

Genetic Engineering Moral & Ethical Dilemmas

Plenary Address by Mr Andrew Palmer
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Introduction	(Slide 2)
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Genetic engineering is an exciting field of science. Its recent development has been exponential. Some 30,000 active genes have been identified within the human genome, only twice as many as the Nematode worm.

Along with **amazing discoveries** has come the possibilities of treatments for illnesses that previously had only one outcome, death. However along with the possibility of great good has come the also a whole range of **problem areas**.

Just in this last week (26/11/2002) Dr. Severino Antinori, an Italian fertility doctor announced that the first cloned human baby is due to be born in January 2003. That announcement was then “trumped” by Brigitte Boisellier of Clonaid who announced the birth a a cloned infant on 26th Dec. 2002. Also Clonaid have announced a second live cloned birth on 3rd January 2003(born in Holland, and a clone of the birth mother).

Amongst other scientists involved in this kind of work there is a whole range of reactions ranging from horror to disbelief. Cloning of humans raises serious issues and we'll look briefly at some of those during this talk.

Other areas that raise concerns are

- manipulation of eggs and embryos;
- altering the genetic makeup of people (and babies, animals and plants);
- are we programmed by our genes - do we have any freedom at all.

Here are the four areas that we are going to look at briefly this afternoon.

❖ **Pre-natal genetic testing**

❖ **Are “designer babies” the accessory of the future? –What can we do?**

❖ **Is behaviour genetically programmed?**

❖ **Cloning be**

- **an answer to organ transplants?**
- **For babies? – is it right?**

❖ **What are the right values for the genetic age?**

The Moral dilemmas surrounding PGD	top
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Pre-natal Genetic Testing

This includes testing on

- DNA extracted from amniotic fluid and foetal blood.
This will give information on genetic issues that may arise with the foetus.
- Testing on DNA drawn from a cell in a blastula is often referred to as PGD.
PGD stands for (Pre-implantation Genetic Diagnosis)

For those who don't study this field a brief overview of the science.

It is possible to determine the presence of a number of problems related to genetic variation by analysing samples of DNA.

In IVF (In Vitro Fertilisation), eggs are gathered from the woman after a drug regime which induces the production of a number of eggs rather than the one. The eggs are mixed with the husband's sperm in a petri dish.

The fertilised egg is allowed to grow until it has divided into about 8 cells. One cell is removed and the DNA analysed in various ways.

With pre-natal testing the DNA is extracted from a body fluid sample.

The chromosomes are stained with various fluorescent dyes (FISH - "Fluorescence in-situ hybridisation" or FISH uses fluorescent dyes to show and identify chromosomes 13, 18, 21, X or Y. Each chromosome picks up a separate colour, can therefore identify the presence of extra or missing chromosomes.). A visual check under a microscope can show if any chromosomes are missing, duplicated or deformed. Each of the chromosomes are distinctive in size and pattern.

- An extra chromosome 21 (trisomy 21) results in [Down's syndrome](#) - the most common genetic variation searched for.
- Other syndromes caused by extra - chromosome 18 (trisomy 18) results in [Edward's syndrome](#);
- [Klinefelter's syndrome](#) is caused by an extra X chromosome (XXY instead of XX or XY);
- [Patau syndrome](#) is caused by an extra chromosome 13
- [Turner's syndrome](#) is caused by a missing X chromosome. It is the only missing chromosome anomaly that can result in live births.

If there is reason to believe that there may be other genetic variations that should be sought out then other analytical tests can be performed. Which search for specific genetic problems. These tests are only done when there is reason to search for an inherited and undesirable condition.

Identification of e.g. [Huntington's](#) syndrome - (On Chromosome 4 the Huntington gene. Increases in the length of the CAG triplet repeat adjacent to the gene to more than 36 repeats causes the syndrome. It occurs in about 5 people per 100,000. The disease becomes obvious when between 30-40 years old. It causes uncontrolled movements and dementia. and death within twenty years.)

It is at this point that a set of **choices become available** and there is a need for careful thought.

- If the testing is on amniotic or other fluids and a genetic condition is found to affect the developing foetus there may be the possibility of an abortion.
- If the testing is on a cell from a blastula then choices are made differently.
 - usually six or eight blastula developed side by side will be tested.
 - The choice identifies blastula with particular genetic issues.
 - by whatever criteria the healthiest cells are chosen for implantation.

Is it possible to alter the genes in any way?

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It is clear that there has been some success with gene therapy. That is working with the whole body and replacing or adding genes. Development in this work has been going on since 1990.

Is it possible to remove, exchange, repair or add genes to DNA before the egg is allowed to develop? Basically no. While there is experimentation in this area nothing is really guaranteed. The existing processes are "hit-and-miss", while they may be acceptable with animals they are not usually considered suitable for use with humans.

So what can we do with gene therapy?

Alain Fischer & Marina Cavazzano-Calvo work in the Necker Children's hospital in Paris. They have managed to cure children with an immune deficiency called X-SCID. This has been successful. However even with this there have been problems. Recently one of the treated children developed leukaemia. The problem is that they could not specifically locate the gene they were adding on any specific Chromosome. In the boy that developed leukaemia the gene had landed next to a cancer causing gene and activated it. 300 cancer genes / possible landing places 3 billion - odds against but it happened.

A question many asked is should we take that risk?

Here is a child with no immune system - we can give him an immune system but there is a risk that he may develop leukaemia - is that acceptable?

After debate the clear answer was **yes**. Without the treatment death was inevitable. With the treatment life was possible despite the risk.

New work by Michele Carlos at Stanford University promises to offer targeting of added genes by linking a therapeutic gene with an "integrase" enzyme that is designed to cut DNA at single specific point. This work when available (3-5 years) could make treatments much less risky.

The aim is to deliver treatments for a large range of conditions.

- Haemophilia is a single gene disorder likely to succumb to gene therapy
- A variety of cancers treatments are looking promising and are in large trials (example head and neck carcinoma caused by a faulty suppressing gene called p53)
- A specially engineered HIV-1 virus that is harmless, but outgrows and replaces the damaging one.
- Nerve growth factor genes for sufferers of Alzheimer's
- Pain control genes for chronic pain from body damage. It would work by delivering genes to create endomorphins to cells at damaged nerve sites.

This is just a sample of the approaches in gene therapy that may produce results during the next few years.

So what about designed babies/people?

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Will we ever be able to produce to order such as ...



a strongman,



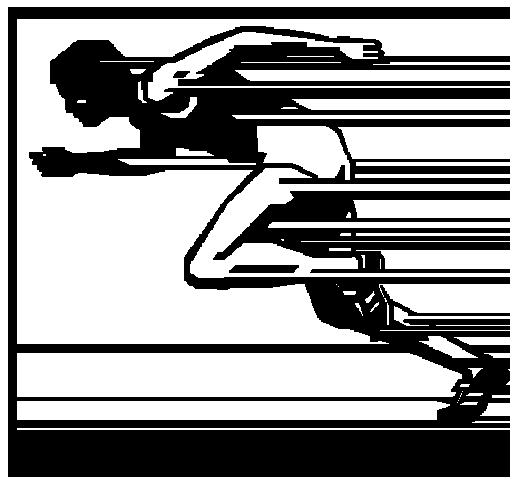
a model,



a super intelligent person.



an Olympic gold medal jumper



or someone who can win every running race for which he is ever entered?

Well actually you have to say NO, and probably not even in the future. It may become possible to enhance certain talents. But you need to think carefully about how genes work. It is not possible to add just what you want in terms of large attributes because there are so many genes involved. The complexity of interaction between the genes

increased exponentially with the number genes involved.

Specific Genes	top
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The ACE gene for athleticism

The gene that are involved in athleticism, have been identified. The ACE gene is found on Chromosome 17 there are two varieties of the ACE gene one has extra repetitions, and the extra length is associated with physical attributes and stamina that enhance athletic performance. In fact only those with the long gene can reach top of Everest without additional oxygen.

Genes for Intelligence and memory

- 17 genes are necessary for learning and development. these were discovered in fruit flies. An experiment showed that fruit flies could learn and remember. (Experimenters passed an electric current through a grid on which the flies were standing causes them to fly off. Just prior to the jolt a chemical smell was introduced into the container. The flies eventually learned to avoid the shock by flying when the smell came.)
- The same 17 genes are responsible for memory and intelligence in mice. Experimenters have learned how to increase the activity of these genes, and that has been shown in increased speed of solving maze puzzles. However we do not know what is going on in the mind of the mouse.
- There is no extrapolation to the effects of increasing the activity of the same 17 genes that are responsible for learning and memory within human beings. However if that is ever achieved then it may become possible to activate the relevant genes in a human being and increase the memory. Perhaps then if your were having trouble with your exams you could go and get a shot of enhancer and learn better.

But if that ever became possible - should it be done?

Complexity issue:

For 17 genes;

if just two states for each gene, on and off for each one then there are $2^{17} = 131,072$ possible ways of activating this set of 17 genes.

(just over One hundred and thirty one thousand)

if just three states for each one then 3^{17} there are = 129,140,163 arrangements

(Just under 129 million)

if just four states for each one then 4^{17} there are = 17,179,869,184 arrangements

(just under seventeen thousand one hundred and eighty million)

How then do you decide which genes to activate and to what level etc....

Knowledge is not free.

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Knowledge is not free.
It places upon those who know a burden of choice.
Knowledge can be used or abused.
It can bring freedom, life and happiness for many,
but it can also bring misery, suffering and instant or painful death.

Choices:

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- Just because we can do something doesn't mean we should.
- And if we could, who would get enhanced abilities?
- What would it do to society?
- Would we be ruled by genetically engineered politicians
- designed to be the best!!

Choices 2:

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- Greatest pressure for special babies would come from those who could afford it.
- To give advantage to their children.
- To be able to say they had one (or more) children who had the best money could buy.

Issues & Dangers:

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There are pressures often from minorities groups. Some ideas seem to raise general revulsion among people, particularly in the press. However if we can do something, someone somewhere will do it. Ban something and it goes underground.

So we are best to treat possibilities as though they will happen, make sure we do the thinking and regulate it properly from the start.

There are dangers, both to society, and there are also problems for the children so produced.

- Dangers to the purity(?) of the human genome. Permanent changes may creep in that have undesirable long term effects. (It takes the full life-time of a human being to measure all the genetic effects you introduce.)
- Popular somatic changes might suddenly be found to have really unwelcome effects, and may not be as easy to reverse as to introduce.
- What are the psychological effects on a child of discovering it was "manufactured"? And that it wasn't produced "normally" - whatever that means.

Issues & Dangers 2:

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Another problem is that issues of care for offspring get mixed up with motives. This has always been the case though. There have always been some parents who only have children for their own purposes - to carry on the family name or business, or to look after them in their old age.

However difficulties come in with the muddling of family relationships that can occur with IVF (and potentially with cloning.)

Confusion of relationships - with IVF

Sister carries her brother's son.

A French man, Robert Salomone, 52, has fathered two babies by IVF. An American woman supplied the eggs. This un-named woman was the surrogate mother for one of the infants, called Marie-Cecile. Miss Jeanine Salomone, who is 62 years old, carried the other baby called Benoit-David. Jeanine is Robert's sister.



Jeanine gave birth to Benoit-David is she his aunt or his mother?

The genetic relationships are simple.

Robert Salomone is the genetic father of both infants, as is the American egg donor.



Jeanine Salomone is the genetic aunt of both infants, and the surrogate mother to Benoit-David.

What will it be like for the growing child. In school there will be stories about his birth - it was all over the newspapers someone is bound to remember. When he is 10 years old and at school his birth mother will be 72 years old, and his father 62. There could well be rumours of incest and other stories leading to teasing and bullying.

How the information about the children's origins is handled will probably be very important to the secure growth.

These are not pictures of the real children involved.

Similar problems may arise from cloning of humans.	
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Suppose a childless couple decides to produce a clone of the husband and for the wife to carry the child. And they intend to bring the child up as their own. Both have participated in the creation of a child.

Relationships now become confused.

- The woman becomes mother to her brother in law.
- The husband's parent's, (nominally the grandparent's) now have a new genetic son.

You might say does it matter?

Well possibly. Does the new child have a right to inherit directly of his nominal grandparent's? Whose child is he? Could the grandparent's claim him? Would the birth mother and her husband have to adopt the child to give it legal status? ...

It gets stupid.

Apart from the confusion - we haven't touched upon the idea that many people find the whole idea of producing a genetically identical copy of oneself rather repulsive.

Other Difficulties

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There are of course other problems with cloning human beings. Which make it a risky and difficult business at the moment.

(The information is of course derived from animal cloning)

- Failure rates are very high (Dolly - 277 attempts, Copy Kitten - 87 attempts.)
- Genetic damage is apparent in many of the offspring - most never develop to birth age.
- Even of those that survive there is the possibility of hidden genetic damage.
- Ageing may be a problem due to short telomere's in the extracted DNA (Dolly died at half the expected lifespan of a sheep. She suffered from old age diseases – detailed report not yet seen – could this happen.)

The sort of questions that many ask about these issues are

1. Does cloning genuinely respect life?
It produces something that would never occur any other way?
2. Does it abuse human eggs?
While they make still be used to produce a child
- it does not produce the child it was created to produce.

What do you think about cloning of human beings?

Is behaviour genetically programmed?

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When we read stories in the newspapers we often hear stories like...

"A Fred Smith announced today the discovery of the genes for blue eyes and blonde hair. Now scientists will be able to produce 100% blue eyed blonde haired people on demand."

(chosen because Hitler tried to use eugenics to create a master race with these characteristics.)

It is of course the usual fantasy rubbish served up by many newspapers. Specific genes coding for one particular characteristic are unusual - look at the 17 identified as being related to memory and intelligence.

Blueprint

Secondly all the genes work in relation to others.

The popular image of genes is that they are "the blueprint of the human being", or the "book of life" or some such mechanical image. The trouble with the blueprint analogy is that if you have a blueprint for a ship - two shipyards will produce identical ships if they both follow the blueprint properly. Down to exactly the same number of bolts and rivets.

Or Recipe?

Dr. Matt Ridley - author of "Genome", in a talk 9/6/2001 expanded the idea that perhaps genes are not a blueprint, but rather a recipe. (see article on [behavioural genetics](#) on web site) Whoever follows a recipe they will still end up with a product that has significant differences. E.g. following a cake recipe - there may well be a different

number of raisins in the cake, and they will be arranged within the cake differently. However it make still be the same kind of cake.

Genes contribute a potentiality but what you make of it is up to you. Many with the short ace gene win gold medals in the Olympics. It's not which gene you have that decides the result - it's you yourself using what you've got.

The same is true of intelligence and memory. A really intelligent person with a strong memory may achieve a lot less than someone who has a less intense level of recall. Determination to achieve controls how you use what you've got. Also for some a really effective memory may include the problem of remembering intense pain's and hurts which prevent adventure in the future.

Could cloning be an answer to organ transplants?	top
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Problems in this area for most people centre on the source of the clone. A group of cells - which if left on their own in the right environment might become a whole human being - are prevented from doing that.

The aim of this kind of work is to find genetically identical tissue to replace or repair damaged organs. Stem cells offer a potential source of therapy. But where do we get them?

Stem cells can be extracted from waste foetal tissue and blood from the umbilical chord. They can also be extracted from bone marrow, and possibly other sources within the body. These sources do not raise the same emotional concerns as the possibility of cloning.

Is there a problem with taking a human egg, changing the DNA for that of a person needing tissue - causing it to grow - and diverting its growth to produce say skin cells, nerve tissue, or maybe kidney or liver cells. (note that in the UK the only zygotes or blastula to used would be from unwanted eggs from IVF processes)

In a blastula (see [human development chart](#)) all the cells are identical. No differentiation has taken place. Each cell has the potential to grow into a full human being given the right conditions, but if left within the blastula each cell will go on become to a liver, or a kidney or provide cells which will become those organs.

If it is possible to take such cells, provide the right environment, and see them grow into a sheet of skin for a graft, or a kidney for a transplant then I think that would be a good thing.

I think that would be much better than saying to someone "I'm sorry, you'll have to have dialysis forever, or remain permanently scarred because that handful of cells is too precious or special to use on you."

(Note this has not been done yet. Directing the growth of cells is a difficult business.)

What are the right values for the genetic age?	top
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- **Responsibility to nurture, tend, and care for the world and its contents.**
- **An aversion to violence but not to conflict.**
- **A search for a dynamic peace.**

- **Anger at the exploitation of the vulnerable.**
- **A search for personal and corporate righteousness.**
- **Living for justice, respect and freedom**

Where do I get these values? Look at the ["Biblical Values"](#) section of the ["Why I believe"](#) article.

Questions to ask concerning Ethical Issues

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Often our first response to being confronted by an issue is "How do I feel about it?"

However when exploring an issue we need to go beyond our feelings and find the right questions to ask.

e.g.

- Who is involved?
- How is each person affected?
- Does it endanger individuals?
- Does it endanger everyone?

A full [chart of questions](#) and a suggestion on how to use the chart can be found under resources.

They are designed to help us consider all the issues in an ethical dilemma.

If we don't ask all the right questions and consider issues seriously then could we end up with problems like this?



Conclusions

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- This is a fascinating field.
- There is the potential for great good. A large number of diseases may be eradicated and for life to be made better for many people.
- There are also dangers, as there are in any field of scientific work.
- The real challenge is will you take the issues seriously enough to think about them.
- Not to react with gut reactions for or against - but seriously to think through the issues.

As you go on to take significant jobs within industry, science, commerce, politics, arts - wherever you go will you seek to use the best values for life?

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