting took place at the arrival of Hon. Maxine Henry-Wilson, Minister of Education & Youth, Chairperson of the Jamaica National Commission for UNESCO. In her opening speech the Minister made reference to Mr. Patrick Robinson's (former member of IBC) continuous insistence on the need for Jamaica to go more into bioethics; as science and technology development and innovation is affecting the lives of everybody. She proceeded by making reference to the General Conference of UNESCO's unanimous adoption of the Universal Declaration of Bioethics and Human Rights in 2005, adding that Jamaica as a Member of UNESCO has a *duty* to follow up this Declaration by establishing a National Bioethics Committee. She emphasised her serious commitment with respect to the ABC project by communicating to the audience that her ambition was to be able to bring something concrete to the General Conference in Paris in October.

After the formal opening of the meeting Mr. Solbakk gave a presentation of the aims and objectives of the ABC-project. In his account Solbakk highlighted the importance of:

• identifying the best approach to starting a committee;

- training committee members in working methods and operational procedures, including legal issues;
- addressing the particular needs of particular committees and of creating a network of existing committees, so that they can get feedback from each other, exchange policy documents between each other and establish partnerships.

He also informed the participants about the cooperation with the Georgetown University ethics library, and the possibilities of receiving for free relevant bioethics documents and materials. Finally, he emphasized the importance of this meeting ending up with a Memorandum of Understanding between UNESCO and the National Bioethics Committee in Jamaica for the next three years.

## Highlights from the discussion:

- How does one assess the functioning of a NBC?
- What should the role of a NBC be?
- What is the decent size of a committee?
- Aren't research ethics committees more focused than NBC's?
- The issue of chair person. The importance of selecting a well-functioning chair ('can make or break a committee').
- The issue of funding sources: The fact that there is funding from the Government does not imply that the Government should have any say with regard to the activities of a NBC.
- The main stumbling block for a committee is the budget.
- Where is the appropriate location of a NBC? Several suggestions were made:
  - in one of the ministries? This option was rejected by the participants in the meeting
  - at the National Commission for UNESCO?
  - at the Faculty of arts?
  - at the National Library? This last option was applauded by the participants in the meeting.

## Day 1 Afternoon Session

The first part of the afternoon session was dedicated to a presentation of systems of ethics committees in the UK and Norway. In his presentation Dr. Harald Schmidt highlighted the following items:

- The Nuffield Council of Bioethics (NCB) is a hybrid between a NBC and a Bioethics Think Tank
- NCB is independent from its three funding bodies (The Nuffield Council, the Medical Research Council and the Welcome Trust), in the sense that it is completely free to select its own working agenda and topics.
- The Council appoints its own members independently
- The three players involved in the work of NCB:
  - The committee members
  - The Secretariat
  - External members of working parties
- Vacancies (in the committee) are advertised openly
- Members receive no remuneration

- NCB publishes two types of reports:
  - Short guides accompanying each report to make more accessible the message to a wider audience
  - Extensive reports (100-200 pages). Examples are Animal research; Critical care decisions in the field of neonatal medicine; Genetics and human behaviour; Forensic use of bio-information; Health related research in developing countries
- The meetings of NCB are not open, while the meetings of the Human Genetic Commission are open. The members of the last advisory body are remunerated
- The Human Genetics Commission's panel of the 100: advisory body to HGC
- Regulatory authorities in the field of bioethics: The Human Tissue Authority (HTA)
  and the Human Fertilisation and Embryology Authority (HFEA). HTA and HFEA are
  in the process of being merged into the Regulatory Authority for Human Tissue and
  Embryos
- Research ethics committees in the UK: More than 150 committees. NRES coordinates the development of operational systems for RECs, including harmonisation of working methods and operating procedures.

# Highlights from the discussion:

- Is there a relationship between committee structures and population size?
- Structures of networking between the different systems of ethics committees in the UK
- How do all these committees influence the funding sources? Answer: These committees are funded by different budget sources.
- The ad hoc perspective of the UK, the pragmatist approach.
- The role of case law in the UK
- What is the benefit (and side-effects) of religious groups in the committees? Answer: Religious groups represent a particular sort of/dimension of experience and knowledge that may play a positive role in ethics committees

In his presentation of the system of ethics committees in Norway Mr. Solbakk highlighted three issues:

- The importance of independency, and various ways of safeguarding independency
- The importance of building up a professional secretariat; i.e. a secretariat with expertise in bioethics, besides expertise in administrative issues
- The importance of having young committee members as well

After Solbakk's presentation followed a discussion of establishing a National Bioethics Committee in Jamaica, with emphasis of status, needs and expectations and the way forward to set up a well functioning NBC. Highlights from the discussion:

- It is important before establishing a NBC on Jamaica to know what is already out there. Jamaica has already:
  - some research ethics committees within university settings
  - an ethics committee within the Ministry of health (advisory panel to the
    Minister of health within medical ethics and medico-legal affairs. The panel
    also deals with issues such as public health, research ethics issues coming from
    local and/or regional research ethics committees. The advisory panel has also
    dealt with the issue of setting up clinical ethics committees)
  - The Medical Council of Jamaica

- Similar bodies for nurses, pharmacists and supplementary medicine
- The professional ethics committee of the Medical Association of Jamaica
- Similar bodies in the Lawyers Association and in the Association of Psychologists
- The National Biosafety Committee
- International agencies such as PAMHO and the Caribbean Food and Nutrition Institute
- Jamaica is a very heterogeneous country
- Public debate is difficult in Jamaica
- What should be the role of a NBC on Jamaica? We do not want it to be viewed as committee in the hands of the Government
- What is needed is a NBC for raising and piloting bioethical debates and in this way influence policy-making
- The NBC should be proactive
- The NBC should address issues beyond the human sphere
- The NBC should be national
- The three important ministries are:
  - The Ministry of Health
  - The Ministry of Education, and
  - The Ministry of Agriculture
- The hottest bioethics issues in Jamaica:
  - Abortion
  - GMO
  - Use of DNA (paternity issues, forensic medicine, criminal cases)
  - Gene therapy research (reference to a case from Barbados)
  - Child abuse
  - Health care delivery
  - Open mining
  - Biopiracy
  - Environmental issues
- The lack of reflective thinking
- The need for governmental support plus sustainable funding
- Disciplines/forms of expertise that should be represented in a NBC:
  - Scientist
  - Lawyer
  - Philosopher/Bioethicist
  - Theologian/Religious representative
  - Medical doctor/Health professional
  - Geneticist
  - Social scientist
  - Consumer group representative
  - Trade unionist
  - Human Rights Group representative
  - Intellectual/Artist
  - School teacher
  - Media
  - Environmentalist
  - Lay person

# Day 2 Morning

Based on the discussions and deliberations of day one Mr. Solbakk presented a draft of suggested statutes for a National Bioethics Committee in Jamaica. In the present draft suggested revisions from the discussion following the presentation are included:

## National Bioethics Committee of Jamaica Draft constitution June 7<sup>th</sup> 2007

## Art.1

The National Bioethics Committee of Jamaica was established on ...initially with the support of the UNESCO National Commission and the Ministry of Education & Youth.

## Art.2 Membership

- 2.1. The Committee shall consist of no less than 15 members
- 2.2. Members shall not act as representatives of specific interest groups but will contribute based on their expertise and experiences from the following fields of knowledge, organizations and institutions
  - Humanities (bioethics, ethics, cultural studies, history, philosophy, religious studies)
  - Human rights studies
  - Health care
  - Molecular biology and/or genetics
  - Science and technology
  - Agriculture
  - Environmental studies
  - Social Sciences
  - Law/Health law
  - Education (school teacher)
  - Youth groups
  - Consumer groups
  - Human Right Groups
  - Media
  - Trade union
  - Industry (pharmaceutical, mining, manufacturing, inter alia)
  - Biosafety
  - Churches/religious groups
  - Lay people
- 2.3. Appointment of chairperson and members shall be the responsibility of the [Minister of Education & Youth] based on open calls and applications and with advice from the National Commission of UNESCO.
- 2.4. The members of the committee shall be appointed for three years and be eligible for reappointment. The chairperson shall not be reappointed for more than two consecutive terms. Other members of the committee shall not be appointed for more than three consecutive terms.

# Art. 3 Mission of the Committee

The National Bioethics Committee of Jamaica (NBCJ) is an independent advisory body which determines its own work agenda.

More specifically the NBCJ shall:

- a) keep abreast of developments in the field of bioethics,
- b) identify and interpret the ethical, social and legal questions raised by scientific and technological advances in agriculture, biology, biotechnology, medicine, genetics and environmental studies.
- c) inform and advise scientific communities, governmental authorities, the public and other interested parties when requested or deemed appropriate,
- d) report on such questions in the interests of promoting public awareness and understanding, informed discussion and education,
- e) coordinate relevant national activities and be willing to represent Jamaica in related international fora.

## Art. 4 Work methods

- 4.1. The Committee shall meet at least (4) times a year
- 4.2. The quorum for a meeting shall be the chairperson or her or his nominee, and 8 members
- 4.3. Decisions of the Committee are reached ideally by consensus. In the absence of consensus differences in view will be recorded and reported.
- 4.4. The Committee can create subcommittees/working groups for specific topics and issues.

The subcommittees/working groups shall report during the meetings of the Committee

- 4.5. The Committee shall publish an annual report of its activities
- 4.6. The Committee shall lay down its own rules of procedure

#### Art. 5 Secretariat

- 5.1. The Committee shall have its own secretariat.
- 5.2. The staff of the secretariat shall include persons with competency in the field of bioethics.
- 5.3. The secretariat shall prepare the budget and provide periodic financial reports on behalf of the committee.
- 5.4. The secretariat shall draft the minutes of each meeting.
- 5.5. The secretariat shall draft and make available the reports and recommendations of the committee to relevant bodies and interested parties.
- 5.6. The secretariat shall be responsible for collecting, archiving and providing basic documentation material relevant for the activities of the Committee.
- 5.7. In order to facilitate communication and dissemination of information the secretariat shall establish and maintain a website.

## Art. 6 Accountability

The Committee is accountable to

- 1) the UNESCO National Commission, or
- 2) the Ministry of Education & Youth, or

#### Art. 7 Evaluation

The Committee shall be evaluated initially [internal, ministerial and/or international] at the end of its first 3 years and guided by this constitution the committee's mandate and operating procedures may be revised accordingly. Thereafter, the committee shall be evaluated every 5 years.

## Presentation of a draft plan for further ABC action in Jamaica:

Before closing of the meeting by the chair, Mr. Solbakk presented for discussion a proposal for a draft plan for further ABC action in Jamaica. As a result of the discussion following this presentation it was decided that the Secretary General of the Jamaica National Commission for UNESCO should ask for a meeting with the Minister of Education & Youth to present the result of the two day's meeting and suggest the establishment of a preparatory committee to start the work towards the General Conference in Paris.