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Our Genetic Future

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In this issue

Last year the Plunkett Centre for Ethics sponsored a one day seminar on 25th October, at the Garvan Institute of Medical Research, titled "Our Genetic Future: The Ethical Issues". In the next two issues of *Bioethics Outlook* we will publish some of the papers presented at the seminar, along with other papers on the subject, with the aim of informing a wider audience of some of the questions involved.

This issue starts with an introduction to the basic science and technology (and to some of the questions they raise) by Keith Joseph. This is then followed by one of the presentations at the seminar, given by Paul MacNeill, on the philosophical assumptions implicit in the Human Genome Project. Fr Jean Kitara-Frisch then presents a view from Japan on the ethics of pre-natal screening.

However, not all is genetics. This issue concludes with an article by Andrew Murray which looks beyond some of the more simplistic arguments about euthanasia.

Contents:

There has been a revolution in genetics over the last twenty five years. The Human Genome Project which aims to map all the genetic sequences to be found on human chromosomes is nearing completion. When it is completed, most human genes will have been located and identified, thus allowing ready identification of abnormal or variant genetic structures. Along with this increased ability to identify particular genes has come the development of our ability to manipulate genes, both in non-human organisms and in humans. In the latter, clinical trials using non-reproductive human cells ("somatic genetic engineering") have begun. Additionally, some crude forms of germ-line genetic engineering (that is, genetic engineering with the aim of having the altered genes passed on to offspring of the engineered animal) have been conducted on non-human mammals. Cloning too - whilst concerned with chromosomes rather than individual genes - obviously lends itself to some of the concerns raised in connection with genetic manipulation, and has recently been a topic of much debate.

These new techniques - often known collectively as the "new genetics" - have given rise to many novel ethical issues. For example, our ability to identify particular genes, and the traits that they help cause, raises problems: will identification of genes in this way lead to discrimination against individuals with "undesirable" traits? Will the new genetics lead to a revival of eugenics or the "manufacturing" of humans with particular traits? The aim of last year's seminar, and of the next two issues of *Bioethics Outlook*, is to

start to address these and many other issues that arise out of the new genetics.

Genetics - an introduction

Every human being is composed of billions of cells. Each cell starts its existence with a cell nucleus. In that nucleus, there are normally forty six chromosomes, twenty three chromosomes inherited from the mother, and twenty three inherited from the father. These chromosomes consist of a long chain of deoxyribose nucleic acid (DNA), in the famous shape of a double helix: that is, two complementary chains of DNA bound to each other. In turn, these two chains are bound together with protein structures to form the chromosome.

Each of these strands of DNA can be divided into various regions, some of which are genes. Genes are the individual units of inheritance. They code for a sequence of amino acids: in turn, these amino acids, when constructed in a chain in accordance with the sequence given on the genes, form a protein. From these proteins, the human body takes its shape either directly (through protein structures) or indirectly. For example, the haemoglobin molecule which transports oxygen in the blood consists of a protein to which is bound an iron molecule. There are some genetic traits in which the DNA sequence which codes for haemoglobin varies for one codon for one amino acid. As a result, the protein which is formed takes a different shape. One family of traits where this occurs is sickle-cell trait; another family of traits is thalassaemia. If we look at sickle-cell (which affects mainly persons of West African ancestry), the haemoglobin molecule changes shape in certain conditions, causing the red blood cell to form a sickle shape. If you inherit this trait from one parent, only half of your red-blood cells are affected, so you may not even know you have the trait, though it does give you protection against malaria! However, if you inherit the trait from both parents, you are likely to develop sickle-cell anaemia, which is a debilitating (and even fatal) disorder.

However, it is too simplistic to say that our genes make us who we are. Our genes act in response to environmental and biological stimuli. For example, a person who has the genes for "tallness" may not necessarily be tall: for example, she may suffer malnutrition or disease while a child, and not live up to her genetic potential. On the other hand there are some genetic structures which will always be expressed in any environment compatible with life: for example, a person with the genes coding for cystic fibrosis will always have cystic fibrosis. There is little we can do to their environment at present to prevent suffering from that disease.

In other words, the expression of a gene is dependent on the environment in which a person lives. Also, most genetic traits are not "single gene". Rather they are multi-genic, that is, they are caused by more than one gene. Additionally, many genes contribute to more than one trait. Thus, it is not simply a case of saying that gene Q causes X: this is true, at best, in only a small number of cases. More often it is the case that gene Q, in conjunction with gene R, and given environment E, may contribute to physical trait Y. This is obviously a somewhat more complex picture than the simple causation often attributed to genes.

The Human Genome Project

This project commenced in the early 1990's and is due to be completed by the year 2005. It is an international effort which is being co-ordinated by the Human Genome Organisation (HUGO). The aim of the project is to map out the entire sequence of bases in the human genome. It is estimated that the total cost will be around $3 billion. It is of interest that about 3% of this budget is being devoted to the Ethical, Legal and Social Implications Program (ELSI) which, as the name suggests, is concerned with a number of non-scientific issues arising from the project.

"...it is too simplistic to say that our genes make us who we are."

One of the more controversial aspects of the project is the Human Genome Diversity Project (HGDP) which is mapping significant variants in the human genome, often involving smaller groups of indigenous peoples such as the Australian aborigines. These groups have often protested, on the not-unreasonable grounds that this is simply another form of colonial exploitation.

Of course, there is also some controversy over the Human Genome Project itself. What are we going to do with the knowledge we gain? Could the money and effort have been better spent? The project lends itself to some new techniques such as gene screening which raise a number of ethical problems.

What is the "New Genetics"?

Traditionally, genetics relied on the study of families to determine if that family (and individual members of it) possessed a particular genetic structure. However, it is now possible in some cases to determine directly whether an individual has a particular gene. In addition, we are working on the ability to manipulate an individual's DNA, and thus to change that person's genetic structure.

The Human Genome Project, which aims to map the entire sequence of the "normal" human genetic structure, will furnish much knowledge about genes and their structures. By comparing part of an individual's DNA sequence against this map, we may be able to determine if that individual has an abnormal genetic structure.

The other development is that of genetic manipulation. These techniques are less developed than those related to genetic screening, and we are not yet capable of performing genetic manipulation which can be passed by a human being onto his or her offspring. However, even the prospect of genetic manipulation is ethically problematic. Thus the "new genetics"- particularly gene screening and genetic manipulation - raise a number of ethical issues of great complexity.

Philosophical Assumptions Implicit in the Science of the Human Genome Project

Paul McNeill

I am speaking today as a lawyer. I teach health, law and ethics at the University of New South Wales in the School of Community Medicine, and as a lawyer who has taken a particular interest in the ethics of medicine in particular and in science more generally. I offer a critique of exaggerated ideas in science, and I consider the Human Genome Project from a "postmodern" perspective.

The Human Genome Project is an expression of the noble desire that science and rationality will lead to human freedom - the freedom from oppression and the freedom from suffering. It is one of the most grand scientific gestures of this century in its scale and in its methodology. The projected expenditure is three billion dollars over fifteen years and it has been estimated that there is something like thirty thousand person years of labour involved in the Project. Its aims, like those of science, are for understanding and the application of understanding to relieve suffering. There have been many statements made in the literature about its potential. Some are modest, some are extreme. It is the extreme, exaggerated ones on which I want to comment. These are important because they reflect the understanding of the Human Genome Project by non-scientists and because they are the source of some of the errors in that understanding.

James Watson, the co-discoverer of the structure of human DNA, suggested that the

Project would enable us *"to find out what being human is"*.[1] An editorial in the journal *Science* suggested that manic depression, Alzheimer's, schizophrenia and heart disease could be solved through the Genome Project, and went on to say that many of these diseases are the root of current societal problems. The editorial talked of the cost of some of these problems and the difficult civil liberties issues that they involve and the pain to individuals, and said *"To continue the current warehousing or neglect of these people, many of whom are in the ranks of the homeless, is the equivalent of providing iron lungs to polio victims at the expense of working on a vaccine."*[2] The editorial finished by saying *"Sequencing the human genome puts us on the threshold of great new benefits, ... to aid the poor, the infirm and the underprivileged. We must step boldly and confidently across the threshold."*

In an article entitled "What sort of people should there be?", Jonathon Glover suggested that in the long run, parents will be able simply to shop as at a supermarket for the genetic qualities of their children.[3] Justice Michael Kirby spoke in favour of this view in an SBS programme shown early this year.[4] He said that *"the human being is the one species on our planet that can query about, struggle through and find the human genome and find what it means, find the keys that unlock it"*. He went on: *"At least potentially you could say that it is this generation, this moment in history, that the old human species found the way to develop the new human species. Only humans could do that and there is at least some writing that talks in the long term that the human species will ride on the shoulders of the current species and that there will be a development from the current species."* And, he added, *"we should be very optimistic about science as it is a part of our intelligence."*

Our expectations need to be scaled down. The Human Genome Project suffers from the same limitations that beset science, which are also the strengths of science and the Human Genome Project. These strengths include the conventions of internal consistency, experimental verification and all of the other things that come along with science, the separation of the observer from the observed, the reliance on empirical testing, the requirements of rational consistency, a preference for the most parsimonious explanation and the process of review and publication and critique.

Two major things need to be said about this process. First, it does not, in and of itself, provide meaning. It may suggest relationships between events, but the narrative that makes these meaningful, the synthesis, is not itself a scientific activity. It is a creative process which steps beyond science in the narrow empirical sense. Secondly, the scientific methodology does not recognise a lot of what you and I would regard as being important, significant and meaningful in our lives. Science is not the arbiter of what it is measuring. The view that what exists is what is measurable is a form of reductionism in which the epistemology (means for knowing) becomes the ontology (what is known). For a very good reason, science wears blinkers - in the same way that the old milk delivery horses used to wear blinkers - so that they would not be distracted by the passing vehicles and so on. The fact that there is a restriction on what can be recognised through science does not deny the existence of the passing cars. They are simply not recognised by that scientific process.

"...the scientific methodology does not recognise a lot of what you and I would regard as being important, significant and meaningful in our lives."

The epistemology that science inherits, of course, dates right back to our earlier philosophical ideas which derive from Descartes and Locke and which conceive of knowledge of the world as consisting of particulate, explicit expressions. The assumption is that there is a world of particulars out there waiting to be discovered. Now, while science may be concerned about truth, or at least falsification, what is true is not necessarily what is significant.

How does this apply to the Genome Project? The Human Genome Project is often presented to us as a research project that will tell us everything about what it is to be a human being, or at least, the mechanisms of disease. Now this is not quite true. It is a misconception that is based in part on a simplistic idea of the Genome Project and on the widespread use of a metaphor amongst biologists which compares the structure and function of genes to a computer program. The usual notion is that the genetic program is supposed to be written in our DNA molecules. Based on this notion, the structures of DNA would be equivalent to what is contained in the Book of Humanity. We have been told that, thanks to this achievement, we will be able to cure diseases and solve social problems, including those of aggressiveness and criminality. Finding the gene of criminality or the relationships between the various genetic material involved would provide the means for genetic therapy to eliminate criminality.

It is important that we subject such statements to philosophical criticism. It is a mistake to take the metaphor of the computer programme to the extreme and expect that genetics will unravel all the mysteries and life as we experience it. There are many different perspectives that are relevant, such as social, moral and legal perspectives, which cannot, without an almost total loss of meaning, be reduced to an understanding in biological terms. Biology itself cannot give an answer to questions about persons since the notion of a person is not a biological one but rather a legal, social, moral and aesthetic one.

It reminds me of a story about Nasrudin, a sheik, who was looking for his keys under a street lamp. His neighbour helped him for some time and when they did not find the keys, the neighbour asked, "What makes you think the keys are here?" Nasrudin replied, "Because this is where the light is. I dropped the keys at the other corner but there is no street lamp there, so there is no point looking there!" Our focus on looking for the cause of disease and problems in genetic structures is, in part, prompted by this same fallacy: that is where the light is. This focus may shift our attention away from more fruitful areas of research.

We need to look at the way in which science itself is a social phenomenon. The French philosopher, Lyotard, said that the general paradigm of progress in science and technology, to which economic growth and the expansion of the socio-political power seem to be natural complements, has been sold in various countries as a basis for generating wealth. He wrote: *"When we examine the current status of scientific knowledge ... science seems more completely subordinated to the prevailing powers than ever before and, along with the new technologies, is in danger of becoming a major stake in those power conflicts."*

Certainly it has been claimed that the Human Genome Project is a way for the United States to maintain its ascendance over Japan. There is quite a strong socio-political aspect to the Project. Francis Bacon's aphorism "Knowledge is power" is obviously relevant here. There are opportunities to harness this scientific knowledge for good or for ill. This is not a small question. It goes to an even deeper level of the process of legitimation within science itself. At a political level, and within the politics of science, it is important that we acknowledge these questions of political power. This is relevant to the Human Genome Project, which is a project needing enormous support from governments, not just the United States, Japan and Britain but other governments also. A threat to restrict knowledge to the participating governments was made at one stage. HUGO is quite opposed to that. However, the fact that the threat was made indicates how important the power issue is. The vigorous attempts to patent genetic material arising from related studies underscores the nexus between legitimacy in science and socio-political power. In fact, the Office of Science and Technology has said that the Human Genome mapping program has enormous potential not only for the improvement of health but also for *wealth* creation.

I want to offer a "postmodernist" view. Modernism includes the view that science

issues from a rational or social operation and is culturally neutral. But we have already seen that the Human Genome Project is not neutral. I want to question the status of scientific knowledge from a cultural perspective. The second half of this century has seen a growing scepticism about science, and about the assumptions of the Enlightenment. From a critical perspective, rationality and an objective view can be seen as one approach among many, albeit a very effective approach towards solving problems. This alternative view is that science is one culture among many. The Enlightenment project was both a scientific and a rational approach. It was based on the ideology of progress and a belief in a linear progress and absolute truth. Václav Havel, the poet who became the President of Czechoslovakia, has said that *"we have to abandon the arrogant belief that the world is merely a puzzle to be solved, a machine with instruction for use waiting to be discovered, a body of information fed into a computer in the hope that sooner or later it will spit out a universal solution".*[5] Words like free will, equality, multi-racial richness, self, aesthetic, emotions, spirituality, poetry and love do not appear in the lexicon of discussions on the Human Genome Project, except in so far as they are talked about as complex behaviours.

It is a very poor and depleted view of human life which accepts only the scientific account. What I am driving at is a downgrading of the status of scientific knowledge as the sole arbiter of what is both real and true and certainly of what is significant. What postmodernist critiques have offered is a greater recognition of other perspectives - all aesthetic, artistic, musical, spiritual perspectives - and a greater tolerance of conflicting realities.

To gain a sense of how this might work in practice, let us look at an optimistic view of the genetics of complex behaviour. Erik Parens wrote an optimistic and helpful paper entitled *"Taking behavioural genetics seriously"*. He said that *"we need not adopt simplistic or reductionist conceptions of the relationship between single genes and complex behaviours to take seriously the information produced by behavioural genetics research".*[6] He went on to say, *"While it is true and important that genetic information can be used to further disempower the already disempowered, it does not follow that it must be used in this way. Moreover, to say that genetic information calls into question some traditional ideas about freedom, guilt and responsibility and the like does not discredit that information. It may be that some of the dominant ways of thinking about these ideas have been simplistic and are no longer tenable."* Equally it *"does not commit anyone to abandoning these ideas"*.

We accept, for example, that people are constrained by economic and social forces while *"simultaneously insisting that citizens must be held responsible for their actions."* Similarly with equality: if we accept the genetic evidence for differences in complex and prized traits such as intelligence, the idea is that we may undermine the idea of moral equality. The "scientific account of why the poor are poor", for example, may be related to their genetic structure. But it would be a great mistake for us to jump to this sort of conclusion. Understanding poverty is a great deal more complex than that. Nevertheless *"it would be exceedingly difficult to make the argument for suppressing helpful information in the name of protecting a simplistic understanding of equality"*.

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The critique of a simplistic view of the Human Genome Project also runs the other way. One does not deny the fact of differences in capacities in order to protect cherished views. *"Strangely enough"*, in Parens' view, *"research into the genetics of behaviour could actually help make our accounts of different ways of being in the world more complex"*. We are not fated *"to use genetic information about human behaviour in simplistic and hateful ways as it has*

been used in the past." That is the optimistic view. And now for the pessimistic view.

Lyotard points out that with increasing computerisation, the *"nature of knowledge cannot survive unchanged"*. In other words, the process of transformation through [computer] language itself brings about change. Language itself leads to a change. The effect of computerisation is leading increasingly to an *"exteriorisation of knowledge with respect to the knower"*.[7] There was a time when, in order to know something you had to go to a person who knew it. Now you simply go to the Internet. Increasingly, knowledge becomes a commodity in the hands of the entrepreneurs. Even the justification for scientific projects including the Human Genome Project is entrepreneurial. And so, as with news and with sport, science and knowledge themselves both become susceptible to the manipulations of the entrepreneur, both in the directions in which science goes and the use to which science is put. Both of these become susceptible to the dollar. On Lyotard's account, it is in the interests of the socio-political scientific autocracy to weigh in on the side of simple reductionism.

What are my conclusions? What kind of an outcome? We have to notice two phenomena: on the one hand, the commodification of knowledge and the benefits of the knowledge that is being produced through projects like the Human Genome Project; on the other hand, the "destructuring" of the significance of that knowledge at a very deep level which is being reflected in all our cultural spheres in developed countries. This movement has been commented on in the arts and dance and music and literature, in philosophy and in science. When we "destructure", or question, meaning in this kind of way, it can lead to nihilism. Alternatively it can lead to an excitement in which we are challenged by multiple realities and faced with richness. We have to learn to live with a loose grip on our intellectual maps of what is reality. We have to learn to live with some scepticism about the simplistic claims that are made by anyone, both scientists and non-scientists. It is no longer a matter of blind faith in science, in the Human Genome Project. The scientific view, in particular the results of the Human Genome Project, are clearly important, but they are not the whole story. The whole story has a much richer fabric.

NOTES:

[1] **David Suzuki & Peter Knudtson, *Genethics: The Ethics of Engineering Life*, London: Unwin Paperbacks, 1989, p. 317.**

[2] **Daniel E. Koshland, 'Sequences and Consequences of the Human Genome', *Science*, Vol 246: 4927, 13 October 1989, p. 189.**

[3] **Jonathon Glover, *What sort of people should there be?*, England, Penguin Books, 1984, pp 25-52.**

[4] **SBS Program 'Talking Heads', 21 January 1996.**

[5] **Václav Havel, 'The end of the modern era', *New York Times*, March 1992, p. E.15, quoted in W.T. Anderson (ed.), *The Truth about the Truth*, New York: Jeremy Tarcher/Putnam Books, 1995, p. 161.**

[6] **Erik Parens, 'Taking behavioural genetics seriously', *Hastings Center Report*, Vol 26: 4 (July-August, 1996), pp 13-18.**

[7] **Jean-Francois Lyotard, *The Postmodern Condition: A Report on Knowledge*, Manchester University Press, 1986, p. 4.**

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Erratum

In the last issue of Bioethics Outlook, in an article entitled 'The Abandoned Ones: the plight of the former patients of psychiatric hospitals in New South Wales', the number of residents currently housed in the 150 licensed facilities in New South Wales should have read 2,175 and not 1,175.

Genetic screening: a view from Japan

Fr Jean Kitara-Frisch SJ

In Japan, as well as in many other countries, all forms of social discrimination, whether based on race, sex or religion, have lately come under heavy fire. A Christian view of man, shared by many non-Christians, sees each person as gifted with the same dignity and we can only rejoice at this trend. Yet, recent advances in biology (particularly human genetics) and their ever more common use in medicine, as well as developments in reproduction such as cloning with its eventual application to humans, expose our society to new risks of discrimination. This could result in the elimination of handicapped persons or in preference being given to the possessors of highly valued traits or potentials.

The social and ethical issues posed by medical genetics are among the most profound and difficult in our age. Indeed, medical genetics may affect the future of mankind in the next century as nuclear physics did for the half century past. This becomes evident when it is realised that the ethical and social issues raised by medical genetics concern not only scientists but all of us. The most immediate problems are not posed by the doctors' clinical work but in the use we all make of the information made available by techniques developed for therapeutic purposes.

In the United States, for instance, people known to have "bad" genes may be denied coverage by health insurance at affordable rates; employers may refuse to hire them. Informal barriers, including a lack of marriage partners, may further injure the individual's future. To an extent, appropriate laws may ensure the privacy of genetic information and prevent their use by outsiders. There are other social issues, however, which though less well defined, are profound and intractable by law. One is the effect of genetic screening and selection on the ideal of human equality. Even without class inequality, an increased emphasis on the prevention of genetic maladies through selective conception and prenatal diagnosis threatens to harden social attitudes toward handicapped individuals whose conception at birth could have been, but was not, prevented.

Needless to say, similar concerns would accompany the developments of the cloning technique now aggressively pursued in the United States and the United Kingdom. Much attention is being paid these days to the social consequences of the cloned reproduction of mammals if applied to humans. However, it is useful to remember that the American bioethicist Richard McConnick (1994) three years ago called our attention on the misgivings he conceived about cloning by the splitting of early human embryos. When used in conjunction with IVF, it could allow couples to know the characteristics of the existing twins or triplets of the embryos they sought to adopt. This sort of selection among embryos appeared to him to open the road to positive eugenics.

A similar warning is found in an article entitled "The New Eugenics", by Dr. Jacques Testart, the father of Amandine, the first French test tube baby. Testart (1995) makes it clear how the treatment of infertility by use of IVF, together with the newly acquired availability of pre-implantation genetic diagnosis, confronts our society with a temptation of eugenic abuse that will be difficult to resist.

This is because the multiple embryos produced in treating infertility, together with the possibility of discovering the potentials and risks of each embryo, makes it possible to select not only the sex of the baby to be born but also his or her potentials for excellence, physical or mental. It will certainly be very hard not to make use of this information!

We can thereby see what happens when a child is no longer born but "fabricated". If these consequences are deemed unacceptable and to be avoided in our society, one can detect here a strong argument against the production of multiple embryos and, at the same time, a potent reason for supporting the position of the Catholic church against procreation by IVF which relies on such production. This is because the technique used in assisted reproduction not only helps infertile couples to conceive and bear children, but also forces the doctor and the prospective parents to select from between a number of embryos the one they want to be implanted in the mother's uterus. This process of selection risks causing grievous damage to the respect due to all members of human society, regardless of their heredity, and could create new forms of discrimination.

If the Catholic church has usually based her opposition to artificial reproduction on the way it separates unitive love between the spouses from procreation, new developments in reproductive biology and genetics as well as in animal cloning now make it clear that human society itself may be seriously threatened by the unintended, but perhaps unavoidable, consequences of artificial reproduction. Indeed, many people who fail to be convinced by the importance of keeping unitive love and procreation closely bound together may be much more impressed by the hidden eugenic mentality likely to be fostered by artificial reproduction, even when it is used by infertile couples. The hard question here asked from infertile couples is : do we have the right, for satisfying our quite natural desire for a child, to make use of a technique that puts at risk the human future of our society?

"...if screening is presented as being taken 'by all', how free is one not to take it?"

A public debate in the Netherlands in January 1994 discussed the social, legal and ethical implications of genetic screening and prenatal diagnosis. In the meeting of patients, parents and handicapped people, great concern was expressed about the possible negative consequences of genetic screening for access to health insurance. Great fear was also expressed by handicapped people that genetic screening would reinforce negative views towards disease and handicapped life, and lead to more stigmatisation and discrimination. Such negative views, they feared, would greatly prevent the further integration of handicapped persons in society.

The final declaration of the debate included a number of statements on genetic screening. It noted that the integration of and support for diseased and handicapped people in society is important, that more technology leads to more medicalisation. A continuing discussion about the limits of intervention during pregnancy was felt to be necessary. Free choice was deemed very important and various forms of social pressure threatening such free choice called for much attention. The declaration ended with pointing out the importance of psycho-social support, and with a remark that the aim of saving health care resources should not lead to social pressure for selective abortion.

Interestingly, this public debate in the Netherlands in 1994 covers similar issues to those raised by Tamai Mariko, a professor at Shinshu University and the mother of a child with Down's Syndrome. In her presentation at a Bioethics Forum in Tokyo University on October 26, 1996, she asked if the mother was really free to undergo screening for Down's Syndrome and to give birth to an handicapped baby as long as there was no adequate support on the part of society. Moreover, she added, if screening is presented as being taken "by all", how free is one not to take it? Also, propaganda by commercial firms offering the "triple mark test" as the surest way to diagnose Down's Syndrome exacerbated such a pressure. This is even more so if the test is offered to all mothers, regardless of age or of the previous birth of an handicapped child.

Tamai also wondered whether such screening may not seem to deny the value of

the life of children with Down's Sydnrome, making them feel that they should not have been born! What then, Tamai wondered, are the advantages of screening? Reassuring the mother if they prove negative and, should they prove positive, allowing psychological and spiritual preparation? Would not the offering of the test rather add one more worry: "Should I take this test?"

In the following discussion following Tamai's remarks, Kyoto bioethicist Morioka Masabiro asked some further very pertinent questions: Given the mere probability of the test results, do they not rather increase the worries of the mother? What are the merits of the test for her? Is the propaganda for taking the tests not seen by clinics as a means to increase again their income, severely reduced on account of the small number of pregnancies? Do not these tests reinforce the pressures felt by the pregnant person to produce a healthy child?

Cannot one detect here a hidden eugenic mentality, aiming at the suppression of handicapped people? Though much is being done these days about "personal autonomy" and "the right to decide about one's own body", is not the conceived baby being forgotten?

What about the danger of seeing insurance companies refusing to support handicapped children whose birth might have been foreseen and avoided? May not pressures for reducing health care expenses in the national budget be behind the propaganda for taking the test, eventually leading to aborting handicapped fetuses?

Although this discussion, as well as the articles quoted above, well antedated the birth of "Dolly", the concern they all manifest about the possible promotion of a eugenic mentality through genetic screening and ensuing selection of the possessors of preferred genotypes finds unintended support in a recent letter in *Nature* (19 June 1997). In that letter, John Harris, Professor of Bioethics at the University of Manchester, responds to the widespread concern expressed by the World Health Organisation and the European Parliament regarding the threats posed by cloning to human dignity and in so doing gives an illuminating insight on the close connection between the techniques used in cloning, those used in IVF and the eugenic mentality.

Referring to objections to using embryo division to create clones for screening purposes, Harris writes: *"It is surely ethically dubious to object to one embryo being killed for the sake of another, but not to object to it being killed for nothing [as is currently done in the destruction of so-called spare embryos]. It cannot be morally worse to use an embryo to provide information about its sibling than to use it for more abstract research or simply to destroy it."* The concluding paragraph of the letter is particularly interesting: *"Of course some will think that the embryo is a full member of the moral community with all the rights and protections possessed by Kant himself. Although this is a tenable position, it cannot consistently be held by any society that permits abortion, post-coital contraception or research with human embryos."* Fascinating, indeed, is the way Professor Harris clearly endorses, though unwittingly, the link seen by John Paul II between IVF research on human embryos, some forms of contraception and the practice of abortion.

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Fr Jean Kitara-Frisch is a Jesuit priest who lives in Tokyo. His comments on the significance of the cloned sheep, Dolly, were published in the last issue of Bioethics Outlook.

Euthanasia: a parasitic question

Andrew Murray SM

One of the strangest things about the euthanasia debate is that it is debated at all. Although suicide has always been with us, it is recognised as an act of desperation in which a person's mind is so disturbed that death appears as a necessity. The notion, on the other hand, of persons fully in control of their faculties calmly and rationally deciding to end life neatly and clinically seems all wrong. One of the fundamental inclinations of ordered life is to preserve life, that is, to live.

Why is it, then, that in our time society should be debating a question that ordinarily would not even be asked? One way of answering this question is to recognise that, before euthanasia could become a problem, many other things had to happen. As a moral issue, it is parasitic on a host of other issues that are being dealt with inadequately in our time. It is worth raising some of them.

How does one live old age? There have been times when few people survived long beyond the years of child bearing and raising and certainly beyond the time of economic necessity. Today the average life span of both men and women has crept into the seventies and many live into their eighties. Medicine and good food keep them alive, and economic planning makes them independent. It should be a time of grace and choice, a time of richness of life, a time of healing. But is it? Are there stages of life that call for different skills and expectations? How do we make the transitions between stages and how do we learn to live anew?

"People seem to want either to hold death at bay or to hasten it."

How does one die? Much is being published about inadequacies in the practice of palliative care, and specialists are telling us that few need die in dreadful pain. These are medical and political issues deserving of more attention.

But deeper issues are at stake. We live in a culture in which the processes of death are shunned. People seem to want either to hold death at bay or to hasten it. We need to learn how to die and how to face death. Death is usually a daunting prospect for an individual, but it is not done alone. Families, friends, nurses, doctors and pastoral carers are all part of the process. Skill, compassion and coordination will surely make the experience of death a more satisfactory and even a profoundly rewarding one.

What is wrong with physical pain? Our culture recoils from physical pain at the same time as we subject ourselves to all sorts of other distress—substance abuse, stress, destructive relationships, emotional violence. Why is it that we should find physical pain so objectionable? Are there not circumstances in which pain might be a tolerable consequence of some greater gain? Indeed, it can be inspiring to meet a person who has developed qualities of endurance and patience in response to persistent pain.

What is medicine for? Medicine has advanced enormously during this century. Its practice is often based on the premises that health is *the primary good of life* and that life ought be extended as long as possible. Are

these premises true? Or is something more subtle needed? Do we expect of medicine something that it cannot provide, and might this not distort our understanding of what it is about?

Even if we are refined in our understanding and expectations of medicine, day to day practice can call for radical and sudden changes of attitude and goal. Where at one moment it might be reasonable to fight desperately to save a life, at the next it might not be. How do we become attuned to recognising the change of circumstances, and how do we adjust our thinking and feeling to the change?

How does one reason about moral issues? Moral reasoning is not like scientific reasoning. In many ways it is harder and deals with the less tangible. People find it easy to disagree. Not many of us are given the opportunity for training in a kind of thinking that would bring clarity and resolution to the issues.

How does one live a happy life? A happy life demands thoughtfulness and discipline, yet how rarely do we ask how one goes about it. Do all the things that we seek to have, to be and to do make our lives better? We tend to live with the assumptions of our culture, many of which are articulated by the world of advertising.

Whom is a life for? Is it for just the one living it, or do others have claims too? When people die well, even though with suffering, there is often a remarkable degree of reconciliation in the lives of family and friends. For this, time is precious, and it is often the press of time as the process of death takes its course that allows people to change their attitudes.

The euthanasia debate is important. While many of us are firm in our opposition, it is not enough to keep repeating the argument "life is sacred". We need to find new arguments that will persuade the people of our time. These will be arguments that work from premises that are held in common with our opponents. They will be dressed in rhetoric that is appealing to a substantial part of the population.

We also need to examine and address the conditions that allow the question to arise. These conditions are not logical conditions, but they are human conditions and remain philosophically interesting. At any particular time, a culture asks the questions that are appropriate to the conditions of its life and thinking. Many other questions, even though they may be abstractly stateable, are not asked because they would have no meaning for the questioners. The issues raised above seem to form part of the condition that has allowed the euthanasia debate to arise. Until they are dealt with, it will not go away.

"...it is not enough to keep repeating the argument 'life is sacred'."

Andrew Murray lectures in philosophy at the Catholic Institute of Sydney. This article is an extended version of a piece that was first published in Sydney's 'Catholic Weekly'.

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