



Genetic Modification: This Time it's Personal

The Case Against Genetic Modification of Human Beings

Introduction

After 25 years of genetic engineering of plants and animals, scientists are now ready to take the ultimate step: the genetic modification of human embryos, as the first step towards the creation of GM babies. For many years a furious debate has raged in bioethical and activist circles about the possibility of Human Genetic Modification (HGM) - for good reason, because all sides acknowledge that it would be a momentous step, the point when humans begin to direct their own evolution.

The British Government has introduced provisions in the Human Fertilisation and Embryology Bill (HFE Bill), which is about to be voted upon by Parliament, which would allow scientists to genetically modify human embryos. This is an extremely serious situation, which is unfortunately received very little public attention. It is the first time that any country has officially sanctioned genetic engineering of human embryos. The worldwide concern about human genetic modification (HGM) is because it is by far the most powerful technology for manipulating the characteristics of human beings. It raises huge concerns about eugenics and the treatment of human embryos and children as commodities (see part 2 below)

Part 1: the current proposals

In the Consultation document preceding the HFE Bill, the Government stated openly that its aim was to allow the development of safe technologies for HGM, and cited the Science and Technology Committee's 2005 recommendation in favour of this. (At present HGM would not be a safe technology, since existing techniques of genetic modification disrupt the embryo's chromosomes, leading to animals with congenital deformities. Such techniques could not ethically be used in humans.)

Although the Bill retains the existing ban on implantation of such embryos, this is not reassuring, since the Government is refusing to state clearly that the creation of GM children would be ethically wrong. (HGA asked for a clear statement about

this in a letter to Dawn Primarolo, but the Government response failed to state clearly that HGM is wrong.) It would certainly be illogical, wrong and a waste of tax payer's money to begin research on something which you intended to remain permanently illegal - we assume, for example that the Government would not wish to allow research on developing technology for human cloning.

The Government would like to present the decision to begin research as minor, given the safeguard against creating GM babies for the present. It would be naïve, however, to believe that research is, in itself, harmless. The creation of GM babies is not just a hypothetical scenario: leading British scientists, such as Robert Winston and Ian Wilmut, have already

patented techniques for doing this, including patenting human semen and embryos (see box 4).

Clearly, what is planned is a normal process of technology development followed by eventual legalisation. In fact, the Government initially proposed to take the momentous step of legalising GM children by way of regulations, without even the Parliamentary and public debate attendant upon primary legislation change!

Once we start down this path, it will be very hard to turn back. When scientists are able to dangle before the public realistic, rather than theoretical possibilities of curing genetic diseases, it will be very difficult to counter well-

meaning support for HGM. Once safe technology is available, it will appear absurd not to legalize HGM, since that will mean that all the work to develop it will have been wasted. As we will show below, in fact, HGM is entirely medically unnecessary, since there are many other ways of avoiding genetic disease. **There is therefore no medical reason to even begin such research.**

In HGA's view, since HGM would be a disaster for our society, it makes no sense to allow research intended to develop it. Since nearly all other European and industrialised countries have permanent bans on HGM for ethical and social reasons (see box 1 below), the EU has banned research into the

Box 1: The legal status of HGM

Because of its eugenic implications, human genetic modification (HGM) has been treated in international law very similarly to human reproductive cloning. Most industrialised countries have banned it, especially in Europe. Every country that has legislated on this subject has banned it. Thus the British Government's decision breaks ranks with the international community, and may lead to the perception that Britain is a haven for irresponsible and profit-driven scientists.

The following countries have banned HGM: Australia (law), Austria (law, implicitly), Belgium (law), Brazil (law), Canada (law), China (guidelines), Denmark (law), France (law), Finland (law), Germany (law), India (guidelines), Israel (moratorium by law), Italy (law), Japan (law), Mexico (law, implicit), The Netherlands (law), Norway (law), South Africa (law), South Korea (law), Singapore (guidelines), Spain (law), and Switzerland (law). The Council of Europe Convention on Biomedicine and Human Rights also bans HGM, as well as a number of other abuses of genetic technologies, such as

genetic discrimination by insurance companies, reproductive cloning and sex selection. Unfortunately, Britain refuses to sign the the Convention. The reason for this is unclear, but seems to be a desire by the Government to minimise controls on medical researchers, because their discoveries may be of economic value to the country. The failure to sign leaves Britain increasingly isolated from the European ethical standard.

It should be noted that these bans are for ethical and social reasons, rather than because the technology is currently unsafe. The indefinite bans imposed by the Convention, and by other countries, show that HGM is regarded in most countries as simply unacceptable. In accordance with the Convention, the EU has, in its last two Framework (research funding) Programmes, excluded research aimed at genetic modification of human embryos from being funded. The EU has also excluded any methods for genetic modification of human embryos or human cloning from patentability, as being unethical, in its Directive on the Protection of Biotechnological Inventions (1998).

development of HGM technology in its last two Framework Programmes (the EU's main science funding budget)¹. The UK should follow the EU example. Once we start down the road to HGM, it will be very difficult to turn back, so it is crucial that this issue is debated now.

The lesson that has been learnt from the GM food debate is that there must be democratic debate at the earliest stages of research, so society can decide which technological paths to go down. If these decisions are left to unaccountable scientists and corporations, often driven by the prospect of financial gain, it is not surprising that the technology is rejected by the public later on, and trust in science is undermined. If people are presented with a *fait accompli* there will be a backlash against science. (In fact, HGA has been contacted by gene therapists (see box number?) who are very concerned about the effect that this

decision will have on the public's support for their work.) Yet very few people are even aware of the Governments plans. Quite apart from its social consequences, the fact that there has been practically no public debate about beginning GM embryo research is a good enough reason not to allow it now.

The current moment is thus very significant for the entire world. Until now, any scientist attempting to begin genetically engineering human embryos would have been regarded by fellow scientists and the authorities as a dangerous maverick. For HGE to be given Government sanction will entirely change the nature of the debate. Even more importantly, such a decision will signal the beginning of the process of research and development of HGE, which will soon acquire momentum and be very difficult to halt.

Part 2: the case against HGM

HGM is medically unnecessary, but will lead to 'enhanced' 'designer babies'

Undoubtedly, the first attempts to apply HGM will aim to cure genetic disorders. However, it is important to realise that this is completely unnecessary. Firstly, many disabled people's organisations have spoken out against what they view as a continuation of the eugenic philosophies of the first part of the 20th century, an attempt to create a sanitised world in which genetic difference and the 'burden' of disabled people on society is eliminated. They argue that human diversity is a benefit, not a burden, and that we should make the world accessible and welcoming to disabled people, rather than try to prevent them being born. This is a very difficult and complex issue, which we cannot deal with fully here. HGA has a great deal of sympathy with those views, but we recognise that in the current

state of society it would not be helpful to anyone to force women to have disabled children that they do not want.

However, if parents wish to avoid having children with genetic conditions, there is no need to use HGM. Firstly, there is the traditional option of remaining childless: the nuclear family is not the only way to create fulfilment through close and long-lasting relationships with children. Secondly, people may adopt children. Thirdly, if parents wish to have children themselves, they can use sperm or egg donation. Finally, if they insist on having children who are 100% genetically their own, there are the options of prenatal testing and abortion, or genetic testing of embryos produced by IVF. It is sometimes suggested that these options would be rejected by those opposed to abortion, and that these people would therefore

prefer HGM. However, any conceivable version of HGM would involve checking the embryos to be implanted and producing surplus embryos which would later be destroyed. Moreover the process of developing the technology would inevitably involve the destruction of large numbers of embryos.

Given the alternatives, one must question why some scientists and doctors refuse to countenance a ban on HGM. It seems that the usual forces of careerism (being the first to use HGM) and the desire to wield the awesome power over nature that HGM would bring may be playing a role here. It may also be that some bio-entrepreneurs have a conscious strategy of proposing HGM to treat genetic conditions as a first step to using it for 'enhancement' purposes.

Once HGM was permitted to treat disease, it would be soon become impossible to prevent its use for 'enhancement'. In a world in which the cosmetic surgery industry is booming and lifestyle drugs are becoming the mainstay of the pharmaceutical industry market forces would soon make genetic 'enhancement' irresistible. Unlike genetic selection of embryos, which can only choose the 'best' of what a couple's genes can offer, HGM can produce real, 'enhanced' 'designer babies', with genes from other people, or even from other species. That, and not the avoidance of genetic disease, will be its main market.

Even if existing regulations on the use of genetic technologies are maintained in Britain, there are many countries in which there will be no regulation whatever, and where unscrupulous entrepreneurs can provide services for fertility tourists. On an issue of such enormous consequences for the whole of humanity, it would be irresponsible in the extreme for Britain to develop this technology, in the certain knowledge that it would be used to create 'designer babies' elsewhere. If we wish to avoid this eventual outcome, therefore, the only policy that has any chance of success will be to avoid HGM altogether, and as

Box 2: Somatic gene therapy vs. HGM

For the past 15 years scientists have been developing the technology for gene therapy, and taking the first steps towards its application. Gene therapy consists of treatment of genetically caused health problems, by direct correction of the genetic mutation, or introduction into the patient's cells of a normal copy of the gene in question. For example, in cystic fibrosis, which primarily affects the lungs, scientists are trying to introduce a correct copy of the cystic fibrosis gene into the lungs.

The crucial difference between gene therapy and HGM is that gene therapists target their interventions to the tissue affected, and purposely avoid allowing the genes to enter reproductive (sometimes called 'germ line') cells such as sperm or eggs. In somatic (soma means body in Greek) gene therapy the treatment affects only the patient and genetic changes are not passed on to any descendants. In HGM by contrast, which is identical in concept to plant and animal GM, the aim would be to introduce the new genes into sperm or eggs or the fertilised egg, so that it is present in all cells of the person who develops from that embryo. This includes their reproductive cells, so the genetic change will pass on to all their offspring, and subsequent generations. One of the concerns about this is that if the new genes do not work as intended or produce side effects, this new problem will affect all the future generations of the family.

Because HGM is generally seen as unethical, gene therapists have been anxious to disassociate themselves from it, and to make sure that there are clear rules against HGM. Dr Michael Antoniou, a gene therapist from Guy's Hospital in London told HGA that he is worried that the Government's plans will jeopardise gene therapy's good public support.

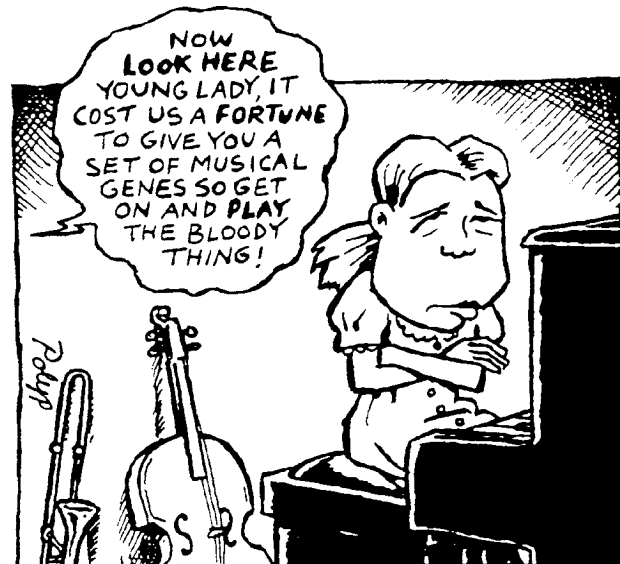
noted above this would not mean losing out on any important medical benefits.

Ethical and social objections to HGM

1. Commodification

A fundamental ethical objection to HGM is that in designing our children's characteristics, we still will be turning them into just another consumer object or commodity. In natural reproduction, and even in IVF, the randomness inherent in the mixing of genes from two parents generates a unique individual, and because we do not control the process, we must accept the child as they are, as a gift of nature, or God. The child has the same ethical status as ourselves: s/he is a person, grammatically, a subject. However, once we begin to design the child's genes, we begin to adopt the same ethical relationship towards it that we have with a refrigerator. We are the controlling intelligence, it is merely an object, manufactured and to be optimised according to our wishes and the current technical limitations. Many people feel that this way of treating children is an insult to human dignity.

This change of ethical relationship can only have profound consequences for the relationship between parents and children, and for society at large. Whereas natural parents will have hope about how their children develop, parents who have designed their child will have expectations. No doubt different parents will manifest this to different degrees, but the overall tendency will be to expect the child to conform to their installed genetic programming. The child in turn is likely to feel themselves somewhat less of a truly free and independent person, and more a vehicle of their parent's desires. If they achieve great things, their sense of achievement will be undermined by the knowledge that they were constructed that way, and that their accomplishments are not entirely the result of their own striving. And if their inclinations are against the direction indicated by their genes, the



result is bound to be conflict. By manipulating a person's genetic constitution we deprive them of much of their freedom to choose their own life course which is fundamental to our concepts of human rights.

An objection is sometimes made to this argument that we already allow parents to dictate much of their children's lives, so doing so by genetic means is no different. Firstly, this is no better than a 'two wrongs make a right' argument. This type of argument urges us to avoid making distinctions, which is how we always end up sliding down slippery slopes: 'you've allowed x, so how can you object to y'.

Secondly, there is a very significant distinction between the unavoidable facts of social conditioning, upbringing etc, which manipulate a child's behaviour, and the child's genetic constitution. Whilst the child, when they become an independent adult can rebel against their upbringing, they are stuck with their genes and the way that their genes influence their bodies or behaviour. This does not imply a simplistic assumption that genes are more powerful than environment, and that genetic influences cannot be changed, which may be more or less true for different genes and characteristics. Certainly, the very fact that the genes were manipulated in the first place is

based on a strong expectation that doing so would effectively change the child's characteristics.

The social implications of allowing the commodification of human beings are likely to be enormous. It is not merely a matter of profoundly distasteful trade in genetically 'enhanced' human embryos. It is often said that while a market economy is a good thing, a market society, (i.e. a society in which nearly all human interactions are governed by the principles of commercial exchange) is not. With HGM, we would be going a step further than a market society – we would be creating a market humanity, in which the principles of the market are written into our genes.

2. Eugenics

Because genetic modification is the most powerful of the genetic and reproductive technologies for modifying the characteristics of human beings, it has the greatest power to harm. Genetic modification would be used as a vehicle of expression of harmful social forces, so those forces would be written into the basic physical mechanisms of our bodies. The wish list of 'enhancements' often expressed by the advocates of HGM, and in public opinion surveys always revolve around enhancing people's ability to compete, because that is the basic way we operate in our free-market societies. For example, advocates hope for more athletic, taller, cleverer, more beautiful

Box 3: Is genetics really too complex?

One objection to the argument that HGM is dangerous because it will lead to 'enhancement' eugenics is that characteristics which people wish to 'enhance', such as appearance, intelligence and athletic abilities are affected by many genes, each of which will only have a small effect, as well as by the life experience of the person. If this is true, then the genetics will be too complex to disentangle, so we will not be able to know which genetic changes to make. Moreover, it is argued, it will be impossible to affect characteristics through genetic modification which can only introduce a few genes at a time.

However, while we should not fall into the trap of simplistically talking about

'the gene for beauty', some attempts at manipulation of complex characteristics may well be possible in future. The complexity of the genetics of many characteristics is still unclear, and is the subject of much research. Although initial attempts to identify genes involved in many characteristics have not been very successful, scientists have by no means given up their efforts. Moreover, there are already some genes known that appear to have major effects on characteristics. An example is the growth hormone gene, which when introduced into animals can have major effects on their body size and leanness. This gene was the first chosen by scientists genetically engineering farm animals, in order to boost meat production and has resulted in pumped up,

grotesque 'Schwarzenegger' animals. In our society, height is a very desirable characteristic, and it is quite likely that the first attempts at human genetic enhancement would involve the growth hormone gene.

Finally, it is a mistake to think that genetic engineering is still stuck at the stage of only inserting single genes. Scientists have developed artificial chromosomes which can transfer many genes into GM plants and animals, whilst synthetic biologists are now able to synthesise the entire genome of bacteria in the laboratory. In HGA's view although it is important not to encourage simplistic genetic deterministic views of biology, it would be equally unwise to be complacent about the possibilities for 'enhancement' on the basis of arguments about the complexity of genetics.

and talented children, never for more caring, kinder, more co-operative children. It is hard to avoid noticing the similarities between the ideals aimed for in the eugenics programmes of the first half of the twentieth century and the characteristics that people hope to enhance through HGM. Moreover, the desirable ideas of beauty will express prevailing sexist prejudices. Social norms of acceptable appearance are likely to narrow, and disabled people will find themselves more than ever rejected by society.

Because HGM technology will be very expensive, wealthy parents will be able to give their children genetic advantages over other people's children. Parents will see such genetic advantages as an investment to be paid back in better care in the parent's old age, financed by the offspring's better jobs and their social status. In one scenario put forward by the American scientist, Lee Silver, this will eventually result in the creation of a genetically enhanced elite group and an underclass of nonenhanced people, and might continue to the point at which the genetically enhanced elite, would have as much romantic interest in the people of the underclass as current humans have in chimpanzees. So what may be at stake with Human Genetic Modification may be nothing less than our common humanity.

Although driven by market forces rather than state intervention, consumer eugenics would tend in much the same direction as those aimed for in the Nazi eugenics programmes. In fact, many of the advocates of HGM, whether 'transhumanist' or libertarian bioethicists, often argue that there is nothing wrong with eugenics except the state coercion involved with forms seen in the first part of the twentieth century.

Overall HGM could lead to a society based on new hierarchies of 'genetic merit'. This would be a decisive defeat

for anti-discrimination and diversity policies, and for all political tendencies based on the idea of fundamental human equality.

The argument about 'reproductive liberty'

Many of those who oppose banning HGM say that to do so would infringe parents' 'reproductive liberty'.

Although the claims of reproductive freedom have a superficial plausibility, they are in fact consumerist extensions of well-founded, but much more narrowly drawn rights. The first legitimate right is a woman's right to choose to terminate her pregnancy. This right is based on the fact that a foetus is part of a woman's body and that women have the right to have control over their own bodies, as a protection of their vital personal interests. That is very different from saying that women have the right to choose the characteristics of their children. Many women argue that technologies that increasingly subject reproduction to medical control actually decrease their personal autonomy, rather than increase it.

The other basis for reproductive rights claims is the Universal Declaration of Human Rights, which includes 'the right to marry and found a family'. This article arose in response to the Nazi atrocities and from eugenics laws restricting disabled people's reproduction in other countries. Again, this right is narrowly drawn to protect vital personal interests and does not include a right to reproduce with whomever a person wishes, using whatever technological assistance. Jurisdictions legitimately restrict whom we can marry (for example, generally prohibiting marriage with close family members). Neither does the Declaration guarantee access to any form of technological assistance needed to reproduce, when this is not possible in the normal way.

A somewhat more plausible way of formu-

Box 4: Patents on GM embryos

Amongst many others, two leading British scientists have patented methods for HGM, including patent on GM human semen and embryos. Robert Winston has worked on methods for creating GM embryos and animals, including humans, by genetically modifying cells of the male germline (cells that develop into sperm). Ian Wilmut has patented his cloning technique used to create Dolly the sheep, which includes variations involving genetic engineering. His patents typically claim cloned and/or GM human embryos. Both these scientists have supported the possibility of creating GM children in their books. Robert Winston has advised the Government on the HFE Bill, and presumably supported the legalisation of the creation of GM embryos.

Many people find the idea of patenting human embryos and semen highly offensive. Firstly, patents protect inventions, not discoveries, so claiming a patent on a GM human embryo, implies a claim to have invented that embryo.

Given that that an embryo is a natural object, a claim of invention is very close to claiming to be God. The patenting of embryos also implies the reduction of the embryo to nothing more than a thing, and an article of commerce. It is not only proliferators who may object to this implication - the embryo is after all, a potential human being. A second objection is that claiming monopoly intellectual property rights on an embryo in order to make money from royalties is very similar to, for example, trading in human kidneys. Most countries have banned the trade in parts of the human body.

1. Patent numbers: US2002138865, WO0069257, WO0029602. In addition to methods, Winston's patents include claims on genetically modified human semen.

2. Patent numbers: US2006064763, GB2331751. The latter patent includes claims on genetically modified human embryos. Note: the claims of patent applications are extremely carefully drafted; general expressions, such as mammal, vertebrate, animal include humans, whereas, where the intention is to only claim nonhuman animals, the claims very clearly use the words 'nonhuman animal', 'nonhuman mammal' etc. Patents can be viewed online at <http://ep.espacenet.com>, go to 'advanced search'.

lating the argument against regulation is to say that reproduction is a private matter, which should be outside the realm of state regulation. However, the issues raised by the proliferation of reprogenetics raise such profound challenges for humanity as a whole that they cannot be left up to individual couples and their doctors. Choice by individual couples to demand new reprogenetic technologies affect everyone, and it is not satisfactory that decisions of great importance to everyone are made on the basis of media campaigns of emotional blackmail, in which those who have ethical concerns about particular techniques are portrayed as not caring about sick children's suffering. Making such decisions without reference to the rest of society will always tend to cross important ethical lines.

The expansion of these narrowly-drawn rights into much broader claims for access

to technology and non-interference by the state are due to a general climate of individualism and consumerism in some countries. Especially in the USA, claims of personal autonomy now dominate in bioethical discourse. It is often thought that strong individual rights protect against eugenic interference by the state. However, at present, as many commentators have noted, in Western countries, the greater threat is of a free-market eugenics, driven by commerce and by consumerist desires for the perfect baby. Rather than non-interference, what is needed now is more state regulation to restrain the eugenic trend.

What is the connection to GM food issues?

Although there may not seem at first to be much connection between these issues and the environmental and food issues

raised by GM plants and animals, because the concerns spring from the same root, there are in fact many parallels. The fundamental concern raised by genetic engineering is the power it gives humans to manipulate nature, and the lack of wisdom that is manifest in the way we already do that. The main element of our lack of wisdom is the way that our manipulations are driven by the demands of socio-economic forces and industrial production systems. Thus genetic engineering tends to reinforce the harmful impacts of those systems upon the integrity of organisms and their environment, and upon farmers, and at the same time reinforces the power of those who direct the genetic manipulation.

In the GM food field this is very clear: we see plants designed to boost corporate interests, eg. to force farmers to buy seed every year from the company, and to boost herbicide sales; we see animals designed to maximise meat production efficiency at the expense of their overall health and the use of cloning to create animals along the lines of predictable production industries, rather than through natural sexual reproduction processes which produces diversity. Although conventional plant and animal breeding has, of course, previously moulded, plant and animal physiology to conform to industrial production systems, thereby creating uniform and often physiologically distorted organisms, biotechnology has given huge new power and impetus to this tendency.

With HGM, the first concern, commodification, is simply about the incorporation of human reproduction into the system of economic production and exchange, and the way this violates the traditional ethical view of human beings as belonging in a different category to industrially-produced goods. The second objection, to eugenics, is partly about the same thing, that human beings are not to be bred and controlled as we breed plants and animals.

It is also partly about the ways in which market forces, acting through consumer desires to make their children conform to social norms will, like, industrial farming, decrease diversity and create inequality.

Those who are concerned at the use of GM to manipulate plant and animal nature should be equally concerned by its extension to human beings. Human beings are the only species left on the planet where there still exist formidable technical, ethical and legal barriers to genetic engineering. **We are now at the point in history where we must choose whether or not to subject human nature to market forces and industrial production systems.**

Conclusion

The Government's proposal to allow genetic modification of human embryos disregards public opinion and is dangerous in the extreme, since it opens the door to HGM. **In our view, on an issue of such huge potential consequences for the whole world, and for future generations, the British Government has no right to break ranks with the international consensus.** Once British scientists unilaterally begin this line of development, it will be very difficult to stop, and will eventually oblige the whole world to deal with the consequences. There are strong reasons why nearly all other industrialised countries have instituted permanent bans on HGM and are therefore refusing to allow research on genetic modification of human embryos. **If we decide to cross this line, and allow HGM, we must accept the consequences. In HGA's view we must not do so. The Government has given no good arguments for taking such an enormous step. We urge MPs to reject the Government's proposals.**

References

1. For FP6, see http://ec.europa.eu/research/fp6/pdf/fp6-in-brief_en.pdf, For FP7, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:412:0001:0041:EN:PDF>