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Ethical Issues in Genetic Screening

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In this issue

As promised, this issue contains two more of the papers presented at the seminar sponsored by the Plunkett Centre on the subject: "Our Genetic Future: the ethical issues". In the first paper Dr Anthony Fisher, OP, outlines the ethical issues which prenatal genetic screening presents to scientists, health care professionals, bioethicists, parents and the community in general. He asks whether several thousand years of 'faith-seeking-understanding' and of 'medicine-seeking-virtue' have any wisdom to contribute to genetic screening and engineering.

In the second paper, Mr Keith Joseph argues that while somatic genetic engineering raises no novel ethical issues, germ-line genetic engineering, with its potential permanently to change the genetic structure of our descendants, most certainly does.

The issue also contains an advance notice of the Centre's annual Intensive Bioethics Course as well as information about two seminars which the Centre will host in the new year.

As this is the last issue of *Bioethics Outlook* for 1997, we take this opportunity to wish our readers a happy and peaceful Christmas.

Until recently the only way to affect the genetic make-up of your child was to choose your partner carefully. Nowadays we can be more selective: California, for instance, boasts a Nobel prize winners' sperm bank from which a woman can buy the sperm of a genius in the hope of producing a genius child. There is no evidence that this works — these children seem to be just like everyone else's! But all that is a fairly ham-fisted way of designing babies.

I Pre-natal screening yields knowledge

We now have a more effective way: we can test the babies we already have to see if they have some of the characteristics we want or don't want. The mapping and sequencing of the genome promises to enable us to identify many more genes and gene sequences associated with particular attributes, desirable or undesirable. That exciting and awe-inspiring project is already altering the very structure and direction of science and medicine.

But we must not allow ourselves to be blinded by our excitement either with the science or with its actual or potential applications. We must consider, for instance, the means by which we come across this information. Fortunately gene mapping and screening can be done in ways which do not compromise respect for human life in its transmission, origins and development, from conception until death. But recent history gives us plenty of cause for caution here. At a recent conference a leading embryologist responded to a question about where she drew her moral

lines with an answer to the effect that she was no ethicist and her limits were whatever her Institutional Ethics Committee would let her get away with!

2 But knowledge of *what*?

Despite longstanding disputes about the relationship between nature and nurture in constituting the physical substratum of the human person, few now doubt the importance of genes in influencing many human characteristics. Hardly a week passes without the announcement of the identification of a possible genetic cause of or contribution to another attribute or condition. In the last few years genes have been identified which are thought to cause or confer predispositions to cystic fibrosis, Down's syndrome, dwarfism, fragile X syndrome, haemochromatosis, haemophilia, Huntington's disease, muscular dystrophy, phenylketonuria, sickle-cell anaemia, spina bifida, thalassaemia and also to very common conditions such as cardiovascular disease, Alzheimer's disease, a great many of the cancers, osteoporosis, epilepsy, asthma, diabetes and hypertension. Genes may eventually be identified which are associated not only with physical diseases but also with various physical features such as height, body shape, body-, hair- and eye-colouring, various immunities, longevity, athletic and other physical potentials.

Then there are psychological qualities. On the list of psychosomatic conditions and behavioural dispositions supposedly wholly or partly genetically determined and therefore potentially genetically identifiable, are schizophrenia, substance-dependency, depression, aggressiveness, domestic violence, criminality, kleptomania, homosexuality, and so on. David Roshland, the editor of *Science*, even attributes homelessness and unemployment to genetic defects! Apart from supposed defects, gene science may eventually be able to identify genes associated with intelligence, memory, creativity and docility. With each hypothesis or actual identification of the genetic cause of or contribution to some human attribute comes the promise that with more investigation (and research money, of course), we will eventually have tests, vaccines, prophylactics or cures.¹

We should not exaggerate the possibilities here. Turning DNA sequence information into causal knowledge is very difficult. Nonetheless, genetic scientists are rapidly identifying genes associated with particular traits. Already to some extent, and increasingly in the future, we will be able to test our progeny, either while they are in the laboratory petri dish or in the womb. If they have characteristics we want, we can transfer them from test-tube to womb or leave them in the womb to go to term. If they don't, we can flush them down the sink, abort them or use them for some other purpose such as

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experimentation or tissue harvesting. In many countries this is already common with respect to certain disabilities which are regarded as so horrible that the children concerned are classed as 'better off dead'. The list of those handicaps is growing, partly as a result of increased technical capacity to identify more and more of them (more and more accurately) and partly as a result of the line moving as to which disabilities are regarded as incompatible with worthwhile existence.

Will people abort their children if prenatal screening reveals that their child carries a gene they do not like? You may have read Nigel

Lawson's moving piece on his daughter Domenica who has Down's syndrome.² He adverted to the complicity of pre-natal screening technology in the current search and destroy mission against Down's syndrome babies. Cystic fibrosis, Down's, diabetes, asthma, where will it stop? One recent American poll found that 11% of couples would abort a foetus with a predisposition to obesity. The National Academy of Sciences has reported that already people are losing their jobs and their health and life insurance because they or their spouse or their yet-unborn or yet-unconceived children are thought to have a genetic predisposition to some condition. So the social pressures on parents to produce the perfect child and abort any imperfect ones are already there. And they are likely to grow.

There is a joke in theological circles that when God made man she was only joking; her serious and improved model was woman. Yet we know that there are cultures, not so far away from here, where a child's being female is regarded as a great disaster. India has recently moved to ban prenatal sex testing with a view to aborting the girls: for this practice has resulted in female to male ratios of 4 to 5 and worse in some parts of the country. Genetic testing has become a new tool for the oppression of women East and West, another grave imposition by parents of their preferences upon their children, and a further rejection of the notion that "children should be accepted by their parents as a ... gift to be loved for what they uniquely are and not merely because they conform to the parents' hopes and expectations".³

Three years ago doctors at the hospital in the university in which I was then working were presented with a couple both of whom suffered from dwarfism. The woman was pregnant and had been counselled to have prenatal screening to see if her child suffered the same disability as she and her husband. Given the high likelihood that the child would suffer this condition too, it was with great satisfaction that the screeners and counsellors reported to the couple that their baby was perfectly healthy. The problem was: at this point the couple declared that they wanted an abortion; they wanted only a dwarf child. The doctors were aghast: despite long experience of effective abortion on demand in Britain,

they had never before faced a case where a child was to be aborted specifically *because* she or he was normal! The case raised all sorts of questions even for those who were committed to abortion on demand. What is disability and what is health? Is disability socially constructed and handicap socially caused? Are we entitled whether as parents or as societies to decide what disabilities are sufficiently serious to warrant the death of the child, whether in the child's supposed best interests or in our own?

3 What *should* we do with this knowledge?

Why do we screen pre-natally? One obvious reason is that our doctors tell us to. For many people that is the end of the matter — at least until they find that their unborn child has some undesired genetic characteristic. Then the doctor or a counsellor may well steer them toward some further step, though under the professional cloak of non-directive counselling. I will return to the abortion reflex later. For now it is enough to note that one of the principal reasons for the supposed demand for genetic screening is that the suppliers (doctors) tell the consumers (their trusting patients) that they both want it: pre-natal screening is an increasingly routine part of the obstetric treadmill.⁴

Two immediate advantages of prenatal screening are that it provides reassurance for anxious mothers whose babies test negative, and time to treat both mother and child when babies test positive. Sometimes a simple drug, hormone or vitamin supplement, administered to the mother, will vastly improve their chances if the defect is identified early enough. Sometimes direct therapeutic interventions upon the child while still in the womb are possible: drugs, surgery, blood transfusions, shunts, laser and radio-therapy, and now gene therapy may be possible.⁵ And there may be benefit in preparing parents and others before the birth for the difficulties ahead. But none of these benefits is without its costs: there is a real risk of foetal loss or injury; there are maternal hazards and anxieties; false reassurance can be given and the resource burden of prenatal tests is now enormous. I would argue that where there is no therapeutic benefit to the child in view, it is an injustice to impose such a risk. But where we can do

something constructive for the child, genetic screening may be a positive boon.

More problematical is the sharing of such information with others, especially without the parents' permission. Relatives are a group who may well want to know. Increasingly health insurers want their prospective policyholders and their unborn children screened so that they can avoid taking on any high risk clients. The implications for privacy and health are obviously enormous. Recently US, British and Australian committees have recommended that laws be passed to make unauthorised release or use of information gleaned from prenatal screening a crime as well as to strengthen anti-discrimination provisions.⁶

Of course the most common use for this information is to give the parents the option of aborting a disabled child.⁷ Many genetic counsellors report that in every case they have dealt with of screening for a particular defect, abortion has followed a positive result. Sometimes these tests are inaccurate, so-called "false positives", so that some healthy babies are lost in the effort to ensure that unhealthy ones do not come to birth. But usually they are accurate and they are accurately used to ensure that those babies who have certain genetic disorders never see the light of day.

I do not need to rehearse the moral arguments for and against abortion. They are well known and I have published my own views in many places.⁸ Suffice it here to say that a cogent case has been made for the view that genetic screening with a view to possible termination of pregnancy is unethical because it involves formal or at least unjust material co-operation in the direct killing of an innocent human being.

Of course there are still people who resort to an arcane metaphysics or a misread biology in order to exclude some unborn human beings from the class of those who have a human 'soul', or who appeal to manifestly indefensible standards of humanity such as how the parents feel towards the child or how society feels. But I shall leave those approaches aside and focus on four liberal-utilitarian arguments commonly adduced in favour of prenatal screening followed by abortion.

4 Freedom to abort the disabled?

First, some assert that the decision to abort is a private decision for the mother and whoever she chooses to consult; it is she who has the right to control over her own body and everything that lives in her body. Since she must carry the burden with respect to the pregnancy, birth and upbringing of the child, her decisions in this matter must be paramount. Few today dare to question the right of autonomy and even if non-pregnant women do not have an absolute right to do what they please with their bodies we are loath to suggest anything less than absolute power for pregnant women. The obvious answer, of course, is that others are properly limits to our own will: a minimal boundary to any right or liberty must be respect for those same rights and liberties for others – in this case, the child in the womb.

But there are deeper questions to be asked about the whole focus on rights in this area – often by people on both sides of the debate. With rights talk often comes individualistic notions of relationships and property notions of bodies and persons. A more nuanced account of human relationships will resist any conception of the unborn as mere tissue, property of, or rivals with, their mothers. Motherhood is not ownership or competition. A richer conception of freedom will also recognise that few pregnant women fit the bill of the

idealised contracting agent in the free market when they are advised to have prenatal screening by doctors and medicine.

Even fewer women suffering the natural disappointment, grief, shame and anger of being told the child in their womb has some terrible ailment will fit that bill. Ambivalence, anxiety and depression, fear of rejection by friends and social stigma, inexperience of what caring for such a child

"A more nuanced account of human relationships will resist any conception of the unborn as mere tissue, property of, or rivals with, their mothers. Motherhood is not ownership or competition."

might actually involve, and much else besides, will radically limit the freedom of the woman or couple in this situation. The contemporary panacea of counselling will not necessarily solve these difficulties. Nor will pressures from outsiders, whether from friends who see termination as the easy or only way out, or from a community which fails to provide adequate alternatives, or from well-meaning doctors who automatically make

appointments for termination of pregnancy without seriously considering any other options. The fact that abortion has become our knee-jerk reaction to a positive

"Positive tokens of our community's compassion for the disabled are all too inadequately evident ... I suspect that there is more prejudice than mercy in our rates of genetic abortion."

genetic test presents a challenge to our supposedly liberal society to look seriously at what real options it is offering disadvantaged and distressed women.

Apart from the natural limits to agency, much 'right to choose' talk fails to take account of the intrinsic morality of our choices and their self-constitutive effects, what they do to us, what they make us and say about us. It also fails to take into account the web of relationships in which any choice operates, to consider the implications of our choices for other people's lives and for the common good. Any choice to screen for and terminate the life of a disabled child affects not only mother and child, but a great many other people. We might ask, for instance, what it communicates to surviving children of the same couple or to those disabled people in the wider community who have survived to birth, or what effect it has on attitudes in the rest of the community towards the disabled. I shall return to the matter of what eugenic abortion says to the disabled. For now it is enough to note that any community which willingly sends out such messages may well further reduce the opportunities of both disabled people and those parents who are 'irresponsible' enough to allow them to escape the gene screening net."

5 But are disabled unborn children persons?

Much of what I have just said is premised on the view that the disabled unborn are our moral equals. That assumption is, of course, far from uncontroversial. There are those who claim that the unborn child, and especially the unborn handicapped child, though human, is not a human person. Some assert that we must *qualify* for the status of person with all its attendant rights and interests. The qualification varies, but it commonly includes consciousness and self-consciousness, memories and preferences, social relationships and/or independence. It is a long and flexible list, which stretches or shrinks to suit the argument—very much like the use of various language tests in the days of the White Australia policy to exclude those regarded as 'undesirables'. If how these qualifications for moral worth are chosen is mysterious, how they are to be assessed and reconciled is even more obscure. This much, however, is clear: the tests are designed to ensure that the likes of the handicapped unborn will fail the "moral worth" exam.

My own view is that disabled people, wherever they live, whether *in utero* or *ex utero*, have the same dignity as everyone else and deserve respect and protection. Human beings only ever manifest the elite capacities so highly valued by utilitarians because they have human natures; and without some such conception of a nature shared by all humanity and worthy of respect, notions such as disability and human rights are ultimately incoherent.

6 Even if they are persons, aren't they better off dead?

Some people are honest enough to admit that the disabled unborn child is one of us but assert that such a child, like many newborn children and older people, is better off dead. I think it is incoherent to regard death as a better state than life, or to presume to balance up the good and bad things of life, as if on a scale. But it is the depth of incoherence and the height of presumption for anyone to make the judgment for *someone else*, to declare that someone else should never have existed, or to pretend to determine which disabilities are severe enough to warrant oblivion and which

ones to merit life.¹⁰ The handicapped themselves seem to be at least as happy as anyone else to be alive!

Of course this 'better off dead' kind of talk is commonly well-meaning, rooted in compassion towards the child rather than an obsession with self on the part of adults. Here the debate over prenatal screening shades into that over euthanasia. But if compassion for the suffering child and her parents were our real concern, we would expect that addressing that suffering directly would be our first response. We would be doing our best to ensure that disabled children were given access to high quality health care, education and a range of appropriate social and human assistance. We would ensure that their families also had access to appropriate support networks. We would be looking for creative responses to disability and very loathe to embrace destructive ones, such as discrimination, abandonment and homicide.

Yet sadly these positive tokens of our community's compassion for the disabled are all too inadequately in evidence. Which leaves me wondering about the *bona fides* of those who argue that compassion for the child is what drives them to support prenatal screening with a view to genetic abortion. I suspect that there is more prejudice than mercy here. Despite the fact that genetics has shown us just how common and relative disability is, despite the fact that sound philosophy has shown us that the disabled are our moral equals, despite the fact that long history and recent experience have shown us how well people can accommodate to or even overcome their disabilities, especially if they are well-supported — there are many who hold on stubbornly to the view that the disabled are better off dead. Dead, they are certainly less burden to others; but then we should be honest with ourselves and with the disabled that we are putting them out of *our* misery, not theirs.

7 Wouldn't we be better off if they were dead?

So we come to a last liberal-utilitarian argument for prenatal screening with a view to genetic abortion: that whether or not the child herself would be better off dead, others would be better off if she were dead. Here people have in mind the burdens that carrying

and raising a disabled child can be upon the couple concerned, their family and friends, and the wider community. They believe that those concerned simply 'could not cope' or that if they did it would be at too great a cost to their interests. Once again this seems to me to rely upon a humanly indefensible conception of our relationship to our children and philosophically indefensible claims to be able to assess that one person's life is more important than another's, or a group's than an individual's, or to balance the good and bad things in one person's life with the good and bad things in some other person's or persons' lives. Once again benevolent feelings get the better of sound reasoning, and compassion or selfishness may draw us to think that killing someone, however reluctantly and with however heavy a heart, is the best thing for all concerned.

The objections to the utilitarian claim to be able to predict, measure in advance, aggregate and compare all the good and bad effects of an action such as killing a disabled child are well-known and I need not rehearse them here. Suffice it to say that there is, in fact, no calculus that can account for the occurrence, timing, gravity, persistence and probabilities of all the various good and bad effects of the choices to 'let the baby live' or to kill her before birth. Even were such things calculable, they could not validly be compared on a single scale. Such balancing acts most often represent self-interested or sentimental intuitions, and the reduction of children to loci for pleasure units or preference fulfilments or occasions for such units and fulfilments of others — a radically dehumanising conception. They also incline us to compromise certain fundamental values, such as respect for the dignity of the disabled person and for medicine as therapy.

8 Some concluding concerns

Prenatal screening presents scientists, health professionals and professional bioethicists with new and intriguing moral quandaries, the stuff of ward meetings, committees of inquiry, university courses and endless publications. It also presents a voyeuristic public with the titillation of promises and dilemmas attractively packaged by our media for easy consumption and just the right amount of indigestion. But there are at issue much more

foundational issues. Is it reasonable to divide science from history, philosophy, theology, literature, and all other forms of reflection upon the world to the extent we commonly have? What should be the relationship between endeavours of human inquiry and techniques such as prenatal screening and the particular needs of individuals and communities? Have several thousand years of faith-seeking-understanding and medicine-seeking-virtue any wisdom to contribute to matters like genetic screening and engineering?

Genetic science, we are commonly told, is marching ahead so fast that ethics, law and theology have been unable to keep up. I suppose that is true to a point. But by 'unable to keep up' I certainly do not mean—as commentators all too often do—too slow to support the current research agenda; nor do I even mean incapable of understanding such complex issues. Rather, ethics, law and theology have been *unable* to respond because they have all too often been *disabled* by those with genetic power and knowledge, by being kept in the dark about developments or informed only on condition of silence or sycophancy. The result has been that while contemporary genetic science enjoys a technical sophistication unparalleled by any previous generation, and the potential for therapeutic applications which is very exciting, its moral wisdom and judgment is often unequal to the challenge of the science and technology.

NOTES:

¹ cf. Thompson, Margaret W (1991). *Genetics in Medicine*, 5th ed. Philadelphia: Saunders.

² Lawson, Nigel (1995). All you need is life, *Spectator* 17 June 1995; reprinted in *Sydney Morning Herald* 19 June 1995.

³ Ashley, Benedict M, O.P.; O'Rourke, Kevin, O.P. (1989). *Health Care Ethics: A Theological Analysis*, 3rd ed. St Louis MO: Catholic Health Association, p. 317; cf. Congregation for the Doctrine of the Faith (1986), *Donum vitae: Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation*, Sydney: St Paul's.

⁴ House of Commons Science and Technology Committee (1995), *Human Genetics: The Science and Its Consequences*, Third Report, 6 July 1995, vol 1. London: HMSO; §87.

⁵ cf. Anderson, W F (1992). Human gene therapy, *Science*, 256: 808-813.

⁶ House of Commons Committee 1995, §226; Atkinson, Gary M; Moraczewski, Albert S, O.P. (1980), *Genetic Counseling, the Church and the Law*, St Louis MO: Pope John XXIII Center.

⁷ cf. House of Commons 1995, §85.

⁸ Fisher, Anthony; Buckingham, Jane (1985), *Abortion in Australia: Answers and Alternatives*, Melbourne: Dove Communications. Fisher, Anthony, OP (1994), What abortion is doing to Britain, *Priests and People*, 8 (Nov), 414-419; republished in *Human Life Review*, 21 (2) (Spring 1995), 69-77.

⁹ Eccleston, Roy (1996), Death before deformity, *The Australian Magazine*, 20-21 Jan, 10-15; House of Commons 1995, §§86, 262.

¹⁰ cf. House of Commons 1995, §90.

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GORMALLY PAPER REPRINTED

*Why the Select Committee
on Medical Ethics of the
House of Lords
unanimously rejected the
legalization of euthanasia.*

In this paper, Luke Gormally explains why a Select Committee of the English House of Lords, which included several people known to think that euthanasia may be ethically-unobjectionable, nonetheless unanimously opposed its legalization. Gormally's paper was cited by several members of our Federal Parliament as the paper which helped them make up their own minds on the issue.

There was such a strong demand for this publication that it has now been reprinted. It is available for \$15 (\$12 to Associates) which includes the cost of postage. Please complete the order form with this issue of *Bioethics Outlook*.

Ethical Aspects of Human Genetic Engineering

Keith Joseph

It is fair to say that germ-line genetic engineering upon humans is not going to occur in the short term. We do not yet have the ability to engineer genetic traits so that they can be passed on to our offspring. Further, our ability genetically to engineer non-reproductive cells is still fairly limited.

If this is the case, then why discuss the ethical aspects of human genetic engineering? The answer is simple enough: if genetic engineering is ethically flawed, then we should not devote large amounts of research and resources towards developing the technique.

There are two forms of genetic engineering that can be done upon humans. The first of these is germ-line genetic engineering, where the genetic material of the reproductive cells of a human are altered, so that the changed genetic material can be passed on to future generations. At present this technique cannot be carried out on humans, though there has been genetic engineering of other species, including some crude attempts involving mammals such as white mice.

The second form of genetic engineering is somatic genetic engineering. In somatic genetic engineering non-reproductive cells, such as blood stem cells, are genetically altered, usually by the addition of extra genetic material. At present the use of somatic genetic engineering is fairly limited, and is usually concerned with remedying enzyme or protein deficiency through the addition of a gene which produces the deficient substance. The altered genetic material cannot be passed on to offspring.

Arguably somatic genetic engineering, because its effect is limited to the treated individual, does not raise any novel ethical problems. Rather it highlights certain ethical problems which already exist with other techniques - such as transplantation - which

are an accepted part of medical practice. However, I would argue that germ-line genetic engineering does raise unique ethical problems, and that at this stage there is insufficient reason to discount those problems and proceed with its development.

One way of looking at the ethics of genetic engineering upon humans is to categorise the uses to which genetic engineering may be put. Thus:

Somatic Genetic Engineering:

1. Therapy
2. Enhancement
3. Control or Punishment

Germ-Line Genetic Engineering:

1. Therapy
2. Eugenics
3. "Brave New World"

Somatic Genetic Engineering

First, I want to consider somatic engineering. The first purpose to which it can be put is therapy - that is, the alleviation of some disease. Now, it could be argued that somatic genetic engineering is still experimental - which no doubt it is - and that it will probably have a number of side effects, as yet poorly understood or unknown. I think all of this is true. However, it does not raise any ethical problems that have not been raised by previous experimental therapies, such as organ transplantation. If a person is terminally ill and has a chance of worthwhile treatment through somatic genetic engineering, then it is likely that the problem of side effects will be outweighed by benefit to the patient. Remember that in somatic genetic engineering, the altered gene is not passed on to offspring, and thus the main interest to consider here is that of the patient.

It might also be argued that somatic engineering is going to be an expensive technique, and that society should not bear the cost of such a technique. Even if this is true - and I suspect that somatic genetic engineering is going to be relatively cheap compared to, say organ transplantation or Intensive Care - it still raises no new ethical problems. Resource allocation is a problem that is already with us in a big way and, whilst we should not ignore this aspect of any new technique, it is hardly a problem limited to somatic genetic engineering. Thus, ethical problems associated with somatic genetic engineering being used as therapy are not novel; in principle, the use of somatic genetic engineering for therapy seems to be a good thing.

The second use to which somatic engineering might be put is enhancement: by that, I mean the use of somatic genetic engineering to enhance some desirable trait, such as stature or intelligence. I would see this as ethically problematic but not in a novel way: we already have a number of techniques for the enhancement of desirable traits, such as cosmetic surgery and the use of anabolic steroids by athletes.

The third use would be for control or punishment - for example, we might force a repeat sex offender to undergo somatic genetic engineering which would change his hormonal balance and thus reduce his

... the use of somatic genetic engineering for the purposes of enhancement, control or punishment raises no novel ethical problems in itself."

likelihood of re-offending. Ethically problematic as this might seem, however, it has its analogies in techniques such as physical or chemical castration. Thus it would seem to me that the use of somatic genetic engineering for the purposes of enhancement, control or punishment raises no novel ethical problems in itself.

Germ-Line Genetic Engineering

Germ-line engineering differs significantly from somatic engineering because the altered genetic trait can be passed on to future generations. As a result the consequences of germ-line engineering are far more significant, and any harms that may result are far more difficult to contain. If a mistake is made with somatic genetic engineering, it disappears within a generation; with germ-line genetic engineering the mistake can last forever.

The first category, as for somatic engineering, is that of therapy. In principle, this seems to be a good thing. After all, if it is good to ameliorate the suffering of one generation through somatic engineering, then surely it is even better to get rid of the cause of the suffering for all generations.

The third category, that of using genetics to create a "brave new world" where people are genetically structured to fit certain social roles, and to be happy in those roles is, I think, wrong. It is therefore the second category, eugenics, which raises the most obvious ethical problems.

Eugenics is based on the idea that there are certain desirable genetic traits that we ought to encourage ("positive eugenics") and that there are undesirable traits that we ought to discourage ("negative eugenics"). It extends well beyond what might be termed "therapy" in that therapy is concerned only with the cure, prevention or palliation of a disorder or disease, whereas eugenics is concerned with the broader concept of what is desirable and undesirable.

Traditionally, eugenics depended on selective breeding; and whilst this has proved possible with plants and non-primate animals, it has not proved effective with humans. The time between our generations has been too great to allow for effective eugenics: for example, to reduce a recessive trait from an incidence of 1 in 100 of the population to 1 in 1,000,000 would require thousands of years. However, germ-line genetic engineering offers the possibility of a more directed and effective eugenics. What, then, is the problem with this?

There are, I think, several serious problems. Firstly, the concept of desirable traits is very

much one that is dependent on social values and fashions. For example, most of us here would see intelligence as a desirable trait - but imagine a society where everybody was brighter. Would that society be any better off than this one? Why concentrate on improving the Intelligence Quotient ('IQ')? Why not try to improve happiness (for which there is just as firm a genetic linkage as for intelligence)? Why not concentrate on improving the 'Happiness Quotient' - 'HQ' - rather than IQ? Here we are the victims of our own prejudices - what is socially desirable for us is not necessarily what is going to be desirable for other cultures or even for our own descendants. Indeed, what is seen by us as desirable can turn out to be quite harmful in the medium to long term. Eugenics is but a form of social engineering - and as such is of dubious value. The history of social engineering is such to indicate that its long-term consequences are stultifying and dangerous to the society concerned: there is no reason to expect eugenics to be different.

Furthermore, what is seen by us as desirable is often that which confers a comparative advantage - such as height or strength. Eugenic intervention would have one of two effects - either it would eliminate that comparative advantage if it were available to all, thus eliminating its desirability, or it would entrench the comparative advantage and the discrimination against the less well endowed that would go with it. Neither of these is a desirable consequence.

Further problems would involve the tendency towards a genetic monoculture that would result from eugenic intervention, as desirable traits became more widely spread, and undesirable traits were eliminated. Almost all genes contribute to a large number of physiological functions; to eliminate a gene can have a number of undesirable consequences. For example, it is known that the gene responsible for sickle cell anaemia also confers protection against malaria; and we are largely ignorant of the various ways in which genes interact. In getting rid of an undesirable trait we are also diminishing our genetic diversity which is so important: for it is genetic diversity which provides protection for our species as a whole against various pathogens and diseases. To run the large risks

for humanity implicit in following transitory concepts of what is genetically desirable seems absurd; it is also running risks with our descendants that we should not be allowed to take.

The strength of our current gene pool has been tested by the slow evolutionary process of mutation and selection. If a mutation occurs, and it is dangerous for our survival, it starts off in a few and then dies out; if beneficial it rapidly spreads. There is thus a process of trial and error

which works its way out from a small base over a large number of generations. In contrast, with eugenics there is the introduction of a mutation in a large number of persons in a small number of generations. A mistake, even if not recognisable in this generation, will soon manifest itself in a large number of people with serious consequences.

Thus, there are good reasons for rejecting eugenics. An argument here, however, is that eugenics and therapy are different issues and can be distinguished; eugenics is broadly concerned with desirable traits, while therapy is concerned with the far narrower and more objective concept of diseases and disordered conditions.

However, this presupposes a fairly simplistic view of disease and genes. Whilst there are a few rare genetic disorders which express themselves regardless of the environment a person is in, in most cases genetic diseases are a combination of genetic and environmental factors. For example, many cancers require not only the presence of certain genes, but also environmental carcinogens. A further problem is that the concept of disease is often socially laden, especially in the case of psychiatric illness. However, even more physical disorders - such as lactose intolerance and melanoma - are an intersection of genetic traits and predispositions, and physical and

"There will often be no clear distinction between eugenic and therapeutic uses, save in the intent of the individual physician involved."

social environments. In a society which does not consume dairy products, lactose intolerance is not a significant problem: the widespread incidence of melanoma requires not only fair skin and sun, but also a society which likes to expose itself to the sun.

So, for example, would germ-line genetic engineering to darken the skin of Australians of Caucasian descent be therapeutic or eugenic? Would the attempt to raise the height of families who are below the average be an attempt to remedy a dysfunction or to encourage desirable traits? There will often be no clear distinction between eugenic and therapeutic uses, save in the intent of the individual physician involved - and the intention of different doctors is going to be a difficult concept to keep clear if we want germ-line genetic engineering for therapeutic rather than eugenic purposes.

In fact, the number of genetic disorders that would be remedied only by germ-line genetic engineering seems very small: most genetic disorders can be treated either by changing the environment (such as dietary control of PKU and lactose intolerance) or by pharmaceutical intervention. Germ-line genetic engineering is a Pandora's Box: by opening it, we may be

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able more effectively to treat some disorders, but we are certainly going to create a new society, and perhaps even a new species. This seems to me to be a prospect that we are quite unready for, and one that should not even be contemplated. I would argue strongly that germ-line genetic engineering of human beings should not be undertaken, and therefore we should not develop research or techniques with the aim of germ-line genetic engineering.

Conclusion

I have argued here that somatic genetic engineering does not, in itself, raise any novel ethical problems. It is, in many ways, akin to organ transplantation: there are ethical problems such as side effects, its experimental nature, and issues of resource allocation. However, these problems are not rooted in the nature of the genetic engineering itself.

In contrast, germ-line genetic engineering does raise serious ethical problems, which result from its objective of permanently changing the genetic structure of our descendants. In particular, there are the problems raised by eugenics, which is simply an attempt at social engineering which is more likely to harm, rather than benefit, future generations. Therefore germ-line genetic engineering is morally suspect, and we would be wise not to encourage its introduction by expending our resources on its development.

Keith Joseph lectures in Philosophy and Applied Ethics at Australian Catholic University. He is also a Research Associate at the Plunkett Centre for Ethics.

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ADVANCE NOTICE

INTENSIVE BIOETHICS COURSE

A virtues-based approach to the ethics of health care

Wednesday evenings 22, 29 April and 6, 13 May, 1998

The Auditorium, Australian Catholic University, Strathfield, N.S.W.

Forum on Reproductive Technologies

Early in 1998 the Plunkett Centre is to sponsor a Forum on the Discussion Paper on Assisted Reproductive Technologies which was recently released by the Minister for Health in New South Wales.

The Minister has indicated that he will introduce legislation to ban human cloning and trans-species fertilisation involving human gametes or embryos. He has also indicated that he wishes to obtain the views of the public on whether other aspects of current reproductive technologies should also be regulated by law in New South Wales as they are in three other Australian states.

Copies of the Discussion Paper can be obtained from: The Better Health Centre, 162 Blues Point Road, North Sydney NSW 2060, ph: 02 9954 1193, Fax: 02 9955 5196

Further details of the public forum will be available early in the new year.

Seminar on ethical issues in the treatment and care of people with mental illness

The Plunkett Centre will hold a seminar on this topic in the second half of 1998.
Further details will be found in the next issue of *Bioethics Outlook*.

Bioethics Outlook is a quarterly publication of the Plunkett Centre for Ethics in Health Care, a joint Research Centre of Australian Catholic University and St Vincent's Hospital, Sydney.

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