

HUMAN VALUES  
IN A  
GENETIC AGE:

**Valuing the right to be different**

**by Amber Carroll**

*THE YEAR 2000 ESSEX HALL LECTURE*

This is the Essex Hall Lecture for the year 2000. It was delivered at Imperial College, London on Saturday 15 April, 2000. Essex Hall is the London Headquarters of the General Assembly of Unitarian and Free Christian Churches and stands on the site of the building where the first avowedly Unitarian congregation in an English-speaking country met over two hundred years ago. The lecture was founded in 1892 and many distinguished persons in various fields have contributed to the series. The delivery of the lecture is one of the leading events during the General Assembly's Annual Meetings.

A complete list of previous lectures, many of which are still available for purchase, may be obtained by application to the Information Department of the General Assembly, at the address printed below.

Published by the Lindsey Press, an imprint of the General Assembly of Unitarian and Free Christian Churches.

Essex Hall, 1-6 Essex Street, LONDON, WC2R 3HY

Tel: (020) 7240 2384 Fax: (020) 7240 3089

E-mail: [ga@unitarian.org.uk](mailto:ga@unitarian.org.uk)

ISBN 0 85319 064 X



[www.unitarian.org.uk/docs](http://www.unitarian.org.uk/docs)

We stand on the threshold of a biotechnology revolution which has been brought about by scientists' increasing desires and abilities to understand and manipulate DNA — supported and fuelled by peoples' desires to know more about their genetic make-up, that of their relatives (particularly their children) and of animals and plants for a variety of commercial and private reasons. Already there is widespread controversy over the nature of the values driving these immense innovations. We hear and talk about greed, commercial gain, lust for power and profit — *and* about willingness to prevent, ameliorate and eliminate suffering; defence of rights and freedoms; and desire to feed the hungry.

Genetic engineering involves the deliberate introduction into an organism's genetic structure of characteristics that will be inherited by all future descendants. This is known as germ line therapy and is not permitted in the United Kingdom — although there are various indications that it might be in the foreseeable future. Somatic gene therapy is another form of genetic engineering that is applied only to an individual's non-reproductive cells, to treat the diseases or disorders in a single individual, and cannot be transmitted to his descendants.

Genetic engineering — including germ line alteration and human cloning — raises fundamental challenges to the dignity of the human being; the value of the human form; and, of course, to the integrity of animals, which are widely exploited in the research. By values I mean the principles and criteria we use for judging what is good, worthwhile, desirable and right. Human values I am focusing on include respect for the dignity of all people and respect for their rights, regardless of their genetic characteristics; and fundamental freedoms as safeguarded in various 20th century international instruments — such as the *UN Charter for Human Rights* and

UNESCO's *Universal Declaration on the Human Genome and Human Rights*, adopted in 1997 — and as reflected in basic principles of modern medical ethics including beneficence, non-maleficence, autonomy, and equity of access to care for all. Such values are the ones needed to underpin and guide this progress. In addition, for those of us who believe in God or in other sources of divinity, there is the principle we value of serving our God through service to the ecosystem as a whole.

Quakers and Unitarians are no strangers to facing up to perplexity, controversy and conflicts in values. Quakers and Unitarians have in similar ways — with reasoning, diligence and courage on numerous occasions — contributed to pursuit of truth, love and the creation of the fruits thereof; have been of service in their communities (many times in hostile and unwelcoming circumstances); and have been involved in extension of justice — such as emancipation of slaves, votes for women, and relief of poverty.

We are entitled to feel that we can make a distinctive contribution in the biotechnology revolution. We have much respect and gratitude for the charity, selflessness and fortitude that so many earlier and contemporary Friends and Unitarians have demonstrated, and are demonstrating, in other revolutions despite the hardship and sacrifice this caused. Our lives, and those of countless others, have been made more comfortable and dignified as a result. The stakes, in terms of potential risk and benefit to our health, are higher here than at any other time in modern medical history — as is the power to introduce widespread lasting change on the rest of creation.

The challenges presented to our faith and practice have the potential to cause considerable discomfort in our deliberations and witness. Yet we owe it to our forbears, more practically to our descendants,

but most importantly to ourselves — and to those who do not have our voices — to engage with these issues. In doing so there is no guarantee that, even with the best intentions and the most humility we can muster, we will be granted in our lifetimes to uncover the whole truth — or that we won't take the wrong path, or make mistakes. We can only offer our best. As Dag Hammarskjöld, a former Secretary General of the United Nations said: "Life only demands from you the strength you possess. Only one feat is possible — not to have run away."

I say distinctive contribution rather than unique. Naturally I cannot speak from the perspective of a Unitarian but, from my Quaker point of view, I have not found anything that is unique in our tradition to offer here and perhaps this is true of your tradition too. That actually pleases me because I feel the issues here are common to all humanity. They concern how we view ourselves and the health of our society, and also our relationship with other animals and the rest of creation. We who are laypeople do not require any qualification to invite ourselves to participate in this debate — although undoubtedly those who have knowledge and proficiencies specific to genetics will continue to maintain a central role.

The public continues to be anxious about the difficulty of determining whom to trust to arbitrate what is democratic, safe, and healthy here. Recently the Prime Minister wrote in *The Independent* (27 February 2000) that: "There is no doubt that there is potential for harm, both in terms of human safety and in the diversity of our environment, from GM foods and crops." Despite denials that this represents a U-turn in government attitude, I am unaware of his publishing this opinion before and it contrasts sharply with what has appeared to be a previously strong, pro-genetically modified crops position by the government. There have been countless claims and



counter-claims by scientific experts, big businesses, politicians, and farmers about the safety of — and necessity for — GM crops. This confusion and lack of unified responses among professionals we have traditionally trusted to give us healthy food crops — i.e., crops that do not contain the possibility of causing long-term harm — have left many people increasingly reluctant to accept such revolutionary changes in agriculture.

Yet it is paradoxical — as Bernard Dixon, a long-standing writer on science, pointed out in the *British Medical Journal* last year — that high-profile concern over GM crops contrasts oddly with the widespread acceptance, and use of, many genetically engineered products in health care such as human insulin and growth hormones, hepatitis B vaccines, factor VIII, and tissue plasminogen activator.

Risk cannot be fully assessed while we lack knowledge about the likely impact of new technologies. We do not even know the range and character of potential impacts and the different combinations in which they might occur — as a group of academics, funded by the Economic and Social Research Council, have shown (*The Politics of GM Food*, 1999). They question the assumptions made in assessments of risk of GM crops, submitting that assumptions embedded in risk assessments are rarely examined despite the existence of straightforward techniques for doing this.

I am not opposed to genetic research, or its possible benefits, and am deeply grateful for all the wonderful benefits that people of goodwill in science and medicine have bestowed upon us hitherto. There are, however, profound issues that should have been adequately addressed before these rapid technological developments were allowed to advance. There is insufficient transparency and democracy surrounding these developments. The free market

provides no mechanism to control injustice or the might of huge multinational corporations. Another well-known commentator on science and society, Colin Tudge has said: “The reason for objecting to big industry is not that it is big, nor that it is profitable, but that it forces the world to operate in particular ways that happen to suit the industry — and everything else goes to the wall.”(Tudge, 1999). If we ignore what is going on we run the risk of allowing *misuse* of information and technology to occur unrestrictedly. Alternatively we run the risk, through scepticism and inertia, of giving up trying to understand and so fail to allow responsible *use* of information and technology — based on humane values — to go ahead.

Those who argue in favour of introducing change into the human germ line to get rid of a gene that causes an inherited disease — such as cystic fibrosis, for example — want to eliminate permanently the risk of descendants suffering from that disease. Such techniques would eliminate also the need for somatic gene therapy.

Those who argue against changing an individual’s genetic make-up cite alternatives that are already available to parents who do not wish to pass on a disabling gene to their offspring: the choice not to have children, adoption, using donor eggs or sperm, having a termination after prenatal and preimplantation genetic testing has shown that the embryo or foetus carries the undesired gene.

There are three areas of human genetic engineering I would like to address:

1. Preimplantation genetic diagnosis (PGD)
2. Genetic “enhancement”
3. Cloning

## 1. Preimplantation genetic diagnosis (PGD)

Prenatal screening during which the foetus is screened in the womb — e.g. for presence of Down syndrome — has been in existence for decades. Preimplantation genetic diagnosis (PGD), an extension of this technique, is one of the most complex current ethical issues encompassing legitimate and competing moral principles. According to the Human Fertilisation and Embryology Authority (HFEA), PGD was primarily developed in the 1980s in response to requests for help from parents at risk of passing on serious genetic disorders to their children and has been practised for about a decade all over the world for a limited number of disorders. It is a two-stage process in which in vitro fertilisation (IVF) is used to create embryos and these are then tested for a particular genetic disorder — or to establish their sex if the disorder being diagnosed is sex-linked. Embryos which do not carry the genetic disorder, or are not of the potentially affected sex, can then be transferred to the uterus in the hope that a normal pregnancy will develop. Bob Edwards — the world-renowned embryologist who worked with the late Patrick Steptoe to produce Louise Brown, Britain's first test-tube baby — believes pre-natal screening for genetic disease confers a moral responsibility on parents not to give birth to disabled children. He has said it will be "a sin" for parents to give birth to disabled children (*Sunday Times*, 4 July 1999).

We can respond in various ways to the question of whether we should support PGD. None is straightforward and for each argument in favour, there is a compelling counter argument. Three main responses are:

- Calling for a complete ban on PGD.
- Accepting it for widespread applications, subject to tight regulations.

- Accepting it, but recommending its use be constrained, minimised and subject to tight regulations.

Before considering any endorsement, we have the moral responsibility to evaluate assurances from policy makers and enforcers that introducing and maintaining tight regulations is a genuine feasibility — embedded in a commitment of equal access to health care for all. More urgently, even before there is further extension of preimplantation genetic diagnosis, further cognisance needs to be taken of public views through meetings such as citizens' juries or consensus conferences — particularly of those who are disabled, or who care for disabled individuals.

Disabled peoples' rights groups have argued for years that it is discriminatory attitudes that oppress them and contribute more to their disabilities than do their physical impairments. They feel that, as long as prenatal testing and "therapeutic abortion" are informed by similar prejudice against them, the availability of such procedures will not increase reproductive choice. The British Council of Disabled People confirmed this view in a statement drafted in 1999. Fears that the introduction of techniques such as PGD will decrease tolerance of disability and genetic diversity were expressed this February when 130 disabled people and parents — delegates to Disabled People International from twenty-seven countries in Europe, Africa, Australia and North America — met in Solihull, England, to discuss bioethics and human rights. Their three page declaration, entitled *Nothing About Us Without Us*, demands an absolute prohibition on compulsory genetic testing and on the pressurising of women to eliminate — at any stage in the reproductive process — unborn children who it is considered may become disabled.

Disabled peoples' rights groups are not alone here. Many of us are deeply concerned that genetic tests will proliferate — and some may become mandatory — forcing parents into eliminating foetuses viewed as “undesirable”; heightening the risk of genetic discrimination by mortgage lenders, insurance companies and employers; and deepening an over-reliance on “geneticisation” of disease and disability.

PGD is already in existence and thousands of couples have chosen to use it. The vast majority of the public does not question women's choice regarding screening for Down syndrome — even though, significantly, a minority do oppose it. There are understandable reasons why PGD may continue to be used for testing when there is a known risk of a disease or a disorder in a family — e.g., the parents request it and they have had access to unbiased information including the viewpoints of people who oppose it — but, with our current level of knowledge, PGD should not become a routine screening technique. Angus Clarke, a fellow Quaker and geneticist in Cardiff who has studied these ethical issues in great depth, has concluded that we should be critical and sceptical of any claims of benefit from proposals to introduce genetic screening programmes on a wide scale; we should call for thorough evaluations of the social impact of those genetic screening programmes now in operation (Clarke, 1999). Unlike with existing prenatal screening techniques, with PGD the long term eugenic potential is much more serious. Extreme vigilance regarding regulation is therefore required and any steps to deregulate these procedures must be resisted. Simultaneously, it is incumbent upon society to change stigmatising attitudes towards people who are disabled — and to provide them with the support and access they have the right to, in order to have the opportunities open to non-disabled persons.

## 2. Genetic “enhancement”

Genetic “enhancement” is another new concept arising from strides in prenatal screening techniques and IVF technology coupled with the expectation that, as the science of genetics unfolds, the blueprint for a wide range of genetic traits — such as height, propensity to alcoholism, maths acumen, sexual orientation, and so on — will be revealed. This will pave the way for some of the medical profession to develop therapies to “enhance” humans by adding or subtracting the requisite genetic material — providing the huge ethical dilemma whether to allow any such genetic manipulation. From what we have been told, it seems likely that future generations of men and women will jointly (or individually) be able to design their baby and then give birth to it naturally, through surrogacy, or through gestation in an artificial womb outside the human body.

The implications affect us all as genetic engineering has the potential to transform long-held radical assumptions about reproduction, birth and parenthood. It can lead us into free market eugenics, where eugenic programmes are no longer imposed by governments but by wealthier individuals — who may be able to purchase manipulation of their offspring, giving them certain advantages denied to other members of society which, in turn, can lead to gross injustices and inequalities. It may also lead to shifts in the way parents look at their children — no longer as subjects worthy of unconditional love but as objects that may or may not live up to expectations behind the prenatal choice of characteristics.

The threat of the reintroduction of eugenics programmes, I believe, is real and is not just more “genohype”. Negative eugenics is usually regarded as the systematic elimination of so-called undesirable biological traits and positive eugenics is concerned with the use of

selective breeding to “improve” the characteristics of an organism or species (Rifkin, 1998). We must not allow the gains made to secure greater equality of opportunity for all to be debased by any new genetic determinism; rather, we should seek to support technological advances legitimately aimed at extending greater equity and reject any mechanistic ways of producing a “genetocracy” — as Rifkin calls it — with individuals, ethnic groups, and races increasingly categorised and stereotyped by genotype.

A defence of the “enhancement” concept was forcefully argued recently by Arthur Caplan, Director of the Center for Bioethics in Philadelphia, in the *British Medical Journal* at the end of last year. He and two colleagues from the Center assert: “Given the power and authority granted to parents to seek to improve or better their children by environmental interventions, at least some forms of genetic selection or alteration seem equally ethically defensible if they are undertaken freely and do not disempower or disadvantage children.” They consider there are certain traits — such as physical stamina, strength, speed, mathematical ability, dexterity and acuity of vision — “that command universal assent as to their desirability”; parents should be permitted to choose these if they wish, as long as there is no coercion or force. Assuming that there will be such dramatic leaps in genetic information and technology, and that this is not another illustration of “genohype”, they ask if it is “any less ethical to allow parents to pick the eye colour of their child or to try and create a propensity for maths” for their unborn children than it is to teach the values of a particular religion or love of sports. They believe: “No moral principle seems to provide sufficient reason to condemn individual eugenic goals.”

Do we have a moral principle that outlaws such steps? Do we have a moral principle that permits this? Or do we turn away because,

frankly, it’s too hard and our tea is getting cold? *Is there any difference between allowing parents to choose to enhance maths propensity for their unborn child and allowing them to spend hundreds of pounds on extra maths lessons for her when she is ten?* This is why we need to debate these issues — openly, and with sound information. We must have the facts. We must also have the fortitude and bravery our forbears had when they confronted those grave political and social issues of their time. You and I are not going to be dispossessed or thrown into jail for questioning “genetic enhancement”. But are we, for example, willing to bring this subject for debate to our religious, or professional, or even our own family gatherings?

What we have witnessed with the use or misuse of surgery and many drugs suggests to me we shall similarly not be able to control genetic enhancement. *The Guardian* reported that Brazil boasts more plastic surgeons per capita than any other country in the world and, in the run-up to the famous Rio de Janeiro Carnival, hundreds of women in their early twenties seek last minute cosmetic surgery to “improve” their bodies in order to guarantee a place on the most prestigious and prominent floats (21 February 2000). We need to analyse whether such technology might increase stigmatisation of those who have not had their maths or physical features enhanced — or whether it can enrich the lives of vulnerable people, as the proponents would have us believe.

### 3. Cloning

Cloning, the process whereby a group of identical cells are produced from a single cell — thus making a “copy” of a foetus, baby, child or adult that is alive or dead — involves taking a nucleus from the cell of another and inserting it into the cell of an embryo. The



nucleus might come from a parent who wants to “replace” an aborted fetus, dead baby or child killed in an accident or to produce compatible tissue (or an organ) for a child dying, say, from kidney failure.

Human reproductive cloning is not allowed in the United Kingdom. Widespread support for the government’s continuing ban on human reproductive cloning was shown in the nearly two hundred responses received to the public consultation undertaken by the Human Genetics Advisory Commission (HGAC) and the HFEA in 1998. Significantly about 23% of respondents indicated that any form of embryo research or manipulation was “simply wrong” because they believe that the embryo possesses the “full moral status of a human being”.

In February 1997 Dolly the sheep, the first clone of an adult mammal, was presented to us as a *fait accompli*. The public was not informed beforehand of all the steps leading to her production. Although hailed as a remarkable scientific development, concerns were raised immediately internationally about the implications of using this technology to clone humans.

UNESCO’s *Declaration on the Human Genome and Human Rights* states that practices which are contrary to human dignity — such as cloning in order to reproduce human beings — should not be permitted. If cloning were permitted to become a routine alternative reproductive technology it would raise critical new questions of values, ethics and spirituality. Any programme of human reproductive cloning is likely to result in an enormous number of miscarriages and malformations.

Nuclear replacement in animals remains highly inefficient and very few reconstructed embryos survive. Dolly was derived from cells taken from the udder of a six year-old ewe, which were then fused with unfertilised eggs and implanted into a surrogate ewe. This technique has since been successfully undertaken in mice and cattle (HGAC et al 1998).

Another incredibly difficult ethical issue which I have not addressed here is the fate of the animals used in this research. The sacrifice of animal welfare for profit in commercial agriculture and the development of animals as genetically engineered models of human disease require deep, searching questions to be asked and answered. We urgently need a new moral vision of our relationship with animals to allow us to proceed in a manner which is ethical and not based on viewing animals simply as resources for humans to exploit.

We live in very privileged times in a very privileged country. We have democracy and equality of opportunity enshrined in law and increasingly put into practice. We have a fantastic National Health Service and belong to religious bodies that promote tolerance, justice and respect for our interconnectedness with the whole of creation. Let us not squander these privileges by any attempts to “play God”. Humanity has masqueraded as God too often in the past with disastrous results.

We are called to serve God, to serve the good in our world by fulfilling our responsibilities — not by waiting until we think we know enough, or we have the time to spare, but by offering our diverse gifts and talents to help ensure that the values we hold dear will be reflected in the outcomes of the biotechnological revolution.



## Reading

Caplan, A.L., McGee, G. and Magnus, D. (1999) "The Human Genome Project: What is immoral about eugenics?" *British Medical Journal* 319:1284, 13 November

Clarke, A. (1999) "Genes, genetics and disease: the relevance of genetics to patients, families and populations" in Carroll, A. and Skidmore, C.(eds), *Inventing Heaven? Quakers confront the challenge of genetic engineering*, Reading: The Sowle Press

Dixon, B. (1999) "The paradoxes of genetically modified foods", *British Medical Journal*, 318:547 –548, 27 February

ESRC Global Environmental Change Programme (1999) "The Politics of GM Food: Risk, Science and Public Trust" *Special Briefing No. 5*, University of Sussex

Goring, J. and R. (1984) *The Unitarians*, Exeter: Religious and Moral Education Press

Human Fertilisation and Embryology Authority (HFEA) and Advisory Committee on Genetic Testing (1999) *Consultation Document on Preimplantation Genetic Diagnosis*; London, HFEA

Human Genetics Advisory Commission (HGAC) and The Human Fertilisation and Embryology Authority (HFEA) (1998), *Cloning Issues in Reproduction, Science and Medicine*, London, HGAC

King, D. (1998) "The Persistence of Eugenics", *GenEthics* 22, February/March

Rifkin, J. (1998) *The Biotech Century*, London: Victor Gollancz

Tudge, C. (1999) "The uses and abuses of science", *Index on Censorship*, 3

Amber Carroll is clerk and a founder member of the Quaker Ethics and Genetics Network. She is co-editor of a collection of Quaker writings on human genetics, entitled *Inventing Heaven? Quakers confront the challenge of genetic engineering*. Amber has an M. Ed. in Special and Inclusive Education and is an Adviser for Personal, Social and Health Education with Hertfordshire Local Education Authority. Her commitment to human rights has been inspired and shaped by the struggle to end apartheid in South Africa, where she spent the first half of her life.

