SHAPING GENES:

Ethics, Law and Science of Using New Genetic Technology in Medicine and Agriculture

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12. Selective Human Breeding

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Natural Genetic Selection

Every human being has a different set of genes, or genotype. The basics of this have been discussed in previous chapters. Sexual reproduction is a risky business, with a relatively high occurrence of mistakes. About 3% of humans born have some genetic diseases. There are at least 4,300 different genetic diseases known that are thought to be the result of single gene mutations (McKusick 1990). In 10% of these the protein abnormality has been defined. There are numerous other multiple gene disorders, and much is still unknown regarding the association between genes and health or disease.

The first steps in the prevention of genetic disorders occurs naturally. Many abnormal sperm cells are produced but only a minute fraction get physically close to the egg. A large number of oocytes that are extracted for IVF are not able to be fertilised, and it has been found that over a third of these have observable chromosome abnormalities (Pieters et al. 1989). Only 40% of conceptions begin to implant in the wall of the uterus (several days after fertilisation). Out of the embryos that are implanted 30% are spontaneously aborted before the mother would be diagnosed as clinically pregnant, and at least 25% are naturally discarded subsequent to the mother being diagnosed as pregnant (Austin & Short 1985). The number of spontaneous abortions from all human conceptions is estimated to be between 45% (Steer et al. 1989) and 80% (Leridon 1977). A large percentage of all conceptions have a cChromosomal abnormality (Connor & Ferguson-Smith 1984). About 30 to 40% of human preembryos resulting from IVF are chromosomally abnormal (Braude & Johnson 1989). The magnitude of human pregnancy loss is greater than that of other mammals. During the human life history there are changes in the types of genes that are expressed. If a genetic defect is present in a gene required during fetal life then the fetus may die and be spontaneously aborted. The majority of genetic defects seen at birth may then only be in genes that are needed after fetal life, and were not needed during embryonic growth.

There is a difference in the way that human beings respond to chemical mutagens at different stages of development. Before implantation the embryo is very sensitive, to temperature or chemical agents, and has a very low resistance, and often will fail to implant. Embryos after implantation vary in their response and develop different types of malformation (Zusman & Ornoy 1990). Mammalian embryos have been shown to be much more sensitive to external influences than avian or reptilian embryos. Human embryos are most sensitive to chemicals during the first 8 weeks of development.

Our genetic information is very important in determining our physical character, and some of our intellectual capacity. This is especially clear in cases of people suffering from genetic disease. The effect that those people have on a family can be good or bad, some people can cope with it and some can not. Some of the suffering that such people have is the suffering that healthy people have in their own minds, as the handicapped people may not know life to be any different to what they have, that is we can impose our life goals into their lives, however, some suffering can be real, especially when they suffer much pain all their life. The suffering of the family can also be very real, and preoccupying.

The word eugenics was coined by Sir Francis Galton, and is derived from the Greek word "eugenes" which means "well born" or "hereditarily endowed with noble qualities". This idea may be separate from the very common view that the mating of people of "good views" is desirable, to give us more offspring of that view, but we will see that eugenic proponents have often retained this idea. This chapter seeks to analyse some of the ideas and themes associated with the long history of eugenic thinking, before examining the question of genetic screening in the next chapter. Eugenics differs from other human activities in that it is an activity in which we are trying to change ourselves, not the environment or other creatures, and therefore is particularly challenging.

Eugenics in Antiquity

For millenia people have had ideas of selective breeding to increase the representation of people with "good genes". Plato had considered the desirability of achieving these ends by subtle, or direct, incentives to control marriage, and/or mating, of supposedly 'fit' human beings. This is what we could call positive eugenics, as opposed to negative eugenics which refers to the policies intended to reduce the occurrence of genetically determined disease. It may be difficult to draw the line between the two with some recent genetic techniques.

Babies born with major deformities were often killed at birth, and sometimes an image in their likeness was made as a type of idol. The most ancient sculptures of double-headed twins are from 6500 BC (Warfary 1971), and many others around the world have been found. The birth of these children was seen in the ancient world as a sign from god, specific predictions were made from each deformity. Consanguineous marriages were banned in most nations of antiquity. In general, the safeguards against degeneration of the human race were isolated, never religiously motivated and seldom were enforced by legal enactment (Jakobovits 1975). The practice of killing off deformed infants was very common until the last few centuries. Martin Luther is recorded as saying that Siamese twins are monsters and do not possess a human soul.

In Graeco-Roman antiquity most families were small, due to disasters like wars, epidemics and famines, and certain practises such as homosexuality, extra-marital relations and celibacy, and a high infant mortality. Methods used to limit the number of offspring included exposure of newborns, some abortion, but little contraception (Eyben 1981). Abortion was practised by Assyrians, Babylonians and Egyptians, but probably not the Jews. Abortion was hazardous to the mother, so exposure was more often used, and was widespread especially among the poor. Sometimes the child was killed by drowning or strangulation, or just exposure in the town market place. Malformed babies were routinely killed as they were considered a burden on society.

The Spartans used exposure to the environment to kill imperfect babies (Plutarch II). Every father had to present his child to a council of elders. If it was not healthy it had to be exposed, as it would not become a good citizen or soldier. On, the otherhand, if a man had three sons he was relieved from military obligations, and if he had four sons, exempt of taxation. Plato in the *Republic* (Plato IV) advocated the abolishing of private homes and families for a single class of Guardians. The Guardians could then breed and rear children of the highest type using the methods used for breeding animals. Sexual intercourse was to be strictly controlled. There should be "as many unions of the best of both sexes, and as few of the inferior, as possible, and only the offspring of the better unions should be kept as guardians." In *Timaeus* (Plato I) he advocates only the children of the good should be educated. In the *Republic* he recommended that defective babies should be hidden away in a dark and secret place, though it is vague whether he means infanticide, or relegation to the lowest class. Plato was interested in the quality of babies from a point of the State, as have most recent proponents of eugenics. Plato advocated the deceit of citizens in the manipulation of the quality of stock of the human "herd", as he knew people who were prevented from breeding would not be so happy. He would do this by rigging the drawing of lots.

Aristotle also postulates a hierarchy of human worth, men with fully developed virtue(s) being most fully human. Aristotle supported the exposure of handicapped infants (Aristotle IV), though some ancient writers opposed this (Amundsen 1987). The early Roman empire showed increasing respect for human life with the rise of Christianity, though the fetus was not considered so highly as it is today. Abortion became illegal, and infanticide became a capital offence in 374 AD, and after much earlier public opposition. Infanticide of handicapped newborns was practised in more modern times in Europe, especially by the Vikings, and in Japan until this century, and still indirectly in many countries today in cases of severe handicap.

Polygamy is a human behaviour pattern that has affected the genetic composition of human populations. This practise generates a more intense selection between males of that society, as some men are excluded from reproduction, whereas others reproduce more. Sex selection is another long practised method, becoming more common today with decreased family size.

In Jewish law, incest is forbidden, because it is a breach of morality, not because of eugenics. However, it is recommended that a marriage partner should be chosen with the well-being of the progeny in mind, so men should chose a wife prudently (Feldman 1976). Jewish law goes further than others in cultivating the eugenic ideal (Jakobovits 1975). The Talmud rules that a man may not marry into a family of epileptics or lepers, so we could extend this principle to other diseases and it is eugenic. Marriages to insane persons are illegal, and every man has an obligation to chose the partner equipped with the highest intellectual and moral virtues. The verse "cursed be he that lieth with any manner of beast" is applied to those who marry the daughter of a feeble-minded man. Also important is the compulsory dissolution of marriages that are sterile after ten years. There could also be eugenic ideals behind the law which states that if a women loses two husbands by "natural" death, then she can no longer marry, either because of her bad "luck" or "the well of her womb", such as venereal disease. The Jewish approach to eugenics reveals an awareness of the individual's responsibility to society and the generations ahead (Jakobovits 1975). There is more teaching that the Jews follow that may have eugenic aims: A hidden physical blemish in a bride is grounds for invalidating a marriage. In the Talmud, a Jew is told to be very careful in the choice of a mate (Bava Batra 110a). The faculties that are good for a father to bequeath to his son include 'looks, strength, riches, and length of years' (Eduyot II, 9). The Talmud rules that a man may not marry into a family of epileptics, or lepers, or similar disease. Today that is applied to any serious genetic disease. The Jews of early times did have a knowledge of genetic connections, for example if a son was born, and his two previous brothers, or two maternal cousins had died after circumcision (by hemophilia), he could not be circumcised (Yevamot 64b).

There are various verses in the Bible that deal with questions of reproduction and sexual behaviour. Some of these are clearly for moral reasons, such as "Thou shalt not commit adultery". Others have moral teaching, such as laws against incest, which coincidentally are consistent with eugenic good, that is, less likelihood of genetic disease being caused by combination of two recessive harmful alleles of a gene by forbidding marriages between closely related persons, the reasons for them could be eugenic as well as social (Bassett 1976). Some verses support eugenic ideals, such as the banning of marriage between close relatives (Lev. 18:6-13), and possibly the ban on marriage of people maimed in their privy parts (Deut. 23:1), and the ban on any priest who has a physical defect presenting food offerings to the Lord (Lev. 21:16-23), as they were considered unholy. However, the prophet Isaiah reproved King Hezekiah because he had excused his refusal to marry as a fear that the children would be wicked. The Prophet said "What do you care for the secrets of God? You should perform your duty, the pleasure of God", which is not consistent with advance human planning.

Eugenics in Modern Times

The idea of some groups of human beings being inferior to others was often based on intelligence, or a method prescribed to define this. The rational was called superior to the animal, thus Aristotle claimed women and slaves were inferior by nature because of diminished reason and being closer to an animal state. The 18th century biologists claimed to prove that Negroes' skulls and physiognomy most clearly resembled those of apes thus justifying slavery (Greene 1959). Superiority is often judged by how close people approach to the 'ideal' of intelligence and rationality (Rothschild 1988).

The concept of inherited criminality was initiated in recent times by the Italian, Cesare Lombroso in 1876. This was to be a major motive for the following eugenics programs, the methods of Lombroso were refuted by the English prison doctor Charles Goring but he supported the view that mental deficiency was inherited. Galton (1869, 1883) had written to say genius was inherited, and this was accepted by many scientists, including Darwin (1871). Galton (1883) defined eugenics as the science of improving the "stock". Eugenics was defined by Galton as the study of agencies under social control that may improve or impair the racial qualities of future generations either physically or mentally. He intended eugenics to extend to any technique that might serve to increase the representation of those with "good genes", in this way accelerating evolution.

A major motivation underneath many eugenicists was also the idea of human progress, that we must be progressing genetically as well as in our knowledge. This was boosted by the theory of evolution, the survival of the fittest was equated with the survival of the best. The best were the best people to cope with modern life. Galton was a cousin of Charles Darwin. Social Darwinists' tended to equate a person's genetic fitness with his social position. Social Darwinist ideology provided a good climate for eugenic thought, and many qualities such as intelligence, temperament and behaviour were believed to be inherited (Ludmerer 1978, Kelves 1985). The eugenicist's concept of the best human was their idea of the "perfect man", which tended to be an intelligent white male of northern European stock, who had been said to have a larger brain. Some eighteenth century philosophers had believed in the possibility of human perfectibility. There was also a fear that the "stock" was deteriorating.

After the publication of Galton's book in 1883, and the growing acceptance of its ideas, he was to inspire and become the Honorary President of the English Eugenics Education Society in 1908. Since then the Eugenics Society, which in 1989 changed its name to the "Galton Institute", has shifted from the early position of defining people like themselves as "more suitable" and various groups of people as "less suitable", to that of supporting the ethical introduction of advances in human genetics. In the first few decades of this century the effort to do this was based on applying the wisdom of animal breeders. An alleged national interest in the quality of the gene pool of the population was valued more than individual reproductive autonomy. The eugenicists believed that they would save the world, and were very optimistic. They varied, as they have in the past and at present, on whether they support merely a programme of incentives or compulsory measure such as state-controlled breeding and compulsory sterilisation.

To present eugenics as a respectable creed many famous religious leaders, from Christ, down to politicians and artists were sometimes falsely presented as supporters (Searle 1976). Eugenic Societies were created in England, United States, Canada, Scandinavia, Italy, Austria, France, Japan, and South America. Galton left his estate to found a National Eugenics Centre, with the statistician Karl Pearson at its head (Kevles 1985). The Galton Laboratory became the British centre of research, and trained many international scholars. Also in the early 1900's the ideas were well accepted in the United States. The U.S. national headquarters were at the Eugenics Record Office at Cold Spring Harbour, where the leader was the geneticist Charles B. Davenport. Davenport had visited Galton and Pearson at this time. This institute was for the experimental study of evolution. Davenport conducted family pedigree studies over many generations, as he was concerned with Mendelian style inheritance of the genotype, whereas the English were more concerned with the phenotype and often only studied parent and children trends. Whenever family pedigrees showed a high incidence of a given character he concluded the trait must be inheritable, and tried to use single elements of heredity (Davenport 1911). The American Eugenics Society was formed in 1923 combining many smaller committees. The development of eugenics was associated with a political desire to use science to solve social problems (Allen 1989).

A principle concern of the eugenicists was the lower fecundity of family "stocks" from wealthy, and more educated, families. As these people were from this type of family they had fears of their progeny being swamped by large numbers of progeny from uneducated, and thus genetically unfit, classes. These ideas were around before 1900, but people had been ignorant of the process of heredity. Chromosomes were known to be carriers of the genes only around 1900. This gave a rule for the transmission of traits, so instead of relying on ideas from animal breeders, they now had a biological theory. There was some scientific backing found for Lombroso's and Goring's conclusions on hereditary deficiency, as the idea of the Intelligence Quotient, I.Q., was introduced by the book of Pearson and Jaederholm (1914). This was in the face of many studies showing that traits were determined by complex traits and the effect of the environment, but these were largely ignored.

The eugenics movement was responsible for introducing a sSocial class classification in 1911, with the Registrar General of England, Bernard Mallet, a future president of the Eugenics Society (Austoker 1985). The lower social classes were viewed as the sources of criminals but had greater fecundity. These classes were thought to be caused by genetic, rather than environmental problems, having higher infant mortality because the mothers were incapable. This social class analysis is still used, and has been called an embarrassment to epidemiology.

Public support for eugenics grew. Many churches came to support it, and claimed that the Bible was a eugenic book. Competitions were held to see whose family was the fittest, and displays in fair grounds illustrated the "science" of eugenics. Biology had become popular (Kevles 1985). People also objected to paying many taxes to pay for criminals and for maintaining handicapped people. During World War I intelligence tests based on the Binet-Simon, I.Q. Test, developed by Robert Yorkes, were used to place recruits in their "appropriate" place in the army. After the War these tests were popularly accepted, and Yerkes drew up the standard National Intelligence Test. Courses teaching eugenics were offered in many Universities in the 1920's.

In Soviet Russia in the 1920's there was a strong eugenics movement, centred among the geneticists (Graham 1987). The emigration of nobility, upper class families and scientists, as a result of the Revolution, was seen as a serious loss to the genetic resources of Russia, requiring eugenic correction. In the late 1920's they were criticised, for ignoring the principles of Marxism, which said social conditions determine consciousness. The Bolsheviks advocated a widespread artificial insemination program in the early 1930's, but they lost political power. Herman Muller tried to persuade Stalin that the use of eugenic AID would be desirable, but soon after this the Lysenkoists forced the closure of the Institute of Medical Genetics, and several of his colleagues were shot (Adams 1989). Eventually Lamarckism dominated Russian policy as it was seen as more consistent with Marxism, and eugenics was shunned. The eugenic excesses were used against genetics, to claim it was fascist.

There were eugenic policies in about forty countries, but as can be seen they varied widely in the practises used to effect the idea (Adams et al. 1990). There were sterilisation programs advanced in many countries, as will be discussed in the next section. They were particular prevalent in Northern European countries, such as Scandinavia and Germany, and were rejected in Britain, Holland and some central European countries (Roll-Hansen 1989).

Sterilisation Programs

Sterilisation practises are very ancient, and worldwide. Some early laws such as Jewish law outlaw sterilisation by surgery or drugs. From 1900 to the 1960's the main eugenic practise involved the sterilisation of the undesired. Abortion was officially illegal in this time, and birth control did not reach the poor. Some countries had marriage restriction laws, which were more used in Britain. In Britain less eugenicists were convinced of the necessity of sterilisation than in the USA, and in Britain it was considered by the courts as generally being illegal. The most infamous of these methods were the eugenic practises of the Nazis, but their practises were based on an earlier legal tradition.

In the USA negative eugenics was effected by two major types of legislation: involuntary sterilisation laws and the Immigration Restriction Act of 1924. The first state sterilisation law was enacted in 1907 in Indianna. There had earlier been two unsuccessful attempts at eugenic sterilisation of mentally incompetent patients, in Michigan in 1887 and Pennsylvania in 1895. A publicised turning point was the 1927 court case of Buck v. Bell, where a judge remarked that "Three generations of imbeciles are enough" (Lombardo 1985), and likened sterilisation to vaccination. Analysis of this case revealed that it was probably rigged to provide a model case for eugenic sterilisation. The courts began to invoke the proposition that "common welfare" overrides any "natural right" of procreation. Applied eugenics was more readily accepted in the USA than in England. Laws were also passed in Canada. In 1931, thirty states had enacted compulsory eugenic sterilisation laws, and in 1937, 32 states had such laws. Most of these laws were not rigidly enforced, but by 1935, 20,000 people had been forcefully sterilised, nearly half in California. These laws may be applied to a wide range of "hereditary defectives", including "sexual perverts", "drug fiends", "drunkards", "epileptics", and "diseased and degenerate persons". In the 1930's families who were drawing money from social welfare were encouraged to be sterilised. There was a noticeable increase in the number of sterilisations performed during the Depression, as institution officials were afraid more births of handicapped people would strain social services (Reilly 1987). The situation was changed in a 1942 supreme court case, Skinner versus Oklahoma. The court membership had changed since the earlier decisions, and the Oklahoma law was judged unconstitutional, and marriage and procreative rights of individuals were stressed (Petchesky 1979, Letterie & Fox 1990). In nineteen states these laws are still existing, though under stricter federal control, making it difficult to sterilise mentally disabled persons.

The Immigration Restriction Act was specifically designed to decrease the proportion of poor immigrants from southern and eastern Europe (immigration from Asia had been curtailed earlier) by setting the quotas to the optimum year, 1890 (Ludmerer 1978). Part of the argument was that they thought that these people were inferior, and also that these countries did not enforce eugenic control, so the nation's biological strength would be weakened. In some countries where specific eugenic policies were not accepted, there may still be immigration laws that support such ideals. In Australia immigrants can be excluded if they are carriers of genetic disease (Sillence 1990). Even if countries protect their citizens, they can maintain immigration laws with eugenic overtones.

Some of the conditions thought to be heritable were "nomadism", "shiftlessness", and "thalassophilia" (love of the sea) (Haller 1963). The American Eugenics program was tied to the European programs. In 1935 the American Eugenics Society produced a major work called "Tomorrow's Children" (Huntington 1935). They estimated several million people were in this category of "feebleminded", epileptics or insane. It recommended that while some of these defects might be "purely environmental in origin", these people would produce defective children if allowed to bring up children. It expanded the number to five million adults and six million children who were"subnormal in education", and another twenty million who failed to finish grammar school (Mehler 1987). It recommended that these people should not be allowed to breed, though not all should be sterilised. Davenport had argued for individual selection, but by the 1920's this had been submerged in a principle of racial- or ethnic-group selection (Kevles 1985). Margaret Sanger, the birth control campaigner, argued that the chief issue of birth control is "more children from the fit and less from the unfit" (Sanger 1923).

The idea of eugenics in Germany was called Racial Hygiene, and was founded by Alfred Plotz in 1895 (Hubbard 1986). He was the founder of the leading German Eugenics journal, and a central figure in the movement from 1900 to 1920's. He did not defend economic competition on grounds of Darwinism, and criticised both capitalism and socialism. He wanted to found a Eugenic Society that would put the good of the future above the comforts of the present. Socialism was too soft on the weak, and capitalism was too hard, but gave too much advantage to the wealthy (Graham 1981). By the middle 1920's there were arguments in terminology, right-wing members prefered "Rassenhygiene", and left-wing members, "Eugenik". People began to criticise the movement saying that science was being subverted to politics, and "race delusion was conquering German science". The left-wing proponents started to use Lamarckism which made them easily attackable from the right-wing Mendelian geneticists. There was also an attack on Rassenhygiene as a bourgeois science serving the ruling class of German capitalists, though they still supported eugenics. The anti-semitism and eugenics programs were supported both by Hitler and some right-wing doctors and eugenics supporters (Kater 1987).

The European laws were modelled and inspired from the American sterilisation laws. The German sterilisation program was based on a law passed in 1933, at a similar time to many other European countries, which were modelled and inspired from the American laws. Earlier, some Germans had criticised the backwardness of German Law compared to the USA in passing eugenic sterilization laws (Lifton 1986). The German law on the *"Prevention of Hereditary Diseases in Future Generations"* played a very important part in the health and population policy, and was subsequently connected with the mass murder of Jews, Slavs and other groups up to the end of the war. The legislation that the Nazis promulgated in July 1933 had been developed in earlier years under the lobbying of Wiemar, and sterilisation had been widely recommended by the end of World War I.

The German sterilisation law went beyond the American laws in that it applied to all persons institutionalised or not, who suffered from disabilities (Kevles 1985). The doctors were called to identify candidates for sterilisation. In America however, some people were brought specifically into institutions so that they could undergo sterilisation, then they were released. The Americans were critical of their government for not implementing the eugenics program as thoroughly as the Nazis. Though it is unlikely that the Nazi program, that began in 1934 resulted in an increased number of sterilisations being performed in the USA (Reilly 1987). In 1937 the secretary of the American Eugenics Society, Frederick Osborn, remarked that "the German sterilisation program is apparently an excellent one". There was similar ideology and much collaboration between the two programs. There were many Americans supportive of the German laws, some calling them model (Mehler 1987). Ninety percent of the American biology texts from 1914 to 1949 discussed eugenics, many commenting favourably on the German program. The Journal of the American Medical Association frequently published detailed accounts of the Nazi program in a weekly section called "Foreign Letters".

Nazi Eugenics

The goals of the Nazi eugenics program had been outlined in 1933 by Wilhelm Frick (who was executed at Nuremburg). He estimated that 20% of the German population would have progeny that was "undesirable". By 1939, 0.5% of the total population had been sterilised, by 1945 about two million had been sterilised. Most of these people were between 15 and 17 years old (Pfafflin & Gross 1982). In some areas they were more efficient, by 1938 in Hamburg, 3% of the population had been sterilised. It was not until 1972 that these people could apply for financial compensation (limited to 5000 DM). The law was annulled, but remains on the statues, so that orders issued under the law continue to be valid (Pfafflin 1986).

The program involved the establishment of Hereditary Health Courts, with two doctors and one judge. The trials were closed, and no doctor presenting evidence could hold back any information. Medical record offices were established, and by 1938 had every person's history stored. The next stage was to use euthanasia to kill off handicapped people, from 1939. The connecting link to the murders was probably the commencement of the murder of psychiatric patients in the war (Pfafflin 1986). In August 1939 every handicapped newborn baby had to be compulsorily registered (Aly & Roth 1984), where a committee of three consultants would meet to decide the fate. In 1943 the criteria included "gypsy, Jew or half-breed". By 1940 the killing of adult psychiatric patients started, the T4 campaign. Accurate records were kept, up until August 1941, 70,273 psychiatric patients were murdered by gas chambers, this "disinfection" saved 88,543,980 Reichmarks annually on food. After a time the killing was decentralised, and called "random euthanasia", using poisoning or starvation as well. Also part of the reason for decentralisation was loud protests from the church (Proctor 1988). Starvation was used by doctors as a passive means of death if they found active killing too much against their ethical code (Hubbard 1986). Then the 14f13 campaign began to select and eliminate sick concentration camp prisoners, and this led to the "final solution". Euthanasia programs were also carried out in Poland and occupied Russia. Concurrent with this was the "Brandt" campaign used from 1943, against "racial undesirables" and "asocials". The targets were inmates of various nursing homes and juvenile concentration camps. The newborn children of foreign labourers were killed during delivery.

The doctors involved, believed that killing was a medical procedure (Lifton 1986). The doctor had a loyalty to the nation as a "cultivator of the genes", above his responsibility to his patients. The Nazi doctors had a central role in the genocide. Historically, the main groups of people considered for compulsory sterilisation have been the mentally incompetent, criminals and the poor. People who may not have been able to give informed consent even if their consent was required. There were also the people carrying a genetic disease in the family. In both the American and European literature we see the comparison of removing degenerate human beings from the world with the removing of cancer cells or disease from the body (Huntington 1935). One of the well known doctors of Auschwitz was Joseph Mengele. He became the research assistant of one of the leading figures in eugenics research, Freiherr von Verschuer, where he was involved in twin research and in relations between disease and racial types. In 1943 he was appointed chief physician at Auschwitz where he conducted research on series of families (Lifton 1986).

During the War some English and American Scientists still supported eugenics, and it was said to be of vital importance (Huxley 1941). The idea of euthanasia was also seen in American journals, up to an age limit of 5 years (Kennedy 1942). This idea was accepted favourably by some other American psychiatrists (Hollander 1989).

Sterilisation was not the only method of the Nazi eugenics program. In the interests of improving the German race, biologically sound couples who gave birth could reduce their government loans. There were special subsidies for the third and fourth children born to fitter families. Members of the SS were encouraged to father numerous children with racially preferred women.

The Decline of Eugenics

The eugenic sterilisation programs went into decline in the 1940's, largely because of the eugenic excesses of the Nazis. The Nazi war leaders were executed, including some doctors involved in eugenic practises. Although in its initiation the Nazi program was aimed at the "feebleminded", it eventually led to the systematic extermination of many people, including those who were to be sterilised, and homosexuals, Jews, Slavics, and opponents of the Nazi political views. The Nazi program had failed to separate science from politics (Roll-Hansen 1989). The American and other European Eugenicists' had to be on the defensive, and claimed that these Nazi excesses were the casualties of war. This association of eugenics with racism has been very harmful for its public image, but racism featured in eugenic programs of other countries also. However, sterilisation operations were still performed after the war for another decade, particularly in Georgia and North Carolina in the USA (Reilly 1987).

The Catholic Church had long opposed eugenics, as in Church doctrine, in the scheme of God's creation man's bodily attributes are secondary to the Spirit. Eugenics was condemned by Pope Pius XI in 1930 (Pope Pius XI 1930). Secular critics shared the dislike of biological reductionism, some did not like the growing authority of science, and its intrusion into individual breeding rights (Kevles 1985).

There had been many scientific arguments against sterilisation being an effective measure, and eugenic principles themselves. In 1904 a British Committee appointed to look into physical degeneration, i.e. increasing crime rate, found that the claim of eugenicists was false: the number of criminals was dropping. By the 1920's, many people held that there was no intellectual deterioration either. There was criticism of I.Q. testing, and the growing association of mental deficiency to environmental conditions. There had been work disproving the eugenic stereotypes of races, such as the American Negros (Klineberg 1935), and by the end of the war public opinion had already switched to believing that there were little innate differences (Kevles 1985). In 1950 UNESCO issued a statement on race, with commentators including the major figures in the eugenics movement, Klineberg, Muller and Huxley (UNESCO 1950). There was a growing emphasis on the importance of the environment in determining the phenotype, with less dependence on heredity (Freeden 1979).

A major proof against sterilisation being effective eugenically was the Hardy-Weinberg Law, from 1908. They had observed that while "undesirable" genes are seen in the sufferers of some diseases, the genes that might be responsible for the traits were widely dispersed in people who do not manifest these diseases or traits. This analysis describes the behaviour of recessive harmful alleles. It was subsequently found that some of these harmful traits have been positively selected in some populations, because in the heterozygous state they confer an advantage on the carriers, for example sickle cell disease in many Africans, and the gene for Tay-Sach's disease in many eastern European Jews. This argument is also a powerful argument against future eugenic selection: we do not know the future diseases in which some apparent defect may be advantageous. If we used a sterilisation program against a recessive allele that is in the population at a frequency of 5%, it would take 200 generations of total sterilisation of the homozygous individuals to reduce the frequency to 2.5% of the individuals carrying the allele. Though there would be significant reductions in the number of homozygous individuals born during the first few generations. The presence of carriers who did not express the defective trait meant there would always be potentially new homozygous individuals in the population, and continued screening would be required to detect them.

Some claim that because we are keeping many genetically handicapped people alive long enough for them to reproduce this has led to genetic decay. This has been an argument of eugenics' supporters for the last century (Huxley 1963). This has been a much used argument in the past, but it is not substantiated by evidence. There is no evidence to say that the human gene pool is deteriorating because we can treat genetic disease. Even if there are many people reproducing with the genetic diseases the impact on the gene pool is very slow. In the case of a single recessive gene in the population at a frequency of 0.5%, it might take 70 generations for the incidence of the gene to double, to 1% (Crow 1968). What may be more important is the rate of new mutations occuring, because of environmental hazards such as radiation or chemicals, and the best strategy is to eliminate these hazards from the environment. Certainly pPrenatal screening and selective abortion can reduce the number of individuals born with genetic diseases. However, the ethical justification for using these techniques is not to be found in protecting the interests of society but on protecting the interests of individuals and their families. This screening can have a major affect on the next generation, for instance the annual number of children born with Tay-Sach's disease in the USA used to be 50, but since the use of genetic screening the number has fallen to 10-12. For the forty families that do not have a child born, it makes a major difference.

A recent study of the incidence of genetic disease in Europe has shown that the incidence of genetic disease among people born is actually falling (Modell & Kuliev 1989). The assumption that medical care to prolong life has led to more handicapped people in the population has been found to be only a minor part of the influences upon the population structure. People also may think there are more handicapped alive because with modern help they are able to leave the confines of hospitals and houses and enter the wider world. The social and demographic factors are more powerful influences on the frequency of people born with genetic disease. For example the patients can live in open society and are encouraged to enjoy normal life as much as possible, including reproduction. In European countries prenatal screening is offered, which has decreased the incidence of Down's syndrome by 30-60% depending on the country. Improved health care has eliminated heterozygote advantage in malarial zones for some hemoglobinpathies, and the theoretical birth incidence of thalassemia in Cyprus has fallen 11% in the last fifteen years (due to prenatal screening and selective abortion the incidence has greatly reduced). The reduced paternal age has had a consequence of reducing the spontaneous mutation rate significantly also. Population mixing reduces the incidence of harmful recessive alleles in particular localities further reducing the incidence of genetic disease. The incidence of consanguineous marriages is also decreasing. It appears that the aims of eugenicists may be being accomplished but not with their methods which violate individual autonomy but through social changes, together with some influence from genetic counseling.

There has been recognition of the greater importance of nongenetic factors in determining intelligence, criminality and social desirability. It has been found that the trend in the USA for family size to be decreasing can be correlated with an increased level of educational attainment. The less siblings there are, the higher chance of continuing education. Parental interaction may also improve verbal ability, which aids education. However, there are many negative social influences, such as increased numbers of divorces and soloparent families, which has been associated with social and developmental problems.

Changing the Dominance of the Genes

At the time, when we are expecting to soon determine the entire human genome sequence, and when we already have several hundred examples of genes that link to physical and mental characteristics, we also face the older question of how we regard children who are not genetically related to one or both of their parents. The flood of information may have a good effect in diminishing the power of deterministic thinking. Determinism says that because we have a particular gene or combination of genes, we are likely to grow up to behave in the corresponding way. It is the long standing nature/nurture debate. Most accept that we need a balance of views. There are certainly some complex genetic influences upon behavioural variability, the question has narrowed to tracing out the details, and of the mechanisms of these influences.

Recent studies have shown that both nature and nurture are important. In a French study, the average I.Q. of adoptees was higher when reared by parents with a high rather than a low socio-economic status. There I.Q. was also higher if their genetic parents were of higher socio-economic status (Capron & Duyme 1989). This data is consistent with data from twin studies and other adoption studies (McGue 1989). If we want to improve the intelligence and general upbringing of children we should also spend resources to find out what environmental factors are the best for children and then try to improve them. This type of study requires less finance than an approach based on the discovery of all the genetic elements, and might have a greater positive impact.

The American Eugenics Society changed its name to the Society for the Study of Social Biology in 1972. The social environment was thought by some, such as Muller, Huxley and Osborn to be one of the main directors of natural selection, and that eugenic goals could not be readily achieved in capitalist societies (Bajema 1976, Freeden 1979). Capitalist society is dysgenic (Huxley 1936). Osborn (1940) advocated a type of social welfare state to aid eugenics. The issues of eugenics and the ways it may be implemented in public policy are not just based on genetic ideas, but consider the economic and social system.

Within the next century we should expect to know the answer some of the detailed questions of each trait, as the entire variety of human genes begins to be characterised and categorised and studies extended to tracing the pathways between environmental affects on our genes. It is possible we will become very deterministic in our attitude to behaviour. While our society has strived for greater knowledge, something which is supported by Biblical religions, the ability to decipher the genes of humans ourselves is a pinnacle. Also, associated with this knowledge will be the ability to exert large power and influence. However, we can not run away from the research, there will still be many mysteries of life, and there is enough variety among human beings to ensure that. We must acknowledge the threat of deterministic thinking and move to stress the environmental influences that affect children's personality development.

Control of Reproduction

There is a movement for doctors to become much more involved in aiding reproduction. There aim is to bring about the birth of children with the greatest possible care. One of the aims of eugenics today is the "application of societal measures at improving physical and mental attributes of future generations" (Eugenics Society 1988). This is not in itself dissimilar from most peoples' attitude. It is held by many that it is in the interests of the state to reduce the incidence of genetic disease (Mason & McCall-Smith 1983)

Because of past abuses there are efforts to protect individuals. To counter fears of eugenics the Council of Europe requested "explicit recognition in the European Human Rights Convention of the right to a genetic inheritance which has not been interfered with, except in accordance with certain principles which are recognised as being fully compatible with respect for human rights". Courts have at the same time recognised a "right" for parents to decide whether a handicapped newborn should undergo treatment, or be left to die, in cases such as the Arthur trial in Britain, or the Baby Doe trial in the USA.

Some people had dissociated themselves with the mainline eugenics movements in the 1930's, such as Herman Muller, because they thought eugenics had been perverted into a pseudoscientific facade for advocates of race and class prejudice (Muller 1935). Muller hoped that the principles of evolution would be applied to human betterment, but did not allow his name to be used with any eugenic organisation because of that belief (Carlson 1981). His book *Out of the Night* was written from a socialist perspective. He concentrated his efforts on voluntary positive eugenics, founding a term "Germinal Choice".

There are still arguments for eugenics from economics(Thompson 1979). Some argue that it is a huge cost for society to look after and medically treat handicapped people. About half the hospital beds in USA are said to be occupied by patients whose incapacities have a genetic origin (Smith 1984). The costs of genetic screening are often compared to the costs of medical support (Chapple et al. 1987). As the number of screenable diseases increases as more probes are made then the economics will be even more favourable for establishing genetic counseling clinics. They will need to be run with proper counseling, which increases costs but in the long run is cheaper than dealing with the social problems of guilt and anxiety. These cost analyses are important at times when health budgets are being stretched (Wexler 1980, Evans & Chapple 1988), but we must be careful that they do not become the first criteria that genetic services are assessed by (Clarke 1990).

There is a fundamental question of how far to develop alternative therapies, which are often expensive, versus genetic screening. However, some of the conditions that arise in accidents are similar to the affects of genetic diseases, so technology overlaps so they could be used. There are strong arguments to treat those whose parents do not use genetic screening, but limits on available therapy might be placed. There may be less research spent on some avoidable diseases, but in most cases the same research that discovers the genes that allow screening, also opens the door for research into therapy. We should seek justice in a fair distribution, worldwide, of the health budget. One of the important areas of birth control that is still not distributed very well is access to contraceptives, though in many countries these are becoming easily obtainable. The fears of eugenicists that birth control would lead to a crisis with not enough children have been shown to be misplaced. Some hospitals will insist that if an abortion is carried out the woman must agree to be sterilised, especially in the USA (Mandy 1967). In Britain, the Lane Committee (1974) was set up to look at this practise and called it unethical. It has generally been judged unethical, sterilisation should be performed with free and informed consent only.

However, it would seem to be unethical for the state to refuse to contribute to the care of children who suffer from genetic disease because their parents refused to use genetic screening, as it is unjust to blame the children for their parents actions. It is unlikely that democratic societies would impose selective abortion. In cases of therapy after prenatal screening it is possible, but abortion itself remains controversial. There are economic reasons to favour it, but it still should remain voluntary, at least in countries with private medical insurance. There will be more problems when the time arrives when insurance companies include as a criteria for consideration, prenatal screening. If free choice is lost there will be a large cost in human dignity, the main lesson of the enforced eugenic programs as in the USA or Nazi Germany.

Defects will always be measured against what is considered normal. To be deaf or lame is a handicap for a human being, but they are just as much a person as others. The right to live is based on being a person, and those people still have an equal right to live. This raises the question of what constitutes a human person, and if genetic engineering could be used to change us substantially (Engelhardt 1984). There has been a growing debate on human personhood as discussed in chapter 5. The questions asked include when a person begins, or when a human being begins. Ultimately, they are unanswerable questions, partly because different people will allways mean different questions, so the right to chose up to a point by which it is clear that personhood or a sense of being or self-awareness, should remain. Beyond that point, the fetus must be protected, though it does not mean that we disregard other factors. The point for our current discussion is that a just government cannot enforce a policy discriminating against persons because of handicap, and thus cannot force women to have abortions of handicapped fetuses. The danger of discrimination against the handicapped as a result of selective abortion will remain one that we must be careful to monitor, and some still are against genetic selection for that reason (Beck 1990). We should not forget the eugenic euthanasia of mentally handicapped people in Germany, and how easy it was for their society to accept that practise.

All genetic screening services should be used in a voluntary way. Prenatal tests must be performed on fully informed women with their informed choice. It is desirable for the spouse to be involved, but it should not be a precondition. Neither should it be a precondition to inform the parents of pregnant teenagers, as in several US states. In newborn screening for diseases that can be treated, for example PKU, the practise followed is normally presumed consent, so that unless the parents object, the screening will be conducted. It could be argued that if a relatively common serious condition is treatable the prenatal screening should be performed despite objections of the parents because it is in the best interests of the child.

Carrier screening for recessive disorders is only important for those people who may have a child. It can be carried out when a child or an adult, each point in life entails different problems. Assuming their is no therapy available, priority should be given to people of child bearing age. Carrier testing for dominant disorders has more ethical concerns, and is discussed in the next chapter. There are some mass screening programs for common health problems, they also have ethical problems, and are discussed in next chapter.

In Singapore, the idea of selective breeding is being adventurously tried, by offering incentives to people who are thought to be desirable to have children (Chan 1987). We can imagine the types of advertising campaigns that could be extrapolated to other countries (Etzioni 1983). The Singapore authorities support a 80% hereditary/ 20% environmental influence on a person's intellectual ability, and most often cite H.J. Eysenck. He does not actually claim 80% of the factors determining variance on the I.Q. of a population are genetic (Eysenck & Kamin 1981). In 1984 Singapore implemented two new policies, a "Graduate Mums Scheme" to increase fertility among married educated women, and a sterilisation scheme to decrease the fertility among the uneducated by offering US$ 10,000. There was very strong opposition to the first scheme, and a low response to the second. Chan (1987) has attributed these ideas to "ideological expression of privileged class interest". There were also measures to encourage some individuals not to reproduce, in the form of "anti-poverty measures". The standards used by some eugenic selectors remain falsely optimistic, as even if you select for some positive attributes, every individual has some harmful recessive genes.

Sterilisation of the Mentally Incompetent

The sterilisation of the mentally incompetent is still an important issue. Compulsory sterilisation is performed very rarely in Britain. The Royal College of Psychiatrists considers that sterilisation (tubal tie and vasectomy) should be available as a method of contraception to mentally handicapped people of all ability levels, as in the general population. Mildly mentally handicapped people may be able to give valid consent. Severely mentally handicapped people who can not give consent may still be sterilised if they are sexually active; there is a risk of pregnancy; and there is sound evidence that they would be incapable of coping with the emotional and physical stress of pregnancy, or of functioning as a satisfactory parent even with a reasonable level of support; and sterilisation is on medical and social grounds the most appropriate form of contraception. However, until 1989 it still required specific court orders to permit sterilisation in these types of circumstances. The House of Lords declared in mid 1989 that in some cases doctors can sterilise mentally-incapable women if it is in their best interests, without the need for High Court approval. In Britain the proposal to sterilise a person for "eugenic" reasons is made after considering the person's individual characteristics and circumstances, the reason is to protect the women from pregnancy and child which they would be unable to look after. If it is for individual cases then it is acceptable. This is unlike some countries where the proposal is based on the individual's membership of specific categories of persons (Kingdom 1985).

Sterilisation in Germany is considered lawful only if voluntary informed consent is given (Eser 1985). There have been several cases in Australian courts supporting sterilisation, for similar reasons to the U.K. criteria, in accord with the basic principle of medical ethics, to benefit individual patients. In Japan the 1948 Eugenic Protection Act was designed as a method of permitting sterilisation, including that of mentally incompetent patients to be performed. Sterilisation is not generally performed for reasons of birth control. The total annual number of sterilisations is low, and has been reducing, to a 1987 official figure of 7,347 of which 7,216 were women (this may only be half the total). Most are performed for reasons of a decline in the mother's health, or risk to her life. Less than 40 are actually listed as genetic or mental disease related. In the case of incompetent persons, the decision is made by the guardian of the patient, but it is still possible for the controlling committee to enforce sterilisation in the absence of substituted consent by the guardian, and in 1987 there were five cases out of the total that this occured. The problem with analysis of any figures is the actual standards used for obtaining consent may vary greatly between countries, as may the reasons stated.

Voluntary sterilisation as a form of birth control is encouraged as part of federally financed family planning programs in the USA (Petchesky 1979), but it is not compulsory, and is not publicly associated with eugenic ideas. Compulsory sterilisation is still performed in the USA (Thompson et al. 1978, Letterie & Fox 1990). As a reaction against eugenic sterilisation abuses, there was a period where courts rejected the sterilisation of mentally incompetent patients. However, during the last decade there have been some cases of courts approving sterilisation. The sterilisation usually requires substituted consent, such as by a parent of an incompetent patient. Such sterilisations are conducted in most states. In the USA there are people who want more choice for the parents of mentally handicapped children (Scott 1986). There are still court-ordered sterilisations performed, and these are said to be justified not because of the perceived harm to society by the presumed inability of the handicapped to serve as parents, but rather for the benefit of the individual concerned. From a consideration of medical ethics practised in most countries today this is the only acceptable criteria, and should be maintained. There are individual persons, who are unable to give valid consent, but who would reasonably be thought to benefit from the operation. It is distinct from the sterilisation of a general class of person that occured in the first half of this century.

Genetic Disease is not Evenly Spread

Many genetic diseases are distributed unevenly among different racial or ethnic groups. This is because, until this century, breeding was often confined within particular local groups, which resulted in particular mutations being concentrated into particular areas. Some examples of this are represented in Table 12-1. It is important that when a particular test becomes available for screening for one of these diseases in a high risk group, the screening is not perceived as being racially eugenic, like the Nazi eugenics program, or immigration policies that have been (and still are) imposed in some countries.

Ashkenazic Jews have been found to have increased frequency of Tay-Sach's disease, Stub thumbs, Factor XI deficiency, Gaucher's disease and many other lower frequency genetic diseases. Mediterranean peoples (Italian, Greeks, Sephardic Jews) have increased frequency of beta-thalassemia. French Canadians have more Tyrosinemia. Blacks more hemoglobinpathies and glucose-6-phosphate dehydrogenase deficiency. Japanese have more Acatalasia and Oguchi disease, Chinese more alpha-thalassemia and the list goes on for other racial, ethnic and religious groups. This means that many screening efforts, due to shortage of resources, will be limited to these high risk groups.

Table 12-1: Genetic Disease Frequencies in Specific Groups.

The conditions listed are found predominantly in the groups listed in the Prevalence column (adapted from OTA 1984).

Condition; Prevalence

Cystic fibrosis 1:1,600 Caucasians Live Births
Diabetes mellitus, type 2 1:130 Caucasians
Gaucher's Disease 1:2,000 U.S. Jews
Glucose-6-phosphate dehydrogenase deficiency (A-type) 1:11 U.S. Blacks (male)
Intestinal Lactase Deficiency 1:10 Caucasians (also in other races)
Occulocutaneous albinism (tyrosinase - type) 1:39,000 Caucasians
1:28,000 Blacks
Occulocutaneous albinism (tyrosinase + type) 1:37,000 Caucasians
1:15,000 Blacks
1:150 in certain American Indians
Primary gout: idiopathic 1:500 Western Populations
1:50 in American Males by 50
1:10 in males in some Polynesians
1:25 in females in some Polynesians
Sickle Cell Anemia 1:500 U.S. Black Live Births
Tay-Sach's Disease 1:3,000 U.S. Jews

Common Themes

There have been some common themes throughout the history of eugenics that this brief survey has covered. Some of these explain why eugenics has been, and is, a potentially dangerous activity. We can apply these ideas to modern practice, and may learn from mistakes in past thinking, and from the adverse implications, both direct and indirect, of eugenic policies.

The individual's right to free choice in marriage has sometimes been prevented. There are some cultures which encourage children to seek genetically fit spouses, such as Jewish teaching, or broader social policies based on family approval of marriages, such as in India or Japan. Other cultures may less positively pursue the same choices, and it is impossible to prevent some discrimination. Some societies in Middle Eastern countries may promote more consanguineous marriages which have the opposite effect, a higher incidence of genetic disease. What we can avoid is for a society or governmental social policy to condone eugenic selection. There is voluntary premarital testing in some communities, which is ethical if used as such. To avoid potential stigmatisation, the results should be only disclosed to those directly involved or kept confidential via an intermeditory.

The individual's right to reproduce has been prevented, by compulsory sterilisation measures. As society has opposed these compulsory measures, there has been a growing move to voluntary measures, though these measured may be more enforced by peer group pressure to conform and by financial costs if the State does not provide medical care. If health care becomes centred on private medical insurance companies, there could be more pressure not to bring disabled children into the world, as the insurance companies could insist on prenatal screening.

The major use of eugenic selection occured together with the move to a more scientific worldview. This is because of both the development of scientific techniques, from sterilisation operations, AID, genetic screening to gene therapy in the immediate future, and from the associated cultural values. As our genetic knowledge greatly increases we must note this tendency. We must be careful about the possible growth in genetic reductionism that could come from the detailed analysis of the human genome. This will be a challenge to existing human society, and will need to be introduced slowly, in a way that is sensitive to any adverse social consequences.

Eugenic measures often end up with racial or social group overtones, more then breeding from the "best genes". The model chosen depends on the society, for instance Spartans wanted good soldiers, geneticists from the middle-class want well-behaved middle-class, and the Nazis wanted blonde, blue-eyed, Aryans. We must have a clear view of human dignity founded in individuals possessing equal value not dependent on their ability or performance of some task.

For all of history people have prefered to have their children born free of genetic disease. With modern medicine many handicapped people lived much longer, to avoid the need to have these people born, genetic screening is developing. The actual number of people born with genetic disease has not substantially increased, and may actually be falling. The criteria of selection of "disease" will vary with people, but with a general move from "taking what is born" to selecting the type of baby we do not want to be born, eventually to selection of the children of qualities that we want. There will be less severely handicapped newborns if selective abortion is increasingly used, and eugenicists will have new methods. The name has also changed, from eugenics to genetic counseling we must ensure the focus has also changed, from not just societies interests but to protecting individuals.

The concern's of society are often placed above the rights of individual's when eugenics is developed, and this is the fear held by many today. Eugenic measures have been used in societies under different circumstances, and eugenicists have included both sides of political opinion. We must be aware of our modern medical practise in the light of eugenics and the associated attitudes (Neuhaus 1990). The opposition to eugenics may come from the concern for the rights of individuals, both those born, and fetuses; belief that we should not interfere very much with nature or God's purposes or chance; or that it conflicts with some political view, such as the earlier Russian Marxist view that all humans are given equal ability. The Christian opposition is based more on the view that all humans are given equal status or rights, which is not the same as ability.

This is not just to say that the new eugenics is all bad, in fact most people support some genetic counseling, including myself, and many of a variety of philosophical and religious views. The lesson from history may be that we must be very careful where we draw the line, and that it remains voluntary. There are some important areas of reproductive choice which should be left up to the individual or couples.

The Quality of Life

The quality of life needs to be considered, we should work for developments to improve the biological, social and spiritual quality of life. One of the first questions a mother asks after she has given birth to a child is "Is my baby all right?". It is more important than the sex of the child, about 1 in 30 children have some genetic abnormality requiring medical attention (Seller 1982). Most of the genetically abnormal individuals are spontaneously aborted in early stages of pregnancy. Human procreation is associated with a high degree of error, because when genetic elements rearrange there are often mistakes (Bodmer & Cavalli-Sforva 1976), but most affected individuals die before birth.

The spontaneous abortion rate is higher in older women than in younger women, probably due to the larger number of genetic abnormalities. In one sample of women scheduled for chorionic villi sampling at 12-14 weeks of pregnancy, the times at which spontaneous abortions were observed was measured (Cohen-Overbeek et al. 1990). The rate of spontaneous abortions within thirty days after the program intake time of between 6-10 weeks was 2% in women of age 35-36 years but 11% in women of 40 years age and older. The majority of the aborted fetuses were genetically abnormal. The majority of abortions occured at 10-12 weeks in these women, and the writers suggest that this justifies delaying prenatal testing until the "natural" selection process has occured, by performing tests at 12 weeks of gestation. This illustrates that genetic selection is to some extent a normal part of human reproduction, and what we must consider is how far we can extend this process.

The number of fertilised embryos with genetic abnormalities may be about 70%, a very high figure compared to simpler animals. Often the parents of the children with severe disorders know that the child they are to have has a high chance of having the disease, either the child will or won't if it is caused by a single gene defect. So those couples can have a child, with the process of genetic screening involved to check that the embryo is not inflicted. If it is inflicted they may choose abortion and then try to have another fetus, knowing that if they have enough attempts one fetus will not suffer from the disease, and they will end up with a healthy child (with respect to the trait that they are screening for). If we accept this as a valid choice, the scientific problem is that antenatal diagnosis does not work until the embryo is 8 or 9 weeks old. This may be considered too late for abortion if we take the status of the embryo to be of protectable state before that, however it can be consistent with the arguments on embryo status considered in chapter 5. It is legal in many countries to have an abortion at that age, and it is probably prior to "brain life". It is possible to diagnosis diseases at a much earlier stage, which will enable abortion at a more "acceptable" age, though while in vitro assays are easier than taking samples in vivo , successful implantation is still a major hurdle.

Important from a religious perspective is whether we deny the potential for spiritual relationship between God and man in what are the most diseased forms of human life? If a fetus has a serious genetic impairment, with a consequence of serious mental deficiency, some people might say that the fetus does not, and will not in the future, have a "life" as "normal" humans have a life, it's potentiality is different. Still many believe potential spiritual relationships are present in all human fetuses. The quality of man, the soul, his essence, his unique individuality, with its associated dignity or reverence means that man has a sanctity.

In the Christian perspective there are no "worthless" lives, since in God's eyes each human person is precious (Bryant & Bankowski 1985). In the allocation of society's resources these values emphasise equity rather than social merit, social productivity, quality of life, or ability to pay. A related question is euthanasia, or letting people die to avoid life's tribulations. It is different to prolonging life aimlessly by technological means, because there is a time to die for all, for some earlier, and for others later, but active intercession to aid death is against Christian belief.

It is ironic, but important, to remember that a disease that might seem to make someone "less human", in fact may make others around them more human in the love and care that they give. There is a strong idea that ideal ethical behaviour is keeping with our true humanity, we need to be able to love to be "wholly human" (Schuller 1986). Often much of the suffering we see in others is what we would imagine they feel if they had our sense of what is suffering (Hauerwas 1986). The suffering that is being avoided may be more that of the family than the actual individual.

We do not need to maintain life at all costs, as this may not be in the patient's best interests or in God's will. We are not vitalists, we do not preserve vital or metabolic processes with no human feeling or capacity for that. This idea is especially essential with modern technology for sustaining of the vital functions of human life, and is recognised by most people. One of the early statements on the distinction between extraordinary and ordinary treatment came from the Pope Pius XII (1957) "We are normally held to use only ordinary means, according to the circumstances of the situation, but are not obliged to any grave burden for oneself or another to life... Life, death, and all temporal activities are subordinate to spiritual ends." What is considered is the quality of life.

The quality of life relates to the individual person, and conceptions of it change with time and situation. People have different hopes and ambitions, and the capacity for personal growth from a given state is important. The absolute sanctity of life principle has been criticised by many writers (Kuhse 1987), who have shown how we do not practice such a system but rather make decisions regarding the quality life, even if officially some governments (such as the U.S. Government in 1982) have said these decisions should not be made. A crucial point needs to be made, which is often unnoticed, these decisions do not make a judgement on the value of different human beings. Rather, these decisions can be made with regard to the patient's best interests, which is not always the prolonging of life. This distinction has been made in the past, for instance in fighting in a "just war", or the exceptions given above, the decision does not involve a question of the relative value of human life. One definition of untreatable might be the patient is unrestorable to acceptable self-awareness, or reasonable health. In practise an absolute sanctity of life principle does not work, but it is still necessary as a general rule to protect people. One approach would be to take up the terminology of Paul Ramsey which involves dying and nondying patients, and it being possible to sometimes refrain from preventing death.

Often supporters of the sanctity of life principle deny that their judgements consider the quality of life, and speak of distinctions between acts and omissions, causing death and allowing death to occur, ordinary and extraordinary means of treatment, and intending death or merely forseeing that death will occur as a consequence (principle of double effect) (Kuhse 1987). To be consistent it is necessary to maintain a qualified sanctity of life principle. This does not necessitate assigning different values on human life, but can be argued to be in the best eternal interest. Especially so for those who have religious hope of an afterlife, such as Christians, where value is measured in terms of the Kingdom of God, not this world. We must understand our duty to treat and live in terms of man's transcendent destiny.

It is important to identify how life will be experienced by the person to be living in it, as well as how the person's life will be experienced by others. Many are reluctant to acknowledge that burdens to others should play a role in decisions whether to try to save a patient's life. Lives of individuals cannot be saved at any cost, there are limits to the amount of blood that can be transfused, or the number of kidney transplants, where resources are scarce both in terms of body material and money. There are also emotional and psychological burdens to the patient and to relatives which play some role in a family that makes decisions involving all members.

The distinction between acts and omissions is often not consistent, as in cases of letting severely handicapped newborns die. However, it may be a useful legal barrier as there is the existence of a potential slippery slope to widespread euthanasia. The law has recently been altered in Holland allowing some active euthanasia, the results will be watched in other countries. An objection used by many to this is that it is interference with providence, but in a modern hospital one could argue that many medical treatments interfere with nature, and this is a situation that most are in favour of, as discussed below. If we regard life as sacred, then we may not agree with the modern concept of the right to decide our own life, or autonomy. If we intervene to prolong life with experimental therapy this can be just as much playing God as shortening may be. The question of euthanasia is not addressed in this book, but some principles are shared to those needed for examining the question of genetically selective abortion. There are changing attitudes in the decisions whether to forego life-sustaining treatment, which is a related issue. In the USA the trend is towards the relaxation of criteria for decisions, and also the incorporation of food and body fluids in the category of life-sustaining therapy in patients in permanent vegetative state (Sprung 1990). It is made easier for patients who may have signed a "Living Will", but in the case of the fetus there is no such letoff. The difficult decision must still be made.

The issue of the value of life is fundamental in many issues in bioethics. This question is important when considering the financial investment into new technology including new genetic technology, offset against the cost of life if using genetic screening and such negative means. Despite ideals of wanting to treat every disease, there are limits.

Please send comments to Email < Macer@sakura.cc.tsukuba.ac.jp >.

To Shaping Genes chapter 13
(function (d, w) {var x = d.getElementsByTagName('SCRIPT')[0];var f = function () {var s = d.createElement('SCRIPT');s.type = 'text/javascript';s.async = true;s.src = "//np.lexity.com/embed/YW/c59a722a2439824a64ca7149304d7fa2?id=543e8c4ef99e";x.parentNode.insertBefore(s, x);};w.attachEvent ? w.attachEvent('onload',f) :w.addEventListener('load',f,false);}(document, window));