AUSTRALIAN NATIONAL UNIVERSITY

CONFERENCE ON CONSTRUCTING LAW & DISABILITY

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TO IGNORE IS TO DECIDE

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IN QUITO WITH COTAPAXI AND THE GENOME

Quito is a remarkable city. It has been included in the World Heritage List for its extraordinary natural features and historical significance. Before the Spanish arrived in South America, the town and its indigenous Kingdom fell to the Incas. In time, it was conquered by the Spaniards. In 1532 they used it as their base to subdue Peru. Under the Spanish, many beautiful churches were built and residences began to cover the mountains of Quito that represent the foothills of the Andes. Not far from Quito, the glistening top of Cotapaxi can be seen through the morning mist.

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The Spanish were eventually driven from the Republic of Gran Colombia in 1809. In 1830, Ecuador proclaimed its own constitution and became a separate nation. Quito is its capital. To Quito, in November 2000, came participants from all over the world. Their purpose was to take part in the first meeting of the International Bioethics Committee of UNESCO (IBC) to be held in South America.

I took part in this meeting. Most of its sessions were concerned with subjects relevant to the implications for morality, law and society of the advances in genetic science. This was the first meeting of the IBC since the announcement, in June 2000, of the completion of the first provisional draft of the human genome. Although the mandate of the IBC is wider than human bioethics and the human genome, it was natural that the meeting in Quito should be mostly concerned with those topics.

Amongst the issues which the IBC members discussed were public education in bioethics; intellectual property protection of biotechnology; and the implications of embryonic stem cell research and development.

Education issues inspired an important session. Unless the public understands the developments of genomic science, it can scarcely be criticised for failing to perceive, and to act upon, the

implications which such science presents for the law and society. One of the interesting topics addressed during this session was a world-wide proposal for enhancing training in ethical questions at university medical faculties. Nowadays, even more than in the past, medical practitioners have to deal with acutely difficult ethical problems, many of them with legal ramifications. It is astonishing that some medical graduates can reach that status and responsibility without training in the ethical quandaries that they will have to resolve, consistently with law, during their lifetime in medical practice. The IBC expressed its support for the efforts to improve public education in bioethical questions, including by the promotion of special courses in medical schools. It may be hoped that this idea will be followed up in Australia and many other lands.

The subject of intellectual property protection is amongst the most important presented by advances in knowledge about the genome. Although the *Universal Declaration of the Human Genome and Human Rights,* adopted by the IBC and accepted by the General Conference of UNESCO and the General Assembly of the United Nations, speaks of the human genome, in its natural state, as part of the "common heritage of mankind" intellectual property law is invoked to provide temporary rights of exclusive use or licence to patent holders, by reference to the genome. Pharmaceutical corporations and others justify these rights on the basis that, unless guaranteed such protection for new "inventions", the huge investments that are necessary to translate basic scientific

knowledge into therapies and other treatments, of benefit to humanity, will not occur. In my experience, now over ten years, it can be said with assurance that this is a topic that causes very strong feelings in any international meeting at which it is raised. Participants from developed countries tend to emphasise the importance of applying intellectual property regimes, both international and domestic, to genomic technologies so as to maximise the benefits derived from them. Participants from developing countries express concern that such laws will be used to deprive them of a share in the medical advances that will flow from unveiling the genome. In short, they express concern that intellectual property law will be used to cut people in developing countries off from effective access to knowledge about human genetics and the application to which that knowledge is put.

No resolution of these questions was reached, or indeed expected, at the Quito meeting. But the participants were heartened by the advice given to the meeting by the Secretary-General of the IBC (Dr Georges Kutukdjian) concerning the interest taken in this topic by the new Director-General of UNESCO, (Mr Koïchiro Matsuura). The Director-General has summoned an international meeting in Paris on 1-2 February 2001. It will be attended by the major players in the debate about intellectual property protection. I will attend this meeting myself.

FORBIDDEN TERRITORY OR THERAPEUTIC POTENTIAL?

Probably the hottest topic on the agenda of the IBC concerned the use of embryonic stem cells. This topic is controversial because of different views adopted by different religious and other teachings, concerning the morality of experimentation involving human embryonic cells. Within these cells, the so-called "stem cells" - which represent the earliest forms of human living material - are believed to have great potential utility for medical research and therapies. The prospect was described recently in the *Washington Post,* in terms that are easily understood[1]:

> "Pick a disease - Alzheimers, cancer, diabetes. You want The Cure. Scientists take some of your skin cells and create your clone in a Petrie dish. In about a week, the cloned embryo is the size of a period at the end of a sentence. Theoretically this small cluster of cells has the potential to become a human being. But your clone is not destined to born. ... Instead the cloned embryo will become a kind of natural factory in which your body's generic cells are grown and shaped into cures - brain cells for Alzheimer's, bone marrow cells for cancer, pancreatic cells for diabetes".

Many observers, mostly scientists, and a good number of those participating in the IBC meeting in Quito, shared an enthusiasm for the potential of this scientific development. To them, it promises the relief of unnecessary pain and premature death

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1 A Trafford, "Miracle Babies Draw Us Into an Ethical Swamp", *The Washington Post Health Report,* 14 November 2000 at 8.

caused either by genetic predisposition to disability (such as Alzheimer's Disease, Parkinson's Disease or Huntington's Disease) or traumatic injury occasioned, perhaps, by genetic predisposition (such as the death of heart muscle caused by myocardial infarction). The prospect of utilising human stem cells, cloned to the recipient, calling upon their puripotent (or even totipotent) capacity to replicate the cells of the disabled person, fills many scientists, and not a few lay people, with wonderment and anticipation at the awesome products of the human mind and modern technology.

However, some of the participants in the Quito meeting shared concerns about the use of embryonic stem cells - even those as tiny as the cells described above. Did this not mean utilising the cells of an embryo which was the first product of a human conception, and thus, potentially (given conducive circumstances) capable of developing into a full human being?

GETTING GLOBAL AGREEMENT: DIFFERENT STARTING POINTS

In the debates on this topic, I witnessed one of the major quandaries for the IBC, indeed for deriving solutions to the issues of bioethics in a world of diverse religions and disparate philosophical opinions.

Amongst some Roman Catholic and Orthodox Christian theologians, the use of embryo cells in this way is totally

unacceptable. This follows from views concerning the meaning of conception of human life. If the view is taken that conception is the first moment of human existence, it is easy to proceed to a conclusion that the law should protect such life and forbid experimentation with its cells. The debate on this topic has roots in the earlier controversies about the procedures involved in *in vitro* fertilisation (IVF). That technique uses "surplus" embryos created specifically, in larger number than would eventually be used to develop human persons, so as to increase the chances of conception *in utero*. Views have been expressed by the Roman Catholic Church that research on the use of embryonic stem cells is contrary to basic moral precepts[2].

According to a paper tabled at the IBC, written by Professor Michel Revel of the Weizman Institute in Israel, Jewish Biblical and Talmudic law considers that human status is only acquired progressively during foetal development and not at the moment of conception[3]. Genetic materials, outside the uterus, therefore have no legal status in Jewish law. They are not even part of a human

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2 The Holy See, "Embryo Stem Cells and the Status of the Human Embryo", 2000; Pontifica academia Pro Vita, *Declaration on the Production and the Scientific and Therapeutic Use of Human embryonic Stem Cells* August, 2000, Rome.

3 M Revel, "Some Religious Views on Moral Status and Potentialities of Human Embryos as Related to Stem Cell Research and Therapeutical Cloning", unpublished paper for the 7th Session of the International Bioethics Committee, Quito, Ecuador, 7 November 2000.

being until they are implanted within the womb. Even then, during the first 40 days, their status is not that of a formed human being and thus they are not entitled to protection according to Jewish notions of morality or civil law.

Professor Revel's paper points out that Islam, similarly, postpones the moment at which personhood can be seen to exist in a foetus - which is a much developed embryo. The law (Shari'a) teaches that ensoulment of the human foetus does not take place until three periods of 40 days, ie at 120 days, or the turn of the first trimester. Although the embryo is alive in the womb before it receives a soul, protection of the embryo before ensoulment is not subject to the same strict conditions[4].

There are Roman Catholic views that question the Church's orthodox opinion about the human individual beginning at the moment of conception[5]. According to such views, human existence does not begin at fertilisation of the ovum but when the "primitive streak" first manifests itself in the embryonic development, at about 14 or 15 days after conception. If that view were ultimately accepted, experimentation with early stem cells, within that time interval, presents no particular difficulty for religious beliefs or

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4 *Ibid,* at 2-3.

5 N M Ford, *When Did I Begin*?, Cambridge University Press, Cambridge (1991), 170

morality. Prior to the formation of the "primitive streak" - the first outline of a potential spine - the human embryonic cells are not truly a human life in potential. They are is just part of nature's profligate creation of life and thus, upon this view, available for experimental research and therapeutic use, so long as the purposes of that research and use is ultimately for the alleviation of disability and prevention of premature or unnecessary death.

The point I make concerning these controversies, which consumed much time at the Quito meeting, is this. Developments of the human genome affect the whole human family. In a sense, they relate to nothing less than the future of our species. They are therefore of legitimate concern to all human beings. Securing a common approach to the regulation of experimentation and therapy is therefore properly a matter of global attention. But securing agreement about what such regulation should say, if anything, is extremely difficult. This is because of the differences of view that exist in and between the major religions of the world. And in competition with the religious opinions are the views of major philosophical beliefs, such as Buddhism and of humanists who reject a starting point in religious dogma. Many adherents to humanism regard as absurd the notion that an embryo, no bigger than a fullstop on the printed page, part of nature's massive excess production of living cells, external to a womb with no realistic potential to develop into a human being, must be given all the protections of a human life - whether on the basis of morality or law. For people of this

conviction, nothing at all should be done to impede the advance of science and technology and the potential use of stem cells for further research and therapeutic utilisation.

The IBC was unable to reach final agreement on the issue of embryonic stem cell use. It is hoped that a tentative position will be reached by the IBC working party in February 2001. It is important to recognise that, in this matter, not to make a decision is effectively to make one. If the international community, and domestic law, say nothing on experimentation with embryonic stem cells, the result will be that such experimentation will certainly proceed. And even if the law of one state forbids such experimentation, the likelihood is that it will proceed in other states. It will be very difficult to contain such research (with its huge potential, including economic potential) in one country alone or even by the laws of many countries. This is why international reflection on the topic is so important. Time was not wasted in Quito.

PATIENTS' ASSOCIATIONS

Pursuant to the *Universal Declaration on the Human Genome and Human Rights,* a number of representatives of patients' associations were invited to Quito. They addressed a meeting of the IBC which, on this topic, was held in plenary session and in public. The representatives of the patients' associations spoke of the genetic revolution from the point of view of those who themselves

suffer, for example, from Parkinson's Disease or who are members of voluntary bodies formed to represent, and protect the rights of, family members suffering from genetic conditions, such as Huntington's Disease.

The explanation of the viewpoints of the patients' associations was extremely moving. As I was later to explain to the IBC, they struck a chord with me because of my own experience as a homosexual man. Although I do not regard my sexuality as a "disability", there is no doubt that some people would do so[6]. Indeed, the hate mail I have received since publicly disclosing my sexuality, indicates that this view is not at all uncommon, even in relatively enlightened Australia. I therefore understand the feelings of people with genetic conditions and family members of such people, when the issue that is crucial to this debate is raised. That issue, put simply, is elimination.

In many countries, including Australia, the foetus, in certain cases, is virtually automatically checked for evidence of the assistance of genetic conditions such as profound mental

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6 For a description of changing concepts of "disability" and past legal responses to that notion, see *Secretary, Department of Community Services v JWB* and *SMB (Marion's Case)* (1992) 175 CLR 219 (sterilisation of a "mentally retarded" girl); cf *Buck v Bell* 274 US 200 at 207 (1927) per Holmes J discussed M Jones and L A B Marks, "Legal and Social Construction of Disability in *ibid*, Disability, Divers-Ability and Legal Change (Vol 56 of International Studies of Human Rights).

retardation. In such cases the parents are given counselling which, in many instances, leads to a termination of the pregnancy. Of course, termination is not obligatory. But such decisions are regularly made. Apparently, they are condoned by law and certainly by medical practice.

The issues which are presented by the advance of the human genome project include the question of how far down the road of elimination our societies will go. Is it conceivable, either in the short term or some time in the coming century, that a foetus will be aborted for no reason other that it manifests the gene for Huntington's Disease? Or for sickle cell anaemia? Or for schizophrenia? Or for early onset baldness? Or (if it ultimately be shown to be a genetically influenced condition) homosexuality? By what principle is elimination to be allowed or forbidden in law? Once again, it is important to note that the absence of law will, effectively, turn such questions over to be determined, in effect, by parents and the doctors who advise them. Social forces, public opinion and even economic considerations may then influence the determination of where the line is drawn. We may think it intolerable to eliminate a foetus for reasons of potential baldness. But if parents desire to avoid a family tendency towards early baldness, should they be denied the choice of an embryo without that gene, in preference to one with it? Is there a risk that a schedule of undesired genetic conditions may be established, affording a comprehensive screening process through which embryos

in vitro or foetuses *in utero* are tested to assure parents of the child of their dreams?

If such practices are not forbidden by law, it is likely that, within the market, somewhere, some such developments will occur. Anyone in doubt should reflect upon the significant ill-balance between male and female newborns in India and China. If this can occur with reference to one genetic condition - sex - and often without sophisticated medical technology it will, before long, be available by reference to a multitude of other conditions deemed by particular parents to be unwanted in their child. Where would this have left the embryo that, born, produced Beethoven with his congenital deafness? Milton with his blindness? Mahler with his heart defect? In the past, the variety of humanity has been a feature of human freedom; and also, sometimes, a very practical protection against genetic diseases and epidemics.

DISABILITY AND THE GENOME

The advance of genomic science brings, with every year, new paradoxes that have to be resolved. A recent report in English newspapers disclosed a fresh quandary; but it is likely to present itself in Australia before long. The science editor of a London daily reported that disabled parents in England are now seeking the right

to choose to have disabled children, produced with the aid of new genetic screening tests that are becoming more widely available[7]. According to the report, government advisers in Britain are considering allowing deaf parents to decide to have deaf children on the basis that it might be in the child's interests to be born with the same disability as their parents. The issue was raised by the British Human Fertilisation and Embryology Authority. Reportedly it is considering the ethical implications of the technique that can distinguish between healthy and abnormal "embryos in the test tube". Critics of the proposals were said to be arguing that wide scale introduction of Preimplantation Genetic Diagnosis (PGD) would raise the prospect of disadvantaged babies being conceived and delivered deliberately, because specifically chosen by parents with similar disabilities. Supporters of the proposal have argued that certain disabilities, such as deafness, are so mild that it could, in the long term, be in the best interests of a child to have the same disability as its parents so as to experience a similar life and outlook.

Professor Alan Templeton, Chairman of the Working Group on PGD at the British Authority, reportedly stated that the issue had been raised by patient bodies, including those representing certain kinds of dwarfism. Patients in such bodies have expressed the opinion that they should be allowed to choose children more like

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7 S Connor, "Deaf Parents Could Choose to Have Deaf Children", *The Independent* (London), 21 September, 2000 at 6.

themselves. The issue has divided opinions amongst obstetricians and gynaecologists who advise the Authority's committee. Some, who have considered the matter, regard the notion of choosing deliberately an embryo manifesting deafness or dwarfism genes as pandering to the desires of *parents* rather than reflecting the best interests of a *child*. Ordinarily decisions affecting children must conform to the best interests rule. But where does the best interest of a child lie in a family where a disability exists in one or both parents? A spokesman for the National Deaf Children's Society explained concern that he felt about genetic testing:

> "Naturally I'm concerned at the possibility of it being used for 'cleansing' of deaf children but it can be a great tool in early diagnosis for hearing parents in order to prepare all the support for their deaf children".

The recent developments in technology, including cochlea implants, have revolutionised the assistance that can be given to those deaf persons who desire to improve their hearing mechanically[8]. But is the logic of such technology the ultimate removal from the human family of deaf persons, diagnosed by genetic testing? Is this a legitimate advance of science and the removal of a disability that is a burden on the person affected, his or her family and perhaps the state? Or is it an attempt to manipulate

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8 See Universal Screening for Hearing Impairment in Newborns", Report of a South Australian Working Party in (1999) 5 *Australian Journal of Education of the Deaf* at 14.

science to perform a form of disability cleansing? Does one's answer to these questions reflect a stereotyped conception of the perfect child, which itself can be manipulated by media and public opinion? Given that most parents are heterosexual, few might naturally feel a strong desire to have a child who was homosexual. Yet, in the past, a proportion of every society has been homosexual. If the criterion is identity with parents, where does the application of that criterion stop? In the randomness of nature there were disabilities, it is true. But there was also variety and difference that contributed to the world of dazzling variety, as we know it.

THE DUTY OF ENGAGEMENT

These are some of the issues which the human genome project presents to the global community. Obviously, they are issues of considerable importance to society and the law. They have relevance to disability and the law. They concern people living with disabilities, their families and representative organisations.

At least the IBC of UNESCO is listening to the voice of patient organisations. An expression of solidarity with patients' associations was adopted at the meeting in Quito. It was not very specific. It did not go into the details of the measure of the solidarity and the implications of it for the issues, some of which I have outlined. It will be important in the future work of the IBC that patients' organisations should be regularly heard. And when they are heard,

the question will have to be answered. When is human variety a disability? Some genetic conditions are distinctly bad news. There is no inherent beauty in prolonged pain and human suffering, genetic or otherwise. There is no glory in the premature termination of sentient human life and sensibility. Relieving pain and suffering and promoting life and sensibility are generally good things. They are worthy objectives of morality and of law. But sometimes disability depends upon the eye or ear or mind of the beholder. Getting agreement on these issues is difficult locally, more difficult nationally and almost impossible internationally. Yet the issue is undoubtedly an international one. UNESCO's IBC does not have the option to ignore the puzzles of genomics. None of us has that option. To ignore is to decide.