

opening address

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Toi Te Taiao Bioethics Council

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In October 2003 the US President's Council on Bioethics handed in a lengthy report on happiness. It may not have been what President Bush was expecting. Certainly the tone of the report itself was cautious rather than happy but it sought to raise fundamental questions about what is a good life and what makes for a good community.

Leon Kass, the Council's president, said that biotechnology promises to make people 'look younger, perform better, feel happier or become more "perfect"' (The President's Council on Bioethics 2003, p.xi). He warned that the meaning of life should not be reduced to medical terms. Obviously we all have our limitations and we all dream of overcoming them. Some of us go to the gym or practice psychoanalysis, but those dreams go far beyond medicine or therapy. How we put biotechnology into practice will depend largely on the opinions, mores and institutions of our society.

It is a truism to say that we live in a secular society. Secularization occurs when supernatural religion based on a belief in God or some future state becomes private, optional and problematic. Secularization has largely transformed Western cultures. Christians, for instance, find that they have become a peculiar people, an anomaly in their own primary beliefs, assumptions, values and norms. But we are also discovering that secularism need not discourage belief but it does require people to be tolerant. The issue will be how do we encourage moral strangers to cooperate.

If the scientific question is: how does something happen? then the theological question is more likely to be: why does it happen? It has even become acceptable to recognize the

spiritual impulses within science. A striking example is Hawking's *A Brief History of Time*, which ends with the overworked line 'if we find the answer to [the question of why we and the universe exist] it would be the ultimate triumph of human reason – for then we would know the mind of God' (Hawking, 1988).

The President's Council was concerned with what the authors called pride, 'the failure properly to appreciate and respect the "giftedness" of the world. recognizing that our talents and powers are not wholly our own doing ... also means recognizing that not everything in the world is open to any use we may desire or devise' (The President's Council on Bioethics, 2003, p.286). This reads like an attempt to raise the debate onto another level, but even in New Zealand I am struck by the persistence of spiritual questions that arise from the perception that we are stewards and guardians of something that has been given to us. In research commissioned by the Bioethics Council we found that older people tended to talk of God as the intangible other who somehow controls the order of life. Younger people tended to put their faith in nature, which equated with the natural order. For them 'unnatural' is a negative word.

The first term of reference of the Bioethics Council requires the Council to 'provide independent advice to the Government on biotechnological issues involving significant cultural, ethical and spiritual dimensions'. Two comments. The Council does not unpick each of these dimensions but sees them as influencing each other and contributing to one rich thread. The Council is a ministerial advisory body that first met in December 2002 and whose continuing existence depends on

the Cabinet. Funding comes through Vote Environment. Within that context we seek to be independent. I brief the Minister but she does not tell the Council what to do. The independent nature of our advice to the Government depends on the Council fostering and guarding its own independence.

The dilemma faced by the Royal Commission on Genetic Modification was whether the Council's recommendations should be binding or not. Certainly any recommendations we make should not be too easy for the politicians to ignore but the decision was made that they should have no legal force and so the problems of creating a new quasi-judicial body were avoided. The danger for the Bioethics Council is that it could become irrelevant. Without sufficient connections to decision making processes values are easily dismissed.

The Council is also charged with the promotion of public dialogue and participation and the provision of information on the cultural, ethical and spiritual aspects of biotechnology. The Council senses that dialogue is a relationship we enter into, it's not just a method we understand. Knowledge, respect and true understanding arise out of interaction. Understanding in fact is about communion. Dialogue is a process that understands that some problems cannot be solved but must still be faced. The problem may remain but perhaps the people concerned can gain a new respect and a better understanding of what is important for each other.

In an ordinary discussion or even in a consultation people hold relatively fixed positions and argue in favour of their views as they try to persuade others to change theirs. David Bohm suggests the purpose of dialogue is to reveal the incoherence of our thought (Bohm, 1996). At its best dialogue is a process of awakening. The aim is that people should participate in a pool of common meaning, open to constant change and development. Dialogue seeks to explore and understand rather than to defend.

Beginning on 18 February and lasting until 17 April the Bioethics Council is undertaking a nation wide dialogue on the issue of human genes in other organisms. We are using thirty facilitated and evaluated workshops of which eleven will be for Maori. For those unable to attend we will provide for an online discussion and we will welcome written submissions. There will be workshops for different age groups, urban and rural dwellers, the various faith traditions, the

physically impaired, ethicists, scientists, scientists with religious and spiritual affiliations, cross-cultural groups and four mixed interest groups where people with differing perspectives will come together. There will be community conferences in Nelson and Hamilton. Some of the groups will reconvene. All of this will be promoted by extensive advertising in the media.

We believe that all New Zealanders should have the chance to make their contribution and debate the dimensions and implications of biotechnology. This is a prime aim.

The Council will act with openness and respect because we want the community to have a better experience of talking together than has been the case up until now. We want them to have a greater understanding and respect for what is important to others. No one can be happy with the quality of our public debate. The strong advocates for or against the policy of conditional release have done little for those who have real concerns but are not prepared to put themselves in either camp.

We have chosen the subject of human genes in other organisms because it was raised with the Royal Commission on Genetic Modification, ERMA has had to deal with a specific application to use human genes in cows and quite obviously profound cultural, ethical and spiritual dimensions are involved. It is an area of biotechnology that is developing quickly, both internationally and locally, and raises questions common to many biotechnologies.

Jackie Scully reminds us 'that the words and concepts of genetics have become so familiar we tend to forget that up to halfway through the twentieth century the actual material of inheritance, the nature of what was passed on from parent to offspring, was a puzzle' (Scully, 2002, p.13). Inevitably then, mixing human and other genes raises issues about what it means to be human and how we understand our humanity especially when technology makes some things possible that previously were not possible. Can we still maintain the human non-human distinction or do we have to consider whether a specie may be dynamic, not fixed, and the boundaries between species may, on occasion, be permeable?

Last year the Council commissioned focus groups to inform us how people felt about the cultural, ethical and spiritual

dimensions of inserting a human gene into another organism. Most people believe that there is something distinctive about being human. That was the easier part. But how do we begin to describe our understandings of what it means to be human? Where do we draw our ideas?

We have produced a useful collection of essays by authors of widely different views. Some of our contributors talked of the distinctiveness of humanness in biological and genetic terms. Others based the specialness of being human not on genes but on shared lineage. Others did not want to use biology as a basis of deciding what is important about being human. They would speak of a capacity to relate to God and the distinctive calling of humanity. Sustained social relationships and recognition of the importance of place were underlined. For many what makes us human is not biology but social and cultural factors. Inevitably others resist the idea that humans are special or enjoy any privileged status. For them humans are but one organism among many in a vast ecological system sharing a common genetic history with all living organisms.

So how do we make sense of all this? Most of us would draw on our own traditions and previous experience. Traditions do not need to be fact or scientific to shape our thinking. There is more to life than facts or objective truth. Aotearoa New Zealand is full of myths, traditions and cultural norms. We have concepts of whanau/family, heritage, whakapapa. We all want to stand on the foreshore. We understand our relationship with the non-human world in a range of ways varying from humans having been granted dominion over the earth to humans as but one species among many. Myths, legends and doctrine, which for many have lost their currency, still continue to influence us. Instinctively we know what people mean when they express unease at 'playing God' even when they have no belief in God.

Out of these many experiences and ways of seeing the world people will summon up different ideas and emotional reactions to the possibility of human genes in other species: intuitive unease, objection to human genes in the food chain, cannibalism, incest, the web of nature, sanctity, the pursuit of a better world, mastering nature, tikanga or living by Maori knowledge and values.

At what level should we make decisions about bioethics? Some approaches would say ethics is about personal choice but in the area of biotechnology bioethics raises questions that need

to be addressed on a wider front. There are various levels of decision-making.

- By the individual or immediate family. Ethics here is individual choice.
- By advisory committees that are government appointments and only loosely tied to the democratic process. The basis of decision-making is expertise and the acceptability of the people concerned to the government of the day.
- By politicians because ethics is not only personal choice but has a collective and political dimension that must be addressed within the political process.
- But how do we deal with minority views? Are some minorities more powerful than others (e.g. scientists and Maori)? How does democracy relate to advisory committees? Some of the issues may seem to be intractable and when there is no resolution the democratic process can feel like the imposition of the values of some on those who do not share them. There are people in New Zealand who experience it that way. There is talk of direct action.

There are biological descriptions of humans and there are social, historical and cultural descriptions of humans. Quite rightly scientific ways of understanding our world carry great authority. But Brian Wynne warns that if you speak of the impact of GMOs it reinforces the belief that the Bioethics Council's agenda starts where science and technology stop: as if there were no questions of a cultural, ethical and spiritual nature in the way that science and technology do their work. Some believe this taken-for-granted down streaming of the social agenda is why the public is uneasy about science and technology.

Science is not the only form of knowledge important when we are making choices about what technologies to develop and how. My doctor needs scientific knowledge to treat a disease but I will need a different sort of knowledge to care for a grieving friend. Knowledge must be tempered with wisdom.

References

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