Ethics and Genetic Discrimination

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LIVING WITH THE GENOME

I am a member of UNESCO's International Bioethics Committee (IBC). High on the agenda of the Committee is consideration of the ethical implications of the Human Genome Project. One aspect of those ethical implications concerns the way genomic science will affect our attitudes and actions in relation to people who manifest genetic variation, causing what are sometimes described as disabilities. This was an issue high on the agenda of the IBC when it last met in Quito, Ecuador, in November 2000. I propose to address the issue of ethics and genetic discrimination against the background of some of the subjects raised in Quito and elsewhere since.

Most of the IBC sessions in Quito were concerned with subjects relevant to the implications for morality, law and society of the advances in genetic science. The Quito meeting 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 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 occupied an important session. Unless the public and its elected leaders understand the developments of genomic science, they can scarcely be criticised for failing to perceive, and to act upon, the implications which such science presents for the law and society. The subject of intellectual property protection is obviously 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 patent holders to licence scientific processes, 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 useful therapies, tests and other treatments, of benefit to humanity, may 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, in effect, to isolate people in developing countries from effective access to knowledge about human genetics and the application to which that knowledge is put. During 2001 UNESCO convened a special symposium on this subject. Arising out of

that meeting a working group has been established to chart future policy. That group met in Paris earlier this month. I am rapporteur of the group .

FORBIDDEN TERRITORY OR THERAPEUTIC POTENTIAL?

Probably the hottest topic on the agenda of the IBC in Quito 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:

"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 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?

GENETIC DISABILITIES AND ELIMINATION

Pursuant to the *Universal Declaration on the Human Genome and Human Rights*, a number of representatives of patients' associations were invited to the IBC in Quito. They addressed a meeting 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. 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 partially 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 retardation. Pre-implantation checking of the embryo is also becoming more common. In such cases the parents are given counselling which, in many instances, leads to rejection of the embryo or termination of a pregnancy. Of course, rejection or termination are not obligatory. But termination decisions are regularly made. Apparently, they are condoned by law in most jurisdictions 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?

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 forbidden 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 prohibited 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 infants 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, DISCRIMINATION AND THE GENOME

With every year, the advance of genomic science brings new paradoxes that have to be resolved. A report in English newspapers has disclosed a fresh quandary; but it is likely to present itself in Australia before long if it has not already arrived. 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. 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 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. 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 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 OBLIGATION 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 ethics and genetic discrimination. 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 or heart of the beholder. Getting agreement on these issues is difficult locally, more difficult nationally and almost impossible internationally. Yet they undoubtedly present an international challenge. UNESCO's IBC does not have the option to ignore the puzzles of genomics nor do we in Australia have that option. None of us has such an option. To ignore is to decide.