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Editorial: Rediscovering our roots

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The application of the concept of informed consent to clinical research in China is discussed in the first paper in this issue of *EJAIB*. There are important messages to those international partners who work with colleagues in Asia and other regions of the world. Seeking to fill the gaps that exist is important to build up a climate of vigorous intellectual scientific research capacity in each country. For example, while some organizations have starting building up mechanisms for approval of clinical trials from pharmaceutical companies, the persons who sit on the established committees often lack a broader background. They often import Western traditions without enough concern for their own traditions, cultures and long established ethical theories. We have to let each country (and the persons and communities within them) to rediscover themselves to be prepared for the transformations occurring in all societies. When I have organized meetings in some countries in Asia the participants are very positive to learn that UNESCO is aiming for a broad approach to these issues and building up intellectual infrastructure in the countries, which will be a basis for sound policy. The fact that many countries have developed their own ethical standards is also evidenced in the reports of recent UNESCO consultation workshops on Codes of Ethics in Engineering and Sciences that mapped the state of ethics in a range of fields (see UNESCO Bangkok website for more).

Other papers in this issue provide some perspectives from across the region with a perspective on German bioethics. Readers views are encouraged.

Informed Consent in Chinese Clinical Research: The Role of Family in Decision-Making

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1. Background and Aims

Informed consent is a richly textured legal and ethical concept. The process of informed consent is based on two fundamental ethical principles: protecting human subjects (non-maleficence) and allowing potential subjects freedom of choice (autonomy). The concept of "informed consent" is addressed in detail by the World Medical Association's Declaration of Helsinki of 1964. The core of the 2000 version of the Declaration with respect to informed consent is its Article 22: "In any research on human beings, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail. The subject should be informed of the right to abstain from participation in the study or to withdraw consent to participate at any time without reprisal. After ensuring that the subject has understood the information, the physician should then obtain the subject's freely given informed consent, preferably in writing."

Today, research must meet strict guidelines and be approved by an IRB beforehand. Most hospitals, universities, and other institutions where research takes place have these formal committees that evaluate research proposals. According to the CIOMS (Council for International Organizations of Medical Sciences) / WHO (World Health Organization)'s International Ethical Guidelines for Biomedical Research Involving Human Subjects (2002), the ethical review committee must ensure that "the provisions of the Declaration of Helsinki are applied in all biomedical research involving human subjects".[1]

Obtaining informed consent from patients and research participants has been an expected part of clinical research in China since 1998. However, informed consent" is still a relatively new ideal. Many Chinese investigators, physicians/scientists and also clinical trial participants may feel that informed consent is merely a formality necessary to obtain the participant's signature on a form in order to allow specific procedure to be performed on the subjects. As a developing country China differs with developed countries in many ways: culture, history, beliefs, size of population and social, economic, and educational status especially status of girls and women in some rural area of the country. There are also significant differences in socio-economic status within the country. This diversity should be taken into account. Obviously, healthcare professionals and investigators have a great responsibility for carrying out informed consent appropriately in their research, especially where the public and participants generally unused to contemporary standards for protection of human subjects. Therefore the target group of this study was healthcare professionals who conducted clinical research as well. Their attitude will be representative of the researchers in clinical research in china. The aims of the study were: to identify perceptions of informed consent; to identify attitudes to the models of obtaining consent in their clinical research; to develop appropriate methods for obtaining informed consent in clinical research; and to examine the mechanism of IRBs (ERBs) in clinical research to determine how they actually function and to assess their capacities.

The survey was carried out by a research group at the Center for Bioethics, PUMC with the co-operation of the Center for Medicine and Humanities, Southeast University, Nanjing and health workers in four Beijing hospitals and three Nanjing hospitals from October 2002 to February 2004. The pilot study was conducted in late 2002 to test the validity and consistency of the survey instrument. Individual interviews were conducted with thirty-four doctors both from Beijing and Nanjing in the pilot study phase. The interviewees were selected by Judgment Sample. This survey was the first of its kind in China to examine research ethics related to the model of informed consent and the IRBs capacity. The findings of the survey have been used in subsequent training programs and also have been placed on the teaching material for program of National Continuing Medical Education (Research Ethics). This report presents a summary of the study and main findings.

2. Study Design

The study achieved its goals through a survey in two selected cities of China: Beijing, the capital, and Nanjing , an important academic and culture center. Four tertiary hospitals in Beijing (represented in this report as hospitals A, B C and D)[2], and three tertiary hospitals in Nanjing were selected and 225 professionals were selected as the samples in order to get results that reflect the target population. The distribution of the samples is indicated in the chart 1. The cities, hospitals and the participants were selected by the judgment sample, i.e., obtained according to the discretion those is familiar with the relevant characteristics of the representative group. Knowledge about the group has been used to build the design into the sample.

The research team members went to the selected departments where clinical research was conducted. Professionals in the departments who agreed to participate were asked to fill in questionnaires. The

[1] *The commentary to CIOMS/WHO Guidelines 14.*

[2] A: Fu Wai hospital, B: Ren Min Hospital, C: Chao Yang Hospital, D Beijing Union Hospital.

research team answered any questions posed by respondents and collected the completed questionnaires.

Table 1: Sample Distribution

		Samples
Nanjing		75
Beijing	Hospital A	45
	Hospital B	25
	Hospital C	25
	Hospital D	55
Total		225

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The self-administered questionnaires were designed to gather information on the respondents' current perception of informed consent and on how they obtained consent in their clinical research involving human subjects. The sample came from the 3 hospitals in Nanjing city[3], (75 samples) and 4 hospitals in Beijing [4](150 samples).

The aim of the questionnaire is to empirically identify 1) the professionals' understanding of informed consent; 2) the professionals' attitudes (preferences) regarding alternative models of information and decision-making in their clinical research; and 3) the role of the local IRB.

All data were collected anonymously and participation was voluntary. Demographic variables (e.g. age, gender, education, occupation status etc.) in the questionnaire were used only to provide information about the group of people who took part in this survey, and also as the basis for group-level comparisons of responses. Participants could refuse to answer any questions, and could end the survey at any time, and their responses were kept private and confidential. Upon request, results were made available to participants after completion of data collection and analysis. The coded data was entered into the SPSS (11.5 version) program (Statistical Package for the Social Sciences) for analysis. The reliability, validity and internal consistency of the questionnaire were tested in a pilot phase.

Interviews with the Professionals

Interviews were carried out in Beijing Union Hospital and Nanjing Renming Hospital with some professionals after they had been given the questionnaires. The aims and objectives of this method were to test reliability, validity and internal consistency.

The Sample

The criterion for inclusion was a record of clinical research in China. The 225 questionnaires were distributed, of which 198 valid questionnaires were returned, a response rate of 88%.

Data Analysis

The data collected from questionnaires were coded and analyzed using SPSS (11.5 version)PC for Windows, with simple statistical analysis (mainly the chi-square test of significance). Chen Qi, from the Section of Epidemiology and Health Statistics, Capital University of Medical Sciences, was solely responsible for the analysis and interpretation of the survey data.

3. Main Findings

Demographic Characteristics

Gender: Female 101 51% Male 97 49 %

Age: Youngest: 22 years old Oldest: 71 years old

Mean: 34.5 (years) （Std. Deviation，9.64）

Table 2 Education Level

	N	%
Technical secondary school	1	0.5
Junior college	7	3.6
Bachelor	87	449
Master	61	31.4
Doctor	38	19.6
Total	194	100

Table 3 Status

	N	%
Medical Intern	20	10.10
Resident	52	26.26
Attending Physician	71	35.86
Vice- Chief Physician	22	11.11
Chief Physician	21	10.61
Others	11	5.56
Total	197	100

This report presents a summary of the main findings. There were no significant differences between the two cities except the answer to the question about the training condition on research ethics.

A. Perceptions of informed consent

To obtain genuine consent, healthcare professionals must do their best to communicate information accurately and in an understandable and appropriate way. The information provided to participants must be relevant, accurate and sufficient to enable a genuine choice to be made. It must include such matters as the nature and purpose of the research, the procedures involved, and the potential risks and benefits. National and international guidance sets out the factors which prospective participants must be informed of.

In order to investigate perceptions of the professionals toward informed consent, they were asked the importance of following aspects of the informed

[3] Zhong Da hospital, Gu Lou hospital and Jiang Su Province Ren Min Hospital.

[4] Peking Union Medical College affiliated Peking Union Hospital and Fu Wai Hospital. Beijing University affiliated Ren Min hospital and Capital University of Medical Sciences affiliated Chao Yang Hospital.

consent process. A five point scale from Unimportant (1) to Very important (5) were provided for their choice.

The percentage of those who chosen very important to the questions were as shown in Table 4.

Table 4: Results on informed consent

Questions	% Very important
Having the potential participant sign the consent form	85
Having the potential participant read the consent form	81
Making sure that a copy of the signed consent form is in the participant's file.	78
Ascertaining that the potential participant comprehends information in the consent form and voluntarily chooses to participate	73
Ascertaining that the potential participant comprehends the research information in the consent form and voluntarily chooses to participate	70
Explaining the research to the potential participant in the presence of a witness.	59

The doctrine of informed consent requires that doctors obtain the individual's *voluntary informed consent* of the subject prior to conducting medical research. Informed consent is more than simply getting a subject to sign a written consent form. It is a process of communication. Nowadays 'Informed Consent' is an essential and indispensable moral and legal prerequisite in medical research and treatment. Obtaining informed consent of patients and research subjects is now a required part of medical practice and research in China. Responses to the survey questions demonstrated that most responders were aware of the requirement of informed consent in their clinical research. But the most common view on "informed consent" is limited to two elements: Read and sign. They view informed consent as a "document" instead of a process that leads the participant to understand.

B. Consent document / process

When asked about the necessity for disclosure of the following components of an informed consent form for research, the responses to the questions were on a five point scale from 1 (unnecessary) to 5 (very necessary).

C. Comments

The Declaration of Helsinki states that participants always have the right to safeguard their integrity and their privacy. The importance of these considerations is that they lead on to the central requirement: that before research related to healthcare can be carried out involving human participants, the participants must first be adequately informed about all relevant aspects of the study including its aims, procedures, attendant risks, potential benefits and discomforts, before they are asked to consent.

Table 5: Results on consent process

Questions	% Very necessary
Available medical treatment in the case of research-related injury	76
The potential of reasonably foreseeable harm	73
The potential of reasonably foreseeable discomfort.	69
The expected benefits to the participants	61
The nature and the purpose of the research	59
Compensation for participation	59
The potential of reasonably foreseeable stresses	57
The participants might be in the placebo-controlled group	45
The procedures to be used	40

Most respondents were aware of the necessity to inform the participants about all relevant aspects of a research. Yet a number of responders didn't think that the procedure of research must be disclosed to participants. The reason for this might be that the researchers believed that it was too difficult to make the abstract scientific terms and theories being understood by participants who lacked biomedical knowledge or who had a lower educational level. The traditional of paternalism is still rooted in medical practices in China. This approach leads to the belief that the interests of participants should be and only could be protected by the conscientious protection of physicians and scientists. Therefore, it is unnecessary for the researchers to explain complicated procedures to participants as long as the research would benefit the participants. This does not mean that the physicians and scientists could or would override the rights of participants. Rather, it means that physicians and scientists believe that they could protect participants' rights better than participants themselves could, even if provided with full information. Most interviewees expressed this perspective. In their understanding, the disclosure requirements of informed consent should be regarded with skepticism if it simply loaded patients down with trivial details. This attitude presents a problem in introducing the requirement of informed consent in Chinese biomedical research.

4. A Model for Obtaining Informed Consent: Role of Family

In order to identify the preference for the "best and practical models for obtaining informed consent in their clinical research in China", they were requested to

Table 6

Scales / Questions	Strongly Disagree 1	2	3	4	Strongly Agree 5
Complete individual informed consent	2 %	3 %	12%	20%	63 %
Informed consent with the support of family	3 %	2 %	20%	31%	44 %
Proxy Consent by the family (Husband/parents) instead of individual subject	27%	21%	16%	16%	20%
Proxy Consent by the head of the work unit instead of individual subject	52%	15%	15%	9%	10%
Proxy Consent by the local officials instead of individual subject	58%	14%	13%	7%	8%

answer the questions with five scales from Strongly Disagree to Strongly Agree. The responses are in Table 6.

Respect for persons is a fundamental moral duty. In clinical research, this duty requires that we do not act against a participant's wishes. His or her consent to participate in clinical research must thus be obtained. The duty upon those conducting research ordinarily to obtain consent is widely recognized in national and international guidance and in legislation.

For principles to be translated into practice a proper procedure must exist. The procedure for informed consent must take into account the distinctive social, cultural, and historical context of its use. As a developing country, China differs from the developed countries in many ways: culture, tradition, history, size of population and levels of education (especially of girls and women in countryside). Moreover, there are significant differences in socio-economic status within the country. In traditional Chinese culture, the interdependence of family members is a given, and great value is placed on honoring and strengthening family ties. Individual self-determination is valued much less. Therefore obtaining informed consent from the spouse or from family members has been a conventional procedure in medical practice of China for many years. This culture has been reflected in the legislation of the country as well. According to *Law for Physicians* which took effect on the first of May 1999, physicians are requested to "truly introduce the state of an illness to the patients themselves or their family members." Physicians are also requested "to ask the permission of the hospital authority and obtain consent from the patient himself or from family members before the experimental treatment will be conducted on patients." [5]

In the pilot study of the survey, interviewees supported the view that respect for a person should include respect for the person's culture, for culture is the part of a person. Therefore in China consent is not merely as a purely individual prerogative or responsibility. It is associated with wider obligations to family. Family members have a responsibility to assist their kin in decision-making. We call this model family-assisted informed consent. Most people in my interview think that consent assisted by family members rather than consent by individuals alone is more valid, given the culture and situation of China. For their part, participants would like to take time to discuss the information with their family members before they make the final individual decision. In China this cohesive family power has had important value, especially where socio-economic status and educational level was low.

Thus, in the Chinese view, respect for persons should not be expressed narrowly as respect for individual autonomy. The Chinese understanding of this principle should not be viewed as less stringent than the Western one. In fact it imposes extra duties on researchers. For example, it requires investigators to allow time for prospective participants to discuss the information with family members before individual consent be sought.

We discussed the need to be sensitive to the cultural context in which research is conducted. However, this does not mean that cultural practices must be accepted uncritically. In the circumstances outlined above, there is sometimes tension between the requirement that genuine consent to research be obtained from prospective participants and the demands, in some cultural contexts, that information and decision-making authority be shared. Some respondents indicated "strong agreement" with two principles that sometimes are contradictory: that participants who have the capacity to consent to research should never be subjected to research without such consent, and that research may be conducted on an individual if the husband or parents offer proxy consent.

In the process of informed consent there are two aspects of ethical requirements: substantial and procedural aspect. The substantial ethics requires what a researcher should do is to provide human subjects with adequate information necessary for their making of decision, to make sure that they comprehend this information provided, to obtain their free consent after

[5] *Law for Physicians*, Article 26.

information is provided and comprehended. The procedural ethics involves the question about who should make decision. Traditionally, the decision–maker should be the individual who is prospective subject. However, when Westerners entered a non-western culture context, they found the claim of individual being decision-maker was challenged by non-western culture, they hastily invented the term "family consent" or "community consent". Now there are two poles in the procedure of informed consent: individual consent vs. family/community consent.

Purely individual consent has difficulty in a non-western, say, Confucian culture context. For Confucians, orderly familial relationships (*ren lun*), which in turn are the foundation of the state. "Marriage is the union of two families into one in order to serve ancestors and extend life to future generations. Man and woman are different, so there is affection between husband and wife, then there is kinship between father and son, then there is political relations between king and his subjects." (*Book of Rites*) Family improves human existence, makes the extending of ancestors' life possible, and sets a foundation for the society and country. In Confucian classics a repeated claim is that a politician who wants to rule the state must manage his own family well, as claimed in Great Learning: "When the family is regulated, the state will be in order; and when the state is in order, there will be peace throughout the world."

On the other hand, a person in Confucian context is not so independent or isolated as being deemed in Western culture. In Confucianism a person is never seen as an isolated individual but is always conceived of as a part of a network of relations. The self-cultivation of an individual person to become a sage is a process that is carried out in and through the social context and for the purpose of fulfilling social responsibility rather than self-actualization *per se*. And to actualize man's nature is to fulfill man's human relatedness; a person is always a "person-in-relations." So the ability to have human relationships is what differentiates human persons from animals, and what is crucial for a human person is to be self-consciously aware of "a keen insight" in human relationships and so "by nature" follow "the path of morality." Human beings may lose this consciousness of human sociality and relationships and thereby degenerate into behaviours not significantly different from animals. This is why Mencius repeatedly emphasized the importance of education and moral cultivation. So for Confucians relations are of the ontological category, in that they both constitute and complete personhood.

For understanding more about the Confucian concept of personhood, it is necessary to learn Confucian hardcore concept of *ren*. In *The Analects*, the term "*ren*" appears 105 times, more than any other term. It has been variously translated as benevolence, humanity, humanness, humaneness, compassion, kindheartedness. *Ren* is a relational term and is used to describe the relational/social nature of man. The Chinese ideograph for *ren* is composed of two characters "human" and "two"(仁), denoting that whatever else the term may mean, its meaning is intended to be accomplished through human relationships.

Ren is loving others"(Confucius),"Seeing the other the same as oneself and greeting each other to express care." (Zeng Zi) To be truly *ren*, and charity as a form of *ren*, must be accompanied by respect. Individual integrity and dignity are presupposed and not precluded by human relations in which *ren* is actualized. *Ren* does not only refer to an achieved state of humanity either as some inner character or spiritual condition, or as an aspect of the outward action or conduct, but as a dynamic process of "person making." This person-making process as fundamentally an integrative one in which the self "with his disintegrative preoccupations with selfish advantage" is transformed into "the profoundly relational person." The feature of this relational person is the ability to show deference to the others, including respectfulness, tolerance, trustworthiness, reverence and generosity. So *ren* involves not only the willingness of the self to respect others in the community but also the readiness to become part of the community.

There are two features of actualising *ren* or person-making: others regarding and retaining the self as the point of reference suggest the interdependency and interpenetration between self and others. Using oneself as the analogical point of reference to assess or treat others. In applying the self as a measure or analogy, one projects oneself into the circumstances of the other to find out what the other person wants or does not want; but this does not entail that one abandons one's own identity or compromises one's own values. In the actualization of *ren*, on one hand, there is the extension of oneself outward to the other; on the other hand, there is the appropriation of the other inward to the self; in the midst of this exchange of each other, there is the resultant reciprocal bonding of one and other. Eventually the self is so united with the other within the matrix of the united "self-other" interest that to love self and the other is no longer distinguishable.

However, Confucius pointed out that the method of actualizing *ren* is from near to far. Actualizing *ren* begins with family. "*Xiao* (filial piety toward parents) and *ti* (fraternity toward brothers/sisters) are the roots of *ren*"(Confucius). If a man cannot even reciprocate the intimate human affections experienced within the family bond, it is not likely that person-making can be achieved in the less intimate environment outside the family circle. [6]

Now it may be probably asked that with the rapid economic increase and social transformation would the important status of family in Chinese society be shaken? According to the structural-functionalist thesis, family form, size and functions are related to changes and transformations in the social environment. Increasing

[6] See Edwin Hui 2004, Personhood and Bioethics: Chinese Perspective, Po-Keung Ip 2004, Confucian Personhood and Bioethics: A Critical Appraisal, in Ren-Zong Qiu (ed.): Bioethics: Asian perspectives – A Quest for Moral Diversity, Dordrecht: Kluwer, pp. 29-44, 49-56.

functional specialization, industrialization and economic development will cause the family to lose some of its functions in training, economic production and personal care to schools, to other economic units of production, and welfare institutions. The extended family[2], as a social unit for providing these functions in pre-industrial societies, is believed to be dispensable in modern industrial societies. Furthermore, it is alleged that increased social and geographical mobilities in industrial societies have contributed to the psychological distance and physical separation between family members, especially between adults of different generations. The extended family is therefore no longer viable as a form of family organization, and the family system will move towards a mode of "isolated nuclear families" which are separate, highly autonomous and independent from extended family ties. [7]

According to Tao and Chan [8] it is true that the number of joint families has been decreasing and that the nuclear family is the most popular family form in contemporary China. Yet, surprisingly, the numbers of *both* nuclear and stem families have increased since the launching of the economic reform, and a significant proportion of Chinese households are in the form of stem family. [9] Their survey findings in China do not support the isolated nuclear family thesis as an inevitable outcome of industrialization and modernization, although this does not imply that the Chinese family in the transitional economy has not undergone some adaptations to respond to the new social environment. Their conclusion is that the family is still highly treasured in the Chinese society in the age of economic reform and rapid social change because the Chinese family expresses the values of mutual care, reciprocal support and human connectedness which are values deeply engrained in the Chinese mind. As a rule in clinical context a decision is made by the family including the patient self, but not the patient self.

However, these two scholars from Hong Kong also noticed the disadvantaged status of women in a traditional Confucian family. So when the family makes decision, the decision may not benefit certain members of the family. In rural areas the decision made by the family is sometimes not in the best interest of girl or woman. If the "family consent" is used as an overarching principle, certain member of the family would be harmed in a given cultural context. The same is the "community consent". The fact that not all members in the family have equal power and the powerless is vulnerable indicates that it is necessary to have a mechanism to protect the rights and interests of vulnerable members in a family. And it should be prudent to use the terms such as "family consent " or "community consent". These two terms would convey a misleading information that it seems the head of a family or a community has the power to decide which member in the family or community should participate in the research. It is unfair because the burdens of participating in the research would be fallen on the subject's shoulder, not anybody else's including head's. Moreover, it would lead to corruptive consequences.

It is why I prefer the term family-assisted consent to "family consent" and "community consent" and it shows that there is more appropriate position between purely individual consent and purely family consent or community consent. [10]

4. Acknowledgements

This presentation is based on findings of a survey which was carried out by the Research Center for Bioethics, Peking Union Medical College and supported by the Program on Ethical Issues in International Health Research of the Harvard School of Public Health. I am grateful for the major contribution of advice and support given by Dr. Cash, the program director, who is an expert on international healthcare research ethics. I am grateful for the contribution of all participants who agreed to be interviewed and who filled in questionnaires, the seven hospitals that agree to take part in the study. This work could not have been done without their support.

[7] Talcott Parsons 1943, The Kinship System of the Contemporary United States, *American Anthropologist,* 45: 22-38;
Talcott Parsons & R.F. Bales 1955, *Family, Socialization and Interaction Process,* Glencoe, Ill.: The Free Press.

[8] Julia Tao & Ho-Mun Chan 2004, The Chinese Family and Chinese Women in the Transitional Economy, Feminist Philosophy and Public Policy, ed. By RZ Qiu, Beijing: Chinese Social Science Press, pp. 152-174.

[9] The nuclear family consists of a couple and their unmarried children. A stem family is defined as a family in which an elderly parent or parents live with one married child, together with his/her spouse and perhaps grandchildren as well. A joint family consists of more than one married siblings together with their spouses, their children, and normally with their elderly parent or parents. An extended family consists of persons related by common descent and their spouses. Stem families and joint families are therefore two specific forms of extended families.

[10] In 1993 at the meeting of drafting CIOMS's International Ethical Guidelines for Biomedical Research Involving Human Subjects Professor Qiu challenged the concept of community consent and first put forward the concept of informed consent with the aid of family or community, see Z. Bankowski & R.J. Levine (eds.) 1993, Ethics and Research on Human Subjects: International Guidelines, Proceedings of the XXVIth CIOMS Conference, Geneva, Switzerland, 5-7 February 1992.

Wrongful Life: A Recent Australian High Court Decision

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9 May 2006: Decision of *Waller v James; Waller v Hoolahan* (2006) HCA 16
Gummow, Kirby, Hayne, Callinan, Heydon and Crennan JJ

The case concerned an appeal from the New South Wales Court of Appeal[11] which was heard together with the case of *Harriton v Stephens*.[12] Both cases deal with the question of whether the tort of negligence is capable of affording relief for *wrongful life*.

The case raised the issue of a medical negligence claim. At first instance the respondent negligently failed during an *in vitro* fertilisation (IVF) program and antenatal care to investigate and advise or warn the parents in relation to the genetic condition of the father where the condition posed a risk to the appellant child. The child was born with an inherited genetic condition and suffered serious disabilities as a result of it. Thus, the question in tort was whether the child can recover damages from the respondents for pain and suffering, special damages for the needs created by his serious disabilities and damages for a loss of earning capacity.

Facts

Keeden Waller (**the appellant**) is the only child of Mr Lawrence Waller and Mrs Deborah Waller. He was born on 10 August 2000. Because the parents had experienced difficulty in achieving conception, they consulted Dr Noonan, who is a medical practitioner in general practice. Dr Noonan arranged for an analysis of Mr Waller's semen. Accordingly, Dr Noonan referred the appellant's parents to Dr Christopher James (**the first respondent**). Dr James is an obstetrician and gynaecologist. He has a special interest in problems of human infertility.

In his letter of referral to Dr James, Dr Noonan noted that Mr Waller suffered from "Factor III deficiency". This is a blood disorder which is also known as anti-thrombin 3 deficiency ("AT3").

Mr Waller consulted Dr James on 3 March 1999. Dr James arranged for Mr Waller to undergo fertility tests to be performed by Sydney IVF Pty Ltd (**the second respondent**) ("Sydney IVF"). These tests were aimed at determining whether there was a genetic reason for the condition of his sperm. The tests were not, as such, concerned with Mr Waller's AT3 deficiency, its genetic basis, or the potential it had to be passed on to his offspring.

Subsequently, Dr James recommended to Mr and Mrs Waller an *in vitro* fertilisation procedure. The Wallers agreed. On 11 November 1999, Sydney IVF successfully injected seventeen eggs with Mr Waller's sperm. On 27 November 1999, testing arranged at Dr James's request, confirmed that Mrs Waller was pregnant.

On 22 December 1999, Dr James referred Mrs Waller to Dr Brian Hoolahan (**the third respondent**). Dr Hoolahan, also an obstetrician and gynaecologist, specialised in prenatal care. Mrs Waller consulted Dr Hoolahan on numerous occasions.

On 10 August 2000 Mrs Waller gave birth to Keeden. Mrs Waller and the appellant were discharged on 14 August 2000. However, on 15 August 2000, Keeden was returned to the Hospital. He was diagnosed as suffering from a cerebral thrombosis.

Keeden Waller has permanent brain damage, suffers from cerebral palsy, has uncontrolled seizures and requires constant care.

Questions to decide

Studdert J put forward two questions which need to be addressed which were the same questions raised in the case of *Harriton*:[13] "1.) If the respondents failed to exercise reasonable care in their management of the parent's of the appellant, and but for that failure the appellant would not have been born, does the appellant have a cause of action against each of the said respondents; and 2.) if so, what categories of damages are available?"

For the purposes of the proceedings it was agreed by the parties that the respondents should have advised Mr and Mrs Waller that Mr Waller's AT3 deficiency was genetic and that it was therefore susceptible to being transferred to his children. It was also agreed that had such advice been given, Mr and Mrs Waller would have (1) deferred undergoing artificial insemination until methods were available to ensure that only embryos without the AT3 deficiency were transferred; or (2) used donor sperm avoiding that risk; or (3) terminated the pregnancy upon discovery of the risks of a child being born with serious genetic disabilities.

History of proceedings

However, Studdert J decided against the appellant not having a cause of action with regard to the first questions, and consequently no damages were recoverable. The appellant then appealed to the New South Wales Court of Appeal. The appeal however was dismissed by a majority (Spigelman CJ and Ipp JA; Mason P dissenting).[14]

Appeal to the High Court

The issue in question was whether the applicant has a cause of action in negligence against the respondents on the agreed facts above. If a cause of action can be established, the second factor to consider is whether damages are applicable.

It was disputed that the appellant's parents should have been given, but were deprived of, a timely opportunity to consider the appellant's best interests, as "their (prospective) child" or as a "potential person", in being implanted and born alive with the genetically transmitted AT3 deficiency. It was submitted that IVF is an important field of medical practice, that public policy and widespread community values (gleaned from legislation permitting IVF procedures)[15] support parents who decide in particular cases that the transmission of genetic disease would not be in the best interests of a

[11] *Waller (by his tutor Waller) v James* (2004) 59 NSWLR 694
[12] 2006 HCA 15
[13] *Waller* (2002) NSWSC 462 at 3
[14] *Waller* (2004) 59 NSWLR 694
[15] *Human Reproductive Technology Act 1991* (WA); *Infertility Treatment Act 1995* (Vic); Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995 (SA).

"potential child", and that IVF processes are specifically indicated to prevent the selection and implantation of embryos which would have such a disease.

The appellant claimed damages for his life with disabilities. However, as addressed in *Harriton v Stephens* [16] at 276 "the damage claimed is not amenable to being determined by a court by the application of legal method. A duty of care cannot be clearly stated in circumstances where the appellant can never prove (and the trier of fact can never apprehend) the actual damage claimed, the essential ingredient in the tort of negligence." However, even if the respondents owed a proposed duty of care to the applicant "as a "prospective child" of the parents, or a "potential child", or a "potential person", or as a foetus" [17], the appellant cannot come within the compensatory principle for measuring damages. Therefore, the appellant's damage is not actionable.

Orders of the Appeal to the High Court

The High Court dismissed the appeal by a 6:1 majority (Kirby J dissenting). It was held that no cause of action in negligence was given because no legally recognisable damage had been suffered. It could not be established that the applicant's life represented a loss, deprivation or detriment compared with non-existence. It was also held that damages could not be assessed because in all the circumstances comparisons with able-bodied children or with a notional life without disabilities could not be made. The decision of the Court of Appeal was be upheld.

A Christian Response to the Issue of "Designer Babies"

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Abstract

This article reflects on the issue of Designer Babies, which once was thought upon as science fiction, but as scientific invention advances this issue is closer to becoming a reality. Therefore it is an issue that must be addressed seriously. The topic also raises serious theological and ethical issues.

Key Words: Designer Babies, Personhood, Human Dignity, Genetics, etc.

Introduction

According to a Christian view, God created human beings in God's image: male (Adam) and female (Eve) (Gen. 1:26). God was pleased with God's creation (Gen. 1:31). Later it is implied in the scriptures that we are co-creators with God. How far can we stretch this idea, particularly in a post-modern society where we are faced with issues like, "genetic engineering", "cloning"[18] and "designer babies"? The already budding reproductive industry is likely to expand as new technologies open up new possibilities for baby-stopping (through Norplant[19], RU486[20] or abortion), baby-making (through artificial insemination, in *vitro* fertilization (IVF)[21], donor semen, donor eggs, frozen embryos and surrogate mothers) and baby-selecting (through genetic screening, genetic engineering, nuclear transplantation, egg fusion, cloning, selective abortion and in *utero* foetal surgery).[22] The decision to have or not to have children or even to manipulate and create the kind of baby we want to have conveys to us the message that the "will of God" and natural process is no longer a matter of importance. The whole enterprise has been made subject to human will and the advancement of technological expertise. This is a new challenge in the post-modern situation for us as theologians with which to grapple.

Since this topic is an up-and-coming issue in the field of science and academics, not much has been written about it from the viewpoint of Biblical Theology. Therefore, an attempt has been made in this paper to address this issue in the light of Christian faith, biblical theology and ethics. As a theologian with little training in biology and bioethics, it is the intension of the present author to create an opportunity and a forum to think and reflect on this important issue, which is most appropriate and apt in the post-modern world.

The "What" and "Why" of "Designer Babies"?

The concept of "Designer Babies" is an advanced reproductive technology that allows medical doctors to screen embryos for genetic disorders and select healthy embryos. In doing so, there is a fear that in the future it

[16] (2006) HCA 15 at 276-278.
[17] per Crennan at 86.

[18] Cloning is the process of making genetically identical copies of genes, cells, or organisms derived from a single ancestor.
[19] Norplant is a birth control method that has come out on the market not too long ago. It is a long acting contraceptive, which will last for up to about 5 years. The Norplants are inserted into a woman's arm surgically. Six small little sticks containing a hormone call progestin, similar to progesterone, is slowly released into the blood stream to prevent pregnancies. Within the first 1 1/2 years, a high dose of progestin is released. After that, the level drops down to the level of what a Pill might contain, for the remaining time. After the 5 year period, the Norplants has to be removed. Because this method requires surgery, the cost may seem a little pricey compare to other methods… http://www.csua.berkeley.edu/~monac/norplant.html#what (accessed November 19th, 2005).
[20] RU-486 is the name commonly used for an artificial steroid that blocks progesterone, a hormone needed to continue a pregnancy. http://www.ru486facts.org/index.cfm?page=whatis (accessed November 19th, 2005).
[21] A process of fertilisation of an ova in a flask or test tube, which takes place in the laboratory, i.e. outside the living organism.
[22] Ted Peters, Designer Children: The Market World of Reproductive Choice, http://www.religion-online.org/showarticle.asp?title=123 (accessed August 8th, 2004).

may be possible for humans to use genetic technologies to modify embryos and choose desirable or cosmetic characteristics. The term "Designer Babies" is a term not used by the scientists but rather by the journalists in order to describe the frightening scenario.[23] In this forum one might ask the question, "Why worry about a hypothetical problem, a problem that may happen or may not happen in the future?" Looking at the past history of humankind it can be said with confidence that any new finding in any field of science has the possibility to be abused, and this abuse can be attributed to the sinfulness of human beings. Following is a real case that took place recently, which raised a number of questions in relation to the present issue.[24] (Please refer to the endnote for the case). Some important questions arise out of this case:

1. If the technology is available to save a life and also save the future offspring of that child without risking others, why not use it? - HFEA[25]
2. Who will take the responsibility for the murder of the rejected or discarded embryos out of which only one was selected for a perfect match?[26]
3. Is it right or wrong to manufacture a child merely as a means to an end, and to thereby treat the child as an object?
4. How will the public be hurt by saving Zain's life with the help of a new sibling who will be a cherished member of a loving family? – The Parents[27]
5. As far as the Hashmis are concerned, this is their only chance. Neither parent nor any of their other five children is a match; therefore they must be given the permission to use the technology for saving their son. – HFEA[28]
6. Should the living child wither away in front of the parent's eyes when it is technologically possible to artificially create a genetically matched baby to cure it?

Some Arguments Against The Trend

An opinion expressed on the BBC website: Of course it would be legitimate to produce a child for whatever reason, including such a noble one. But the motivation for producing offspring is actually NOT the problem here. Rather, the nasty issue is hidden in the phrase "selecting an embryo": selecting here means picking one and killing all other embryos whose tissue does NOT match. And since intentional killing of human life is murder, it would not be appropriate to select. If a method is found that does not kill embryos, there could hardly be an objection to the treatment, but all embryos are living human beings, and as such basic human rights apply.[29]

The Homerton Baptist Church opined that: The whole life of the new child is like an experiment and

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[23] What is a designer baby? http://www.bionetonline.org/English/Content/db_cont1.htm (accessed August 8th, 2004).

[24] (The Hashmi [Raj & Sahana Hashmi] family had four children. The youngest Zain was found to have Thalassaemia. He requires frequent blood transfusions and other treatments, which seriously affect his quality of life. He is unlikely to live beyond his thirties. Thalassaemia is caused by a defective gene related hereditary blood disorder. Inheritance is recessive, Zain must have two defective genes, one from each parent; the other children in the family do not have the disease.
This condition can be cured with a transplant of bone marrow cells; however these cells much match the recipient if they are not to be rejected. No one in Zain's family is a good enough match. It is also possible to transplant stem cells from the umbilical cord of a newborn baby, if the baby is an exact match. When they discovered the problem the family had another child in the hope that its cord stem cells could be donated to Zain. Unfortunately it did not match.
The Hashmis then applied for permission to use IVF and PGD (Pre-Implantation Genetic Diagnosis- When the fertilised egg has divided to an embryo of about 8 cells one of these can be removed without harming development. The DNA in this cell can then be replicated and tested for defects. If a defect is found the embryo is discarded, if not the embryo may be implanted in the uterus as with any IVF treatment.) to select, from several fertilised embryos, one that would match Zain. As well as knowing that the new baby would not have Thalassaemia, they would be sure that it would be able to act as a donor, because they had selected it specifically to serve this purpose. Many people support the family in their wish to do everything possible to save the life of their child and believe that they will also love the new baby for its own sake. Others see serious ethical objections, describing the process as creating a 'designer baby'. The legal process has been uncertain too and permission was first granted then overturned then granted again by higher and higher legal authorities.) AS Science For Public Understanding,DesignerBabies,page6.©TheNuffieldFoundation,2004, http://66.102.7.104/search?q=cache:oqDp1jaR204J:www.scpub.org/filelibrary/pdf/designerbabies.pdf+AS+Science+for+Public+Understanding%2BS9.5/Genetic+diseases/chapter+6/page+4+Angela+Melamed&hl=en (accessed August 8th, 2004).

[25] Human Fertilisation and Embryology Authority (HFEA)

[26] A better example of this can be seen in the cloning of Dolly. It took 277 attempts to produce Dolly, the first genetically cloned mammal. If this had been an attempt to clone a human being, would there have been 276 losses of cells and DNA (Deoxyribose Nucleic Acid is a protein structure formed from sequences of bases. It is found within the cell and encodes genetic information, i.e. genes are made from DNA) material or 276 lost human lives? Infact in the process of selecting a perfect match, the other embryos are rejected as unwanted and the big question is what is the dignity of those human embryos which are potential would-be human beings. Although for some this may be too extreme a way a to pose the question, we cannot avoid honestly asking about the value or moral status of the human embryo.

[27] AS Science For Public Understanding,DesignerBabies,page6.©TheNuffieldFoundation,2004, http://66.102.7.104/search?q=cache:oqDp1jaR204J:www.scpub.org/filelibrary/pdf/designerbabies.pdf+AS+Science+for+Public+Understanding%2BS9.5/Genetic+diseases/chapter+6/page+4+Angela+Melamed&hl=en (accessed August 8th, 2004).

[28] AS Science For Public Understanding, DesignerBabies, page7. ©The Nuffield Foundation, 2004, http://66.102.7.104/search?q=cache:oqDp1jaR204J:www.scpub.org/filelibrary/pdf/designerbabies.pdf+AS+Science+for+Public+Understanding%2BS9.5/Genetic+diseases/chapter+6/page+4+Angela+Melamed&hl=en (accessed August 8th, 2004).

[29] AS Science For Public Understanding, DesignerBabies, page7. ©The Nuffield Foundation, 2004, http://66.102.7.104/search?q=cache:oqDp1jaR204J:www.scpub.org/filelibrary/pdf/designerbabies.pdf+AS+Science+for+Public+Understanding%2BS9.5/Genetic+diseases/chapter+6/page+4+Angela+Melamed&hl=en (accessed August 8th, 2004).

that child cannot withdraw from that experiment nor give consent.[30]

The Daily Mail said: The HFEA's distinction fails to address the central issue of using one child to benefit another. The danger is that any such "designer" children will think they have been chosen and others discarded principally to save a sibling's life. What if the attempt fails and the older child dies or remains seriously ill? And might the parents feel differently towards the child that needs to be saved and the baby they have brought into the world to provide that help? Children need to be valued for themselves. They should never be used as commodities. [31]

Christian Medical Fellowship: The Hashmi ruling has opened the door for human beings to be manufactured for the prime purpose of providing tissue for someone else.[32]

Advantages and Disadvantages of this Medical Technology

This technology was discovered to enable parents with a child suffering from a genetic disease to choose embryos that have a perfect tissue match with an older sibling. The baby's stem cells are then transplanted to the sibling to cure its disease. As stated above, theoretically, any new medical or technological breakthrough can be abused. Therefore as a result of this discovery there is a danger that this technology can be used to create "designer babies" with a particular eye colour, intelligence, skin texture, sex, or any other demand fitting to the fancy of the would-be parents.

Dr. Michael Wilks, the chairman of the British Medical Association, is believed to have said to the BBC that this technology will be permitted only when the disease is very serious and life threatening, and when there is no other way to treat the child.[33] But this is as far as the UK is concerned. According to one source, "Currently the United Kingdom is the only country that has some form of regulation in place. In the US, for instance, 'saviour sibling' is totally unregulated."[34] This is why the Hashmis were permitted a 'saviour sibling' in the UK as an exception, where as Charlie Whitaker who suffered from a sporadic mutation (disorder) called Diamond Blackfan anaemia, was rejected and his family took him to the US for medical treatment. This incidence took place during 2002.[35]

Calling our attention to the disadvantages of "designer babies", Gilbert Meilander in his article quotes Oliver O' Donovan who points, "to the contemporary significance of the distinction between one who is *begotten* and one who is *made.* One whom we beget shares in our being, is equal in dignity to us. One whom we make has been distanced from us, and becomes the product of human technological spill (and we know how limitless that can be). Of course, parents are responsible for the nurture of those whom they have begotten, and such nurture can and should sometimes be demanding. But when we know ourselves as begetters and not as makers, we will seek to shape and nurture only those whom we first accept without qualification."[36]

Although this point may not be true always, there is a valid point for us to ponder.

There are other issues that have not been thought about: the emotional trauma the "designer" child is likely to suffer when it discovers that it was created to serve a purpose. They may feel less loved by its "parents", whether it serves the purpose for which it was created or not. How will the "designer baby" process affect the child's emotional integration later in life when the child knows that it has not been valued in its own right and for its own sake? Should the parents be allowed to view themselves as "consumers" who can shop for children of their choice?[37]

Parental choice may mean that criteria such as fitness, worth and convenience will determine which children see the light of day. "The danger is that selection methods will commodify children in a way ultimately harmful to their welfare. Carried to an extreme, parents will discard less than 'perfect' children and engineer embryos and foetuses for enhanced qualities. A worst-case scenario envisages repressive political regimes using these techniques to create a government-controlled Brave New World of genetically engineered social classes."[38]

"Hereditary advance could proceed through the creation of "high-grade" embryos that are implanted and brought to term. Should these embryos be bought and sold? If we put a price tag on physical stature, intelligence, race, or eye or hair colour, as well as relative freedom from disease, our unborn children will become commodities. What kind of society will emerge

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[30] AS Science For Public Understanding, DesignerBabies, page7. ©The Nuffield Foundation, 2004, http://66.102.7.104/search?q=cache:oqDp1jaR204J:www.scpub.org/filelibrary/pdf/designerbabies.pdf+AS+Science+for+Public+Understanding%2BS9.5/Genetic+diseases/chapter+6/page+4+Angela+Melamed&hl=en (accessed August 8th, 2004).

[31] AS Science For Public Understanding, DesignerBabies, page7. ©The Nuffield Foundation, 2004, http://66.102.7.104/search?q=cache:oqDp1jaR204J:www.scpub.org/filelibrary/pdf/designerbabies.pdf+AS+Science+for+Public+Understanding%2BS9.5/Genetic+diseases/chapter+6/page+4+Angela+Melamed&hl=en (accessed August 8th, 2004).

[32] AS Science For Public Understanding, DesignerBabies, page7. ©The Nuffield Foundation, 2004, http://66.102.7.104/search?q=cache:oqDp1jaR204J:www.scpub.org/filelibrary/pdf/designerbabies.pdf+AS+Science+for+Public+Understanding%2BS9.5/Genetic+diseases/chapter+6/page+4+Angela+Melamed&hl=en (accessed August 8th, 2004).

[33] R.Prasad, *Saviour Siblings:commodity or boon?*, The Hindu (Chennai), 29th July 2004,16.

[34] R.Prasad, *Saviour Siblings:commodity or boon?*, The Hindu (Chennai), 29th July 2004,16.

[35] R.Prasad, *Saviour Siblings:commodity or boon?*, The Hindu (Chennai), 29th July 2004,16.

[36] Gilbert Meilaender, *Mastering Our Gen(i)es: When Do We Say No?* http://www.religion-online.org/showarticle.asp?title=814 (accessed August 8th, 2004)

[37] Hasan Saroor, *The Designer Babies Debate*, The Hindu (Chennai), 26th July 2004,10.

[38] Ted Peters, Designer Children: *The Market World of Reproductive Choice*, http://www.religion-online.org/showarticle.asp?title=123 (accessed August 8th, 2004).

if we begin eyeing each other's children as we do each other's cars, clothing and houses, mentally calculating "what that one must cost"?"[39] We might be entering into a new world where the naturally born would be inferior to the artificially born, giving rise to a superior race.

A Theological Response To "Designer Babies"

Dr. Lewis Bird, who served as the Eastern regional director of the Christian Medical and Dental Society from 1964-96 and also as editor of *Bioethics Newsletter*, opined, "Christians have sought to honour two moral goals: the sanctity of human life and the mandate to alleviate suffering. Both goals are biblical, yet they conflict."[40] This is interesting because how does one reconcile these two conflicting moral goals? How does one protect the sanctity of the genetically produced baby while engaging in the alleviation of the suffering of the diseased child?

Dietrich Bonhoeffer states in his writing that Christians are called to find the "significant in the factual," which means that we can neither make moral judgments apart from knowing the scientific facts (including an assessment of the potential benefits and threats of human cloning) nor allow scientific facts to be the sole determination in making moral judgments.[41] We are caught up in a dilemma on this whole issue because, on one hand, this technique can help human society alleviate human suffering and bring order in the midst of chaos, furthering and enhancing a better human society; but on the other hand, it can also create chaos if it is abused as a free for all and falls into the wrong hands. Where does one draw the line?

No matter how well we learn to manipulate genetic matter or replicate human life, we do not create life the way God does. In the creation event recorded in the Hebrew Bible, the word for "create" is used only with God as subject. The theological claim that only God can create human life is no less true if we learn to clone human beings than it is now. We do not create the human soul. We do not, as God does, call human beings into existence. Nor do we, as God does, call human beings into different identities and tasks.[42] We are by no means God's equals, even if we are in some sense co-creators. As neo-orthodox theologians in the era of Reinhold Niebuhr have reminded us, technological advances cannot vanquish original sin. In fact, the greater the technological power, the greater the potential for evil. The Human Genome Initiative, a three billion dollar project, may provide us with the power of knowledge and the opportunity for attaining a new and unprecedented level of human health, but it may also provide us with opportunities to exercise our greed and short-sightedness so as to open up new depths of human injustice and misery.

From a Christian perspective, we can affirm that all children truly belong only to God.[43] They are not ours to manipulate, control, or abuse. But even apart from religious convictions, there are good reasons (both compassionate and practical) for the society to put the best interest of children first.

Co-creators and Stewards of God's Creation

Part of the creation mandate, and part of what it means to be made in the Image of God, is to be caretakers of God's estate, the world. "We are to subdue it and rule over it" (Gen.1:28). Andrew Rollinson in his article quotes Donald Mackay on this who, "urges us not to so defend a contentment with the unalterable that we forget the sin of complacency in the face of the alterable. He quotes the proverb of Jesus, 'He that knoweth to do good, and does it not, to him it is sin.' In other words, to run away from all that genetic technology holds out can be as much a denial of our human responsibility and dignity as is an arrogant usurping of the limitations of stewardship."[44]

It can be a false humility to throw up our hands in holy horror and say, "Don't play God", when it is actually part of a God-ordained stewardship. True science is a religious function. Tom Torrance, the Scottish theologian, calls the scientist "the priest of nature"; we are co-workers with God in nature. Genetic engineering, within proper limits, is not playing God, but serving God. As Christians, we need to affirm much that is good in this revolution and use it with restraint for the common good of the society at large, and not to fulfil the whims and fancies of a few.[45]

The human role is to be co-redeemers with God, using technology to help correct the disorder of nature and bring it more into accord with God's intentions. Genetic engineering is one way of doing this. As said earlier, the important question in relation to this concept is how far can we go in this venture? Cobb opines, "If anything intrudes too far into the divine prerogative, it would seem to be the human creation of human beings."[46]

Paul writes in his letter to the Corinthians, "All things are lawful, but not all things are beneficial" (1 Cor. 10:23). The issue here is that in genetic engineering more and more is becoming alterable, giving rise to the more fundamental question: "Does the possible mean permissible?", "I can, therefore I ought", can so easily

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[39] Ann Lammers and Ted Peters, Genethics: Implications of the Human Genome Project, http://www.religion-online.org/showarticle.asp?title=813 (accessed August 8th, 2004).

[40] Alan Mc Carrick, *ASA Explores Stem Cell Research and Christian Ethics*, January 1st, 2001. http://www.stnews.org/News-1968.htm (accessed August 8th, 2004)

[41] Nancy J. Duff, *Reflections on Human Cloning*, http://www.religion-online.org/showarticle.asp?title=432 (accessed August 8th, 2004)

[42] Nancy J. Duff, *Reflections on Human Cloning*, http://www.religion-online.org/showarticle.asp?title=432 (accessed August 8th, 2004)

[43] Psalm 127:3 – Sons are indeed a heritage from the LORD, the fruit of the womb a reward.

[44] Donald Mackay, *Human Science and Human Dignity*, Hodder & Stoughton, 1979 p.58.

[45] Andrew Rollinson, *A Christian Perspective on Genetics*, http://www.christian.org.uk//html-publications/genetics.htm (accessed August 8th, 2004)

[46] John B. Cobb, Jr.Cloning -- *Has Dominion Gone Too Far?* http://www.religion-online.org/showarticle.asp?title=1088 (accessed August 8th, 2004)

become the maxim of the modern technologist. This obviously needs to be challenged, and one challenge is to ask whether there is a certain givenness to creation. Is there a point when a legitimate taming of God's world becomes an illegitimate tampering with it?

Personhood

When is the individuality of a person established – at the embryonic stage or at a later stage? Here I would like quote John B. Cobb, Jr. who in his article, *Cloning – Has Dominion Gone Too Far?* , gives an answer to this question. "Broadly speaking, there are three main views. The most prevalent is the gradualist approach, where it is maintained there is no one logical point from fertilisation to birth where a line can authoritatively be drawn. Rather, as development takes place and the foetus becomes increasingly differentiated, the foetus has, correspondingly, more claim to protection. The second view is that there is a decisive stage where human personhood begins. Some see this at conception, some at implantation or individuation (in the case of twinning), some link it with brain development. The third view is the importance of potential. A decision may not be possible as to when a person comes into being but, because each embryo has the potential to become a person, it is wrong to destroy it." [47]

On the issue of personhood, Andrew Rollinson further explains that, "What is very clearly understood is that personhood is not merely to be defined by a list of characteristics or abilities. A human embryo may not be rational or sentient – but personhood goes deeper than this. Being has priority over behaving. Persons are largely shaped and defined by relationships. In the Godhead, three divine persons are in a community of being. Thus, we as Christians assert that the ultimate ground of our personhood is God's relationship to us, and Psalm 139 implies that this goes back to our earliest embryonic beginnings." [48]

With is understanding of personhood and placing it beside Kant's practical imperative we must "always treat individuals as ends in themselves and never as means to an end," and we must condemn the discarding of spare embryos, and all non-therapeutic experimentation on human embryos. [49]

Human Dignity

The strongest affirmation of human dignity is found in the incarnation of God as Jesus, a human being and not any other being of the creation. Therefore both as human beings and as Christians it is our responsibility to preserve and uphold human dignity. Created in God's image, human beings are more than the sum of their genes (Gen. 1:27; Acts 17:28). Human dignity should not be reduced to genetic mechanisms. People should be treated with dignity and respect for their individual qualities, and not be stereotyped on the basis of their genetic heritage.

In a quest for human freedom, genetics must be careful not to lead us into a new slavery. Is it not true that genetic screening can lead to agonising choices some of us would rather not make? What are we sowing for future generations whose individuals may discover that their biological father was deceased, or their mother was foetal tissue? May not germ-line therapy consign us to more that we bargained for? And who will increasingly be in control? More than 40 years ago, C. S. Lewis noted: "What we call man's power over nature turns out to be a power exercised by some men over other men with nature as its instrument." The end of this process, which we picture as the creative exercise of our rational freedom, proves to be bondage. [50] Kenneth Cauthen in his article quotes the opinion of Paul Ramsay a theologian[51] who opines that the human race is not a patient, that we need not redesign this human race through our advanced bio-technologies. This would undermine the perfection with which God created human beings and certified it with the stamp of God's approval that what God created was good. God's covenant with the world is reflected in the union between sexual love and reproduction where the key factor is agape love. God created the world out of love and we create new human life out of love. In the process of genetic engineering this aspect would be missing and that would be a violation of the covenant of God. "It is an attempt to play God by redesigning the race before we have learned to live as the human beings we were created to be." [52] This form of genetic engineering is intrinsically forbidden by the divine covenant that sets limits to our freedom. This would ultimately lead to the violation of human dignity.

Justice, Peace and Integrity of Creation

With what has been discussed above, it can be emphatically said that if human dignity is at stake with the creation of designer babies, then there is no justice in it. The creation of designer babies also has the potential to disturb the integrity of creation as discussed above. Therefore, it is the prime responsibility of the Church to oppose the creation of designer babies in order to promote justice peace and harmony in creation. At the same time, the Church should not become an obstruction in the path of scientific progression, but rather effectively play the role of a watchdog in the misuse or abuse of scientific inventions, as it is in the case of

[47] John B. Cobb, Jr.Cloning -- *Has Dominion Gone Too Far?* http://www.religion-online.org/showarticle.asp?title=1088 (accessed August 8th, 2004)

[48] Andrew Rollinson, *A Christian Perspective on Genetics*, http://www.christian.org.uk//html-publications/genetics.htm (accessed August 8th, 2004)

[49] John B. Cobb, Jr.Cloning -- *Has Dominion Gone Too Far?* http://www.religion-online.org/showarticle.asp?title=1088 (accessed August 8th, 2004)

[50] Gilbert Meilaender, *Mastering Our Gen(i)es: When Do We Say No?* http://www.religion-online.org/showarticle.asp?title=814 (accessed August 8th, 2004)

[51] Kenneth Cauthen, Bioethics and Bioethical Decision-Making, http://www.frontiernet.net/~kenc/bioethics.htm (accessed on November 19th, 2005)

[52] Kenneth Cauthen, Bioethics and Bioethical Decision-Making, http://www.frontiernet.net/~kenc/bioethics.htm (accessed on November 19th, 2005)

designer babies, and thereby help in perpetuating and establishing justice, peace and the integrity of creation.

Conclusion

The Church rightly understands that sin can lead us to use scientific advances for extremely evil purposes. We can never support the pursuit of knowledge for its own sake apart from asking serious moral questions about the implications of that which we seek to know.

With the dangers mentioned above, we need to take caution and start discussing and thinking about these issues in order to educate ourselves, as well as to create awareness in our church and society, so that we are not caught off guard when we suddenly stand face to face with the problem. It is high time for the Church to develop a Christian theology on the scientific development of designer babies, so that she can effectively educate its members and society of the seriousness of such a scientific adventure and its implications on the present and future generations of this global community. Having browsed through the WCC website, I could find nothing of importance to the related topic. There is one declaration made by the National Council of Churches of the Pacific on the issue of cloning, genetic engineering and bio-ethics. In this document they strongly condemn any form of manipulation of the human genes. Nevertheless, we are living in the post-modern society where scientific knowledge has reached its heights. Therefore, the challenges that we face in this age, are also unique in their nature, where morality is disintegrating into a situation, and where one is confused and disoriented to discern the right from the wrong.

In closing I would like to quote Prof. Robert Edwards, one of the gurus of reproductive technology, who wrote a few years ago: "I found only confusion...indecision...changing ideas and concepts, when I sought inspiration, advice, and leadership" from religious sources.[53] This is the reality of our times. Hence we need to have the grace of God and the guidance of the Holy Spirit, to be alert and discerning enough to choose right from wrong. In the end we need to decide (often our indecisiveness is our weakness) and take a stand. Only then can we effectively play the role of being co-redeemers with God.

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[53] Andrew Rollinson, *A Christian Perspective on Genetics*, http://www.christian.org.uk//html-publications/genetics.htm (accessed August 8th, 2004)

Report of the UNESCO New Delhi Consultation Meeting on Codes of Ethics in Engineering and Sciences

- Darryl Macer
Meeting Date: 24-25 April, 2006
Venue: Qutab Hotel, Shaheed Jeet Singh Marg New Delhi, India

Introduction

This consultation meeting was the result of a collaboration between UNESCO New Delhi, the Regional Adviser for Social and Human Sciences in Asia and the Pacific, UNESCO Bangkok, and the Indian National Commission for Co-operation with UNESCO.

In the ***Opening Session***, Ms. Minja Yang (Director, UNESCO New Delhi) explained that this was a two-day public consultation to look at the needs and priorities in different fields of science and engineering: What are the good points that uphold responsible professional conduct in these professions? What codes of ethics work, and what do not? Can we link these to international codes? In the global community, are international codes needed? Mr. Keshav Desiraju (Secretary General, Indian National Commission for Co-operation with UNESCO) reaffirmed the solid support of India to the programme of work of the Division of Ethics of Science and Technology, and the work of the World Commission on Ethics of Scientific Knowledge and Technology (COMEST).

Context and Goals of the Meeting

Session 1 was on the ***Ethics of Science and Technology, and Goals of the Meeting***, chaired by Judge Leila Seth (Indian Jurist and Member of COMEST). Prof. Jun Fudano (Kanazawa Institute of Technology, Japan, and Member of COMEST) reviewed *Codes of Ethics in Science and Engineering in Japan, with International Comparisons.* He mentioned how engineering ethics had become mandatory curriculum for engineering students in Japan. He reviewed the content of Japanese codes of ethics, and few mention whistle blowing. When he asked the participants whether there is a need for a universal code, there was unanimous agreement. He then outlined some previous attempts, introducing the NAFTA principles for ethical conduct for engineers (1995). He also reviewed themes for an international code (quoting Heinz Leugenbiehl).

Prof. Darryl Macer (Regional Advisor in Social and Human Sciences for Asia and the Pacific, a.i., UNESCO Bangkok) made an overview for the meeting in a talk on *UNESCO Programmes in Ethics of Science and Technology and Goals of this meeting*. The expected outcomes he outlined were:

1) List of current national, regional and international codes of ethics in science and engineering that are actually being used/implemented.

2) Review of these codes with summary of positive and negative points, and discussion of their origins and evolution.

3) Expert cross-cultural review of the UNESCO 1974 Recommendation on the Status of Scientific Researchers, covering topics included in that recommendation.
4) Recommendations for UNESCO and COMEST on the needs for codes of conduct for scientists and engineers, and their scope in topics and geographical alliances.

Prof. Dinesh Mohan (Coordinator, Transporation Research and Injury Prevention Programme, IIT, Delhi) talked on *Codes of Ethics in Engineering in India.* He has spent 25 years in biomedical engineering and transporation safety research, but his talk was focused on the overall issues of ethics of the governance of science and scientists. He observed that faculty members say different things pending which political party is in power, and that freedom of expression decreases as the society moves towards privatization. He asked how to continue to advance knowledge, standards, and intellectual cooperation in order to facilitate social transformations where the values of rights are presently lost. He considered article 42 of the 1974 Recommendation (that scientific researchers need to be able to make trade unions) as being important in the Indian context, as many organisations prohibit trade unions. If scientists purely say what they believe to be the truth, they may not get funding.

The Indian Institute of Technology rules of conduct tell employees that they should neither undertake any political activity, nor criticise the institute or the government in public. He wondered whether this violated the Constitution of India, and considered it a barrier to the development of policy decisions based upon freedom of research and expression. He gave some examples from highway and road engineering, and the lack of safe places for pedestrians in urban areas, which go against international recommendations and standards. He also discussed the Delhi and Kolkata metros, asking whether they were justified as public works projects on a per capita basis of expenditure, and suggested bus lanes as a more economically fair and efficient way to achieve the goals of alleviating traffic. Should we assign responsibility to those who do feasibility studies and question the ethics in such activities? When environmental impact statements that include worst-case scenarios and cost effectiveness analysis seem to justify most projects proposed by big industry or the government, shouldn't there be a case questioning the ethics of those involved?

Dr. Rajendra Prasad (Scientific Secretary to DG, Council of Scientific and Industrial Research (CSIR), New Delhi) talked on "Ethics in Engineering Sciences in a Research Environment". He said an engineer is a grand translator between science and technology, who creates and uses new knowledge and also makes new standards. They also deal with many new research areas. He said that a universal code of behaviour, including items such as against discrimination, is essential.

In response to the 1974 UNESCO recommendations, he thinks CSIR is doing well when it comes to: using scientific and technological knowledge for the enhancement of cultural and material well being; public funding and public investment; conditions for mobility of scientists; and vocation of intellectual freedom. These values are also in the mission statement of CSIR. Societal benefit is a core value for ethical transmission of science. There are some other issues that need discussion, such as secrecy, IPRs, use of material in partner institutions, and answerability to society.

He discussed three codes of ethics in India and social responsibility, including: Consulting Engineers Association of India, item code 17; Institution of Engineers, India, Annex II (this code also includes corporate members); Code of the Computing Society of India (this code discusses compliance with anti-piracy law, personal integrity and transparency, and ways to take action against any members).

The following ***discussion*** focused on mapping existing codes of ethics and conduct relating to physical sciences and engineering in India. The issues discussed included a need to consider gender perspectives, a need for a universal curriculum guide, and resources for teaching ethics of science and technology. There was also a need to consider the implications of information overload, given all the information that is available on Internet. There is a need to consider the ethics of knowledge production as well as in the dissemination of knowledge. Although there are IRBs to clear research in medical and life science, there are no ethics committees in engineering. The general principle is that the projects need to be for the good of the country.

Session 2 was on ***Discussion and Review of the 1974 Recommendation on the Status of Scientific Researchers.*** Dr. Darryl Macer, UNESCO Bangkok, chaired the discussion, that followed the paper by Prof. P.N. Tandon (President, National Brain Research Centre, Manessar, India; Member of UNESCO International Bioethics Committee), entitled, *Does the 1974 Recommendation fit Emerging Areas of Life Sciences?* Tandon's reply to the question is a clear "no". The very fact that UNESCO established the IBC implies that the existing guidelines were not sufficient to deal with life sciences and technology. Many recent issues are not discussed in the 1974 document, which is really looking at science promotion. The three UNESCO Bioethics Declarations focused on human rights. But in Asian society, community rights are more important than individual rights.

Since 1974, India has implemented everything in the Declarations, including the demanded national science policy. In India, in the life sciences, there are guidelines on protection of research subjects; for human genome research; and now there is work on an overwhelming document (under the chairmanship of M.G.K. Menon) that will cover all documents including engineering.

Despite their existence, codes and even laws are not implemented. Since the implementation is by country, there is little UNESCO can do. In the 2005 Declaration, the inter-governmental commission rejected monitoring that the IBC had drafted. Also, most

countries have no monitoring ability; policy formulation is not enough. International codes are needed, given the industrial influences across countries. He said IPRs are the most important ethical issue in the international community today.

In response to the issue of individualism, Dr. Jasdev Rai said that not all communities in the East are communitarian. For example, individuals are sovereign in Sikhi; also, the Indian constitution is based on the individual level. Dr. Tandon replied with examples of seeking permission for medical research which first required the village head permission, then family head, and finally individual. There was also detailed guidance for genetics research in the 2003 International Declaration of UNESCO, including informed consent, donor issues, risks and benefits of competing values.

Dr. Matar, from the All Indian Institute of Medical Sciences (AIIMS), described their IRB as well as biosafety and animal welfare committees. Implementation and monitoring are very important to them. There was also general discussion of fetal rights, organ donation, and advance directives. There was a call for social scientists to be included in these bodies, and for interdisciplinary research principles.

Dr. Anwar Nasim mentioned that busy scientists do not have time to read all the guidelines, nor are familiar with all the committees. He is a member of the Pakistani National Bioethics Committee, and they spent days just trying to understand how to apply informed consent. He asked how we can facilitate knowledge sharing between regions, and, secondly, how to really deal with these ethical issues, given that we live in an unethical world.

There was then extensive **general discussion** on the need for ensuring motivation of persons to develop a voluntary code for their life. Internal qualities like self-control and intellectual honesty are as important as life goals. The institutional responsibility is important to separate from the duties of every scientist.

Publication Ethics and the Internet have emerged as important issues in the past decades. Science has undergone a transformation in issues such as peer review. There was skepticism of impact factors and other measures to assess quality. Piggyback writing, where the head of the department automatically is added, is a problem in India. Plagiarism is also important, and second language publishing made it more difficult to prove plagiarism.

IPR's interference with open publication is difficult, as it leads to differences in access to scientific data between countries. There is a need to have a level playing field, because access to journals and publications is often difficult. Also, in molecular biology much research is based on borrowing of gene constructs, not just published results.

There followed an extensive discussion on commercialization. There was a debate between supporters of commercialization and industrial sponsorship of funding, versus traditional public science. It is difficult to clearly separate basic and applied research, as commercial interests are increasing in many fields.

Dr. Prasad mentioned that the government of India is discussing a new legal framework for the university sector to be more aware of patents and their filing. Others mentioned that in the agricultural field it is a very critical issue, as both private and public partnerships are needed. Issues in marketing and publishing were discussed.

Also, 3-4 major tragedies relating to industrial disasters have occurred, including Bhopal.

Prof. Sivakami pointed out that the state does not make the technology available. Rather, industry or NGOs make it available, as in the case of medical techniques.

There was discussion of military research, given that more than 55% of funds from the government for research go to defense and strategic research. These areas are "sacred cows", and we cannot talk about these; little knowledge comes out of this. There are risks of research and development (R&D), but currently there were minimal debates on these subjects. Biological warfare was a common concern. There were also interlinkages between civilian and military R&D.

The second day started with ***Session 3,*** which was a ***Roundtable Discussion on Ethical Codes in Life Sciences***, chaired by Leila Seth. The first speaker was Prof. S.P. Thyagarajan (Vice Chancellor of University of Madras, Chennai). He reviewed the need for codes of ethics in research, and the ethical foundations of current codes that govern biomedical research in India. They are related to the system of international guidelines. The professional members have to be made conscious of these guidelines in order to implement them. He cited article 19, UDBHR that spells out the responsibilities of the ethics committees. In 2000, The Indian Council of Medical Research (ICMR) also laid out guidelines. In universities they also have animal welfare committees, governed by freedoms including: freedom from discomfort, hunger, and thirst; freedom from pain, injury, or disease; freedom to express normal behaviour; and freedom from fear and distress. He concluded that professional ethics is equal to good discipline.

Dr. Nandini Kumar (Deputy Director-General, ICMR, New Delhi) then reviewed the basis for ethical considerations in biomedical science, which included the ten recommendations of innovation technology by the UN millennium project. The statistics showed that the most common causes of death created a disastrous situation for the poor countries, as they led to great economic suffering. Thus, health influences economy. Many examples of ethical issues pertaining to health research and biomedical research were mentioned, including: funding for R&D, managing IPR, vaccine trials, drug delivery systems for rural health care systems, advocacy for policy making, pharmaceutical R&D requiring ethical codes, access to genetic resources, informed consent, community consultation, prenatal diagnosis, DNA technology, fora of ethics committees like FERCAP, FERCI (for India), etc.. She stated that within India, there is interagency collaboration between ICMR and DBT on framing related ethical guidelines that would soon be legislated.

She informed that ICMR has already initiated sensitization and training of scientists in bioethics, and from the Grants received from NIH (Fogarty), USA and WHO, it has targeted trainers, researchers, and students for education on this subject.

Mr. Saionton Basu (Advocate, Supreme Court and Associate, Amarchand Mangaldas, New Delhi) made comments from a legal perspective on stem cell research and the clauses on punishment. Using the example of the "seven pillars of good governance", at the Rajiv Gandhi memorial, many issues are common. He called for national bioethics committees. He discussed animal rights committees, mentioning that local ethics oversight is needed rather than reliance on a central committee. He called for the development of comprehensive, uniform regulatory implementation, and the need to devise means to implement international instruments in each jurisdiction. It was necessary to engage in discourse and debate with stake holders in every jurisdiction.

Dr. Anwar Nasim (Adviser Science, COMSTECH, Islamabad, Pakistan; Chairman, National Commission on Biotechnology of Ministry of Science and Technology) said that the principles outlined for India apply equally to the situation over governance of life science research in Pakistan. Recently, there was positive cooperation in biotechnology forums to bring persons from India and Pakistan together, which can also provide an opportunity to discuss bioethics. There needs to be a good method of implementation, and therein lies the challenge. There should be initiatives for promotion of knowledge sharing. He also talked on the many useful books and information being produced by various groups, including UNESCO, and the need for international discussions.

In Pakistan, the National Bioethics Committee under Pakistan Medical Research Council has been set up. There are both research ethics and medical ethics committees. He also applauded the Centre for Bioethics and Culture at the Sindh Institute of Urology and Transplantation in Karachi, and their joint UNESCO Bioethics Conference in 2006. Religion can help with resolution of these issues; there is flexibility in religion, and Islam means peace and submission to the will of Almighty Allah. In terms of basis of Islamic society, there is a need for discussion; *Ijtihad* is a concept which gives flexibility to examine and adopt new developments and resolve issues in the light of basic sources of Islam.

Dr. S.K. Tandon (ADG, Indian Council for Agricultural Research, ICAR, New Delhi) discussed the types of choices in agriculture. By 2020, India needs to double production. There are many centres of agriculture, and each is doing regionally relevant research. For example: design of tractors requires agro-morphological data to reduce drudgery in the farm, and reduce accidents. There was a need to create infrastructure in the villages. Poor farmers need to get returns from crops, if they use hybrid crops. Biological control of pests and Bt cotton were important concerns given the pesticide usage without these methods. Indian farmers could not compete well in a global market, as India cannot afford to pay subsidies to farmers. He considered that IPRs are only for industrial benefit. A code of ethics means we need to acknowledge the work of others.

There was then **general discussion**. Dr. Kondon at the National Center for Biotechnology suggested that we should not waste too much time discussing biosafety and IPR issues, but focus on conducting research ethically. There was discussion over genetic engineering and the contrast between some NGOs and the Indian Department of. Biotechnology. Dr Matar from AIIMS discussed that they had spent a long time discussing guidelines on stem cells, and there are two sets: one on adult stem cells, and one on embryonic stem (ES) cells. He argued for the need for a central monitoring committee. There was widespread discussion on topics including ethics and IPRs, embryo research, common heritage, genetic testing, and GMOs.

After lunch, ***Session 4*** was a ***Discussion on Ethics Codes in Society***, chaired by Dr. Darryl Macer. Professor V. V. Krishna (Professor in Science Policy and Chairperson, Centre for Studies in Science Policy (CSSP) School of Social Sciences, Jawaharlal Nehru University, New Delhi) made a presentation discussing globalization and the changing structure of science as social institutions. There was a trend away from open science. Too much policy focus on the commercialisation of knowledge and intellectual property rights and secrecy by public research systems in developing countries in Asia is giving way to a "new social contract of science". This trend that drives science more to market and commercialisation needs to be checked and regulated. Co-production of knowledge involving the participation of different stake holders in the decision-making process in biomedical and biological sciences needs to e strengthened in developing countries, particularly SE Asia and South Asia. This will not only arrest unethical practices, but will regulate new knowledge in the interest of society.

There was a call by Prof. Sivakami that we should develop ourselves in the name of globalization. Then there was discussion of the lack of spending on R&D, and high funding of military research. There was a need to distinguish between fundamental research and applied research.

Comments from the **religious groups,** including Hinduism, Islam, Christianity, and Sikhism, were presented. Mr. Gokulnanda (Ramakrishna Mission, New Delhi), discussed how to make people ethical. He gave quotes from the Bhagavad Gita that the interconnectedness of persons is important. Spiritual intelligence is beyond emotional intelligence. Students need self-reflective processes, as well as education on the ability to review both their short- and long-term goals. Religion can help develop the commitment to work and do good, without dividing among ourselves.

Father Pinto (Catholic Diocese of New Delhi) described some basic moral rules: Whatever our actions are, our intentions are really important. We have to respect the human person, so we cannot harm them. There is respect for life from the womb to the tomb. Sex

determination and abortions are very wrong. If we are concerned about life, we are called to improve the quality of life. On stem cells, if love is the hallmark of our behaviour, then life is for procreation, not for production. The church does not accept ES cell research, as it kills the embryo.

Dr. Jasdev Rai gave a presentation on Sikhi and the ethics of engineering and science. Science has become value laden; he said that Science is a knowledge of "how" rather than a metaphysics of "why", but it has claimed the public space as a culture in the last century. He reflected on why science in Chinese, Indian, and Islamic civilisations had failed to develop compared to Western science. Technology is a race, and we need codes of practices. Maybe science did not stagnate in earlier civilisations, but rather society in the past thought it was dangerous; those civilisations may have made a decision of when to stunt the development of science. We may have to reflect on wisdoms from history. He also thought that India, the land of Dharmashastras, may have some useful insights to offer in the field of ethics.

Jun Fudano said that Buddhism and Shintoism are combined. Considering the relationship between man and the world, there is no separation between creator and creation. They emphasise the relationship between human beings rather than God, so when we define ethics, we try to consider these relationships. There is a lot of emphasis on our ancestors; there is also a basis for an intergenerational ethics. He thought we do have some basic universal values. We can identify these, and see how each culture can use them.

Anwar Nasim said that in Islam, one has freedom to behave, but in consonance with the basic Islamic principles. How do we behave with regard to our neighbour? What is our role in society? We have non-government individuals (NGIs). If we wish to become more positive in our thinking, we must consider this: The world we live in has great scope, but we as individuals need to be motivated. We must examine our purpose of existence and have a well-defined mission in our lives. No religion teaches you not to be friendly and considerate to your neighbour. In Islam, there is no final authority for moral decisions.

Macer mentioned that there was not time to reflect on all the various interpretations of these religious teachings, but that the remaining time be used to consider the 1974 document and ethical codes. There is a common basis in all religions to have individual and social responsibility for ethical action as professionals. Plenary discussion reverted to some discussion of IPRs, and it was pointed out that discovery of nature is the property of all of humankind. Genetic resources were also part of the common heritage of humankind.

Concluding discussion of the **1974 Recommendation** on the Status of Scientific Researchers included the additional following points.

1) It is hard to distinguish applied and basic science, science and technology, and nature and culture. Science is both a system of knowledge and a specialized activity that we need to sustain.

2) Ethics education is important, and the sentence in the definition of science in the 1974 document includes the importance of questioning. Science both solves and creates problems. Science graduates should receive education in ethics, philosophy, science, and society, and perhaps comparative religions and culture. Jun Fudano asserted that as we generate many engineers and scientists, we need to ask: What are the basic values for science to rely upon? What is the platform for science? We need some behavioral guidelines for students to absorb. In most engineering colleges in India, there used to be a social perspective in philosophy and social science. But nowadays it is lost from the curriculum. Leila Seth mentioned that children learn social responsibility, honesty, and sharing early in life.

3) There was debate over whether the importance of religious values should be specifically mentioned. There is a lot of disagreement over religion, but some common agreement exists on some values. Moral integrity is important to mention. Respect for life is important as an attitude, and there are some examples of this in prayers for cadavers in anatomy classes or animals sacrificed for research in some countries such as Japan.

4) Scientific knowledge needs to be open.

5) The 1974 document is different from another document called *A Code of Ethics*. We need to think of the relationships between codes of ethics. There is sensitivity in a few areas.

6) Referring to p.2, section II does not take into consideration the whole context of scientific decision making. Participatory decision making should be included. The earlier role of science was more deterministic; civil society is now asking questions. Stakeholders should participate and discuss science. That element must be brought into the development. There is a need for relevant social groups to be involved in shaping discussion.

7) This document does not say much about employment of scientists in private research labs. Nowadays there are many multinational companies. What codes of ethics are important in this context? What are the norms that govern this?

8) For a code of ethics in medicine, we have a medical council model which can be adapted in other sciences and engineering, to be able to punish those who are unethical. But although there are many codes of ethics in India, there is no implementation there. When it comes to punishing unethical doctors, the council feels sorry for the professional who will be punished. How can we ensure it is implemented? For example, how can we ensure that scientists get proper equipment or environment? And if there is some deviation, what should happen? The lessons from the United Nations and human rights commission was given, as well as recent improvements in women's rights. The body may need to be outside of government; an independent body. The forum for research ethics committees (FERCAP) was discussed.

9) Ishmar Verma noted that this document should be structured into three sections for target groups: One

for states, one for individuals, and one for institutions. He considered that some reference to all the issues discussed is in the document, but it needs extension. Others pointed out that sciences may differ with specialty, and they reaffirmed the need for separate sections. Also, different countries are at different stages in knowledge use and production.

10) There was discussion of the vocation of scientists, and on p.4, article 13, it says that the work of scientists is knowledge production. This needs to be emphasized.

11) The term "mankind" needs to be changed throughout to "humankind".

Conclusions of the meeting were given by Darryl Macer, UNESCO Bangkok, who thanked everyone for participating and for the staff of UNESCO New Delhi Office. The follow-up would be developed with the Indian National Commission to UNESCO, and the COMEST committees. The participants requested more meetings on ethics in India; Macer said that there would be more meetings with network partners, and that the feedback given in the consultation had been very useful for the work of the Division of Ethics of Science and Technology and the regional programmes out of UNESCO Bangkok.

Report of the UNESCO Bangkok Consultation Meeting on Codes of Ethics in Engineering and Sciences

- Darryl Macer
Meeting Date: 15-16 May, 2006
Venue: UNESCO Bangkok, Thailand

Fifty participants representing a range of professions including: Science, Technology, Engineering, Architecture, Agriculture, Education, Government, Law, Nursing, Medicine, Social Science, and Philosophy attended the workshop. Participants were from 14 nations (Australia, Canada, Indonesia, Japan, Malaysia, New Zealand, Norway, Romania, Singapore, Sri Lanka, Republic of Korea, Thailand, USA, Vietnam). The background presentations may be requested from RUSHSAP, UNESCO Bangkok. The agenda and participant list are available on the UNESCO Bangkok website: http://www.unescobkk.org/index.php?id=639

The participants agreed that:

• There are a range of codes or guidelines in different associations and in different countries relating to engineering, science and technology, and there are some common elements. These can provide useful guidance to researchers, professionals, scientists and engineers, but these are not sufficient to ensure good conduct. Ethics education is even more important to ensure professional responsibility.

• To build capacity in the research community, any guidelines/codes should highlight education on ethics and professional responsibility across all ages, in many different learning environments, and at all stages of career development.

• For codes of conduct to be effective, the guideline/code should provide options for monitoring and sanctions.

• A regional or global code of conduct would be useful to address to governments, institutions, professional associations and universities, and scientists, and the participants agreed that it would be useful for UNESCO to explore common elements and a framework for such a code.

Monday, 15 May

Session 1: Ethical Codes of Science and Technology.

Prof. Darryl Macer (Regional Advisor in Social and Human Sciences for Asia and the Pacific, UNESCO Bangkok), workshop chair, opened the workshop with a presentation on UNESCO Programmes in Ethics of Science and Technology and Consultation Goals.

The workshop was linked to the recommendations of the 1999 World Conference on Science, and contextualized as a response to regional calls to examine the issue.

The workshop objectives were:

1) To generate a list of national, regional, and international codes of ethics in science, technology and engineering currently implemented,

2) To evaluate these codes and summarize their origins and evolution,

3) To cross-culturally review the UNESCO 1974 Recommendation on the Status of Scientific Researchers, and

4) Recommend to UNESCO and COMEST on the needs for codes of conduct for scientists, technologists and engineers, and their scope in topics and geographical alliances.

Prof. Warwick Anderson (Dean, Faculty of Life Sciences, Monash University, AUSTRALIA; from 7 June, Chief Executive Officer, National Health and Medical Research Council), presented the forthcoming Australian Code for the Responsible Conduct of Research.

The National Health & Medical Research Council (NHMRC) has been responsible for research in Australia for 40 years since being established by its own Act of Parliament. The forthcoming Australian Code for the Responsible Conduct of Research is being jointly developed by the NHMRC, the Australian Research Council (ARC), and the Australian Vice-Chancellors Committee (the council of Australian University Presidents). To date, two public-reviewed drafts of the code have been produced. The revised code will not be legislated, but adherence will be required via contracts between the NHMRC and ARC, and institutions in receipt of research funds. The current code targets the public sector, with the revision to include the private sector. The process of review and revision of the content of the code was presented.

The Australian Code for the Care and Use of Animals for Scientific Purposes, and the National Statement on Ethical Conduct of Research Involving Humans were also presented. Ongoing international consultation on these codes, and development through networks with UNESCO and other organizations was welcomed. It was noted that the code development process has a strong lay person representation, with additional input from wide research disciplines sought through The Australian Society for Humanities.

A legally endorsed independent committee has been established to address research misconduct.

Dr. Nadja Tollemache (Commissioner, NZAPEP Quality Commission Office, NEW ZEALAND; Member—World Commission on the Ethics of Science and Technology, COMEST) spoke on Codes of Ethics in New Zealand.

The 2003 revision of the Royal Society of New Zealand Code of Professional Standards and Ethics and the 2005 Institute of Professional Engineers of NZ Code of Ethics were the focus of the presentation. For codes to be effective in controlling the conduct of those bound by the code and in instilling a feeling of trust in the public, they must be available to the wider community. In addition a clear and transparent process for addressing complaints and applying sanctions is required.

The need for ethics education for scientists, technologists and engineers, as well as the general public was highlighted. Unfortunately research in New Zealand has shown that ethics academics may not be fully abreast of the specific codes of conduct.

The New Zealand Institute of Food Science and Technology code's provision for advocates or "buddies" to advise and, if requested, support individuals who make an ethical stand vis-à-vis an employer or other influential person was suggested as a possible model, particularly in the case of young or inexperienced professionals. As a statutory authority gives support in such whistle blowing situations, it was concluded that effective codes of ethics require the credibility of legal or at least influential sectoral, backing.

Other codes presented include;

- The Code of Ethical Conduct under the Animal Welfare Act 1999 enforcing institutional Code of Ethical Conduct and an Animal Ethics Committees.
- The Ethics Code of the New Zealand Institute of Agricultural and Horticultural Science.
- The mandatory New Zealand Institute of Medical Laboratory Science (NZIMLS) Code of Ethics.
- The Code of the New Zealand Institute of Food Science and Technology (addresses conflicting loyalties).

Dr. Somsak Chunharas (Secretary General, National Health Foundation, THAILAND; Member—COMEST), gave Reflections on the Feasibility of Codes of Ethics in Science and Engineering in Thailand.

In Thailand "professional laws" attempt to ensure quality of education, personal conduct, and service standards (licensing and investigation of misconducts) rather than guide ethical conduct. And where personal conduct is governed it is generally with in the services provision industry as opposed to research. For example, engineers follow ethical conduct guidelines to ensure safety of clients and the public, but the codes do not cover research ethics. Teachers have educational standards, while architects are meant to keep good quality standards. Other than debate on bio-safety concerns, scientists have not yet been discussed.

In the 1990's the Ministry of Public Health attempted to pass a law to administer the research sector. There was great resistance from medical and clinical schools, especially on the issue of centralization: they were concerned about the possibility of manipulation and unethical conduct by the central committee.

The National Research Council drafted guidelines on fair treatment on animals, but they have not been disseminated or enforced as they were considered a lower priority for research oversight. There have also been inconclusive government discussions on GMO and stem cell research. The concept of stewardship had been discussed in the National Research Council with linkage to WHO, in order to strengthen the national health functions. Dr. Chunharas concluded that work with the media to develop ethical science was necessary. In discussion, there was consideration of ethical oversight of new surgical procedures, benefit sharing, and interactions with the private sector.

Dr. Amru Nazif (Secretary, National Bioethics Committee, INDONESIA; Indonesian Institute of Science (LIDI)), spoke on Codes of Ethics in Indonesia.

In Indonesia, all scientific fields have their own organizations, from anthropology to mining and engineering, which adopt codes of ethics included in their respective statutes. Codes of ethics are usually not considered as recipes for decision-making, but as considerations to bear in mind—an ethical framework rather than specific solutions. Adherence to them is prerequisite to membership of the professional organizations.

Indonesian scientists promote the issue of biodiversity as a bioethical concern; threats to biodiversity include population pressure, unsustainable logging, and others. The commitments under the Rio Summit of 1992 overrode other codes of ethics such that those using the environment should conserve as much biodiversity as possible to slow the loss of primary forests; to expand data and information; and to foster utilization of biological resources. The issue is not so much to focus on illegal and unethical logging, but to recognize that it is an unethical practice of *science and engineering*.

In the following discussion, the participants unanimously called upon UNESCO to continue work on environmental ethics, as had been discussed during the consultations on the Universal Declaration on Bioethics and Human Rights. There was also discussion of local communities embodying the lifestyle and traditional knowledge concept, and the participants called upon UNESCO and the World Intellectual Property Organization (WIPO) to be more active in this regard. The Convention on Biological Diversity (CBD) group

working on Article 8(j) to agree upon ethical principles for these issues was suggested as a starting point as they have been in the discussion stage for over a decade.

Following each presentation, there was discussion with a focus on mapping existing codes of ethics and conduct relating to engineering and science in the South East Asian and Oceania region.

***Session 2*: *Discussion and Review of the 1974 Recommendation on the Status of Scientific Researchers*.**

Prof. Song Sang-Yong (SOUTH KOREA; Vice-Chair, COMEST) gave Reflections on the 1974 Recommendation and International Codes of Ethics.

The theoretical foundation for the presentation was based on how the traditional view of science, with the norms of 'objectivity' and 'disinterestedness', had shifted since the 1970s. The UNESCO recommendations should reflect this changing concept of science. The two cultures of C.P. Snow and post-modern understandings of science were discussed. The change in emphasis from rights to responsibility of scientists was also noted: the Standing Committee on the Freedom in the Conduct of Science (SCFCS) in 1963 had focused on the freedom of science and the rights of scientists, whereas from 1996 to 2002, the focus was on the social responsibility of scientists and the ethics of science.

Prof. Song called for the inclusion of animal rights, animal welfare, and the concept of sustainable development to be added to the recommendations. The bioethical issues should be a top priority, even though the questions of military research remain very important and sensitive. Some ethical codes should address new problems such as privacy, alienation, cyber crimes, inequality driven by the internet, and international security. The inclusion of the precautionary principle was also suggested as misconduct cases have caused public anxiety concerning research integrity. Prof. Song also called for inclusion of gender concerns, and guidelines against any form of discrimination. Ethics education was noted as a priority area for COMEST.

In the discussion, participants agreed that this presentation and accompanying paper offered important points for UNESCO to address. In addition to educating science students about ethics, there is also a need to teach basic science to those who will not be scientists to facilitate understanding and trust. The stereotype that science has nothing to do with society was reinforced as fallacious. Training to connect science and society was supported; for that, education in humanities and social science is important, and education in science, technology, and society (STS) in interdisciplinary fields is essential.

The participants noted that since the 1974 document had been accepted by the member states, any future revision could be politically difficult. It is, however, important to assess what is missing. The 1974 document is a progressive document for those times, but it omitted issues of women and science. In the 1974 document, the scientist is always a "he"; throughout the document, "mankind" must be changed to "humankind". The lack of public trust is an important issue.

Dr. Siti Nurani Mohd Nor (Dept of Science and Technology Studies, University of Malaya, MALASIA) talked on Philosophical and Practical Reflections from Malaysian Science.

The national policy on S&T in Malaysia, which sets out broad objectives for science, was presented. Scientists rank among the top professions that Malaysians trust. Some cultural issues were discussed regarding the universality of codes. For example, the giving of gifts for research partners is not coercion in many developing countries: it is custom. The religious implications of bioethics were presented within the context of the human genome. In Malaysia, religions groups have agreed that alterations to the human genome interfere with the heritage of God. Although the religious leaders all opposed reproductive human cloning, organ transplant was supported as an act of charity. It was noted that an integrated ethics course (12 credits in addition to 108 in science; the courses are taught by science professors) is compulsory in the science degree at the University of Malaya.

Dr Chan Chee Khoon commented that the Malaysian government does not appear to have a monolithic policy in science and technological development, maintaining instead a flexible balance between needs-driven research (e.g. as a founding partner of the Drugs for Neglected Diseases Initiative, DNDi; invoking TRIPS flexibilities for compulsory licensing of essential medicines), and market-driven research for product development (incentives for the commercialization of patents arising from publicly-funded research).

There was broad support for the initiatives Dr. Siti described in education of ethical issues in science in Malaysia, with calls for UNESCO to help in the teaching of ethics across the region, as well as in developed integrated curriculum for including ethics across all subjects in science and technology.

Dr. M.C.N. Jayasuriya (Director, National Science Foundation, SRI LANKA) described how senior scientists in the community came up with A Guidebook on Research Ethics, published by the National Science and Technology Commission (see electronic copy).

The Guidebook covered a number of issues and commitments that scientists should make. The National Science Foundation in Sri Lanka is in the process of training school students on general ethics, as all students require an ethical foundation to become good citizens. Dr. Jayasuriya expressed his concern about the increasing reproductive technology "shops" in Sri Lanka which is a serious ethical concern to the medical services industry.

The rise in the use of personal websites by biomedical researchers challenges controls on **publication ethics**, as the content does not go through peer review. Thus the term "dissemination of knowledge" is more appropriate than "publication" (in its traditional sense) for the way research results are now distributed. It was also noted that in conventional

journals results can only be published once, but the internet allows the publication of the same information in multiple places. Questions were raised on the contribution required by researchers to be listed as an author on papers, particularly the inclusion of the head of department as an automatic last author. It was noted that the traditional research journals still play an important role in the research community as the citation index is still being used to measure scientific output. Although there is a general concern on the credibility of the information available on the internet, participants acknowledged that there are some credible internet journals that are as good as mainstream hard copy journals.

The discussion also validated the suggestion that the digital divide is growing, because, just as in the past developing countries could not get hard copies of journals, due to expensive subscription fees now they are not privy to electronic copies. Meanwhile, researchers in richer countries can instantly access digitized journals that were previously in only central locations.

The legal perspective of patenting research results was discussed. It was agreed that the patent developer should have rights to the patent, but the same owner should have a responsibility to publish freely. It was noted that in many countries, a criteria for patenting is that the information cannot be made available to the public. Dr. Paul Teng used the term "scientific constipation" to describe cases where information was blocked from public view for years to ensure patents grants, which created a waste of funds in establishing the same knowledge. There was agreement on a responsibility to publish appropriate research results. The issue of who decides what is appropriate was discussed within the example of military research, which has traditionally claimed privacy protection from public dissemination. This area of publication ethics remains controversial.

Dr. Graeme Bristol noted that publication and patent issues are not uniform across all disciplines, using the example of architecture, where publications are primarily picture books and magazines.

The ethical issues evolving from public and private funding of research was raised. Dr. Chan Chee Khoon mentioned that since the 1974 recommendation we have shifted from a reliance on government to a larger contribution by the private sector for research funding. In the example of clinical trials, with public funding there is an obligation to publish; but contractual agreements between researchers and private organizations can include restrictions on the distribution of results. In market-driven economies, the only scrutiny is the stock exchange. The underlying ethical issue is: Should the scientist under contract be bound by public ethics? Dr. Warwick Anderson mentioned that the Australian code requires scientists to maintain public research ethics. It was noted that in Thailand most of biomedical research is reliant on private sector funding, and in the case of Mahidol University, a clause has been included in contracts leaving the discretion of publication with the researcher as opposed to the funding group. This was a result of positive pressure from medical journals' editorial policies, and preserves some scientific ethics in publication rights. Prof. Watanalai Panbangred gave a Thai example of how sponsors had asked her to delete some results when writing a paper. Dr. Pakapun Skunmun highlighted the role of the Thailand Research Fund (TRF) in promoting the publication of science.

Another component of "dissemination of knowledge" with ethical consequences is feedback to the participants in the research. This was contextualized in examples of people being subjected to research without their consent, and in an anecdote from Sri Lanka, without their knowledge. Dr. Tollemache noted that in New Zealand part of funding and ethical approval applications require participants to be notified of the outcomes of the research. All workshop participants agreed that there is a responsibility to share information with participants, and international sanctions should be in place to stop such human rights violations as were described in Sri Lanka.

Dr. Mattias Kaiser reported that government discussions at the 1999 World Conference on Science also addressed the issues of publication, patent and public versus private funding. It is important to apply universal standards in order to enforce the checks and balances for scientists through the accountability of governments. Without these frameworks it will be difficult to have ethical research in science, technology and engineering. However it can not be denied that while one statement on ethics of science may attempt to cover all, there are many practical issues for those in different sectors.

The discussion moved onto the issues of **commercialization**. Some important biological discoveries were delayed some years due to patents, as discussed above. In Singapore, funds are industry driven but actually from the government. Among the workshop participants, less than ten persons said they had actually done research for private companies. More robust ethical principles could assist privately funded scientists in dealing with issues such as conflicts between the researcher and the funding group on the publication of results. Binding contractual agreements at the outset of research between the parties can clarify this. Dr. Watanalai Panbangred noted that researchers were at a disadvantage in negotiating contracts with large, multinational companies as they are unable to acquire suitable legal representation. There was a call for fairness to all, with Dr. Tom Gionis suggesting UNESCO could coordinate an ad hoc advisory body to support researchers in legal and ethical issues. Dr. Miyako Takagi mentioned that there was controversy in Japan regarding the large number of venture capital companies that arose as a result of government-funded research from tax revenues.

There was discussion of several examples of international partnership with Intellectual Property Rights (IPRs). While exclusivity is a problem, the publication delays in Asia are not excusable. Drug

resistance is one example, and the delay of research publication indirectly tolerates a large number of deaths of regional inhabitants. Even if the discoveries are eventually made public after patents are awarded, there is also the issue of access to affordable patented drugs. A regional study of the impact of commercialization that would include qualitative case descriptions as well as quantitative research context was encouraged. As scientists in Asia are in a situation of dependency, a normative ethical instrument addressing these concerns was suggested. There was a call to develop codes of ethics on intellectual property (IP), and to implement the 2002 recommendations of the UNESCO IBC report on Ethics, Intellectual Property and Genomics.

Regarding the question on whether ethical standards inside companies are lower than in academia, it was noted that the potential financial and business cost of inaccurate or unethical research to companies is great. These factors are significant drivers for ethical science. In Universities, the consequences of ethical breaches are based in damaged reputations.

Several issues of **professional and scientific responsibility** were discussed. There is a perception that the use of science is less ethical in the military, and an assumption that some research is attributed to "defense" to bypass standard ethical checks. Other examples of potential violations of professional or scientific responsibility discussed were the use of pesticides, and handling of data. Dr. Miyako Takagi flagged the rapidly advancing field of neuroscience as an area where potentially ethical concerns may need to be addressed. Dr. Amru Nazif suggested the use of an ethical matrix, with roles and stakeholders versus the ethical principles (which could be those in the Universal Declaration on Bioethics and Human Rights) to solve moral dilemmas over the responsibility of scientists. Dr. Jayasuriya noted that there may be a role for the media to play in both the public and private sectors as journalists raise awareness which can benefit people.

The workshop agreed that ethical codes should inform future generations through the context of the **teaching of ethics**. Education is a primary source for humankind to maintain dignity, and is supported by all religions. Teachers need to teach professionals what to do as well as how to do it in the context of their professional life. With teaching of environmental ethics, it was considered important to introduce learners to a range of world views. There was also a call to teach ethics to politicians. UNESCO could continue to collect cases and examples of ethics materials, with examples of good and bad practices, as a regional and global contribution. The ongoing text/resource book project of UNESCO Bangkok was applauded, and more chapters should be added to broaden the coverage of chapters. Dr. Jackie Street mentioned that it is not sufficient to teach students ethics, ongoing professional development is required. There is also a need to develop courses for graduate students, as they are going to do thesis research. Dr. Warwick Anderson noted that most working early career scientists learn from the ethics of those around them. Participants highlighted the importance of ongoing professional development.

Dr. Graeme Bristol mentioned that there was limited awareness of ethics codes and laws in university students taking his courses, and that in teaching a particular code the inadequacies should be identified. Part of the architecture ethics course allows students to see the role of ethics in building and design by visiting slum areas around Bangkok and discussing the consequences of city development. The relationship between human rights and architecture was presented. This practical approach to teaching ethics highlighted the general workshop view that students have to realize ethics themselves.

Dr. Siti described how a problem-based teaching style is used in the University of Malaya: students visit laboratories related to their field to assess practical issues. Dr. Teng noted that science teachers for Singapore schools are required to complete a course on science and society. Dr. Juraporn Pongwecharak (Prince of Songkla University, Thailand) uses movies to teach ethics. UNESCO could nurture such models and adopt the idea of the Third World Academy of Science, which promotes awards from a national level in order to train ethics teachers. There was also support for the UNESCO Bangkok initiatives to work on ethics displays in museums, and to work with science educators.

Tuesday, 16 May

Session 3*: *Implementation and Practicality of Ethical and Professional Codes.

Prof. Paul Piang-Siong Teng (National Institute of Education, Nanyang Technological University, SINGAPORE) presented Codes of Ethics, Communication, and Genetically Modified Plants.

The Bioethics Advisory Committee (BAC) was appointed by the Cabinet in December 2000 to develop Singapore's bioethics framework for biomedical research. It aims to provide the public with information on key biomedical research areas such as stem cells and cloning, and their related ethical, legal, and social issues. In Singapore there is no overriding code of ethics for all sciences or technologies; rather, ethics oversight is provided by specific government/academic entities, including: Genetic Modification Advisory Committee (GMAC); Agri-Food & Veterinary Authority (AVA); Institution Animal Care and Use Committees (IACUC); and Institutional Biosafety Committees (IBC). The Biosafety Act and Animal Protection Act were also approved in the past few months.

Prof. Teng emphasized the role of risk communication as an approach developed to deal with situations where uncertainty, suspicion, and even fear has been created in people's minds about an issue or technology. It is a set of tools based on scientific, empirical research to provide more targeted, understandable, and effective communication without inadvertently provoking hostility and mistrust. It can provide skills for those who need to communicate in low-trust, high-concern, and controversy-laden situations**.** Risk communication theories were discussed,

including the trust determination theory; risk perception theory; mental noise theory; and negative dominance theory. The trust determination theory proposes techniques on how to "win" another person's trust in order for one's views to be accepted. As stated by Dr. Teng, "People need to know that you care before they care about what you know!" The risk perception theory increases effective communication by minimizing the perception of risk as a factor that reduces trust and acceptance by another person. Dr. Teng: "When people feel there is no risk, they are more likely to accept something new." The mental noise theory crafts messages in simple ways that people under stress can readily accept. Dr. Teng: "When people are stressed, they miss 80% of incoming messages and only accept simple language which is repeated." The negative dominance theory teaches how to avoid negativity in your communication. Dr. Teng: "When people are upset or stressed, they tend to put more weight on negative information." The media and government use different theories for communication.

In general discussion, tobacco advertising was given as an example of a risk linked to, in this case, sex appeal. Another example of skiing was used to illustrate how risk can be countered by the allure of adventure. These communication techniques modify risk perceptions. The modification of risk through communication can influence people, and can be used for good or bad. In this context the public perception and science behind GMOs were discussed.

Dr. Thomas A. Gionis (St. Thomas University of Law, USA) contributed a paper on Violations of Human Subjects Protection.

Dr. Gionis has professional experience in both the profit and not-for profit sector. The origin of the Joint Study Committee on Clinical Research Ethics was presented. Examples of the transition of clinical research into big business were given from the USA with significant funding from both the National Institute of Health (NIH) and private companies. The oversight of protection of human subjects was discussed, given that there are insufficient funds allocated to the monitoring of research ethics. The Food and Drug Authority (FDA) has acknowledged it's lack of awareness of the amount of Institutional Review Boards (IRB) currently active in the US. The average IRB meets for 2.5 hours and reviews so many applications that questions are raised over the quality of review. While the FDA performs some site visits, the other oversight body, Office of Human Research Protection (OHRP), mainly completes phone and paper reviews of research practices. There have been multiple ethical lapses in all countries, which argues for better monitoring of ethics review. The Joint Study committee has examined the violations of human subject protection in 503 letters between institutions and OHRP; a total of 3,150 violations were reviewed in this study. The types of violation were analyzed and presented; the research presented noted that the most common type of violation of human subject protection consisted of insufficient informed consent.

In general discussion, there was a call for funding organizations to take more responsibility for paying for ethical review oversight, in order to enhance the quality of research and to maintain human dignity and the protection of human research subjects. Workshop participants felt that the results presented for the US are probably indicative of the situation in other countries. Although under no government body to accredit them, private IRBs are appearing, resulting in variations in quality.

Prof. Paungphen Choohapran (Faculty of Nursing, Chulalongkorn University, THAILAND) talked on Professional Nursing Ethics Principles and Practice, to give a practical picture from inside clinical practice in Thailand.

Prof. Paungphen prefaced her presentation with the contention that nursing care is the most important care given to a person. Professional nursing ethics guidelines in Thailand have been revised several times (1955, 1979, 1987, 2005). There were eleven principles of ethics of professional nursing outlined in her presentation. Practical illustrations were used, for example, confidentiality to protect women with HIV was needed, to avoid being ostracized from the family. In October 1974, during violent clashes between police and students in Bangkok, Prof. Paungphen recollected how, as head nurse at the Intensive Care Unit (ICU) in Police Hospital, she lied to the police to protect injured students who would have been arrested and thus unable to receive medical care.

The ethics of health care funding that has resulted in the same nurse to patient ratio that existed 50 years ago (3:60) was discussed, with attention drawn to under utilization of the political strength of the nursing council in Thailand. Nurses also have to counter social misunderstandings and misleading pharmaceutical adverts with concerned patients. Ethnicity, stigmatization and lack of understanding of elderly patients are important issues for communication in Thai hospitals. Beyond the clinical ethics, other issues, such as use of disposable equipment which pollute the environment, were also raised.

In general discussion, the divide between private and public care was raised. Labour shortages in public hospitals are contributed to by lack of funding and nearly across the board retirement by nurses at age 50. Dr. Suthin Nophaket from the National Human Rights Commission queried the rate of human rights violations in medicine in Thailand. Dr. Choonhapran replied that the multiple layers of management and supervision resulted in tough regulations that limit such violations. Dr. Wasinee Wisesrith added that nursing schools have developed intensive graduate courses in ethics, which address sensitive issues such as palliative care, end of life care, and spiritual care.

Education in human rights and ethics was commended as areas to develop. The challenge of embedding ethics in the hearts of students rather than just teaching with books was raised.

A call was made for the construction industry to protect the rights of manual labourers, as many

construction workers are hospitalized due to fall from buildings, electric shocks from welding, iron and wood splinters in eyes, etc. There are additional ethical issues as many of the workers are migrants.

Dr. Matthias Kaiser (National Committee for Research Ethics in Science, NORWAY) contributed a paper entitled, "From rights to responsibility of science: Comments from Norway, with a focus on the new Norwegian ethical guidelines."

The proceedings of the World Conference of Science, held in Budapest in 1999 were presented. The consultation at the Conference on an Oath for Scientists and the drafting process of the declaration was discussed. It was agreed that ethics and responsibility should remain central to the declaration, but an Oath was not adopted. The Conference called for COMEST, in co-operation with ICSU's Standing Committee on responsibility and Ethics in Science (SCRES), to work for follow-up. Dr. Kaiser then described the SCRES study of 115 documents, discussing aspects of individual and community responsibility.

The Norwegian situation was reviewed, where the goal was an overriding ethics code. In the Norwegian guidelines (electronic file available), science is committed to securing peace. Examples of misconduct, issues of alternative knowledge and traditional knowledge, whistle blowing, contract research, and giving credit to scientists who popularize science were discussed. There was positive support from the workshop participants to use of the proposed Norwegian oath when obtaining a PhD. Dr. Darryl Macer suggested the oath could be taken at Bachelors degree level based on the impetus that the Sarin gas attack created in including ethics in Japanese general science degrees.

Dr. Ioan Voicu mentioned that as codes were often inspired by public international law they may not always reflect community values. This could result in codes not being based in reality, thus limiting their practicality. He suggested, for example, respect for nature to be included in ethical guidelines as the UN listed it as one of it's six fundamental pillars. There was also discussion of solidarity. Popularization of science is important to attract good students to sciences, instead of the recent trends towards business studies.

Dr. Supot Teachavorasinskun (Associate Dean, Faculty of Engineering, Chulalongkorn University, THAILAND) talked on Codes of Ethics in Engineering.

Many types of engineering were introduced including Chemical, Civil, Computer, Electrical, Environmental, Industrial, Mechanical, Metallurgical, Mining, Nuclear, and Water Resources. In Thailand, there are different councils controlling each specific area particularly through the granting of engineering licenses. Although there are many ethical issues, the principle difficulty is conflict of interest in questions of safety versus cost. Dr. Supot discussed the Council of Engineering, and the Engineering Institute of Thailand, that have produced a preliminary code of ethics. Engineering curriculum at university level is controlled, but there are no ethics courses currently in the curriculum, with no mention of ethics in course syllabi. The materials used in class are very teacher dependent. There is a motto, however, that students with good ethics will be engineers with good ethics. Comments on case studies were starting to be used, and the Engineer community welcomes assistance in integrating ethics into the curriculum. In discussion, it was noted that social responsibility is not just by law but by heart.

Dr. Suchinda Chotipanich (Deputy Permanent Secretary, Ministry of Science and Technology (MOST), THAILAND) talked on Follow-up to the Bangkok Declaration on Ethics in Science and Technology.

The workshop participants were reminded that the Declaration that arose from the Ministerial meeting at the Fourth Session of COMEST, agreed on the following principles:

1. To enhance S&T co-operation, which emphasizes fair trade over free trade;
2. To develop co-operation in intellectual property (IP), which aims to benefits humanity over commercial interests, especially in the least developed countries that have less ability to access IP;
3. To promote the role of youth in S&T to encourage early career scientist's professional development; and
4. To urge mutual understanding of the importance of ethics in emerging technology (such as nanotechnology, radiation, satellite, biotechnology, and human organ replacement) based on public understanding, and due care for the impacts of technology.

Dr. Suchinda presented examples of the work of MOST in meeting these objectives, especially with regard to helping rural and poor communities share in the benefits of science and technology. The plans for regional outreach were being developed in discussion with UNESCO and other countries. Youth camps are also being held to help promote the role of youth in S&T, where students study ethics at the same time as learning science. MOST urges mutual understanding of the importance of ethical standards and steadfast development of technology. Examples of such developments include research reactors, rice genome, satellites, and biotechnology. Dr. Darryl Macer thanked MOST for the ongoing collaboration with UNESCO, growing out of the cooperation in hosting the Fourth Session of COMEST in Bangkok in March 2005.

There was general discussion on the comparison of fair trade and free trade. It was noted that it is difficult to satisfy both fair and free conditions for trade. Thailand has a particular interest in these issues within the region. Respect for dignity in trade is important to avoid advantage being taken of smaller world players and developing nations. Dr. Macer gave some examples of ethics guidelines being used by some rich countries as trade barriers with the developing world. Awareness of cheap imports (coffee production discussed as an example), and the ethics of their production which may exploit workers and compromise safety, is recommended. While ethics guidelines are important, they must be culturally appropriate and applied fairly in solidarity with people across the world.

Dr. Pakapun Skunmun reinforced the difficult nature of discussions about ethics in trade due to the diverse issues involved, but as Thailand signed bilateral free trade agreements with developed countries, we should wonder whether it is *fair* trade. It affects the people in Thailand, especially given that 60% of people are involved in agriculture

Session 4: General discussion

Dr. Somsak Chunharas suggested there are at least three different approaches to making ethical issues more relevant to scientists. A top-down approach would be an overriding code of ethics that scientists could follow. An alternative approach is the creation of an enabling environment with a focus on capacity building. When we talk of ethics, we are generally talking about principles and standards. The dimension of the system has a lot to do with practice, thus scientists have to deal with these issues. The third approach is access to S&T. A framework for ethical conduct in science, technology and engineering was endorsed.

Indeed, the Bangkok COMEST consultation witnessed a tension (dialectic) between a perspective on ethics which fore-grounded the individual and her/his responsibility ("the morally culpable sentient individual/professional"), and a perspective which gave due regard to an "enabling environment" for ethical behavior. Graeme Bristol offered an inspiring notion of the "extended responsibility" of the professional (e.g. the responsibility of architects and engineers to anticipate the likely social and ecological consequences of their practice norms and milieu, etc), but some participants nonetheless felt that the onus should not be solely or largely an individual responsibility. CK Chan acknowledged that “individual effort and acts of conscience undoubtedly can make an important difference in many instances, but too often, it is progress achieved despite the system, not because of the system. It's not unreasonable to tweak the system to make it more ethics-friendly. Hence, I think COMEST should also address the institutional and systemic contexts for individual choices, and embrace a more "embedded" ethics which encompasses the ethical consequences of the operations of institutions and systems. In the area of health systems, a fusion of the social ecology of health and disease (social epidemiology), together with ecologically-responsible human rights, is the substantive content of what might be called public health ethics”.

“What does this mean concretely? Some proposals have emerged, e.g. from the numerous task forces and commissions (WHO, Nuffield, UK DfID-Barton commission, MSF-DNDi, etc), in the area of intellectual property regimes, in relation to developmental priorities and human needs - a greater role for public production and ownership of intellectual property (plus nonexclusive licensing), alternative reward systems for researchers and inventors, viable business models for open access publishing (PLoS, BioMed Central, Bioline, wikipedia, etc), patent pooling to get around serious obstacles to follow-on research, open access software (e.g. Linux). These are feasible and working alternatives which can get avoid some of the serious deficiencies of mainstream IP regimes, which these commissions were convened to address”.

Science ethics needs to include the benefit of all people. Dr. Amru Nazif discussed the concept of monitoring of greenhouse gases and how G77 and ASEAN said this was a new added cost to development. Despite 14 years since Rio, there are no clear new funding sources to cover these additional costs. Dr. Alongkorn Laowngam gave some information about the technology being developed by MOST, which was close to real people’s lives and helping in rural areas.

Dr. Tran Han Giang described practices and surveys being conducted in Vietnam among many companies. Some issues included: no forced labour; no child labour; right to organize; collective bargaining; no excess working hours; and health and safety. There was improvement in the results of surveys and interviews with workers between 2002 and 2006. The 2002 violation of codes of conduct was used by FNV, a Netherlands Trade Union, to report these results to the International Confederation of Free Trade Unions, and put it on the internet. In 2006, when she revisited the factories and made a comparison, the working conditions had improved. This was an example of the role that codes of ethics can play in technology and industry, and how international codes were important to protect people. Dr. Suthin Nophaket called for networking of human rights. Consumer complaints were identified as crucial steps in stopping abuse of human rights.

Dr. Graeme Bristol used the example of construction workers to reinforce the need to do something to protect the rights of workers. Some construction workers in the developing world are housed in conditions less than the UN accepts for refugees, can work 15 hour days with little or no training, in dangerous conditions, and for very low wages. As an architect, he proposed that not insisting on adequate conditions for sites under his supervision would be professional and ethically negligent. In these issues, the consumer is well downstream, whereas in the examples of companies that make or sell products, the consumer is directly in contact.

Sanctions could be part of a code if an association adopts it. Dr. Jayasuriya mentioned that as a funding agency NSF, Sri Lanka, has the options of “punishing” ethical violations by making the grantees “defaulters” or making them no longer eligible for grants. The most common default on the current Sri Lankan code that the NSF deals with is researchers not supplying a final project report on time. Dr. Kaiser endorsed making examples good standards and practices rather than publicly sanctioning defaulters as a more effective means of securing compliance. If the scientific community adopts a code, then those acting outside of this framework are easily identified as “bad scientists”.

Dr. Nadja Tollemache pointed out that it is important to distinguish between different professional

associations' codes of ethics and guidelines. These codes vary in the features and extent to which they hold members accountable, with internally agreed upon injunctions for violations specific to the association in question. Guidelines can be positive in terms of making recommendations on how professionals should act. In Thailand, a risk management committee works in the hospital to oversee the treatment of patients and potential risks that they may face.

The provision for whistleblowers is also important. Procedures need to be developed to deal with whistle blowing fairly and accurately. A lot of analysis has gone into this area.

Dr. Jayasuriya mentioned that the National Science Foundation in Sri Lanka has identified the need for penalties for the defaulters, but has also taken into account methods for identification of "good scientists". The Foundation has a scheme to reward the people who do well, by encouraging (financial support through national awards) the publication of research results booklets and technology transfer.

Prof. Song highlighted the useful comments in the Delhi meeting report where participants agreed that we need a code of ethics. Workshop participants unanimously agreed that a common document on ethics would be useful. It should set a standard, and act as a checklist. There were, however, discussions on whether it should be called a guideline, code, oath, or pledge. There was also consensus that education for students and as professional development should be a focus of the code. Popularizing research also means sourcing funds for post-research review.

Conclusions of the meeting were given by Dr. Darryl Macer, UNESCO Bangkok, who thanked everyone for participating. He described how there was expressed need for both descriptive and prescriptive approaches to codes of ethics. Model guidelines might be possible after more documents were mapped. In response to calls from member states UNESCO Bangkok and Paris are currently working on the important task of mapping codes. As participants have stated, the 1974 document is a recommendation rather than a code of ethics. Any follow-up should be developed with the National Commissions to UNESCO in the region, and the COMEST committee. The participants supported UNESCO's initiatives in this area as being very relevant to the regional needs. Dr. Macer said that the feedback given in the workshop had been very useful for the work of the Division of Ethics of Science and Technology and the regional programmes out of UNESCO Bangkok, and UNESCO would try to meet the needs expressed by the participants by continuing collaborations.

Report of the Seminar / Workshop on Bioethics (2 – 3, March 2006) organized by Department of Philosophy, University of Kerala, India

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The world faces great challenges due to the phenomenal growth and application of science and technology. The understanding that science is not free from the disciplinary background, beliefs and practices of scientist points to the importance of the study of ethics. Bioethics is applied ethics in the sense that it is the study of ethical issues that exists and anticipated in the context of real activities of practicing biological disciplines. Medical and health care ethics are a major component of bioethics. But it is accepted that it extends well beyond health care ethics to not only ethics of research in life sciences but also environmental issues covering pollution, the question of the proper relationships between humans, animals and the rest of nature; ethical issues in sexuality, reproduction, genetics and population and the various socio-political issues including unemployment, poverty, discrimination, crime, war and torture. The interest in bioethics is a concern for all and is going to stay like the new changes brought about by science.

Today it is an integrated branch of study covering almost every issue of our society with its special concern in life. Bioethics is an interdisciplinary study of value judgments pertaining to human conduct in the technology society.

The seminar / workshop on Bioethics organized by the Department of Philosophy, University of Kerala was an attempt to introduce the subject to the students of the campus, sensitize them and to create awareness among them regarding the possibilities – both positive and negative – of the advancement of technology in individual and social relationships. The target groups of the two day program were the post-graduate students and researchers of the various teaching departments of the campus. Over 75 of them from different departments like Psychology, Aquatic Biology, Bioinformatics, History and Life sciences participated. Fifteen invited presentations by specialists from different disciplines provided ample food for thought for the participants.

The theme of the seminar / workshop was introduced by Dr. Nesy of the Philosophy Department. Dr. Ekbal, a neurosurgeon by profession and a popular science activist chose to speak on Ethical Implications in Biotechnology Revolution. Introducing the Human Genome project he said 99.9% of the nucleotide bases are the same in all human beings, but the notion of 'designer babies' will be a threat to this equality of

human beings. Further biotechnology has the possibility of altering human nature so that a 'post-human nature' in history may be evolved. The commercial application of the immense possibilities of Biotechnology can create problems. Hence measures like initiating public debates, genetic literacy, inter and multi-disciplinary approach and extensive discussions on the ethical, social, economic, political and legal dimensions of the issue need to be addressed, according to him.

Prof. G.M Nair of the Botany Department dwelt on the topic Genetically Modified Organisms / Food: Bioethics and Biosecurity. The transgenic technologies have potential therapeutic effects but raise several questions like creation of new life forms, crossing species and boundaries, long term effects on human health and environment and unintended personal, social and cultural consequences. A re-definition of 'normal' would be required. Hence biosafety and environmental safety are to be ensured.

Genomics: An issue of Ethical Revolution was the topic of presentation of Dr. Moinak Banerjee of the Rajiv Gandhi Centre for Biotechnology. The unraveling of the human genome sequence is the biggest achievement of the 20th century according to him that revealed 97% of DNA in the human genome has no known function. There are areas of research like DNA and Cell-line banking, Genetic testing and Counseling, Epidemiological research, Human genetics and Transplantation research, Assisted Reproductive Technologies, Gene therapy and human cloning, Genetic privacy and Discrimination, Intellectual property Rights and Benefit sharing where immediate and effective measures in the fields of teaching, education, culture and information, privacy and confidentiality etc need to be ensured.

Sri. C. P. John, Member, Kerala State Planning Board spoke on Bioethics from the point of view of eco-philosophy.

Ethical Principles and issues in Research was the topic of Dr. Sudhakaran, Professor & Head of the Department of Biochemistry. Addressing the social concerns of Genomics, he made reference to principles like fairness in the use of genetic information; privacy and confidentiality; psychological impact and stigmatization; reproductive, clinical, health and environmental issues etc. By way of risk minimization and precaution he recommended the following of ethical guidelines, addressing of ethical issues and ethical clearance and review process by Institutional ethics committees.

Dr. Amar Fettle, Pediatrician by Profession and Dr. Mohanan Nair, CEO, Indian Institute of Diabetes and Fogarty International Fellow in Bioethics concentrated on Research Ethics particularly in the Medical field. In a world in which commission and / or omission are equally killing, the principles of respect for persons, Beneficence, justice, confidentiality and informed consent are very valuable according to Dr. Amar Fettle. Referring to issues in Public Health research, Dr. Mohanan Nair made a distinction between experimental research and other forms of research and said that protecting the health and well being of populations, respect for their rights and self determination; their privacy, integrity and self-esteem and equitable distribution of benefits are very important in medical research.

The importance of environmental ethics was introduced and discussed by Dr. KRS. Krishnan, Director, Science and Technology. Environment concerns can be local or global with abiotic, biotic and human levels of impact. Environmental ethics is prescriptive in character that demands action like understanding the relation between man and his bio-physical environment, sharing information with the public and education on environmental issues.

Sonny Jose, Social Work Faculty of Loyola College of Social Sciences dwelt on the topic Ethics in Research- Principles and Practice. He said that there are dilemmas in the search for knowledge where ethical principles become all the more important. Informed consent often turns out to be crucial in research. He cited a case study: is community consent tenable?

Sri Gouridasan Nair of the National Daily, The Hindu, spoke on Media Ethics wherein he stated that print media is 700 yrs old and hence more responsible than the visual media of recent origin. Freedom of the reader is important and mentioned about the 'Reader's Editor' of the *Hindu* in this context. Sri Ranjith from the Centre for the Development of Information Technology (CDit) spoke about the digital divide, in particular the akshaya project of the Govt. of Kerala. Professor Rajakrishnan dealt with the topic Ethics and Literature. Dr. Balaganapathy, Professor of Philosophy spoke on Transhumanism which is a quest to develop further so that we can explore the hitherto inaccessible realms of value. Transhumanism help us to go further but with caution since existential risks are to be avoided at any cost, he added.

On the whole the seminar was a big success. As a follow up of the sessions, the participants were asked to register their feed back. 95% of participants expressed their interest in Bioethics while all of them agreed on the application of ethics in the field of Biotechnology, teaching of Bioethics and a basic knowledge of ethics is a must for all students.

On the strength of this feedback, the Department of Philosophy has proposed the University to establish a "Center For Bioethics Research" which is under consideration of the University. Also the proposal to start add-on courses like Bioethics has been endorsed by the subsequent faculty meeting. I request the collaboration of UNESCO Bangkok in this connection.

Bioethics: A view on the contemporary discussion in Germany compared to Asia

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Abstract

What is understood by the term "bioethics" varies widely. Whereas in Germany the focus of the discussion centres on biotechnological issues like Preimplantation Genetic Diagnosis (PGD), research on human stem cells and cloning, in Asia the concept is understood more broadly including among others environmental ethics, animal rights and medical ethics. This article tries to set out the discussion going on in Germany on two rather different levels: On the one hand, it is a legal discussion on whether research on human stem cell should be allowed and whether to put forward PGD. On the other hand, this discussion is entangled with a highly speculative discussion on the issue of manipulation the human genes – if ever possible – in order to improve the human genes. The main aim of giving this account of the ongoing deliberations in Germany is to introduce this discussion to the Asian context in order to enrich the discourse in bioethics going on here.

1. Introduction

Coming from Europe, one experience in an Asian country is that the discussion running under the title "Bioethics" has barely something in common with the discussed issues in Europe. In Europe in general, and especially in Germany, the discussion's focus lays nearly exclusively on the legal matters concerned with the issues of Preimplantation Genetic Diagnosis (PGD), embryonic stem cell research and cloning. Moreover, this discussion about legal matters in biotechnological research is somehow overlapped by a highly speculative discourse on Peter Sloterdijk's "Rules for the Human Zoo" [54] [55] and Jürgen Habermas' "Future of Human Nature" [56]. This discussion focussed on the question, whether we should manipulate our genetic makeup in order to create "better" human beings; whatever "better" might mean.

In the Asian context the concept of Bioethics appears to be rather broader and not so much concerned with legal matters. It includes issues concerned with the environment, with health care, animal rights and others – or, to summarize it, with the "love of life" [57] in general.

The aim of this article is to stipulate a productive discussion by introducing the basic lines of the discussion on bioethics in Germany into the Asian context. I will start this paper by giving some remarks on bioethics putting emphasis on the problematic linked with this concept. I will then draw attention and set out the techniques that will be discussed. The next point is to sketch out the speculative discussion which started in Germany in 1999. In France this discussion is known under the name of "The Sloterdijk Habermas scandal" [58]. Finally, I will draw attention to the actual debate about research on PGD, on embryonic stem cell and cloning which is discussed in politics, public and academics alike in Germany.

2. Some remarks on the concept of Bioethics

Nowadays, Bioethics is a frequently used concept in academic as well as in public debate. Twenty perhaps even ten years ago, only very few people were familiar with the concept of bioethics. Thus, bioethics appears to be a rather recent phenomenon in the history of philosophy. The question then arises what is this bioethics discussion all about.

A recent book entitled "The fiction of bioethics" supposed to reflect on the fictional character of the whole concept of bioethics evaporating – as it were – when examined closer. However, the book turns out to reflect on the implications of literary texts when taken as case studies. It urges that the way of representation affects the way moral problems are examined. [59] But the title would perfectly make sense in order to explain the fact, that the concept of "bioethics" is applied to very different areas. And sometimes one cannot help the idea, that the catchword bioethics is simply used in order to have better chances to get government funding for a scientific research project. [60]

A narrow concept that is mostly applied in Germany understands bioethics as follows: bioethics is concerned with the ethical questions that arise due to the new possibilities given through technological innovations in the field of medicine and biology. However, sometimes bioethics is understood in a broader sense including the moral questions about all actions of human beings that might help or harm other organisms. In this broad sense, bioethics can barely be distinguished from "applied ethics". Indeed, as it is put

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[55] SLOTERDIJK, Peter: Regeln für den Menschenpark. Ein Antwortschreiben zu Heideggers Brief über den Humanismus, Frankfurt am Main: Suhrkamp, 1999. Even though that this book iniciated a excited public debate, it has not been translated into English.

[56] HABERMAS, Jürgen: Die Zukunft der menschlichen Natur. Auf dem Weg zu einer liberalen Eugenik?", Frankfurt am Main: Suhrkamp, 2001. A translation of this book has been published 2003 by Polity Press: „The Future of Human Nature"translated by Hella Beister and William Rehg.

[57] MACER, Darryl R.J.: Bioethics is Love of Life: An Alternative Textbook, Christchurch, N.Z.: Eubios Ethics Institute, 1998

[58] Sloterdijk, p. 59

[59] CHAMBERS, Tod: The fiction of bioethics: cases as literary texts, London/New York: Routledge, 1999

[60] The reason for this in Germany is a change of government policy. The vast majority of universities in Germany are run by the government. As the government want to make these institutions more effective, it tries more and more to grant money for certain research projects within the university rather then to the university as such. And projects which can show that they are for some interest for economic application are more likely to be successful.

in "A Cross-Cultural Introduction to Bioethics", bioethics is in many cases simply the new name for what has formerly been discussed under the heading of ethics.[61]

3. The bioethical issues discussed in Germany

As already noted, in Germany normally the narrow sense of bioethics is applied. Due to new technological inventions at the beginning of human life and at its end these questions arise. The technologies at stake are PGD, research on embryonic stem cell and cloning.[62] So I will briefly explain the biological facts concerning these technologies before entering the ethical discussion.

3.1 Pre-Implantation Genetic Diagnosis (PGD)

As we know, it is not the stork that brings the children. And the fact, that there are less and less children born in Western countries, is not due to the fact that the number of storks has decreased as well. However, one reason of the decline of population in European countries is the increase of infertility.[63] *In vitro* fertilization was developed as a means to help infertile couples to have their own children. It is a technique where egg cells of a woman are fertilized outside her body. It is a major treatment to overcome infertility, when ordinary conception failed. At the same time, it is the necessary prerequisite for PGD. Thus, I will set out the basics of IVF before turning to the techniques of PGD.

IVF was successfully applied for the first time in 1978. Since then it has undergone different improvements as well as a large extension. In Germany for example around 10,000 children are born every year through IVF, which sums up to 1 – 2% of all children.[64] Fifteen years ago, probably less then 1.000 children were born in Germany through IVF.[65]

To put it in a short form, the process of IVF runs as follows: Hormonal treatment stimulates multiple developments of human eggs. Through surgery these eggs, on average around 9, are removed. In a culture media, these human eggs are brought together with male sperm in a ratio of about 1:75.000. In about 50% to 70% of the cases fertilization takes place after around 20 hours.[66] After some days of cultivation, the embryo has reached the 8-cell-stadium, and up to three embryos are implanted in the woman's womb.[67] In around 25 -30 % a clinical pregnancy can be established, and in around 15 – 20% a child is born.[68] It is important to note that in order to increase chances of pregnancy several human eggs are fertilized and up to three are transferred after cultivation.[69]

PGD takes profit of the situation, that the first stages of the development of the embryo take place outside the woman's womb. Three days after fertilization, a single cell is removed from an 8-cell embryo through micromanipulation. This can be done without causing damage to the embryo. This cell is then analyzed for chromosome or genetic anomalies, and due to the outcome of the analysis, the embryo is then transferred to the woman's womb or not. Thus, PGD is a method of testing embryos for diseases in order to select the genetically healthy ones for transfer. The goal of this testing is to increase the possibility of establishing a pregnancy with a genetically healthy child.[70]

3.2 Research on embryonic stem cells

IVF is not only prerequisite for PGD but also for the research on embryonic stem cells. However, unlike PGD, the goal of doing research on embryonic stem cells is not the well being of children but rather understanding the functioning of cell evolution and finding therapies for incurable diseases.

After IVF, the embryo develops within 4 to 5 days to the blastocyst stadium, where a cell differentiation between the inner cell mass and the trophoblast already takes place. The inner cell mass, also known as the blastocyst, is then removed and the embryo destroyed. The cells of the blastocyst are embryonic stem cells. They are still undifferentiated and possess the potentiality to differentiate in all different cell types. In order to get a stem cell line, it is required to place a

[61] MACER, Daryl (ed.): A Cross-Cultural Introduction to Bioethics, Christchurch, N.Z.: Eubios Ehtics Institute, 2006, p. 11

[62] At the end of life, especially the question concerning euthanasia initiates bioethical debate. That this discussion was intensified in the last ten years is due to the medical and technical innovations that allow to maintain the life of elderly patients much longer, than a generation or two ago.

[63] Bernhard Irrgang speaks of a dramatic increase of infertility that has doubled in the last fifty years in Western countries. (See: IRRGANG, Bernhard: Einführung in die Bioethik, München: UTB 2005, p. 135)

[64] See: DIR-Jahrbuch 2004, p. 7. http://www.deutsches-ivf-register.de/jahresbericht.htm (on 5/19/06). According to the free encyclopedia Wikipedia, in Denmark even 4% of all children are conceived through IVF (see: http://en.wikipedia.org/wiki/In_vitro_fertilization).

[65] In 1990, only about 7.000 IVFs have been conducted with a probability of around 15% of finally giving birth to a child, it is likely that the total amount did not surpass 1000. Especially, if one takes in account the technological progress in this new technology (i.e. IVF) that has been achieved in the last 15 years. That implies that the success rate was well below 15%. (See: DIR-Jahrbuch 2004, p. 7, http://www.deutsches-ivf-register.de/jahresbericht.htm on 19may 2006)

[66] See: DIEDRICH, Klaus/LUDWIG, Michael: Überblick über die medizinischen Aspekte der Reproduktionsmedizin, in: Das Bundesministerium für Gesundheit (Ed.): Fortpflanzungsmedizin in Deutschland. Baden-Baden 2001, pp. 32 – 39

[67] Sometimes one waits until the blastocyst stadium, around 2 days later, when the embryo has 50 – 150 cells, for implantation. See e.g.: http://www.ivf-infertility.com/ivf/blastocysts.php (on 5/20/06)

[68] These numbers refer to Germany. We will later see, why the numbers might be different in other countries. (see: DIR-Jahrbuch 2004, p. 7. http://www.deutsches-ivf-register.de/jahresbericht.htm (on 5/19/06)

[69] Technically, there can be more then three embryos transferred. However, there is an increasing possibility of multiples pregnancy. It is for that reason that the German legislater has limited the number of transfered embryos to three.

[70] The selection through PGD avoids that genetically damaged embryos are transfered which will not have a chance to successfully implate. This is the reason why PGD might increase the possibility of pregnancy. However, there has not been done sufficient reasearch on this matter to decide.

single stem cell in a Petri dish and provide sufficient nutrients for growth. The stem cell will divide as long as it has enough nutrients and stay undifferentiated and thus available for research. However, the development of an embryonic stem cell line is not as easy and straightforward as it seems to be. To establish a stem cell line, is a difficult task, only successful in very few cases. So it was not until 1998, that the first human stem cell line was established.[71] Instead of getting human stem cell lines through IVF, it might be possible to get them through cloning, which will be discussed in the next section.

The purpose of the research on embryonic stem cells is to understand the logic of cell differentiation better and maybe to be able to provide therapies for diseases such as Parkinson and Alzheimer's disease in future. But the knowledge so far is too little to tell, whether embryonic stem cell can ever be applied for therapies.[72]

3.3 Cloning

It was the birth of Dolly, the first cloned mammal, in 1997 that brought cloning to public attention. Technically, cloning means producing individuals, which are genetically identical. That can be done by mere embryo splitting, which just separates two embryonic cells, or by somatic cell nucleus transfer. In the second case, the DNA of a cell of the organism to be cloned is put in a human egg which had its nucleus removed. After the fusion of the nucleus with the denucleated egg cell, the embryo should – theoretically – take the same development as an embryo produced by fusion of sperm and egg cell.[73]

Asking about the purpose of cloning, it has to be differentiated between cloning for reproductive purpose and cloning for research or therapeutical purpose. The first one tries to achieve a living organism genetically identical with the cell donor. It is widely regarded in the academic community as well as in the politic community to be immoral to try to clone a human being for reproductive purpose. The moral evaluation is different in the case of cloning for research purpose. The goal of cloning for research purpose is more or less the same as in doing research on embryonic stem cell: It may help to get knowledge about the differentiation of cells and – in the future – serve as therapy for diseases.

3.4 Summary of the techniques discussed

To summarize the biotechnical issues discussed, it can be said that they derive with the exception of cloning from IVF. All of them are much elaborated techniques, which are combined with much technological know-how and high costs. As it can be seen by this sketch of the bioethical question, the discussion running under the label of bioethics is heavily depending on the spread of technologies and on culture.

I will now turn to the discussion on bioethics in Germany, which, as already mentioned, takes place on different levels. I will start with what I call the "speculative level", on which bioethics was introduced to a public audience.

4. The Sloterdijk Habermas Debate

4.1Sloterdijk's paper on "Rules for the Human Zoo"

If one looks for a starting point of bioethics becoming a public issue, than the paper presented by Peter Sloterdijk in July 1999 in the castle of Elmau in Germany is one.[74] The title of his paper was: "Rules for the Human Zoo". The speech of Sloterdijk was incorporated in a conference on Heidegger and Lévinas, which was attended by an international group of philosophers and theologians from mostly European and American countries. In September and October of the same year an agitated and controversial debate was going on, that had Sloterdijk's paper as its starting point.[75] So the question arises what this paper was about that led to so much public notice.

Knowing the bioethical discussion that followed from Sloterdijk's paper, one is surprised that his main concern is a discussion on humanism. Especially, Sloterdijk is concerned with Heidegger's letter on humanism. The starting point of his paper is a quote from the German poet Jean Paul that books are bulky letters to friends.[76] With this quotation, one is already close to the essence of humanism, which consists in – as Sloterdijk points out – a model of literary society. A humanist society is then one that is bound together by shared readings, by a sort of literal canon. This shared literal canon is central to what holds the society together. But humanism is not just a movement that functions as an amalgam for society; it is directed against the falling back of humanity into barbarism. There is a permanent fight to be fought in order to civilize human beings, understood as animals under influence, for not letting them fall back in a wild and barbarian ages. And it is seen as the task of humanism to avoid the relapse in barbarism. This task should be achieved through cultivation by means of a shared literal knowledge.

But the humanistic age is over, as Sloterdijk puts it. Due to the medial mass culture, especially radio and

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[71] Vgl. SCHNEIDER, Ingrid: Beschleunigung – Merkantilisierung – Entdemokratisierung? Zur Rolle von Patenten in der embryonalen Stammzellforschung, in: Fuat S. Oduncu et al. (Ed..): Stammzellenforschung und therapeutisches Klonen, Göttingen 2002, pp. 211 –245

[72] DEUTSCHER BUNDESTAG (Hrsg.): Zweiter Zwischenbericht der Enquete-Kommission „Recht und Ethik der modernen Medizin" – Teilbericht Stammzellforschung, Drucksache 14/7546, 12.11.2001, pp. 16 – 25. This report of the German parliament is also online as a full version in German and as a excerpt and motion in English. See: http://www.bundestag.de/parlament/gremien/kommissionen/archiv15/ethik_med/dokumente/index.html (on 5/20/06)

[73] In practice, there are many technical problems linked with cloning. Evidence of these problems is that until today no cloning of a human embryo has been achieved.

[74] There was an article pubished in "The New Atlantis" in 2004, which presents this rather speculative discussion and draws special attention to the German Nazi past and the biases linked with this past. (BROWN, Eric: The Dilemmas of German Bioethics, the New Atlantis, Spring 2004 – 53)

[75] For an account of the unfolding of the debate see Sloterdijk, p. 57-60

[76] See Sloterdijk, p. 7

television, we are living in a post-humanistic age. It is no longer that a literal canon or common readings are crucial for the cohesion of society. It is at this point, where Heidegger's letter on humanism comes in. The point of Heidegger is not to revitalize humanism but rather to question the roots of this very concept. Because two parts of the concept of humanism run against Heidegger's conviction. First, Heidegger opposes the idea of human beings as *animal rationale*, as rational beings. Then he asks "whether the essence of man primordially and most decisively lies in the dimension of *animalitas* at all".[77] He opposes the view that human beings are animals under influence; a conviction that is at the core of humanism. The second critique is that the concept of humanism tries to put on the human beings dominating their world and imposing – as it were – their will on Being. The proponents of humanism try to master the world even though this should be achieved by literal education and not primarily by technical conquest. This target of mastering the world contradicts the central idea of *Gelassenheit* (letting be) of the philosophy of latter Heidegger.

Whereas Heidegger unfolds his philosophy evolving around the human being as shepherds next to the clearance of Being (*Lichtung des Seins*), Sloterdijk is trying to give the discussion about the end of humanism a different turn. And there it is where finally the bioethical issues come in. It is in the clearance that incarnation takes place.[78] But not only its peaceful parts like writing and reading, but this clearance is also a place of fights and selection. Behind the force of civilization, there is a different force at work: behind the force of reading (*lesen*), there is the force of selecting (*aus-lesen*). Lectures and selections have more in common than one is willing to think.[79]

The stage is set for Sloterdijk's claims that caused a highly emotional debate in Germany. As well as through books (lections) human beings have educated and reared, as well it might be made through selection. So we will enter truly in a not only technical but anthropo-technical age. Once humankind has achieved this power of selection, it cannot retreat behind the veil of ignorance. If humankind still does not want to use this power and still want to blame a higher power for his destiny – like God or chance or the others – then this indicates human immaturity. A refusal of using this acquired power is, as Sloterdijk argues, out of question. What has to be put in place are rules how to use this anthropo-techniques. Thinking not only in centuries but in millenniums, Sloterdijk sees our time at the edge of the ages: the age of books has come to an end. In the centuries to come, human beings will have to take important decisions concerning the future of its own kind.

Even though that Sloterdijk puts forward a clear cut argument that humankind has no choice of using its new genetic knowledge or not – it simply *has* to use it – he somehow retreats and explains that it is not sure that the development will lead to a change of explicit planning of our genetic makeup. But with this lecture of Sloterdijk, the initial step was done for a public debate.

4.2 The debate initiated through Sloterdijk

What happened then was an excited public debate, which was joined by nearly all philosophers of rank in Germany: Ernst Tugendhat, Manfred Frank, Ludger Lütkehaus, Ludger Honnefelder, Günter Figal, Micha Brumlik, Robert Spaemann and others.[80] Jürgen Habermas, the probably best known living German philosopher, did not enter the discussion, until he was directly attacked by Sloterdijk who claimed that Habermas has initiated the critique on his speech.[81]

Most, if not all, philosophers were very critical about Sloterdijk's ideas of "Rules for the Human Zoo". As an example, the view of the chairman of the general society for philosophy in Germany, Jürgen Mittelstraß, probably was shared by most of the disputants: "Sloterdijk has naively and unsteadily trespassed all scientifically and philosophically justifiable limits."[82] Even though that Habermas, as mentioned above, has not entered the discussion but for a short letter to the editor, this debate was labelled – at least in France – "The Sloterdijk Habermas scandal". However, Habermas was already preoccupied with bioethics and published his reflection on that issue in his book "The Future of Human Nature. Towards liberal eugenics?" exactly two years after Sloterdijk's paper in 2001.

4.3 Jürgen Habermas "The Future of Human Nature"

The starting point of Habermas' book is an analysis of technological invention, which led to the issues discussed in bioethics. On the one hand, the medicine of reproduction has made impressive progress since the first successful *in vitro* fertilization in 1978. In less then 30 years, the techniques of artificial reproduction have become more and more elaborated and are applied in more and more cases. In fact in Germany the number of IVF-treatments has doubled every 4 years since the early 1980ies.[83] Through IVF human stem cell got accessible

[77] And he continues: „Are we really on the right track toward the essence of man as long as we set him off as one living creature among others in contrast to plants, beasts, and God?" (Heidegger, Martin: Letter on Humanism, in: Heidegger Martin: Basic Writings, edited by David Farrell Krell, New York: HarperCollins, 2nd ed. 1993, p. 227)

[78] See Sloterdijk, p. 37

[79] See Sloterdijk, p. 43

[80] For an account of all articles published in German newspapers, see: http://www.uni-oldenburg.de/EthikProjekt/Liste_der_Artikel.htm (on May 22, 2006) and for an account on the philosophers that entered the debate see: http://helmutwalther.privat.t-online.de/sloterd.htm (on May 22, 2006)

[81] This attack of Sloterdijk on Habermas opened a meta-debate involving the relation (or non-relation) of Habermas and Sloterdijk, on which I will not enter.

[82] http://www.petersloterdijk.net/international/texts/en_texts/en_texts_PS_psychonaut.html (on May 9, 2006)

[83] In 1982: 742 treatments, 1986: 4201 treatments, 1990: 8651 treatments, 1994: 23.684 treatments, 1998: 45.459 treatments and in 2002: 87.044 treatments. However, it can be expected that due to a legal change in Germany (patients have to pay a

for human genetic analysis and experiments. On the other hand, the genetic knowledge has increased enormously and it human genome project has achieved to decode the whole of the human genome. It is the coming together of medicine of reproduction and genetic engineering, Habermas argues, that raises new ethical questions. Especially, the ethical question arises about Preimplantation Genetic Diagnosis (PGD) and future prospects of breeding of organs and therapeutical inventions that change the genetic makeup.[84]

These interventions at the beginning of human life would constitute a liberal eugenics. They would be "eugenics", because a selection is made through PGD between embryos that are life worthy and ones that are not life worthy. This eugenics would be "liberal" because the decision whether to apply a selection is in the hand of the single person using these techniques and not dictated by the state.[85] The speculative question Habermas asks is, whether this liberal eugenics applied on a large scale would change our self-understanding as human beings.

For Habermas, there are two reasons, why our self-understanding as human beings would be damaged due to genetic engineering. Firstly, the possibility of an autonomous life would be in danger. Secondly, the free egalitarian exchange of persons within society could no longer be guaranteed.

Turning to the first reason, Habermas' argument runs as follows: It is part of our self-understanding as human persons to decide about our own life. We plan our life as autonomous persons and make our choices according to our beliefs. Being children however, we do not have this freedom to decide about our life as this decision is normally taken by our parents. However, education works through the medium of questions and answers. There is always a possibility to oppose what one is taught. In the case of genetic engineering, the medium of formation is no longer question and answers. Genetic programs would not allow the children to raise their voice.[86] The determination caused by genetic enhancement would be definitive, in contrast to the determination by education.

Imagine – making Habermas point plausible with an example – that your parents have chosen a genetic makeup that will fit perfectly for becoming lawyer. However, in your adolescent time you desperately want to become an artist, but your parents simply say that they have chosen genes for you to become a lawyer. It will be distinctly more difficult to oppose your parents, if they have chosen a genetic makeup for you becoming a lawyer, then if they have just provided you with the best education of becoming a lawyer. Or as Allen Buchanen puts it comparing these two forms of formation: "The force of feeling locked in may well be different."[87]

The second argument Habermas is putting forward is that genetic engineering would affect the equality in society. Not only the relation between parents and children would exist, but a new form of relation would come into existence: the one between genetic designers and the object they designed, i.e. the genetic enhanced children. Unlike in the relationship between parents and children, where the children can oppose and counteract the education of their parents, the objects genetically designed cannot counteract their design and designer.

Of course, these two arguments rely heavily on the development of genetic engineering and it is not at all sure, that such knowledge about the working of genes will ever be available. Moreover, it can be asked whether Habermas' arguments only work on the presupposition of genetic determination. Habermas is aware of the danger of falling into genetic determination. However, he seems sometimes in his book to have too much belief in the power of genetic regulation.

4.4 Making sense out of this debate: Some Remarks

First of all it has to be noted that Sloterdijk and Habermas argue on different levels. Sloterdijk's focus is on the far future of human beings and them becoming their masters not only about the outer nature but also about their own human nature. The formation of humankind should not only happen through lectures but also through selections. Habermas concerns are the actual political decisions in Germany about PGD and research on embryonic stem cell. However, he tackles this question in a consequentialist way asking where this technology might lead. And coming from the picture of liberal eugenics, he criticizes the technologies that might lead towards it.

Thus, it turns out that both philosophers have more in common, than one might expect due to their very different starting points. They both share a concern about using the means of genetic technology to manipulate human beings. Whereas Sloterdijk looks forward to these possibilities of genetic engineering, Habermas is sceptical about them and fears that they might damage our self-understanding as human beings.

Both books can serve as an interesting starting point of discussion, asking about the relation between technology and human beings and about the question in what our human being consists in. However, as already pointed out, this discussion takes place on a speculative level assuming a successful development of genetic knowledge and embryo manipulation.

Apart from the so-called Sloterdijk debate (or Sloterdijk Habermas scandal) there is foremost a legal discussion going on in Germany about the question whether PGD and research on embryonic stem cell should be allowed. Behind these two subjects, the

certain amount for their treatment), the growth rate will be significant smaller. (DEUTSCHES IVF REGISTER 2002, p. 7. See: http://www.deutsches-ivf-register.de/ under „Jahresberichte")

[84] Habermas, p. 34f.

[85] Authoritarian eugenicists would do away with ordinary procreative freedoms. Liberals instead propose radical extension of them." (Nicolas Agar quoted in Habermas, p. 87) In Germany, one is particularly careful about any kind of authoritarian eugenics due to the totalitarian past in the first half of the 20th century.

[86] See Habermas, p. 123

[87] Allen Buchanan quoted in Habermas, p. 106 (footnote)

question about right rules for IVF treatments seems to be still unsettled.

5. The bioethical discussion in Germany about PGD and research on embryonic stem cells

In general, one can say that the public and political discussion in Germany is focussing on the beginning of human life and its end, i.e. on the question of euthanasia. The discussion about euthanasia I will not enter as it is a completely different question, which would go beyond the scope of this article. The bioethical questions at the beginning of life however evolve around what was discussed by the book of Habermas.

It is the question whether PGD and research on embryonic stem cells should be allowed. The decision taken by the parliament was to forbid PGD and to set narrow limits to the research on embryonic stem cells. Prior to both decisions a parliamentary commission was set in place and the political decision was accompanied by public as well as academic debate.

The reason why the parliament decided against PGD was first and foremost that it contradicts existing law. German law rules that human life starts with the fusion of the nucleus of the sperm with the ovum. As PGD takes place two days after "conception", a human embryo would be used for a purpose other then his life – namely for testing. A second reason why PGD was not allowed was that it consists in selection. It was viewed as not in accordance with the human dignity that embryo is considered as life worthy only after testing.

In the case of research on embryonic stem cells, the solution found was not that straightforward. Research is only allowed on imported stem cells that were gained before the 1st January 2002 in order to avoid that for research purpose more embryos will be destroyed. In only allowing to do research on existing stem cell lines, it is avoided that more and more embryos are used for research purposes.

To summarize, it can be said that the German legislators took a lot of pain in carefully deciding what should be allowed and what not. Of course, there was vehement critique from economic pressure groups who wanted to allow especially research on embryonic stem cells in order to catch up technologically with other countries. But there was critique as well from religious groups arguing that any research on embryonic stem cells should be prohibited, because it makes one partisan to the usage of embryos for other purposes then reproduction.

6. Conclusions

It was shown in this article that the discussion on bioethics in Germany takes place on a speculative level on one hand and on the legal level on the other hand. The speculative discussion led by Sloterdijk and Habermas evolved around the question whether humankind should start to take evolution in their own hands, if this ever is possible. However, Sloterdijk is not so much concerned about what is possible in the next couple of years or decades, but rather he thinks, as he says, in centuries or millenniums. Having in mind such a vast period of time, he suggests that humankind should actively elaborate anthropo-techniques. Habermas, on the other side, is sceptical about Sloterdijk's vision and sees our human self-understanding as autonomous and equal beings in danger. Not only might genetically designed children be less free, society as whole might be damaged as new unequal relations will come into existence.

The legal discussion, which I briefly set out, on the other hand is concerned with the new technological possibilities of PGD and research on embryonic stem cells. In the last couple of years the parliament set up different commissions discussing these issues. The result was a rather sceptical point of view of these techniques, and the German legislators followed the view of the commissions and prohibited PGD and only allowed research on embryonic stem cells within narrow limits.

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