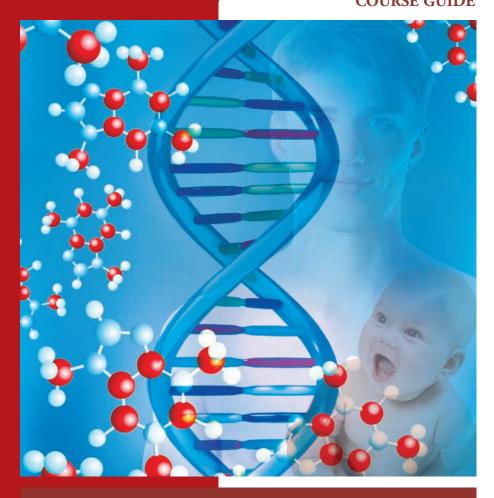


# CREATING HUMANS:

ETHICAL QUESTIONS
WHERE REPRODUCTION
AND SCIENCE COLLIDE
COURSE GUIDE



Professor Alexander McCall Smith
THE UNIVERSITY OF EDINBURGH

# Creating Humans: Ethical Questions Where Reproduction and Science Collide

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## Creating Humans: Ethical Questions Where Reproduction and Science Collide Professor Alexander McCall Smith



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#UT037 ISBN: 978-1-4025-8596-8

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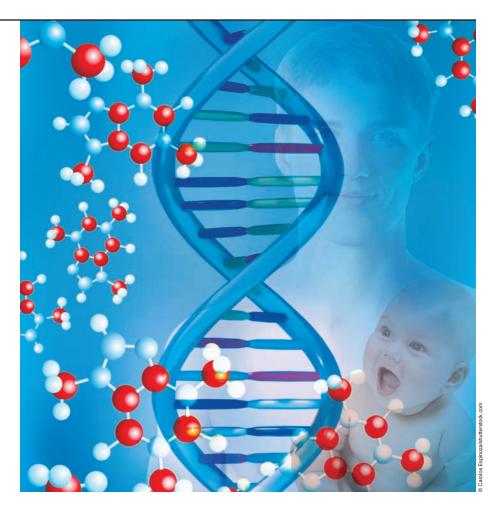
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## About Your Professor Alexander McCall Smith

Alexander McCall Smith has written more than fifty books covering a wide range of topics directed at many different audiences. His works include Forensic Aspects of Sleep and The Criminal Law of Botswana. A professor of medical law at Edinburgh University, he was born in what is now Zimbabwe and taught law at the University of Botswana. Smith's other important accomplishments include being vice chairman of the Human Genetics Commission of the United Kingdom, a member of the International Bioethics Commission of UNESCO, Chairman of the Ethics Committee of the British Medical Journal, chairman of the Ethics Committee of the Roslin Institute, author of the phenomenally popular No. 1 Ladies' Detective Agency series of mystery novels, and winner of the Saga magazine award as Britain's funniest writer in 2003.



#### Introduction

Human reproduction is about life and its perpetuation. If there is anything that we have to take seriously from the moral point of view, then surely that is human life. We value life because it is all that we have which is our own. We construct elaborate systems of belief about it; we guard it through rules we have devised for it; it is everything to us. How we begin human life, how we bring it into existence is a matter of the most profound importance.

In this course, we will discuss the various moral aspects of human reproduction from methods of conception to methods of ending a pregnancy. We will discuss the moral, cultural, legal, and political influences on reproduction as well as the scientific advances in reproductive technology.

Hopefully at the end of this course we will not have arrived at answers to the various questions raised, but will have provided a base for us to consider the issues at hand and a desire to pursue more study in the important aspects of creating humans.

## Lecture 1: An Overview of the Techniques for Creating Humans

The Suggested Reading for this lecture is Aldous Huxley's *Brave New World*.

#### Introduction

All human societies seem to agree that the business of reproduction is culturally and morally significant. For this reason the institution of marriage and the welcoming of children into the human community have been surrounded by elaborate rituals, beliefs, and traditions. The conception of children may be a relatively casual matter now in our freely structured western societies, but there are many societies where that is far from being true.

In this lecture we look at the ethics of reproduction in a broad manner, discussing issues that we will cover in depth in further lectures.

### I. Do We Want Reproduction to Be a Natural Matter, and What Exactly Does Natural Reproduction Mean?

- A. We have a very good idea of what natural reproduction *isn't*, and the best example of this perhaps is to be found in Aldous Huxley's futuristic novel, *Brave New World*.
  - 1. Huxley wrote this book well before the artificial reproductive techniques became established and well before the possibilities of modern genetics had been revealed. In the novel, reproduction takes place in hatcheries, and people are consigned to passive, controlled lives out of which human freedom and variety has been firmly extracted.
  - 2. The world he describes is a nightmare, of course, but one wonders whether it is a nightmare because it strikes us as unnatural or because it is a world that lacks freedom of thought and choice. It is not so much the unnaturalness of being born in a hatchery that worries us, but the implications of what that will do to our later lives. If we are born in a hatchery because the State does not want us to have families and form all the ties that go with families, then that is indeed a nightmare. But if we decided to hatch ourselves in this way and still live in our accustomed manner afterwards—that is, in families, with parents—then we might not feel so uncomfortable.
- B. It is one thing to identify that which is natural—it is another thing, though, to say that the natural is good and should not be interfered with. Fighting over the availability of mates is probably a perfectly natural thing to do, as is fighting over territory, and yet we would combat infertility: there must be some limits. These limits will be dictated by our sense of what is ethically acceptable, what is in the interest of the child, and what is in the interest of the parents of the child.

#### II. What Are the Methods of Artificially Assisted Reproduction?

- A. The simplest method—a technique that has been available for a very long time—is artificial insemination.
  - Artificial insemination by the husband or partner must be one of the most uncontroversial techniques, and it is difficult to see any ethical objection to it.
  - Artificial insemination by a donor is different. This used to meet with objections on the grounds that it involved the intrusion by another into the relationship, and was therefore the moral equivalent of adultery. There was also an objection based on the asexual nature of the process.
  - 3. There is, though, a potential objection that focuses on the fact that artificial insemination by donor means that a child may be brought into existence without a father. This method may be used by a single woman who wishes to have a child but who does not have a relationship with a man.
  - 4. There are strong views on the issue of homosexual parenthood. Some people are vigorously opposed to this; others hold that the individual has a right to be a parent whatever his or her sexual orientation. In this latter view, the child's welfare will not be threatened in any way by the fact that the mother, for instance, is a lesbian; children conceived in this way and brought up by a same-sex couple will, they argue, be every bit as loved as children brought up in a more conventional family setting.
  - 5. Interesting legal, and ethical, issues may occur where sperm is frozen and the man who donated it dies before it is used.
  - 6. Then there is the question of whether one should be able to select one's donor on the basis of intelligence or physical attributes.
- B. Oocyte donation may be used in cases where a woman has a condition that prevents her from producing eggs of her own, or where there is a reason why she would not wish to use one of her own eggs to reproduce. It may be, for example, that she has a genetic condition which she wishes not to pass on.
  - 1. With oocyte donation, the donor's egg is fertilised in vitro—usually with the sperm of the recipient's partner—and the fertilised egg is then implanted in the woman who is to bear the baby.
  - 2. The resultant child is born to that woman, but is not genetically related to her. Should she therefore be considered the child's mother?
  - 3. There is a very major question that arises in respect of oocyte donation, and that is the age of the recipient woman. This technique allows for a woman past the normal age of child-bearing to have a child.
- C. In vitro fertilisation (IVF) is a very common technique involving the extraction of an egg and its fertilisation in a petri dish prior to its replacement in the woman from whom the egg has been taken.

- The child is genetically the child of the woman and her partner there is no outside involvement.
- The ethical issue that arises here is that of risk. There is some evidence that children conceived of by IVF are more susceptible to certain conditions than others.
- D. And then we get to cloning. Cloning is not currently available and is unlikely to become available as a method of artificial reproduction. In theory, though, it should be possible to use this technique to ensure that the resulting embryo is a copy of the person from whose cell a nucleus has been abstracted.
- E. There are one or two other means of assisting reproduction but these are, in essence, the main methods that might be employed. Some of them raise very particular ethical issues. All of them, however, have been subject to serious objection from a feminist perspective.

#### Summary

We have discussed some of the areas in which science has provided options for artificial reproduction. In the next few lectures we will discuss each of these techniques in detail and consider the ethical questions each raises.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. Have the technology options for reproduction been primarily good or primarily bad for society?
- 2. Does the use of reproductive technology adversely affect the "natural" feelings of love and intimacy couples traditionally experience?

#### Suggested Reading

Huxley, Aldous. Brave New World. New York: HarperCollins Publishers, 1998.

#### Other Books of Interest

Mason, John K., Alexander McCall Smith, and Graeme Laurie. *Law and Medical Ethics*. 6th ed. London: Butterworths, 2002.

Ramsey, Paul. Ethics at the Edges of Life: Medical and Legal Intersections. New Haven: Yale University Press, 1993.

——. Fabricated Man: The Ethics of Genetic Control. New Haven: Yale University Press, 1970.

Ramsey, Paul G. *Patient as Person: Exploration in Medical Ethics*. New Haven: Yale University Press, 2002.

#### Lecture 2: When Does Life Begin? The Human Embryo

The Suggested Reading for this lecture is Michael Mulkay's Embryo Research Debate: Science and the Politics of Reproduction.

#### Introduction

At the heart of the debate about many of the developments in modern reproductive medicine is a very clear but very troubling question—when does human life begin? This question is important in many different contexts: in the debate about abortion, in the debate about stem cell research, and in the debate about the new reproductive technology.

#### I. Human Life: The Basic Argument

- A. It is simple to agree that there is something special about human life—we regard the value of human life as being at the heart of our moral practices. It is wrong—profoundly wrong—in all codes of morality to take the life of another.
- B. However, there are some areas in which there is debate:
  - Some people take the view that it may be morally permissible to bring a life to an end with euthanasia in cases of severe illness.
  - Many feel that it is permissible to take a life in the case of selfdefence or defence of one's family.
- C. While the idea of protecting the lives of others finds ready agreement on the world stage, there is less agreement when it comes to the issue of when that protection comes into effect. Does this happen at birth, when the child enters the human community, or should human life be protected even before that—when it is an embryo or fetus?
- D. If we look at how criminal law approaches this, we see that there are respects in which criminal law does protect the human being before birth.
  - 1. It is an offence, for example, to bring about a miscarriage except in those circumstances where the law licenses abortion.
  - 2. The law also provides protection for the fetus that is damaged in utero and then suffers the consequence of this injury after birth.
  - Similarly, if a person damages a fetus in utero—for example by assaulting a pregnant woman—and the child dies after birth as a result of injuries received in the womb, then criminal sanctions may be imposed.
- E. So what we see here, then, is some degree of recognition of the legal personality before birth. This accords with our commonly held notions that life before birth is significant and merits some degree of protection. But how are we to analyse this philosophically—how do we decide

what degree of protection it deserves and when it should be offered? This is an immensely important issue because it governs how we respond to embryo research, IVF, and then, of course, the persistently controversial issue of abortion. No discussion of abortion gets very far before the issue of the moral status of the embryo is raised.

#### II. What Defines Life?

- A. Many would describe our personal biography as beginning with the time of our birth. But did we come into existence at the moment when we emerged? To say yes to this is surely counterintuitive: after all, parents may have an ultrasound photograph that shows a curled-up but recognisable baby. And this physical entity that is the baby at, say, five months of gestation, is physically the same entity as the newly born child, and indeed it is the same physical entity, although more developed, as the fetus of six weeks' development. Indeed, if one is looking for physical continuity one can point out that the connection between the fetus of six weeks, say, and the embryo of one day, is continuous.
- B. Everything that the embryo needs is there: the stem cells that will develop into different types of tissue and the DNA that will provide the template for development. And to prove the point, if one took the cells that make up the embryo and destroyed them, the more complex organism which was destined to emerge some nine months later would never come into existence. They are therefore the same thing, even if one is the precursor of the other. There is one biological caveat here, though, because it is an important point in the moral debate about embryo status.
  - At an early point in its development, the embryo can divide into twins or remain a single individual.
  - 2. This is important because one might say that before this stage has been reached we do not have an identifiable individual.
  - 3. It is only when the embryo can no longer divide in this way that we can say that a distinct individual has come into existence.
- C. What is the moral status of the human embryo? Is it human life? Is it a person? Is it a thing? Can we do what we like with it, or do we have to treat it with a certain degree of respect? The questions come flooding in, and a whole range of answers are provided.

#### III. If Someone Can Be, Are They?

- A. Certainly an embryo is not an adult.
  - 1. Physically: The human embryo, in its earlier stages of development, does not look like an adult. However, as it develops into a fetus we can see its arms and legs, its head, and we can see it moving as a human child would move. Obviously at that stage, if we are going to use the criteria of appearance, it is difficult not to see it as a human being.
  - Morally: The embryo in due course becomes one of us. It is, therefore, one of us, even if it does not look like one of us.

- B. This leads very quickly to one of the central arguments in the discussion of embryo status: the argument from potential. This argument holds that if something has a potential to become something else, then it should be given the respect that it would merit if it were already that thing. Therefore, the fact that the embryo has the potential to become a fully functioning, self-existent member of the human community means that it should be treated as such from the beginning.
  - 1. The argument for potentiality very quickly meets the objection that in our day-to-day lives the fact that something is not yet something else is taken as very good grounds for treating it differently from the way in which one would treat it when it does become what it is due to become (that is, a tube of paint is not a masterpiece based on potential).
  - 2. Of course, the potentiality argument does not go away as quickly as that. Its supporters argue that there are other, very good grounds for regarding potentiality as being of moral significance.
    - One of these is to ask what would happen if we were to fail to recognise the moral significance of potential altogether? If we were then able to treat all embryos alike—as if they had no moral status—then that would surely involve grave consequences for ourselves as a species.

This consequentialist argument, of course, suggests that we are *likely* to do this, whereas, in fact, as intelligent beings we are not.

- C. The potentiality question, of course, is not the end of the discussion: it is really only the beginning. There are other grounds for giving the embryo moral standing, the principal one being that of personhood.
  - Personhood is viewed by many as being the basis of our claim to moral consideration: we respect persons simply because they are persons.
  - 2. The difficulty with the personhood debate is that it quickly deteriorates into a strident exchange of assertion and flat denial. The embryo is a person; no it is not.
  - 3. What is personhood? At its simplest level it is about being something physical—having a human body. The argument for potentiality holds that if something has a potential to become something else, then it should be given the respect that it would merit if it were already that thing.

#### IV. Is It the Mind That Makes the Man?

A. In the absence of agreement as to the significance of the bodily, it might be more productive to move on to the issue of the mental. One way of looking at personhood is to say that it exists as a concept to give protection to that which we regard as valuable in human life. This is not so much the body but those things that bring meaning to an individual's life—awareness being the first and pre-eminent of these. Approached from this point of view, we see that what counts in personhood is human consciousness.

- B. For some, simple awareness of oneself or one's surroundings is not enough: what counts for them is interaction with the human community and the ability to relate to others and pursue projects. In this view, personhood is a much richer concept, and the embryo, or the fetus, simply does not have it.
- C. And, of course, not all embryos are the same. Some are surplus to requirements, having been created by IVF and not used for implantation purposes. To use such an embryo for research purposes is different from creating an embryo specifically for research. This will be expanded in a later lecture.

#### V. The Argument Continues

- A. The argument goes on, and one might be forgiven for thinking that we shall simply never agree over this vexed issue. What are the consequences of granting, or denying, full moral standing to an embryo or fetus? What will this do to our society?
- B. The proponents of embryo standing will probably say something like this: If we fail to protect the human embryo, then we fail to protect human life.
- C. Is it that simple? Is not the claim of the embryo just one out of many moral claims that we must address?
  - These claims include the claim of the woman to control her own body—surely a very major claim by any standard. If we give full moral standing to the embryo and the early fetus, then that will mean that women no longer have the right to end an unwanted pregnancy.
  - 2. And similarly, if we recognise the claim of the embryo, then we might be said to undervalue the claims of those many people—persons already in existence, one might add—who feel that embryo research is going to help them to overcome infertility, for example, or, if we're talking about the use of embryos in stem cell research, to conquer crushing illness.
- D. So whose claim is greater, the claims of an entity that is unaware (in the case of the embryo, not the fetus, of course), that has no responsibilities to others or a developed sense of a past and future, or the claims of those who have all of these things?

#### Summary

It may be that at the end of the day we make a choice that is a simple preference for one claim or the other. The other possibility is that we negotiate a compromise, and this compromise involves a recognition of some moral standing being attributed to the embryo, but not the same moral standing as that which we normally attribute to full members of the human community. This may leave some unsatisfied—and indeed indignant—but ultimately that's how a reasonable, tolerant society feels its way through these moral problems. A moral conversation takes place—alternatives are weighed—and decisions are made that most people will be able to live with. That sort of compromise seems to be emerging in the sort of society in which we live. As a result, we have edged our way to allow some forms of research involving embryos, although the circumstances in which this will be allowed are controlled.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. When does life begin according to the current laws?
- 2. Can an objective definition of what constitutes life be made?

#### Suggested Reading

Mulkay, Michael. *Embryo Research Debate: Science and the Politics of Reproduction*. Cambridge: Cambridge University Press, 1997.

#### Other Books of Interest

Green, Ronald M. *Human Embryo Research Debates: Bioethics in the Vortex of Controversy.* New York: Oxford University Press, 2001.

Maienschein, Jane. Whose View of Life?: Embryos, Cloning and Stem Cells. Cambridge, MA: Harvard University Press, 2003.

Mason, J.K. *Medico-Legal Aspects of Reproduction and Parenthood*. 2nd ed. Brookfield, VT: Ashgate, 1998.

Roberts, Melinda A. *Child Versus Childmaker: Future Persons and Present Duties in Ethics and the Law.* Lanham, MD: Rowman & Littlefield, 1998.

#### Lecture 3: What Sort of Children Shall We Have? The Science of Reproduction

The Suggested Reading for this lecture is the Lynda Beck Fenwick's Private Choices, Public Consequences.

#### Introduction

Aldous Huxley's *Brave New World*, with its human hatcheries is the night-mare vision, par excellence, of artificial reproduction. We are still some distance from this, but human reproduction is certainly a much more technologically sophisticated matter than it used to be. Science has rendered fertility more achievable in those cases where nature is failing. Why have such major resources been put into the development of human reproductive science? This is a fundamental question in bioethics.

#### I. Human Fertility and Infertility: What Are the Issues?

- A. The growth of the world's population suggests that human fertility is not a problem viewed globally. However, for some societies and some individuals it is a problem.
  - 1. There are countries where there are not enough children being born to keep the age profile of the population healthy.
  - There are some societies in which both male and female fertility is being affected by environmental factors, such as pollution or an increased incidence of sexually transmitted disease.
- B. Then there are the cases where infertility is a problem for the individual because of some condition particular to that person—there can be many causes of this, including low sperm count in the male.
  - 1. For the infertile person, infertility is clearly a medical problem. The desire to have a child is, for many people, one of the most important human drives, and its frustration is therefore a medical issue. The psychological distress which childlessness involves is very real.
  - 2. Viewed from this perspective, the cause of infertility research clearly merits its place on the research agenda, and the spending of resources in this way is quite justified. There should, however, be a balance—and this balance is both financial and, as we shall see, ethical in nature.
  - 3. We cannot justify doing everything to combat infertility: there must be some limits. These limits will be dictated by our sense of what is ethically acceptable, what is in the interests of the child, and what is in the interests of the parents of the child.
  - 4. We will now discuss some of the methods of combating infertility.

#### II. Artificially Assisted Reproduction: Who's My Father?

A. Broadly speaking, there are two categories of artificial reproduction.

- Techniques that involve assistance to a couple, who will provide the reproductive material—and hence the genetic material that goes to the making of the child.
- 2. The second category involves donation by others.
- B. These have very different ethical implications that we will address later in this course.
- C. The simplest method of artificial reproduction is a technique that has been available for a very long time and may not involve much sophisticated science. This is artificial insemination, either by the woman's husband or partner, or by a donor—usually anonymous—who has no connection with the woman.
  - 1. The first method is artificial insemination by the husband or partner. And this must be one of the most uncontroversial techniques, and it is difficult to see any ethical objection to it.
  - 2. Artificial insemination by donor is different. This used to meet with objections on the grounds that it involved the intrusion by another into the relationship, and was therefore the moral equivalent of adultery.
- D. There are several ethical objections that have come to light with this secondary process of artificial insemination.
  - There is an objection based on the asexual nature of the process—a naturalness objection that might be raised against any of these artificial reproductive techniques.
  - 2. There is, though, another potential objection that focuses on the fact that artificial insemination by donor means that a child may be brought into existence without any social father. Artificial insemination may obviously be used by a single woman who wishes to have a child but who does not have a relationship with a man who might agree to father her child.

There are all sorts of possibilities here, including the use of artificial insemination by lesbian couples who wish to start a family. There are strong views on the issue of homosexual parenthood. Some people are vigorously opposed to this; others hold that the individual has a right to be a parent whatever his or her sexual orientation.

There is an objection that it is better for a child to have a father in his or her life—and there does seem to be fairly strong evidence that the children of two-parent—male and female—families do better in their education and general social development. It may no longer be politically feasible or indeed desirable to oppose same sex parenting. The social patterns of contemporary society are such that society cannot police the private sphere of our lives.

Interesting legal, and ethical, issues may occur when sperm is frozen and the man who donated it dies before it is used. This might arise in a case where a male is suffering from a serious illness and would like his spouse or partner to be able to start a family after his death. Posthumous children may occur naturally, as in the case when a father dies before the mother gives birth; the difference in

- the case of frozen sperm is that the child may be born quite some time after the death of the father. This may raise questions as to whether one should deliberately bring into existence a child who may not have a father.
- 3. Then there is the question of whether one should be able to select one's donor on the basis of intelligence or physical attributes. We have all heard of the advertising of schemes that would allow the selection of a super-intelligent donor—a Nobel laureate, for example. This strikes some as being abhorrent, and yet surely people already select fathers when they choose a partner on the basis of any of these attributes. There are, no doubt, women who think in terms of the advantages to future children of their marrying a man who is particularly intelligent or successful. If we allow people to do that without censure, then why not choose a donor on a similar basis?
- E. Of course it all sounds very cold and calculating. Reproduction production is normally a bit of a lottery—you take what you get and you do your best to cherish and love the result. If one sets out to ensure that a child is intelligent, or exceptionally good at sports, then one is implicitly saying that the child will be loved because of those attributes rather than for himself or herself. It is this that makes many people uncomfortable.

#### III. Oocyte Donation: Who's My Mother?

- A. Moving on from artificial insemination, there are other techniques that may be used to assist reproduction in cases of initial infertility and which involve donation. Oocyte donation may be used in cases where a woman has a condition that prevents her from producing eggs of her own, or where there is a reason why she would not wish to use one of her own eggs to reproduce. It may be, for example, that she has a genetic condition which she wishes not to pass on.
  - 1. With oocyte donation, the donor's egg is fertilised in vitro—usually with the sperm of the recipient's partner—and the fertilised egg is then implanted in the woman who is to bear the baby. The resultant child is born to that woman, but is not genetically related to her.
  - 2. The ethical question here is, should she therefore be considered the child's mother? There is a strong consensus that she should. She, after all, is the person who has been pregnant with that child—she has nurtured it and developed a bond with it. This is a far greater claim than the donor would have—all she has done is provide the genetic material.
- B. There is a very major question that arises in respect of oocyte donation, and that is the age of the recipient woman. Many artificial forms of reproduction will merely mirror biological realities, resulting in the creation of children who will fit into a pretty standard family arrangement of parents of child-bearing age. But along comes a technique, such as this one, that allows for a woman past the normal age of child-bearing to have a child. Should that be allowed? Should we be at all worried about a mother of sixty giving birth to a child?

#### IV. In Vitro Fertilisation: Parents in a Petri Dish

- A. In vitro fertilisation (IVF) is a very common technique involving the extraction of an egg and its fertilisation in a petri dish prior to its replacement in the woman from whom the egg has been taken. The child is genetically the child of the woman and her partner—there is no outside involvement.
  - An ethical issue that arises here is that of risk. There is some evidence that children conceived of by IVF are more susceptible to certain conditions than others.
  - 2. There are also issues of regulation. This is an expensive treatment, and it is important that those who undertake it are informed of the success rates (about one in five for each treatment cycle). Obviously, people might be taken advantage of in their eagerness to have a child.

#### V. Cloning: Another Me?

- A. And then we get to cloning, which we shall return to in a later lecture. Cloning is not currently available and is unlikely to become available as a method of artificial reproduction. In theory, though, it should be possible to use this technique to ensure that the resulting embryo is a copy of the person from whose cell a nucleus has been abstracted. The technical difficulties facing this are, however, immense.
- B. Cloning is an issue on which passions run very high, even to the extent of attempts being made within the United Nations to secure an international convention to prevent the practice of human reproductive cloning in any country.
- C. There are one or two other means of assisting reproduction, but these are, in essence, the main methods that might be employed. Some of them, as we have seen, raise very particular ethical issues. All of them, however, have been subject to serious objection from a feminist perspective, and it is this critique which we will now address.

#### VI. The Feminist Perspective

- A. One cannot talk of a single, agreed feminist perspective on human reproduction. There is a vast amount of feminist literature on this subject, and there is a lively and continuing debate amongst feminists on all aspects of the new reproductive technology.
- B. Most feminists see eye to eye on one matter, though, and that is that male control of reproduction is intimately bound up with patriarchal notions of society and that these need to be confronted head-on. Women should assert control over all aspects of their bodies, reproduction included, and reject male attempts to dictate the terms of reproductive activity.
- C. The ancient vision of society in which women were treated as chattel is pretty universally discredited in contemporary western societies. But some feminists would still argue that women's role in reproduction still involves them in oppression, and that women have yet to assert control

over this aspect of their lives. They go on to say that the new reproductive technology makes it worse in some respects. These new techniques, they argue, involve a tyranny not only of men but also of maledominated science.

- D. It is of course easy to make broad assertions about oppression: if there is such a tyranny, just how does it manifest itself?
  - Some feminists argue that it comes in the form of pressure: women are assumed to want to reproduce at all costs; it is something that society expects of them and manipulates them into holding.
  - 2. In this analysis, the experience of childlessness, which could otherwise be accepted by women, becomes something that should be overcome by every possible means. As the technology develops, then women feel that they must resort to yet further efforts—often at the cost of personal pain and inconvenience—merely to show they are doing everything they can to become pregnant.
  - 3. There is a very important insight in this critique. The provision of medical solutions may give rise to pressure to avail oneself of them. What is at first merely an option may become a necessity, and what is at first a matter of personal choice may become a matter of social responsibility. The message that women may therefore receive is this: you owe it to your partner or spouse, or indeed to yourself, to go that extra mile to conceive. This means that the individual decision, far from being one freely entered into by women, is one that is forced upon them by a medical establishment, maledominated perhaps, which expects them to comply with ever more complicated treatments.
- E. Not surprisingly, the feminist position has itself been criticised by other commentators, not all of them men.
  - This criticism points out that the feminist position overstates the extent to which the views of infertile women are indeed views they genuinely hold as expressions of their real preferences.
  - If infertile women say that they wish to resort to these techniques in order to explore every possibility of conception, then perhaps they really do want that.
- F. There is a middle position on this, and that would involve saying the following:
  - Yes, we understand that assisted reproductive techniques may put women under pressure to undergo all sorts of invasive procedures.
  - Yes, we recognise that the development of artificial procedures gives rise to a risk that we might depersonalise the whole business of reproduction. These are dangers.
  - 3. But it would be retrograde to block these avenues of scientific exploration; what is required, surely, is a yardstick by which each technique can be measured for ethical acceptability. We should be aware of the dangers of railroading people, but as long as we bear in mind the overarching requirement of individual dignity, then we should be

able to judge between what is acceptable and what is not. Human dignity again provides the measure by which we assess the process: there is indeed a great deal of moral work for that concept to do.

#### Summary

In this lecture we began thinking through the ethical issues involved in human reproduction. In the first cursory view of the issues we have set the stage for our later in-depth discussion of these salient issues. In the next lecture we continue our discussion with a look at the controversial issue of cloning.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. Is it more important to consider ethical issues or health issues when considering the use of reproductive technology?
- 2. Do women have more rights than men in determining the use of reproductive technology?

#### Suggested Reading

Fenwick, Lynda Beck. *Private Choices, Public Consequences: Reproductive Technology and the New Ethics of Conception, Pregnancy, and Family.* New York: Dutton, 1998.

#### Other Books of Interest

- Cohen, Cynthia B., ed. *New Ways of Making Babies: The Case of Egg Donation*. Bloomington: Indiana University Press, 1996.
- Daniels, Ken and Erica Haimes, eds. *Psychosocial Perspectives on Donor Insemination: International Social Science Perspectives*. Cambridge: Cambridge University Press, 1998.
- Sher, Geoffrey, Jean Stoess and Virginia M. Davis. *In Vitro Fertilization: The A.R.T. of Making Babies*. New York: Facts on File, 1998.
- Wolf, Susan M., ed. *Feminism & Bioethics: Beyond Reproduction*. New York: Oxford University Press, USA, 1996.

#### Lecture 4: Cloning: I Want Them to Take After Me

The Suggested Reading for this lecture is the Gregory Pence's Flesh of My Flesh.

#### Introduction

Back in 1997 an announcement was made about the birth of a sheep. At the Roslin Institute in Edinburgh, in Scotland, Dr. Ian Wilmut had successfully cloned a sheep known as "Dolly." No male sheep was involved in the birth of Dolly—she was a copy—a clone of her mother. This was the first time that a mammal had been cloned and a whole new chapter had been opened in the history of biology.

#### I. Dolly: The World's Most Controversial Symbol

- A. Dolly lived for some six years before she succumbed to a disease that affects common sheep. Today she can be seen, after the attentions of the taxidermist, standing quietly in a cabinet in Edinburgh's Royal Museum. For her brief life she was a celebrity, immensely symbolic—a symbol of what we can do and, in the view of some, of what we should not do.
- B. The responses to Dolly's birth ranged from great satisfaction to frank outrage. Those who welcomed the development felt that this was a giant step forward in animal husbandry, enabling us to respond to the challenges of producing animal protein more effectively. Those who were outraged felt that she represented a critical milestone in our race to play God—to be in a position to create life, asexually, for our own purposes.
- C. The argument that this would lead to attempts to clone human beings is an interesting one, because it is an example of an important and frequently used argument in the ethics of reproduction and indeed in bioethics in general—that of the slippery slope.
  - 1. The gist of the slippery slope argument is this: if you take an initial step in a particular direction, then even if you say that you only want to go so far, you are likely to end up going further than you had envisaged in the first place. That is because there will be relentless pressure in favour of extending the boundaries of what is permissible.
  - 2. In this context it is quite simple: allow the cloning of animals and you will end up allowing the cloning of humans.
- D. There has been a lot of discussion amongst philosophers of the slippery slope argument. Many do not like the argument because it makes an assumption that there is no necessary, or unavoidable, connection between events, as long as choices can be made.

E. On the other hand, if the first demand in a series meets with public approval, then the second becomes the focus and will more than likely meet with public approval and so on. Then it is probably true that allowing this first demand will increase the likelihood of the second demand in the series being met simply because it is now the demand that will be in the front line of the debate. So in this sense the slippery slope argument would appear to have some force.

#### II. Dolly Creates Political Fervour

- A. It is not surprising, then, that the slippery slope argument featured prominently in the discussion over cloning. Indeed, the reaction to developments in cloning technology has resulted in a fairly frenzied attempt by governments and politicians to emphasise that human reproductive cloning would never be allowed, no matter what happened in animal biology.
- B. This led to the drafting and adoption in a number of European countries of an additional protocol to the European Convention on Human Rights and Biomedicine, the Oviedo Convention.
  - 1. This protocol expressly prevents any activity directed towards human reproductive cloning.
  - 2. That convention is a product of the Council of Europe. At a world level, France and Germany sought to raise the matter in the United Nations, with a view to securing agreement on an international convention prohibiting human reproductive cloning. The aim of this would be to prevent any reproductive cloning of human beings anywhere in the world.
- C. Why have politicians been so keen to become involved in this debate?
  - One possibility is that they see it as a very clear moral issue, in which a thoroughly unacceptable procedure threatens our basic values. They feel, then, that this is something that they have a duty to prevent.
  - 2. The other possibility is that they are keen to establish their bioethical credentials, and this is an issue that touches a particular public nerve. Cloning could be a line in the sand—and opposition to cloning could be a public statement that science is under control and that all is well. This could possibly pacify those who fear that anything now seems to be accepted and that there are no limits to what science will be allowed to do. At least here's a limit.

#### III. What Is Cloning?

- A. The discussion of cloning, which has become intense at times, has resulted in some confusion about what cloning actually is. In particular, reproductive cloning has been confused in the public mind with socalled therapeutic cloning.
  - Therapeutic cloning is a very different thing and involves the cloning of cells from an embryo in order to develop stem cell lines than can be used for treating disease.

- 2. This has nothing to do with reproduction, although the slippery slope argument has been invoked to oppose this form of cloning.
- B. Both forms of cloning—reproductive and therapeutic—may involve a process called cell nuclear replacement.
  - 1. This is a process whereby an ovum is taken from a donor.
  - 2. The nucleus of this cell is taken out and the nucleus of another cell is put in its place.
  - 3. The resulting cell then is encouraged to develop into an embryo.
  - 4. This embryo will have the same DNA as the cell of that which was in the nucleus of the donor cell. It will not be genetically identical, as the mitochondrial DNA—the DNA that surrounds the nucleus—will be different. But it will be very close to it; in other words, the donor organism has been cloned.
- C. There are other respects in which the cloned embryo, if then allowed to develop into a full individual, will be different from the donor of the cell nucleus.
  - Environmental factors are important in the development of the organism and in the development of DNA—this means that the cloned person would not be an exact copy of the donor.
  - 2. Of course there is another, major reason why the cloned person would not be identical to the donor, and that has to do with environmental influences on the development of personality. Although genetic influences have a major bearing on what sort of person we become, a significant part of what we are is determined by our experience of the world. Thus, if you take identical twins, separated at birth, and look at them, you will expect to find some similarities (which prove the genetic part) and some differences (which prove the environmental part).
  - 3. There is also the question of free will. We create ourselves—to some extent at least—by our free decisions as to what we are going to think and do. The cloned person would have created that part of his or herself which can be created in this way, and thus this is going to be unique to him or her and not something that is determined by genetic inheritance. In this way, too, cloning does not involve the creation of a person doomed to be identical to the donor. He may actually be quite different.

#### IV. How Close Are We to Having a Human Clone?

A. Of course the whole debate on human reproductive cloning has gone forward on the assumption that people are lining up to do it. Are they? Not really. On the other hand, one should not discount the possibility that serious and properly equipped biologists might be tempted by the fame that would undoubtedly accompany a successful attempt at human reproductive cloning. Dolly would probably pale into historical insignificance in the face of such a development.

- B. Responsible scientists would not undertake human reproductive cloning at present not only because of concerns over public moral antipathy, but also because of risk. The procedure would be difficult and would involve considerable risks to the resultant child: it would therefore fall into the category of excessively risky and therefore unethical experimentation.
- C. But if reproductive biologists were prepared to try, then might there be possible candidates?
  - Paid research subjects might be prepared to go through with it—and there would have to be a woman who was prepared to have the cloned embryo implanted in her womb.
  - 2. Cloning could be attractive to a man who wanted to reproduce but who could not do so because of infertility. Such a person would not be able to avail himself or herself of any of the other methods of assisted reproduction and might therefore be attracted to cloning.
  - 3. There may also be cases where a person's partner is affected by genetic disease and where the couple wants to have a child, but does not want to pass on the genetic condition and does not want their child to have a genetic relationship with any person other than one of them. Cloning would answer that demand.
  - 4. And then there may be—just possibly—cases where a person of overwhelming vanity wishes to see a copy of himself made just for the sheer pleasure of securing what he misguidedly sees as a form of immortality. This is the motive of selfishness, and it is this motive that so offends many opponents of the idea of reproductive cloning.

#### V. What Is Wrong with Cloning?

One of the most succinct statements of the arguments against human reproductive cloning is made in the Report on Human Cloning of the President's Council on Bioethics, published in July 2002. We will look at these objections in turn and ask whether any of them, or all of them jointly, make a sufficiently strong case to persuade us that in no circumstances should we ever contemplate human reproductive cloning.

Risk and experimentation. This was the first of the grounds that the President's Council considered pertaining to the moral implications of cloning. They looked at the issue against the background of the general ethical principles surrounding research involving human subjects.

- A. Cloning is an untried procedure when it comes to humans; any attempt to clone, then, would be a human experiment, and there are serious and substantial restrictions on this form of experimentation.
- B. These principles of ethical human experimentation have been developed, in their modern form, since the end of the Second World War, initially in reaction to the extreme and cruel experimentation that took place in Nazi Germany.
- C. The Nuremberg Code of 1947 set out clear limits to what could be done on human subjects and stressed that this research must be consensual and must be subjected to limits as to what can be done. The aim of this

- code, and of the Declaration of Helsinki, which was a later code adopted by the World Medical Association and since then has been substantially revised, is to ensure that people are not used by experimenters, but are treated with respect to their right of autonomy.
- D. It is unacceptable, then, to do anything that would involve too great a risk to a human research subject.

#### Summary

Can cloning be said to be of such value that it justifies the taking of risks? Cloning is a challenge to the way we think about family and reproduction. But a great deal of human reproduction is unconventional. Reproduction is already affected by artificial interventions. The argument has been made that cloning denies the child an open genetic future. What is meant by an open genetic future? Is there any real benefit to the child in having a random selection of genes rather than one that is more predictable? In fact, how the genes will interact with their particular environment is still an open question. There has been discussion that a cloned child would be raised in a confused family setting—relationships would not be clear. There are many other causes for confusion in human relationships. This issue will continue to be one to explore over the next several years. In the next lecture we turn to the issue of sex selection.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. Did Dolly the cloned sheep die early because she was aging more rapidly than normal?
- Cloning is a rapidly developing science. Look at the latest news and consider the implications of cloning on your lifestyle.

#### Suggested Reading

Pence, Gregory E., ed. Flesh of My Flesh: The Ethics of Cloning Humans: A Reader. Lanham, MD: Rowman & Littlefield, 1998.

#### Other Books of Interest

- Agar, Nicholas. *Perfect Copy: Unravelling the Cloning Debate*. London: Icon Books, Ltd., 2004.
- Drlica, Karl. *Understanding DNA and Gene Cloning: A Guide for the Curious*. New York: John Wiley & Sons, 2003.
- Kass, Leon. Human Cloning and Human Dignity: The Report of the President's Council of Bioethics. New York: Perseus Publishing, 2002.
- Maienschein, Jane. Whose View of Life?: Embryos, Cloning and Stem Cells. Cambridge, MA: Harvard University Press, 2003.
- Wilmut, Ian, Keith Campbell, and Colin Tudge. Second Creation: Dolly and the Age of Biological Control. Boston: Harvard University Press, 2001.

#### Lecture 5: A Boy Please: Sex Selection

The Suggested Reading for this lecture is the Mary Ann Warren's Gendercide: The Implications of Sex Selection.

#### Introduction

Sex selection—choosing the sex of one's child—is not something that has just been invented in the course of the new reproductive revolution. For centuries people have been practising sex selection through the effective, but cruel, device of exposing unwanted female children. There is a great deal of evidence of this, some of it going back a very long time. In ancient China and in Arabia, female children were routinely disposed of, and proverbs from those societies spoke of the wisdom and indeed kindness of doing this. And this is by no means a thing of the past: infanticide is still widely, if discreetly, practised in some countries, as evidenced by persistently higher rates of female infant mortality.

#### I. Why Choose Boys?

- A. Why did people in these societies wish to dispose of female children? There are various explanations for this.
  - 1. Some societies were patriarchal, and in a patriarchal society there is always going to be a strong preference for boys.
  - This preference may be integrated into beliefs that give particular emphasis to the role of sons in the perpetuation of the family name or in the performance of religious rituals.
  - There are also economic reasons: in a society that favours males, the earning power of males is likely to be considerably greater than that of females.
- B. Sex selection today is predominantly practised in countries in the developing world, where social attitudes may be particularly favourable to male children. In such societies, where state provision for old age is either non-existent or weak, people may rely on sons to support them in later life, a role that may be denied to women because of social constraints.
- C. Sex selection in the developed world has not been so prominent, and yet, with an increasingly pluralistic population in Western Europe and North America, it may become more of an issue as the social attitudes of immigrants make more of an impact on the broader society.
- D. In western countries, too, there may be quite separate reasons for practising sex selection—reasons connected with family balance or, in

some cases, medical reasons. At present the demand is small, but it is easy to imagine it becoming larger if it were to be more readily and cheaply available. So the issue of sex selection is one that is likely to loom larger in our lives. And it is one that is likely to engender considerable passion, as some feminist writing labels it as a form of genocide, or gendercide as it has been called.

#### II. How Is Sex Selection Practised?

- A. We have already mentioned infanticide, which is the most radical and morally objectionable form of sex selection practice.
- B. Abortion is another crude method. The sex of a child may also be detected by chorionic villus sampling, which is carried out at about eleven weeks of gestation, and which may then be followed by an abortion if the child is not of the sex that the parents want.
- C. Both infanticide and abortion involve measures with potential criminal liability and obvious risk.
- D. There are other methods, though, that may be performed within the law; these are at one end of the spectrum of "folk methods" and timing of conception methods, all of which are of unproven effect. At the other end, there are scientific methods that are comparatively effective. These methods may be carried out pre- or post-conception.
  - The preconception method that has the greatest success rate is the separation of X and Y sperm. Sperm is sorted prior to artificial insemination and although this method does not provide a guarantee of producing the desired sex, it very significantly increases the chance of this result.
  - 2. A reliable postconception method involves sorting male and female embryos that have been conceived in vitro. Testing involves the use of fluorescence in situ hybridisation (known as FISH) a technique that allows for the detection of chromosomal abnormalities as well as the sex of the embryo. This method, however, requires in vitro fertilisation, and not only does this have a high failure rate, but it also involves a possible risk for the child conceived in this way. It would only be resorted to, then, in those cases in which there were very strong grounds for avoiding the conception of a child of a particular sex—such a reason would be a medical one, associated with the transmission of sex-linked genetic disease.

#### III. Sex Selection: Is It Ethically Acceptable?

A. To test the ethical acceptability of sex selection, we might imagine cases in which people may wish to engage in it. Here are some cases, cases one to four, in which couples have opted for sex selection. These are hypothetical cases, but are typical of some of the instances that may arise.

#### **CASE ONE**

#### SITUATION

A and B live in a country in which the provision of a dowry for daughters is considered a social necessity. Their resources are stretched. They have no pension expectations. They already have two daughters and the birth of a third would be considered a catastrophe, as it would limit the amount of money available for the payment of a dowry for the existing two daughters. B, the wife, is also aware of her husband's strongly expressed displeasure at the fact that they have so far had only daughters. He has been violent to her on numerous occasions and has threatened reprisals should she produce another daughter. She fears for her safety if this should prove to be the case. She notices an advertisement in the press for "sympathetic pregnancy testing," which she correctly interprets as the offer of prenatal testing and abortion to prevent the birth of a daughter. She goes to this clinic and is offered a termination of the pregnancy, as testing establishes that the fetus is, indeed, female.

#### DISCUSSION

Would we condemn B for her decision to opt for sex selection? From the perspective of a society in which woman are relatively well protected against violence—or where it is at least not socially acceptable for husbands to assault their wives, it is easy to condemn the use of abortion in such a case. And yet from the point of view of the threatened woman, this choice is a matter of self-preservation akin almost to self-defence. She might also argue that her choice is in the interests of the existing daughters, whose future would be adversely affected by the birth of another sister.

The issue in this case seems to be one of the extent to which the interests of existing people may be taken to outweigh the interests of one who is not yet born. This is a form of the necessity argument: the suffering of the two daughters will be assessed against the harm that is caused to the interests of the aborted child. Many people would say that the interests of the fetus are greater than any of the other interests involved—including the woman's safety—but we should perhaps remind ourselves that we are making this assessment from the comfort and safety of our vantage point. For a woman in desperate circumstances, a quite different decision may seem much more appealing and indeed one which she may feel herself entitled to make.

#### **CASE TWO**

#### SITUATION

In this case, C and D are the parents of a daughter who, unfortunately, succumbs to a disease of childhood. They have no other children, and they have a strong desire to replace their daughter with another female child. They understand that this new daughter will have a personality and identity of her own, but they are strongly motivated to have a child who will remind them of their lost daughter. They engage in sex selection in order to ensure their choice of a daughter.

#### DISCUSSION

If we think about this case, it is rather different from a case of a mere idle preference for a particular sex; this is selection based on a very strong desire to replace a child. The tragic circumstances in which this desire comes into existence perhaps serve to underline the potential privacy of the decision: these are powerful, private reasons that may be beyond the scope of the rational. Would the rejection of such a request be considered rather harsh? One might be tempted to think so.

#### **CASE THREE**

#### SITUATION:

We now move to a case of D and E, a couple with four children, all of them boys. E, the wife, has nobly raised this masculine family but feels that a final try for a girl would be desirable. She fondly imagines the pleasure that she will get from the company of a daughter, with whom she will be able to share certain interests. Her sons are able to share interests with their father, and he realises that she would be much happier if she had a daughter.

#### **DISCUSSION**

The reason for sex selection in this case is family balance. A utilitarian would also see a very strong justification here in terms of greater happiness. Everybody would be happier with sex selection in this case: the parents would have their happiness increased; a daughter would be particularly loved and cherished, and therefore might be expected to have a happy and satisfying life. And even the brothers, that masculine band, might be happier if they had a sister rather than another brother. This, therefore, is a case in which calculations of the overall happiness of those most intimately involved in the decision point in the direction of allowing sex selection.

#### **CASE FOUR**

#### SITUATION

A misogynist father, F, wants to have a son because he does not particularly like girls. His wife, G, does not mind either way, but in order to keep F happy she agrees to resort to a sex selection process. Is this wrong?

#### **DISCUSSION**

The reason here would appear to be a light one—a particular prejudice of the father. It could be argued that if sex selection were to be allowed in such circumstances he, the father, would be happier, but society as a whole would be harmed by the sexist nature of the decision he has made. Allowing sex selection in such cases would merely perpetrate a situation of general injustice to women and girls. This is certainly the least justifiable of the four cases.

B. Some of the cases above highlight the reasons why sex selection might be allowed. It is clear that there are at least some cases where the choosing of the sex of a child will be done in order to avert a harm to existing people, or indeed a harm to the child himself or herself. If the selection process involves abortion, then one is going to have to decide whether the averted harm is sufficiently serious to justify taking that step, and that obviously will not always be so.

#### IV. Opposition to Sex Selection

- A. Some of the objections to sex selection focus on the effect that sex selection would have on attitudes toward women and on women's place in society. There is a strong tradition of feminist objection to this practice, based on the grounds that the deliberate choosing of a boy amounts to an expression of distaste for women in general and is therefore a sexist act. Insofar as sex selection perpetuates such attitudes, its effect on society in general is deleterious. In this view, too, it is an act of extreme discrimination to prefer a fetus of one sex over a fetus of another.
- B. Allowing sex selection might thus become an act of symbolic preference that would suggest that other discriminatory practices would be acceptable. For this reason, there are those who would argue that sex selection should only be allowed in those cases where there is a clear medical reason for allowing it, and those cases where the choice was being made on economic grounds or grounds of personal preference should not be allowed.

#### Summary

Can sex selection be considered a private act—something that is a matter of individual choice? On balance the answer would seem to be no, and the reason for this is that it is potentially discriminatory and it also has an effect on society in that it disturbs the sex ratio. This last consideration is important: there is already evidence that in societies in which sex selection of various forms has been practised, the ratio of males to females has tilted in favour of males to an observable extent. This will have effects on society that we cannot ignore and that we might well wish to avoid. Some feminists point out that a preponderance of males leads to a greater degree of violence within society. Whether or not one accepts this, intuitively a balance of the sexes seems to be more likely to result in social stability. In the next lecture, we turn to the right to reproduce.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. Is sex selection simply an extension of the legalization of abortion?
- 2. What are the best reasons to avoid sex selection?

#### Suggested Reading

Warren, Mary Ann. Gendercide: The Implications of Sex Selection. Lanham, MD: Rowman & Littlefield. 1985.

#### Other Books of Interest

- Bainbridge, David. *The X in Sex: How the X Chromosome Controls Our Lives*. Cambridge, MA: Harvard University Press, 2003.
- Birkhead, Tim. *Promiscuity: An Evolutionary History of Sperm Competition*. Cambridge, MA: Harvard University Press, 2001.
- Pence, Gregory E. Who's Afraid of Human Cloning? Lanham, MD: Rowman & Littlefield, 1998.
- Sen, Gita, and Rachel Snow. *Power and Decision: The Social Control of Reproduction*. Cambridge, MA: Harvard School of Public Health, 1994.
- Silver, Lee M. Remaking Eden: Cloning and Beyond in a Brave New World. New York: Avon Books, 1997.
- United States Congress. House Committee on Commerce. Subcommittee on Health and Environment. *Cloning: Legal, Medical, Ethical, and Social Issues*. Washington, D.C.: Superintendent of Documents, United States Government Printing Office, 1998.

### Lecture 6: Abortion?

The Suggested Reading for this lecture is the Rickie Solinger's Abortion Wars.

#### Introduction

Few topics arouse such passion and polarisation as abortion. This is a moral issue that has become intensely political, and indeed has led to violence and murder. The shooting of doctors who perform abortions is a shocking reminder of just how strongly feelings on this issue may run. We can change the terminology we use, of course, in an attempt to take the heat out of the issue. So people talk about the medical termination of pregnancy, but the moral issues involved in abortion are too clear, too persistent, to be massaged out of existence in this way.

#### I. Abortion—A New Issue?

- A. For a long time, abortion was the subject of a peculiar compromise. A proportion of pregnant women have always tried to bring about the miscarriage of unwanted babies and have resorted to a variety of folk remedies to achieve this, or they have consulted unqualified, clandestine abortionists, so-called backstreet abortions. The mortality associated with these attempts was immense, and generation after generation of women died from horrific infections following these crude interventions.
- B. At the same time, in some countries and in some hospitals, medical abortion was discretely available, in spite of the general legal interdiction of such operations. This was done through a broad interpretation of medical necessity, where abortion was necessary to save the life of the mother. The liberality of this interpretation depended on the area, the hospital, and the individual doctor.

#### II. The Legalisation of Abortion

- A. Abortion was legalised in the United Kingdom in 1967, with the passage of legislation that allowed the procedure on a number of grounds.
- B. In the United States, a major change came with the important case of *Roe* v. *Wade*, which we shall discuss later in this lecture.
  - Opposition to abortion has remained intense: in 1996, one third of abortion clinics in the United States has been violently attacked by "pro-life" campaigners, and, at a more law-abiding level, "pro-life" groups have tried to shock the public by publicly displaying pictures of aborted fetuses.
  - 2. In spite of this, there is evidence that around two out of three Americans still support the right to abortion. Abortion rates in the United States, though, are dropping: 29 out of 1,000 women of childbearing age had an abortion in 1980, while in the year 2000 that had

- gone down to 21 out of 1,000. This is quite high among developed nations, but the global rate is higher still, at 35 out of 1,000.
- C. Abortion is not legal in every country, but the general trend in the developed world is certainly toward liberalisation. But this is not all in one direction.
  - Russia (where there are roughly thirteen terminations per ten live births) has recently placed severe restrictions on availability of abortion after the twelfth week of pregnancy.
  - 2. This has been seen by "pro-choice" campaigners as a first and hostile step toward an attack on the rights of women.

#### III. How Do Doctors Feel About Abortion?

- A. Interestingly enough, abortion was specifically outlawed by the Hippocratic Oath, which says, "Nor will I give a woman a pessary to procure abortion." But even at the time this was probably not a consensus. or even dominant view.
- B. Other declarations of medical ethics have been more ambivalent or pluralistic:
  - The Declaration of Geneva originally prescribed utmost respect for human life "from the time of conception," but was amended in 1994 to read "from its beginning."
  - 2. The Declaration of Oslo describes abortion as "a matter of individual conviction and conscience."

#### IV. The Debate Continues

- A. At the heart of the abortion debate are fundamental disagreements about the nature of human life and the role of various conflicting rights.
- B. Looking first at the nature of human life, the disagreement here is about the status of the fetus, which we considered at some length in an earlier lecture. In this context, the issue is whether the fetus deserves protection and should always be allowed to develop and be born.
  - Opponents of abortion have no difficulty in stating their position in unambiguous terms—they argue that the fetus is a person and that since it is wrong to kill a person it is wrong to kill the fetus. They deny that this position places them in direct opposition to the position of women's rights.
  - 2. This position is vigorously opposed by those who believe that the choice of whether or not to proceed with a pregnancy is solely a matter for the pregnant woman. This position—widely known as the pro-choice position—holds that the principle of procreative autonomy requires that the woman's choice whether or not to have a child should be respected.
- C. The debate about abortion has become somewhat sterile, with the two sides occupying seemingly irreconcilable positions. Can there be any form of compromise? What is possible is the creation of a compromise between the two positions that will effectively be accepted by society as

a whole and allow each side to believe that at least something has been achieved. Thus, an abortion regime that makes abortion available, but only if fairly stringent criteria are met, may be a solution with which opponents of abortion may live, while arguers for the choice position will feel that their requirements are at least partly met.

#### V. The Legalities of Abortion

- A. Because abortion is a matter for the law, the negotiation of a compromise in these circumstances has been the task of the legislators or the courts. In some countries the courts have resolved this on constitutional grounds, through the interpretation of privacy provisions.
- B. There are several possible approaches to regulation, ranging between the extremes of total prohibition and total legalisation.
- C. Modern abortion regimes differ widely.
  - 1. The United States is comparatively liberal, allowing abortion "on demand" until approximately the end of the sixth month of pregnancy. This was achieved through litigation through the courts, culminating in a landmark decision of the Supreme Court.

This was Roe v. Wade (1973). This case involved a challenge to a Texas statute (enacted in and substantially unchanged since 1854) prohibiting abortion outright, except to save the life of a pregnant woman. The majority of the judges decided that the constitutional "right to privacy" was wide enough to cover the right of a pregnant woman to choose to have an abortion.

But the U.S. Supreme Court did not legalise abortion completely it established a framework for legal abortion. The starting point was that the right to abortion, like other privacy rights, could be abridged by "compelling interest" of the state. In abortion cases, the state has two interests: an interest in the life and health of the pregnant woman and an interest in the life and health of unborn children. These become "compelling" interests at different stages.

The court based its framework around the three equal "trimesters" of pregnancy recognised by physicians.

- i. At the end of the first trimester (approximately three months after conception), because until that point risk to the life of the mother in abortion is less than risk in childbirth.
- ii. At end of the second trimester (approximately six months after conception), because it is about that time that the fetus becomes viable (that is, capable of being born alive).

Significantly, the majority also decided that a fetus is not a "person" within the meaning of the Fourteenth Amendment, and therefore was not itself entitled to protection under that Amendment of its "life, liberty or property." So:

 First Trimester: abortion freely available. State has no interest sufficiently compelling to justify abridging right to privacy.

- ii. Second Trimester: state may regulate so as to protect life and health of mother, (i.e., may prescribe where and by whom abortion can be carried out). Subsequent jurisprudence has developed "undue burden" test.
- iii. Third Trimester: state may proscribe abortion completely, except where necessary to preserve the life or health of the mother.

Roe has not gone unchallenged. Indeed, on one view it has been partly retreated from. In a series of subsequent cases, the legitimacy of state obstacles to abortion has been recognised, allowing elaborate consent and information regulations to be imposed.

In the United Kingdom, the Infant Life (Preservation) Act of 1921 created an exception to offence of abortion when it was done "for the purpose only of preserving the life of the mother."

The case of *Bourne* in 1938 concerned a fifteen-year-old girl who became pregnant after a vicious rape: an abortion was performed by a qualified obstetric surgeon. The judge held that on a reasonable view of the words of the 1921 Act, "preserving the life of the mother" included the case in which continuance of pregnancy would render the woman "a physical or mental wreck." Clearly this exception is potentially very broad.

Then legislative reform came in the shape of the Abortion Act of 1967, which allows abortion up to the twenty-fourth week of pregnancy where there is a risk greater than if the pregnancy were terminated, or injury to the physical/mental health of the pregnant woman or any existing children of her family. The opinion of two medical practitioners was required.

D. One has to bear in mind that the legal position does not necessarily affect availability and prevalence of abortion. When abortion was illegal in the United Kingdom, "back-street" abortions were always available, but very risky for women. The abortion rate in countries where it is illegal is not much different from that in countries where it is allowed: around 26 percent against 20 percent.

#### Summary

The possibility of achieving a social concensus on abortion seems remote. The issues are clear enough, but neither side in the debate will yield. In these circumstances the only response seems to be to adopt a pluralistic one and accept that disapprovals will be fundamental. The talk then becomes that of identifying a position that will cause the minimum friction between the differing parties. This sounds a bit unsatisfactory. That may be so; however, that may also be the best we can do. In the next lecture we will discuss surrogacy.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. Does the existence of reproductive technology complicate the arguments for and against abortion?
- 2. Are there any conditions under which you would support a view opposite to your own on abortion?

# Suggested Reading

Solinger, Rickie, ed. *Abortion Wars: A Half Century of Struggle, 1950–2000.* Berkeley: University of California Press, 1998.

#### Other Books of Interest

- Dwyer, Susan, and Feinberg, Joel, eds. *The Problem of Abortion*. Belmont, WA: Wadsworth, 1997.
- Ginsburg, Faye D. Contested Lives: The Abortion Debate in an American Community. Berkeley: University of California Press, 1998.
- Githens, Marianne, and Stetson, Dorothy McBride, eds. *Abortion Politics*: *Public Policy in Cross-Cultural Perspective*. New York: Routledge, 1996.
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- Reiman, Jeffrey. Abortion and the Ways We Value Human Life. Lanham, MD: Rowman & Littlefield, 1999.

# Lecture 7: Who's My Mother? Who's My Father? Surrogacy

The Suggested Reading for this lecture is the Phyllis Chesler's Sacred Bond: The Legacy of Baby M.

#### Introduction

There was a time when surrogacy was very much in the news—a time when a few high-profile cases caused a considerable stir. We hear less about it these days—the issue seems to have settled down a bit—but there are still some very significant moral questions to which it gives rise. It represents one of the alternative methods of reproduction that is currently available.

# I. Will You Have My Child?

- A. Here's a typical surrogacy arrangement. A successful professional couple with good careers, and a good marriage, is unable to conceive through natural or artificial means. A healthy young woman offers to have her baby for a fee. Artificial insemination is arranged and the child is conceived. That child is the professional couple's, in the genetic sense, but not the young woman's.
- B. The pregnancy goes without a hitch and in due course the baby is born. The surrogate mother, to whom has now been paid a handsome fee, gives up the child. A happy ending: the surrogate mother has been paid handsomely; the couple has a baby and the baby will have loving parents and a good home. Why should anybody object to this?
- C. Well, they say, things could go wrong. What if the surrogate mother had refused to give up the child? Would the happy couple have been able to do anything to assert their rights in the face of her claim as the child's mother? Or, alternatively, what if there had been something wrong with the child? Could the couple refuse the child? There are many ways in which the whole arrangement could go wrong, and some surrogacy arrangements have done just that.
- D. But in the example we considered, things did not go wrong—they went rather well—and surely the fact that something can go wrong with a procedure is not grounds in itself for rejecting that procedure altogether. Perhaps not, but then there are further objections round the corner.
- E. Those who object to surrogacy may argue that surrogacy is wrongful quite independently of anything that can go amiss with the arrangement. In this view, surrogacy is immoral and the law should certainly not assist people who are unwise enough to get themselves entangled in such contracts. Is this a somewhat unsympathetic view of the situation or will that be the conclusion to which any moral assessment of surrogacy inevitably leads us?

#### II. Surrogacy Under the Moral Microscope

- A. To answer this question, we work out how surrogacy works, what people expect of it, and how it affects the interests of all those involved—the mother, the commissioning couple, and the child.
- B. Surrogacy can be partial or traditional (complete).
  - 1. Partial surrogacy exists where the gametes from the male in the commissioning couple are used to impregnate the surrogate mother. This might be done by natural sexual intercourse, but it is more likely to be achieved through artificial insemination—not too difficult a task. There have been many successful impregnations in this low-tech way. The fact that the insemination is artificially achieved is quite important, as it removes from the moral equation any suggestion of adultery that might be used as a stick with which to beat the practice.
  - 2. In complete surrogacy, the gametes from both the man and the woman will be used. Fertilization takes place in vitro and implantation then follows. The fact that this involves IVF means that the resulting child is going to be the biological child of the commissioning couple.
- C. Let's look at the issue of moral acceptability of surrogacy.
  - 1. The libertarian might be expected to say that there is nothing wrong with surrogacy because it is merely another exercise of procreative liberty. The proponent of this view would say that the sole grounds for intervention in this area of life is the possibility of harm to others, and in this case, as long as the child is not harmed, then there is no possible objection.
  - 2. Not everybody subscribes to this view. A range of objections is available to surrogacy starting with the objection that this is prostitution, no more and no less. The prostitute makes the body available to another in return for money. Is this not exactly what the surrogate does? Even if surrogacy is to be put on a par with prostitution, is prostitution in itself wrong?
  - 3. There are other arguments against the practice of surrogacy. The most obvious of these is the argument that it imparts to the whole process of human reproduction a commercial connotation, and this commercial connotation in due course leads to a commodification of the child.

Certainly for some of the public bodies that have looked at surrogacy, the danger of commercialisation and commodification is quite a major one.

For example, the New York State Task Force on Life and the Law saw surrogacy as a "radical departure from the way in which society understands and values pregnancy." It substitutes, they went on, "commercial values for the web of social, affective and moral meanings associated with human reproduction."

In many countries, it has long been accepted in adoption laws that the buying and selling of children for adoption should be illegal. Now, although such purchases undoubtedly take place, often in the context of foreign adoptions, domestically the law likes to maintain that there is something intrinsically wrong in paying for a child.

- i. But why should it be wrong to do so? Is it something to do with an objection to slavery? If you pay money for an adoption, is it appropriate to say that you have bought that child?
- ii. What you have done is you have acquired parental rights in respect of that child, and these rights are different from the rights which an owner exerts over his or her property.
- iii. So, as long as the child's autonomy is going to be respected—as it must be—the fact that the adoptive parent has acquired the child by paying money does not mean that the child is going to be any the worse off, in autonomy terms, than if he or she had stayed with the original birth parents. The slavery analogy thus does not seem appropriate.

Leaving slavery aside, why should the fact that money has changed hands make a difference to the transaction? This is probably something to do with our belief that the presence of money in a transaction corrupts it. But why should this be so? Is it because we believe that there are some relationships in life that should not be based on gain of any sort, but which should spring from affection, or duty, or some other such value?

Is this objection going to focus, then, on the fact that the commissioning parents are prepared to pay for the child, or on the fact that the mother was prepared to give up the child for money? Looking first at the position of the commissioning parents, one must consider their potentially altruistic motives—to have and care for a child.

#### III. And What of the Vessel?

- A. The position of the surrogate mother is rather different as far as commercialization is concerned. Many people find it offensive that she should be prepared to give up a child in exchange for payment. This is because we expect a mother to love her child and to keep it; the idea that somebody could willingly part with the child after nurturing it for nine months seems to many to be a complete negation of the normal maternal impulse.
- B. Yet, why would this weaken our notion of motherhood? Mothers abandon their children left, right and centre, and have always done so. The fact that some mothers do this does not mean that we have any less attachment to the notion of motherhood. Yes, possibly, but if we are to clothe surrogacy arrangements with legal recognition, then we are taking a step in the direction of endorsing a particular attitude toward children—we are effectively saying, yes, this attitude of rejection is sufficiently acceptable to warrant legal regulation. Usually when the law encounters a practice that it regards as immoral it refuses to countenance the transaction altogether. In this way the law has effectively been drawn into the issue, usually reluctantly.
- C. Some people will object to any condemnation of the surrogate mother.

They take the view that the real victim of the whole enterprise is, in fact, the woman who bears the child. This is because she will probably only have entered into the contract through economic need. This is probably true. The majority of surrogate mothers are poor; the commissioning parents are well off, or certainly better off than the mother. This prompts two concerns:

- The first concern is that the mother may not have entered into the contract in an entirely consenting way—one does not necessarily give valid consent to a contract in which one is the distinctly weaker party.
- 2. The second concern is the related, but more general concern that these arrangements will lead to the exploitation of women.

#### IV. And What of the Child?

Is there any risk to the child in all this? There probably is not a great deal of risk. If the arrangements work, then the child will probably stand a good chance of a happy life. Of course, if the child were later to be informed of the circumstances of his or her conception, then there could be psychological complications, but such complications already exist for adopted children and we manage to accept that risk.

#### Summary

Surrogacy has become an established way of making up for the limitations of nature. It requires some regulation, but on balance there is no great case for seeking to make it illegal. And it is always possible that surrogate arrangements may be made in a spirit of altruism rather than one of commercial gain. That is done in some African societies, for example, where a fertile sister may carry a baby for an infertile one. Far from being an act deserving moral censure, that probably deserves moral praise.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. What are the most important points you would require in a surrogacy contract as both a parent and then as a surrogate mother?
- 2. What of the child's right to know her origins? Should she be told?

# **Suggested Reading**

Chesler, Phyllis. Sacred Bond: The Legacy of Baby M. New York: Times Books, 1988.

# Other Books of Interest

- British Medical Association. *Changing Conceptions of Motherhood: The Practice of Surrogacy in Britain*. London, England: British Medical Association (BMA), 1996.
- Gostin, Larry. *Surrogate Motherhood*. Bloomington: Indiana University Press, 1990.
- Rae, S.B. The Ethics of Commercial Surrogate Motherhood: Brave New Families? Westport, CT: Praeger, 1994.
- Raymond, J.G. Women as Wombs: Reproductive Technologies and the Battle Over Women's Freedom. New York: HarperSanFrancisco, 1993.
- Shanley, Mary Lyndon. Making Babies, Making Families: What Matters Most in an Age of Reproductive Technologies, Surrogacy, Adoption and Same-Sex and Unwed Parents' Rights. Boston: Beacon Press, 2002.

# Lecture 8: A Sorting Vat for Babies: Screening for Abnormalities

The Suggested Reading for this lecture is the Karen Rothenberg's Women and Prenatal Testing.

#### Introduction

In the days before antenatal screening, the only way in which anybody could predict anything about the health of a future child was by looking at the family history of the parents, at their own state of health, and by working out what genetic risk there was for any future offspring of those particular parents. Even if there was no history suggesting a heightened risk, it was still possible to give some idea of general risk. So people could be told, for example, that the risk of conceiving a child affected by Down's Syndrome is one in six hundred, and that this risk increases with age. So reproductive decisions have not always been entirely in the dark—at least since the development of Mendelian genetics.

#### I. Science to the Rescue

- A. But things have certainly changed. With the development of our understanding of what genes cause which conditions, and with our ability to detect these in a fetus, we can now say very much more about the condition of the child before it is born. And these tests are not just genetic ones—biochemical tests may be used that don't even have to examine the DNA of the fetus, but test, for example, a blood sample from a pregnant woman.
- B. This process is called antenatal screening, and it is now a regularly offered medical service. It works and is resorted to by many, and yet there are those who are very unhappy about its ethical implications.
  - Opponents raise the spectre of eugenics—the process whereby a society seeks to eliminate the occurrence of certain conditions in its children with a view to affecting the overall genetic profile of the population.
  - 2. The eugenics movement has been a deeply unpopular one over the last half century and any sign of its return is greeted with the gravest suspicion. Some people take the view that eugenics is creeping back onto the agenda, and that one way in which it is doing so is through antenatal screening processes.

#### II. How the Screening Is Done

- A. What can screening actually achieve and how is it done? Well, there are numerous tests currently available, but two of the most common are those for neural tube defects and Down's Syndrome.
  - 1. The main forms of neural tube defects are anencephaly and spina bifida.

- i. Anencephaly is a fatal condition, but spina bifida is not necessarily so, and the seriousness of it depends on the degree to which the infant is affected. Some people who are affected by it lead very full lives, even if they may have to endure muscular limitations and other hardships.
- ii. Screening for this condition is reliable: it involves taking a sample of maternal blood, which is then tested for alpha-fetoprotein.
- iii. Ultrasound may also be used to detect some of these anomalies in the fetus, and this helps to limit the extent to which false positives are received. So this is a relatively simple and inexpensive test that can be offered on a standard basis to pregnant women and can have a dramatic effect on the incidence of the conditions in question. In countries where this screening is offered, the incidence of these conditions has fallen by as much as 95 percent.
- Down's Syndrome takes its name from the English physician, Dr. Langdon Down, who identified the particular features of the condition in the middle of the nineteenth century. It is a condition with which most of us are familiar.
  - i. Down's Syndrome children are not uncommon; one in every six to seven hundred births is a Down's Syndrome child, which is a fairly high number, and indeed the condition is usually the most common cause of learning disability.
  - ii. Down's children may have other problems, such as serious heart conditions, and this may lead to a shortened life expectancy. The extent of intellectual impairment will differ, though: some children affected by Down's will never be able to lead independent lives; others may be able to do so to an extent.
  - iii. The actual causation of the condition is the presence in the child of an extra chromosome number 21 (trisomy 21); it is this that leads to the characteristic physical appearance and the limited intelligence.
- 4. Down's Syndrome is preventable, as long as one agrees with the remedy, abortion. It cannot be detected before conception, and therefore the only way of doing anything about it in advance is to control the statistical risk of having a Down's child by choosing to procreate early: a woman age twenty has a chance of 1 in 1667 of giving birth to a Down's child; at 35 this risk is 1 in 385; and at 45 it is 1 in 30.
- B. But for most people this sort of information will either not be available or they will not wish to take it into account. And so we are left with maternal screening as the main means of detecting whether a baby will be born with Down's Syndrome.
  - 1. This testing is done between the fourteenth and twenty-first week of pregnancy and involves a process of amniocentesis, which involves drawing off a small sample of amniotic fluid. This process is not without risk, as it can result in miscarriage in about one percent of cases.

- Ultrasound screening can also be used, and this may be done as a means of identifying those cases where amniocentesis will be necessary to establish the position clearly.
- C. It is important, when talking about these matters, not to be carried away by the miracles of the science. We need to consider the effect of these tests on the people involved and to understand the potential difficulty of the ethical issues which arise. Decisions in this area are not necessarily all that simple. Such tests involve psychological and ethical factors that have to be taken into account; we cannot simply welcome them as simple means of avoiding a condition that we might find awkward or demanding.

#### III. The Ethical Objections to Antenatal Testing

- A. Antenatal testing sounds useful, we say. Why should there be ethical objections to the process? Critics might say that the right response to this question is to pose a counter-question and ask, well, why should we want to do it in the first place? And that, certainly, does draw attention to the fact that antenatal testing ultimately is about offering termination. There will be cases where a woman goes through with a pregnancy in spite of knowledge that her child will be born with a serious condition, but these cases are the exception. Most people, faced with information about a serious condition will choose to bring the pregnancy to an end. Of course it could be argued that it is useful to have advance warning of a child's condition, so that preparations may be made, and one could therefore have testing even if abortion is not on the agenda, but is unlikely to overcome the objection to abortion in those who hold it.
- B. Opponents of abortion would say that the argument should stop there, but the fact of the matter is that many of us live in societies in which abortion is accepted, both ethically and legally. The question for us then is rather not whether antenatal screening should ever be offered—it is an offer and it will continue to be widely used—but just how it is offered—for what conditions and in what circumstances. That is the real focus of the current argument.
- C. At the permissive end of the spectrum are those who say that there should be no restriction on the circumstances in which screening is offered and that the decision is purely for the woman to make. They hold that if the science exists to allow any information about the fetus to be detected, then it is up to the woman to decide whether or not she wishes to know it. We might call this the libertarian position on screening.
  - 1. Libertarians of this view argue that if the decision to proceed with a pregnancy is one which the individual is entitled to make on her own, then she must have as much information as possible—or as much information as she wishes to have—in order to make the decision in an informed way.
  - 2. It is not for others to say that information about her own body—and the fetus is part of her body—can be withheld from her.

- D. Now this draws us unavoidably into the argument over abortion. If the abortion decision is going to be entirely for the woman to make, then she should be entitled to take whatever tests she likes and to interpret the results in whatever way she wishes. So in a maternal choice system of abortion, it would be up to the woman to decide whether the prenatal detection of, say, cleft palate, should be grounds for terminating the pregnancy.
- E. If the decision is left to the pregnant woman, then the choice of what tests to offer becomes crucial, because the decision as to which conditions to test for may, in effect, influence the decision to terminate the pregnancy. A test result that reveals some imperfection—even one that is ever so slight—may convince the woman—or the parents perhaps—that there is something wrong with the baby, and that it would be better not to proceed. So what really becomes crucial is the offering of the test in the first place. If we wish to prevent abortion for slight reasons (such as cleft palate) then we have to consider whether such a test should be offered in the first place. But here we are up against right-to-know issues, and it may be difficult to discourage testing if the technical means of doing it exists.
- F. Some feel that the end result of this will be that more specific and wideranging antenatal testing will have the effect of encouraging perfectionism in reproduction. People will not bother to ask themselves whether
  the degree of defect in the fetus is really incompatible with a reasonable quality of life, and may believe that the fetus should pass every
  test before it is allowed to continue to term. For this reason, in those
  countries in which there are public antenatal public screening programmes, efforts have been made to provide guidance as to which
  tests should be offered and when.
- G. The final, but very strong criticism of antenatal testing is the criticism voiced by some sections of the disability movement. This is a powerful voice of dissent and needs to be considered carefully.
  - 1. Disability advocates take different views of testing. Some of them accept it, but others are quite strongly opposed to it. They argue that testing encourages a eugenic approach and that it inherently devalues those who are disabled. It has this effect, they say, because it implies that it is better if those with disabilities were not to exist. They argue that the occurrence of disability is something that we should accept, and, what's more, we should value those who have a disability.
  - 2. Now on that point—that we should accept and value those with a disability—there can surely be no disagreement. Of course we should do that, and more than that, we should ensure that disabled people are given every chance to lead afull and productive lives. This is widely accepted and indeed it underpins many government policies that are intended to protect the disabled from discrimination and are designed to ensure that the workplace is welcoming for them. So if there is any disagreement, it must focus on the question of whether there is an irreconcilable conflict between the approach of offering pregnant women the opportunity to test for disability in the fetus—

- and, implicitly, to accept that they might decide to terminate the pregnancy—and, a policy of valuing disabled people for what they are. Is there such a conflict?
- 3. There is no incompatibility between a policy of testing and a policy of valuing the disabled. This is a case where two sets of claims can co-exist, and to place the claims of some disabled people above the claim of the mother to make up her own mind as to whether she wants a disabled child is to give undue prominence to the disability claim. The right to make decisions about reproduction is now too firmly entrenched to be queried in this fundamental way simply to ensure that those who are disabled do not feel unwanted. At the same time, the disabled lobby gives us a reminder here as to the folly of perfectionism. This means that decisions about genetic testing, whether these are community decisions or the decisions of individuals, should be made with due sensitivity to the impact that these decisions may have on our general social perception of the disabled. Again, we come back to dignity as a central value.

#### Summary

In this lecture we have focused on the science and ethical considerations of antenatal screening for defects. Now we move on to discuss the way man has learned to enhance the genes that create the potential human life.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. Your doctor recommends a particular (somewhat risky) screening procedure based on your age or family genetic history. Do you allow it?
- 2. Weigh the value of knowing about a genetic defect against not knowing. What are the advantages and disadvantages of both?

# Suggested Reading

Rothenberg, Karen H., ed. Women and Prenatal Testing: Facing the Challenges of Genetic Technology. Columbus: Ohio State University Press, 1994.

#### Other Books of Interest

Andrews, Lori B. Future Perfect: Confronting Decisions About Genetics. New York: Columbia University Press, 2001.

Drlica, Karl A. *Double-Edged Sword: The Promises and Risks of the Genetic Revolution.* Reading, PA: Addison-Wesley Publishing Company, 1994.

Rothenberg, Karen H., and Elizabeth J. Thomson, eds. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus: Ohio State University Press, 1994.

# Lecture 9: Superboy and Wondergirl: Genetic Enhancement

The Suggested Reading for this lecture is the Roger Gosden's Designing Babies.

#### Introduction

If we look about, we can hardly but avoid the sights of our impact upon our world. We have physically changed this world—built upon it, tunnelled into it, covered it with stone and concrete—and destroyed large chunks of it. In the midst of all this physical change, natural species have continued their existence, often against our best efforts. This natural world—the world of biology—has itself not been immune to our interventions. Some 40 percent of the world's flowering plants and 70 percent of all grasses are the results of our efforts at hybridization, and there are many hybrid animal species that we have produced through our interventions. These animal hybrids are not new species, but are certainly different from the original breeding animals from which we produced them. This is a significant intermeddling by humans, and in some respects it represents a crossing that has already taken us from being observers of nature to being creators. And that worries us—the thought that we are taking upon ourselves a role which will ultimately lead to disaster in human terms. Creating Frankenstein is not something that most of us relish.

# I. It Began at the Dog Show

- A. We may have concerns about interfering with the breeding of animals, but we have certainly been doing that for a long time. This may take the form of hybridisation or it may take the form of selective breeding within species. We can certainly see the results of the latter around us all the time. The cow with a particular capacity for giving a high milk yield, the dog with accentuated features thought desirable in a particular breed—these are examples of the many forms of animal husbandry that have shaped the way in which animals look and behave.
- B. At times we may consider this to be a questionable activity—as when dogs develop defects associated with the selective breeding of particular characteristics—but it is far too late for us to hold back very much on this now. It would, apart from anything else, be practically impossible to control animal breeding on a wide scale.

#### II. Eugenics: And Now . . . Humans?

- A. We have been much warier of intervening in human reproduction in the same way as we have interfered with animal reproduction, although there have certainly been interventions around the margins. The eugenics lobby, which was particularly strong in the earlier part of the twentieth century, was enthusiastic over selective human breeding.
  - 1. They argued that one could improve the human stock, so to speak, by ensuring that those people with desirable qualities produced children

- (positive eugenics) and those people who were afflicted by conditions deemed to be undesirable did not (negative eugenics).
- Remarkably enough, several states implemented eugenicsinspired laws, the most notorious example being Nazi Germany, which introduced compulsory eugenic measures under so-called racial hygiene laws.
- 3. In the United States, enthusiasm for human eugenics took the form of sterilization laws, the objective of which was to ensure that people with certain conditions were compulsorily prevented from having children. The principal concern here was the prevention of the genetic transmission of mental disability, but there were other conditions, too, which this movement wished to stop.
- B. The post-War reaction to the excesses of eugenicists and racial theorists in Nazi Germany was profound, and during the second half of the twentieth century eugenics became a distinctly dirty word.
  - 1. The emphasis now was on human rights and ensuring the protection of the individual against mistreatment by the State.
  - And there was also a profound and abiding distaste for racism and for the notion that some persons were inferior or less entitled than others to share in society's goods. The eugenics gospel, then, fell on very stony ground and one might be tempted to say that it all but disappeared.
- C. Or did it? Ideas and enthusiasms have a way of masking themselves, or surfacing in different guise. In one view, eugenics has not gone away altogether, but has redesigned itself and has advocated its ideas in a different context. So while one might not hear many people talking about improving the human stock by breeding out traits, the desire to obliterate these traits may be just as strong, but could be expressed in different language. From compulsory measures we may simply graduate to measures that are based on individual choice.
- D. It would be very surprising if our increased knowledge of the human genome—a body of knowledge that is vastly more extensive since we mapped the genome—were not to result in a fresh conversation about the possibilities of intervening in human reproduction.
  - This is because now we know a great deal more about which genes do what and we might then be able to advise against their perpetuation. That's the negative eugenics side.
  - 2. But there is also a positive side—if we know what genes do, then might we be able to manipulate them in such a way as to change the person in question, or, more dramatically, to change the sort of children we produce?

# III. I Want a Healthy Child

- A. This is genetic engineering, and we now stand at the edge of it. The implications for human reproduction are considerable.
  - 1. On the one hand, genetic engineering promises us the key to con-

- trolling or eliminating various illnesses that we are at present power-less to deal with.
- On the other hand, it could enable us to control the characteristics of our offspring, either as individuals, or, and this is very important, as future reproducers of the species.
- B. There is a very important distinction here between two forms of genetic engineering.
  - 1. Somatic cell line engineering is not really about reproduction at all, but is designed to deal with a defect in the genetic constitution of the individual patient. Any modification that is achieved in that person will not be passed on. This form of genetic engineering is already with us, in the shape of gene therapy. However, it does offer immense hope for otherwise incurable diseases and those who question it are usually not so much concerned with whether we should do it at all, but how we can do it with an acceptable limiting of risk.
  - 2. Germ line modification is more radical. It involves intervention in the genome of the individual in such a way that the genetic characteristics produced will be passed on to that person's offspring. This means that germ line intervention could produce what we might loosely call new breeds of super humans.
- C. The term genetic enhancement is used to describe any form of intervention that is intended to add something to another person, either to a living person through somatic intervention or to the children not yet born.
- D. At the moment we cannot engage in genetic enhancement of future persons because we do not have the technology to do so; however we may, just may, be able to do this in the future when we understand more about the function of genes and their interaction. So, in a crude way, we might be able to ensure that reproduction produces tall people, or strong people, or people who are very good at sports or mathematics or whatever quality we imagine. If we had this power, should we use it? Is there anything wrong in ensuring that our offspring are better in the ways that we see as desirable? What would be wrong with that?

# IV. Do We Already Engage in Human Genetic Enhancement?

- A. One way of approaching this question is to ask whether genetic enhancement is any different from any of the things that we currently do and find morally acceptable.
  - 1. In general, we do not find it unacceptable to provide for children, both those that are born and those that are in utero, an environment that will be as conducive as possible to sound and healthy development. Some of these measures may be aimed at protecting the interests of the fetus from unnecessary risk or damage. We discourage drinking in pregnancy, for instance, because of the dangers of fetal alcohol syndrome, and these measures are universally welcomed. That, of course, merely involves an attempt to secure natural development; we are not trying to give the child anything that it does not already have itself.

- 2. But what if pregnant women take dietary supplements in order to encourage healthy development? Here they are doing something they would not otherwise do, but again we are unlikely to conclude that there is anything wrong in this, provided the supplements are not harmful.
- 3. And then, when the child is born, we engage in massive efforts in some cases to ensure that he or she gets the best chance in life. Education is one of these efforts, and parents may go to great lengths to ensure that the child's talents are developed as much as possible. This is all considered quite natural, although parents have a clear intention here of shaping the child. But again they might argue that they are not giving the child anything that is not already there.
- B. Enhancement seems different. We have seen that there may be no objection to the cultivation of traits, but genetic enhancement goes beyond that and gives to the child something that it does not already possess, and something which is not part of its constitution. Genetic engineering involves changing the essence of the person who is engineered.

#### V. Why Not Improve on the Natural?

- A. Why should it be wrong to change the essence of a person? One possibility is that genetic enhancement constitutes a restriction on the degree of freedom available to the future person. By imposing on the genetically enhanced subject a particular characteristic, we are closing off options.
  - This argument, though, seems a little strained. If we enhance sporting prowess, I suppose it could be said that we are closing off the option of being mediocre at sports, but that seems rather weak. What we have done is to alter the odds of this being done; we have therefore intervened in the child's future.
- B. And what, one may ask, is wrong with interfering in the future of another? The answer is that another's future is none of my business—in general. Even if I think that what I do amounts to a positive intervention, it is my judgement which states that it is positive; the other person may well take a different view. So the principle of autonomy would normally preclude interventions in the future of others no matter the outcome.
  - 1. This may be so, and yet there is a problem with this argument when the intervention is made by a parent or prospective parent. This is because a parent has the right to intervene in the life of a child, even if this right is limited. It is this standing that grants the entitlement to make decisions about how a child will turn out in life by subjecting the child to influences, such as education.
  - 2. That constitutes a massive interference in how the child will develop, and yet it is generally considered a positive intervention. That being the case, we cannot exclude genetic enhancement simply on the grounds that the parent has no right to interfere with the child's autonomy; if genetic enhancement is to be excluded, then it must be excluded on some other grounds.

- C. What could these grounds be? Well, there are a couple of candidates.
  - 1. One is the ground of the natural—again. And, of course, arguments as to nature are subject to the same objection that we have seen raised against them in other contexts, and we are left with the test as to whether the intervention constitutes an intervention in the natural to such a degree that they might offend human dignity. It is possible that genetic enhancement might do this, but we shall have to work out why it should be considered such an egregious intervention as to offend human dignity. This argument implies that genetic enhancement constitutes implicitly rejecting the natural baseline from which we all start. It effectively says that the ordinary genetic endowment of humanity is not enough. This is quite different from engineering out so-called negative genes—a gene for a serious medical condition for example—it is a statement about the ordinary genome. And this, therefore, amounts to a slight to the dignity of the normal human genome. It says that that is not good enough.
  - 2. Our intuition that there is something wrong with genetic enhancement may also follow from the view that there is something questionable about the parental motive. Is the parent acting in this way in order to give something to the child that the child may want or to satisfy a parental desire for an exceptional child?
  - 3. Finally, there is a major issue as to whether genetic enhancement would offend the principle of justice and equality. We do not all have the same chance in this life—there are inequalities, and some of these will involve genetic endowment. If there are genes for high intelligence, then a child with clever genes will usually do better than a child without them.

#### Summarv

A society that strives for equality as a matter of justice would generally not like to give one person an unfair advantage over another. Genetic enhancement could stand accused of offering some people the chance of having a significant advantage over the rest of humanity, and this might well give grounds for opposing it. We see it as offensive because it could create a whole new class of people who are going to be better than the rest of us in various respects. Of course, this objection would not apply if there were equality of access to the technology that produces it, but that is something of a pious hope. This will be a technology for the wealthy and not one for the poor. In the next lecture, we look at the topic of "spare-part" children.

# FOR GREATER UNDERSTANDING



# Questions

- 1. If otherwise healthy, why intervene in the "natural" development of a child?
- Suppose a genetic solution has been found for a serious health defect, but it is expensive. State your reasons why genetic intervention should be covered by medical insurance.

# Suggested Reading

Gosden, Roger. Designing Babies: The Brave New World of Reproductive Technology. New York: W.H. Freeman, 1999.

#### Other Books of Interest

McGee, Glenn. *The Perfect Baby: A Pragmatic Approach to Genetics*. Lanham, MD: Rowman and Littlefield, 1997.

Reiss, Michael J., and Roger Straughan. *Improving Nature? The Science and Ethics of Genetic Engineering*. New York: Cambridge University Press. 1996.

Walters, LeRoy, and Julie Gage Palmer. *The Ethics of Human Gene Therapy*. New York: Oxford University Press, USA, 1997.

# Lecture 10: Spare-Part Children

The Suggested Reading for this lecture is the D.S. Davis's Genetic Dilemma.

#### Introduction

This lecture is concerned with the use of children. We like to believe that we do not use children—that they are conceived and brought into the world not for any gain that the parents may make from all that, but for their own sake. In fact, children are often used as an end to a means, whether economic or social, but also, as we shall see, for medical ends. In this lecture, we explore is whether it can ever be legitimate to use one child as a donor of biological materials for another. In particular, I'd like to look at the difficult issue of screening embryos in order to ensure that a future child is a compatible donor for an existing one. This issue has been given the rather emotive name—the problem of spare-part children.

#### I. Selection of an Appropriate Embryo

- A. As we have already seen, pre-implantation genetic diagnosis allows tests to be carried out prior to pregnancy. As it involves the testing of embryos, it is only available to those undergoing IVF treatment.
  - 1. A cell is removed from each embryo and tested for the presence of the feared genetic disorder. Only those unaffected are implanted. This has been taking place since the early 1990s. But pre-implantation testing has further possibilities. A more recent development is the combination of pre-implantation genetic diagnosis with a process commonly known as "tissue typing."
  - This allows embryos to be tested for tissue compatibility with existing individuals, the intention being to allow the child born to act as a donor for the existing person.
  - 3. On birth, umbilical cord blood is retained instead of being discarded, as is usual, and stem cells transplanted in the hope of cure.
- B. Several cases have already arisen worldwide: certainly they have been documented in the United States, the United Kingdom and Australia. The United Kingdom and Australia have been reluctant to allow developments in such a controversial area, whilst other jurisdictions, notably the United States, leave the situation virtually unregulated.
- C. This has been done in three well-known cases.

#### **CASE ONE**

The first case to use HLA was that of the Nash family in the United States. Molly Nash was dying of the rare disease, Fanconi anaemia. There was a risk that any subsequent Nash child would also be afflicted by the disease. PGD was used to select embryos that would be free from the disease. At the same time, tissue typing tests were carried out to select an embryo that would match Molly. Adam, the resulting child, was born healthy and the transplant of stem cells from his umbilical cord blood saved Molly's life.

#### **CASE TWO**

This might be contrasted with the case of the Whitaker family, whose four-year-old son, Charlie, suffers from Diamond-Blackfan anaemia. Again stem cell transplant offered a hope of cure. His only sibling, a naturally conceived younger sister, was not a match and so his parents sought to conceive a tissue-match using IVF. The problem: that DBA can arise as a genetic mutation as well as being passed on by carrier parents. The former appeared to be the position here: neither parent appeared to be a carrier and so the child who would be born would not be at increased risk of contracting the disease. The relevant United Kingdom authority therefore refused permission to carry out tissue typing and the Whitakers travelled to Chicago for treatment. This was successful in that Mrs. Whitaker duly gave birth.

#### **CASE THREE**

In the United Kingdom, the Human Fertilisation and Embryology Authority (HFEA), a regulatory body which supervises artificial reproduction, has recently issued contrasting decisions in superficially similar cases. Indeed, one academic commented that the authority was "quibbling over a minor distinction." The Hashmi family already had five children. Zain, the fourth, was critically ill with beta thalassaemia. It was sought to use IVF to conceive another child. The embryo would be selected to ensure a tissue match with Zain, allowing a stem-cell transplant. Any child born to the couple would be at risk from developing the same illness and so PGD would have been required in any event to ensure that the child did not inherit the condition. The HFEA permitted the same cells that were being used for PGD to be tested for tissue compatibility, and this licence was upheld by the Court of Appeal following a legal challenge by a pro-life campaigner in *R v HFEA ex p Quintavalle*.

#### II. When Is It Lawful to Conceive a Spare-Part Child?

- A. At present, therefore, the United Kingdom position—and this is echoed in Australian law—is that tissue typing to select a suitable embryo for transplant is acceptable only when PGD is required to screen for genetic disease. A set of criteria have been developed for its use, which demonstrates the concerns that have been expressed over it. These criteria require the following:
  - 1. The condition of the affected child should be severe or life threatening, of a sufficient seriousness to justify the use of PGD.
  - 2. The embryos conceived in the course of this treatment should themselves be at risk from the condition which affects the existing child.
  - All other possibilities of treatment and sources of tissue for the affected child should have been explored.
  - 4. The techniques should not be available where the intended recipient is a parent.
  - The intention should be to take only cord blood for purposes of the treatment, and not other tissues or organs.
  - 6. Appropriate implications counselling should be a requirement for couples undergoing this type of treatment.
  - Families should be encouraged to participate in follow-up studies and, as with PGD, clinics should provide detailed information about treatment cycles and their outcomes.
  - 8. Embryos should not be genetically modified to provide a tissue match.
- B. The rationale appears to be that any interference with the embryo carries a risk, the long-term consequences of which are not yet known, and that this can only be incurred when it benefits the embryo or resulting child.
  - Public opinion on the matter is unclear, although there is a clear majority in favour of PGD to avoid inheritance of a serious disorder: 70 percent.
  - 2. The bulk of United Kingdom newspapers applauded the Whitakers' enterprise, adopting a pragmatic view and following the opinion of the British Medical Association:
    - "As doctors we believe that where technology exists that could help a dying or seriously ill child, without involving major risks for others, then it can only be right that it is used for that purpose. The welfare of the child born as a result of the treatment is of crucial importance. But in our view this is not incompatible with allowing selection of embryos on the basis of tissue type."
- C. Equally, opinion on the international stage appears to favour the Whitakers' actions. The American Society of Reproductive Medicine is in favour, and the European Society of Human Reproduction & Embryology believes that "there is nothing wrong with saviour siblings so long as they are loved themselves."

# III. What Then of the Arguments For and Against Such Technology?

- A. We may start with a definitional problem: the Nash, Hashmi and Whitaker stories resulted, certainly in the British press, in many headlines focussing on designer babies. One should be clear that there is no question of genetically manipulating embryos to achieve desired features in these cases. Embryos are selected, not designed.
- B. What these arguments do show, however, is that the debate is often future-focused, motivated by concern as to what precedent could be set for the future, rather than the actual possibilities at present.
- C. It may also be that there is a strong distaste factor at work here. An instinctive reaction motivates many people's distaste at the procedures. An example which might provoke such distaste is that posited by the French National Ethics Consultative Committee (CCNE): the prospect of families being engineered as self-sustaining units, with matching tissue types to enable repairs should the need arise.
- D. There is also the fear that allowing donor selections entails an unacceptable instrumentalization of the child:
  - 1. An interesting phrase has been used to describe this—the term "tentative pregnancy": the parents want a child, but only under certain conditions. This is akin to treating a child as a commodity.
  - Human life is no longer valued for what it is, but rather for what it can achieve.
  - 3. Superficially, the experience of the families so far would refute this suggestion. Adam Nash, for example, seems to be much loved. Equally, the Whitakers claim that in the run up to birth they were not concerned with the possibility of transplant but rather the well-being of James.
- E. Others point out that instrumental reasons for child birth are not new: the difference here is that the couples in question are being forced to be open about their reasons, whereas others, who may wish a child for tax or inheritance reasons, for example, face no such requirement. Given the importance of emotional honesty in the psychological relationship with a child, this may actually be a positive factor.
- F. The crucial question is whether the couple are having a child solely to provide a donor, for it is generally agreed that using someone as a means is not, in itself, unethical. Rather, using someone solely as a means is unethical.
  - 1. The French CCNE emphasizes the importance of an authentic parental project. It raises two interesting points. First, what if none of the embryos produced are a tissue match, but some are healthy? Would a rejection of implantation demonstrate that the child is really wanted only for its life-saving potential?
  - More worrying, perhaps, the committee discussed the position if the ill child's condition deteriorated during pregnancy. Unlike any instrumentalisation that may take place naturally, here the child need not be born alive to serve its purpose. Would there be pressure for

premature delivery or, worse, abortion in order to harvest stem cells and save the child?

# IV. Does the Spare-Part Child Have a Say?

- A. Moving from the abstract notions of "human value" to the concrete effect on the child, concerns about the procedure have been raised:
  - 1. The effect on the child.
  - The fact that the transplant is being done for another's benefit without his or her informed consent.
  - The child will bear "the spectre of being born for somebody else's benefit throughout his whole life" and will be "beholden to his older brother."
- B. The consent issue is interesting, however not that important because the transplant uses the umbilical cord, which is usually thrown away. Winston states that the procedure is of no benefit to the child. However, the lack of benefit does not prevent non-therapeutic research from being carried out on neonates, where it seems reasonably clear (in the United Kingdom at least) that parents may consent to such research so long as it is not against the child's interests and provides minimal risk. Ultimately, though, this may be rationalization to explain the decision: in reality one couldn't say to the donor child "we're doing this for your own good."
- C. In later years, questions about free consent may arise if subsequent transplants are needed, say of bone marrow. The pressure on the child will be immense. The HFEA Ethics Committee considered whether to restrict the technique to cases where it was unimaginable that hard organs would be requested; however, given assurances that in the United Kingdom no doctor could proceed with such a transplant without a court's approval, it decided against such a ban. It was clear, however, that such harvesting of "hard" or non-regenerating organs would be unacceptable.
- D. Pro-life groups have been particularly vocal in the debate, expressing their concerns about the unnecessary destruction of embryos. They are primarily opposed to IVF treatment in general, and not specifically to PGD or HLA. However, one could conceivably approve of IVF yet disapprove of donor selection, for the following reason. IVF should be available to assist infertile women, for which purpose some may be willing to accept the loss of embryos as a necessary evil inherent in conception. In "donor child" cases, however, there is typically no infertility involved: the women could conceive naturally, but prefer to be assisted in order to select a match. As such, one may view the loss of embryos here as unacceptable.

#### Summary

In this lecture we have considered the rights of children selected to aid their siblings. In the next lecture we consider another controversial but important topic—that of the rights of each individual to reproduce.

# **LECTURE TEN**

# FOR GREATER UNDERSTANDING



# Questions

- 1. The abortion debate centers on the rights of the mother vs. the rights of the unborn. The debate surrounding spare-part children revolves around the rights of the unborn and the born. Research some of the latest legislation on this issue. Consider your own opinion on whose rights prevail and when.
- 2. What are the implications of stem cell research to the field of genetics?

# **Suggested Reading**

Davis, D.S. Genetic Dilemma. New York: Routledge, 2001.

#### Other Books of Interest

Gustavsson, Peter. *Diamond-Blackfan Anemai: Mapping and Identification of the Disease Gene*. Cambridge: Uppsala University Press, 2000.

# Lecture 11: The Right to Reproduce

The Suggested Reading for this lecture is the Nuffield Council on Bioethics's report Mental Disoorders and Genetics: The Ethical Context.

#### Introduction

We are fairly accustomed today to talking about rights, and one of the rights to which reference is sometimes made is the right to reproduce. This is the right to have children, or, as the language of some human rights documents would have it, the right to found a family. But is there a real right to reproduce? Does it make sense to say that everybody can have a child?

#### I. Can Everybody Have a Child?

- A. Some people would say yes: This is a recognised human right and one which must be defended in the legal system.
- B. Others say that it simply doesn't make sense to talk about a right to reproduce, that having children involves a range of other interests—including a general social interest. Having children affects others, not least the child that one produces, and therefore we simply cannot talk about a right to reproduce in the same way in which we talk about a right to life.

# II. What Is Said by the Courts?

- A. There have been some judicial sources for this.
  - 1. The United States Supreme Court appeared to be talking about a right rather like this in the case of Skinner v. State of Oklahoma in 1942. This case concerned the punitive sterilization of a man in accordance with one of the compulsory sterilization laws that were then on the statute books. As the court said in this case:
    - "This touches a sensitive and important area of human rights.

      Oklahoma deprives certain individuals of a right which is basic to the perpetuation of a race—the right to have offspring."
- 2. This seems unambiguous enough, but in fact it is not clear whether the court saw this right to reproduce as a discrete right, separate from the clearly recognised constitutional right to be free of cruel and unusual punishment. Of course, there might be some other constitutional basis for a right to reproduce.

#### III. Mandatory Sterilization?

A. In the earlier part of the twentieth century there was considerable enthusiasm for eugenics, and as a result a number of eugenic laws were passed in various jurisdictions, including the United States. These laws were based on the premise that mental disability was predominantly heritable, and that this provided justification for the compulsory sterilization of those affected by it. An early challenge to these laws was the case of *Buck v. Bell*, a decision of the Supreme Court in 1927.

- This concerned a Virginia statute, under the terms of which the sterilization of a mentally retarded woman had been ordered on the grounds that she was, as the court described her, "feeble minded."
- 2. This was endorsed by the court using a eugenic view of public policy. The words that the court used are revealing:
  - The judges said, "That public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the state for these lesser sacrifices . . . The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes."
- B. The eugenics approach has now been discredited, and the sterilization of mentally disabled people would not be undertaken on those grounds. But it may still take place—even if the grounds have shifted. This is because there are circumstances now where courts are prepared to see such sterilization as taking place in the best interests of the mentally disabled person.
  - 1. The reasoning behind modern cases of sterilization is quite subtle. In a decision of the Supreme Court of New Jersey, for example, in the case of Lee Ann Grady, the court was faced with a request from the parents that they should be permitted to have a sterilization operation on their nineteen-year-old daughter, who had Down's Syndrome.
  - 2. There was no dispute over the fact that should this severely disabled person become pregnant, she would not be able to care for a baby by herself. In their response, the Court saw two rights in conflict with one another: the right to be free from voluntary sterilization and the right to obtain sterilization.
  - 3. The court felt in this case the young woman in question lacked the capacity to make an informed decision about that matter, but that she should not be deprived, through that lack of capacity, of the opportunity to make a meaningful choice.
  - 4. The court resolved this case by making the decision for her on the basis of what the court considered to be in her best interests, and it was felt that her best interests would be served by a decision to go ahead with the operation.
- C. Other courts have taken a different view of the grounds on which such operations might be justified. One of these is public policy, but there are major objections to this approach. Public policy is notoriously difficult to define.
- D. The best interests test was given a thorough outing in the Supreme Court of Canada in the well-known case of Eve, a woman who suffered from acute aphasia—an inability to understand and communicate through speech—and was thought to be unable to understand the link between intercourse, pregnancy, and birth.

- Her mother was concerned that if Eve became pregnant, she—Eve's mother—would end up having to look after the baby. She felt illequipped to do this task at her advanced age.
- 2. The matter went both ways as it progressed through the courts, but finally, in the Supreme Court of Canada, it was held that although the courts could authorise operations on mentally disabled people in their best interests, it was doubtful whether a sterilization operation could ever be in the best interests of such a person.
- E. This cautious approach has been echoed in British courts, where the right to reproduce has been specifically mentioned and where any limitation of this must be shown clearly to be in the best interest of the individual before sterilization can be ordered.
- F. Ultimately the right to reproduce emerges as fairly strong, at least in the legal sense. Our view of the right in all other contexts might be a bit less enthusiastic.

# Summary

There are obviously strong social reasons for suggesting that this is a right that should be exercised for social responsibility. We might even go so far as to criticise irresponsible reproduction. But that criticism—or disquiet—will usually fall far short of the taking of steps by the state to prevent feckless procreation. So we are left with a situation where many people will not procreate with proper attention to the burden that they might be creating for others, or for the suffering that they might be visiting upon the resultant child. And perhaps we do not countenance state intervention here because we realise what a massive restriction of freedom that would be. As we shall see in a subsequent lecture, this is not necessarily the case everywhere; other countries may take a different view of the overpopulation crises and may reach a very different conclusion as to this right—which demonstrates that one's view of rights is often very much influenced by where one is sitting at the time.

#### FOR GREATER UNDERSTANDING



#### Questions

- 1. Consider the decision made and opinions rendered in *Buck* v. *Bell*. Where are the legal lines drawn today on who has the rights to reproduce?
- 2. There is debate regarding the rights of a person with a mental disability to physically, emotionally, and mentally care for a child. What guidelines should determine the answers to these questions?

# Suggested Reading

Nuffield Council on Bioethics. *Mental Disorders and Genetics: The Ethical Context*. London: The Council, 1998.

#### Other Books of Interest

Great Britain. Lord Chancellor's Department. Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults. London: The Stationery Office, 1997.

Levy, Robert M., and Leonard S. Rubenstein. *The Rights of People with Mental Disabilities: The Authoritative ACLU Guide to the Rights of People with Mental Illness and Mental Retardation*. Carbondale, IL: Southern Illinois University Press, 1996.

National Bioethics Advisory Commission (NBAC). Research Involving Persons with Mental Disorders that May Affect Decisionmaking Capacity. Volume 1: Report and Recommendations of the National Bioethics Advisory Commission. Rockville, MD: NBAC, 1998.

# Lecture 12: Life-Boat Ethics: Population Control

The Suggested Reading for this lecture is Louis Horowitz's Taking Lives: Genocide and the State Power.

#### Introduction

So far in this course we've been looking at issues that might fairly be described as issues that concern the developed world. The new reproductive technology is not really an issue of great importance to many sections of the world's peoples. If bioethics has any resonance for them it must speak to questions of the distribution of scarce resources.

We now turn to some of the ethical issues that surround population. The relationship between reproduction and population issues is obviously a close one. But this will not be about matters of high-tech scientific intervention; it will be about the ethical issues that go with attempts to secure control of human numbers in the face of a burgeoning world population. How can we reconcile respect for human rights with a coercive policy of population control, or do we need to attempt this reconciliation in the first place?

# I. Running Out of Room: The Expanding World

- A. The population of the world is currently about six billion. It was half that figure in 1960; a remarkably quick increase over a period of a little more than forty years. If fertility rates remain constant, the world population will have doubled again to twelve billion by 2050. According to the United Nations Population Council, it could be nineteen billion by the year 2100.
- B. The existence of a very large number of people is not in itself a bad thing. In fact, if we subscribe to the view that human life is good—and most of our moral systems are based on that supposition, then surely the existence of human life in profusion is something that we should welcome. This does not necessarily follow.
- C. Respect for human life, which must involve some notion that it is a good thing, is quite compatible with not wanting there to be more human life. We may quite reasonably say that while we value those human lives that already exist we would prefer there to be less human life in the future.

# II. Prophets of Doom or Visionaries?

A. Neo-Malthusian thinkers have been particularly concerned with the problems caused by growth in population. In their view, population growth is bound to be greater than resources can support, and any attempt at the redistribution of the world's resources will have no effect on outbreaks of famine.

- B. At the extreme end of this position, Neo-Malthusians argue that famine and starvation are the only remedies for population growth and, somewhat uncomfortably, any attempts to intervene in this process will only lead to greater population growth and a greater number of deaths in the future.
- C. One of the most controversial contributions to this debate came from the biologist, Garrett Hardin, who argued that, like a lifeboat, Earth has a "carrying capacity" limited by the amount of food and other resources it can yield. So measures to control population are required, if we are to avoid overloading the lifeboat and making it sink, in which case everyone loses. Hardin argued for curtailment of "freedom to breed" by coercive means. His criticism was especially directed against states with high birth rates. These tend to be developing states as they are not at such an advanced stage in the demographic transition. Facing an explosion in population, some states, believing that the alternative is economic and social ruin, feel they have no choice but to impose family planning on their citizens to curb birth rates.

# III. How Big Is the Problem?

- A. The population figures that show dramatic and continued increase in numbers are based on the assumption that fertility rates will remain constant. However, according to the United Nation's World Population Prospects (an important demographic survey), fertility rates should go into decline by, at the latest, 2015. According to "low variant" estimate, absolute numbers should go into decline by 2040.
- B. It is likely that what we are actually facing in the medium to long term is demographic evolution, a process in which high birth and death rates are transformed into low birth and death rates. However improvements in medical care and in hygiene and public health medicine are occurring faster than changes in traditional societal norms such as family size.
- C. Death and infant mortality rates have decreased dramatically, whilst birth rates decrease only very slowly—this means that countries undergoing transition still face population explosion in relatively medium term.
- D. In the face of such a population explosion, what can countries afflicted by this phenomenon do?
  - 1. They must act in some way if they are to preserve standards of living and to avert social disruption. But it will almost certainly not be possible to act merely by appealing to the sense of responsibility of their publics, many of which may have little interest in national population goals and who may see fertility and large families as their best protection against poverty in their old age.
  - 2. Like many issues in ethics, this may be seen as a conflict of community interest pitted against individual interests. One of the most striking examples of mass, state-imposed family planning is collectivist China.

#### IV. China: The Solution or an Abomination?

A. China's family planning project is unparalleled in the rest of the world. Since 1979, the Chinese government has pursued what is known in the West as a "one child policy." This involves state-supervised family

- planning. There is an official slogan to go with this, and this reads: "later, longer, fewer." In practice, this is translated into the encouraging of marriage at a later age—and hence later childbearing. And then there is the crucial programme of encouraging each couple to have only one child.
- B. How has this been achieved? Officially it is simply a policy of mass-mobilisation on family planning issues. The objective here is to effect amongst the people "a complete change in their concept of childbearing." This involves the persistent stressing of the central message at every opportunity, using all the resources available to the state, including the works of writers and artists.
- C. The one-child policy is not strictly enforced as such, but it nevertheless amounts to coercion. Officials at all levels are given population reduction quotas, which are imposed by central government. Based on their results, people are rewarded for success and punished for failure. The same officials, of course, exercise a great degree of control over many aspects of people's lives, by controlling access to job and other social goods, and so they are well placed to ensure that transgression of the policy will result in difficulties for the transgressor.
- D. Rhetoric used in support of policy emphasizes that there are benefits for society as a whole: alleviation of pressure on resources such as food, clothing, and housing, and services such as medical treatment and education. But individual rights are subordinate to these goals, as one might expect in a state with China's socialist background.
- E. In spite of its undoubted success in limiting family size, it would appear that the policy is slowly being dismantled. This may be seen as one aspect of economic liberalisation and changes in methods of regional government, in which the state has historically exerted a great degree of control over the lives of its subjects.
- F. Has the one-child policy been successful? It is estimated that China's population will peak in 2030 (but it might not: "high variant" estimates of UNPP have it continuing to increase past 2050), but this may be simply part of the "demographic transition" that has been identified. China has a major problem of an aging population. Increasing lifespan means more and more support is needed for the elderly. But fewer and fewer younger people are there to provide this, a problem particularly acute in a country with such poor social security coverage.
- G. Policies such as these are often said to come into conflict with a whole raft of human rights: private and family life, religion, and expression.

# V. Human Rights

- A. In traditional human rights theory, the state has no rights of its own. What it is allowed to do is limited by rights of individual citizens. To what extent do these rights, as recognised at an international level, limit interventions in individual reproductive decisions? Certainly, there is support for these rights in international documents.
  - The International Covenant on Civil and Political Rights 1966 (ratified by the United States in 1992) states in Article 17 that "No one shall

- be subjected to arbitrary or unlawful interference with his privacy [or] family." And Article 23 says, "the family is the natural and fundamental group unit of society and is entitled to protection by society and the state . . . The right... to found a family shall be recognised."
- 2. Similar provisions are to be found in most other major human rights treaties. Whether there is a specific right to reproduction is another issue but clearly human rights culture places high value on the family unit and its privacy. The right to make decisions concerning one's own family, free from outside influence, would appear to be fundamental.
- B. One side effect of the one-child policy in China is serious discrimination against girls. Tradition and, in rural areas, practical necessity dictate that male children are preferable. If a couple can have only one child the couple will prefer a boy to a girl.
  - 1. For this reason, many more girls are given up for adoption (from twenty-six to thirty-seven boys per one hundred girls given up), or worse, not registered and then killed. The right to freedom from discrimination on the basis of gender is one of the most fundamental human rights. The traditional nature of society in many developing states means this phenomenon is likely wherever coercive family planning is imposed.
  - But according to the Chinese State Family Planning Commission, the status of women is, in fact, "greatly enhanced" by the one-child policy, which gives more opportunities for women to participate in activities such as politics and culture.
- C. From an individualistic, human rights point of view, coercive state interference with reproductive decisions is probably unacceptable.
- D. But human rights may be derogated from in time of public emergency. But is what we have here an emergency? Not an absolutely pressing one: the population of some industrialised nations is actually decreasing. Resources are unlikely to run out in the 100 to 150 years this turnaround in population is estimated to take.

#### Summary

We should bear in mind the argument that human rights are meaningless outside a reasonably favourable socio-economic context. There is increasing emphasis worldwide on group rights (that is, those enjoyed by a people as a whole) as opposed to individual rights. Foremost amongst these is self-determination, by which people possess inter alia the right "to pursue their economic and cultural development." Chinese government sees policy as part of its overall socio-economic programme of sustainable development, geared toward improvement of general quality of life for all. This cannot be done, it argues, in the face of a population crisis. Are there less coercive methods? Per UNPC, the education of women is the most effective method of controlling population: women become no longer "breeding machines," but citizens in their own right, and thus it becomes possible to reduce population growth by empowerment rather than coercion. In the next lecture we will discuss the difficult decisions confronting those in the neonatal intensive care.

#### FOR GREATER UNDERSTANDING



# Questions

- 1. Are there other countries who exercise the one-child policy? Could this or has this happened in the United States? Why or why not?
- 2. Which is more important—the right of individual freedom or the idea of patriotism? Where do people draw the line in the United Kingdom? The United States?

# Suggested Reading

Horowitz, Irving Louis. *Taking Lives: Genocide and the State Power*. New Brunswick: Transaction, 1997.

#### Other Books of Interest

Mann, Jonathan M. *Health and Human Rights: A Reader.* New York: Routledge, 1999.

Médecins Sans Frontières/Doctors Without Borders. *World in Crisis: The Politics of Survival at the End of the Twentieth Century*. London: Routledge, 1997.

# Lecture 13: Hard Choices: Ethics in Intensive Care

The Suggested Reading for this lecture is John D. Lantos's Lazarus Case: Life-and-Death Issues in Neonatal Intensive Care.

#### Introduction

Advances in medical technology may bring particular complications. Infants may now be brought into the world in circumstances in which, previously, a live birth would not have been feasible. Despite everything we can do for them, some of these children will not survive. Losing them, though, may be a slow and rather difficult process—one that requires some hard choices to be made.

### I. The Scope of the Problem

- A. We are not talking about small numbers of children here: in the United States alone, it is estimated that there are some thirty thousand severely defective babies born each year. Many of these babies will be kept alive for some time by the employment of advanced, and expensive, resources. But then, eventually, the battle has to be abandoned and treatment stopped. It is estimated that, as a result, up to 30 percent of neonatal intensive care deaths may follow from a withdrawal of life support.
- B. An example of the problem, and perhaps the most commonly cited one, is the treatment of spina bifida.
  - Until the mid-50s, this was virtually untreatable, as operating to close the wound merely led to the building up of spinal fluid in the brain (hydrocephalus).
  - 2. In 1955, however, great strides were made with the development of a valve that allowed the brain to be drained. This led to the belief that treatment should be offered in all these cases, a view that was not universally shared.
  - 3. In some medical centres, the position was that the mere saving of life was not a worthwhile goal if the life that was saved was so uncomfortable and difficult that it did not seem worth saving. Differences of opinion thus opened up, with some doctors taking the view that every effort should be made to keep such children alive, while others regarded this approach as, frankly, cruel and unhelpful.
- C. In one United Kingdom centre, a study was made of the policy of attempting to save all the children affected by this condition.
  - Over eight hundred children treated over a fourteen year period were followed.
    - i. Half of these, some four hundred, had survived.

- iii. Seventy five percent of the deaths had occurred during the first year of life.
- iii. Of the survivors, 80 percent were afflicted with a serious handicap and just over 50 percent had a severe mental handicap.
- One can imagine the cost of this, not only in terms of the medical budget, but also in terms of suffering. Many of the children who survived had between thirty and forty orthopaedic operations in the period under review.
- 3. On average, those who reached five years of age had spent a total of two of those years in hospital being treated.
- D. These figures seem bleak, and one view is that they merely demonstrate that a policy of pursuing treatment regardless of the consequences does nothing but add to the overall suffering of all concerned—children, parents, and the wider community. But if we are not going to persist with treatment in these cases, how are we going to justify this and how are we going to distinguish between cases which are worth treating and those which are not. Some people take the view that we can too easily slip into a policy of euthanasia just because it is easier and more convenient. So the question to be asked is, what approach should we take to such cases?

#### III. Just What Do We Do?

- A. Typically, two options are seen as presenting themselves: the sanctity of life approach and the quality of life approach.
- B. The sanctity of life approach at least has the advantage of certainty. Under this approach, we are obliged to respect and cherish human life no matter how marginal it seems. Treatment is ordered no matter what quality of life will result. Any possible effort to save the child must be adopted.
- C. The sanctity of life approach, in addition to the certainty that it brings, has the attraction of being non-discriminatory. Nobody can say that treatment is offered more to one group than another because no such decisions are made—everybody is treated. It also removes the decision from the human arena, and this satisfies those who say that it is not for us as human beings to decide on the lives of others, that this is a matter for divine resolution.
- D. A very strong criticism of the sanctity of life approach has been mounted by two well-known bioethicists, Peter Singer and Helga Kuhse. They argue that sanctity of life is "speciesist." That someone is biologically a human being should be irrelevant when it comes to moral assessments. Rather, we should judge whether a person has a right to life on the basis of whether he or she satisfies certain criteria of humanhood—these criteria include awareness of self and a sense of a past and a future. If, then, one may legitimately abort a disabled fetus, why should one not be able to bring an end to the life of the newly born child?
- E. This rejection of the personhood, and hence the right to life, of newborn infants has met with little support. This does not mean, of course, that

one need support an absolutist right to life approach. We might recall that even the Catholic viewpoint does not require every effort to be made to save life: we might recall here Pope Pius XII's distinction between ordinary treatment, which must be attempted, and extraordinary treatment (that is, that which would impose an extraordinary burden on doctor and patient), which need not be. Today this distinction may be made in terms of medical futility, that is a criterion which is more flexible than the ordinary/extraordinary treatment standard.

#### III. Who Determines Who Is Treated?

- A. Once it is accepted that in some cases decisions will have to be made about when infants should not be treated, further problems arise concerning the framework for making such decisions. Upon what basis should they be made? And by whom?
- B. At present the legal positions in the United States and the United Kingdom appear to be converging; in both countries there is a focus on the "best interests" of the child as the determining factor.
  - 1. In the United Kingdom, Re B is still the leading case. A Down's Syndrome baby also suffered from an easily treatable blockage of her intestine. Her parents refused to consent to an operation to clear it. Life expectancy with the operation, as a Down's Syndrome child, was twenty to thirty years, although she would be severely mentally and physically handicapped; without it, she had only days to live.
  - 2. In his judgement, the judge in this case said the following: "The question . . . is whether it is in the interests of this child to be allowed to die within the next week or to have the operation in which case if she lives she will be a mongoloid child . . . it devolves on this court to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die . . ."
- C. But how are we to decide whether something is in an infant's best interests? Some find this test morally unacceptable and argue that it is impossible for one to make a judgement about another's best interests, especially when one of the options is death.

#### IV. The Responsibility of the Decision-Maker

- A. It is also true that the decision-maker is not in a position to assess best interests. He can only call on his own experiences when reaching a conclusion. The infant, however, will never have been aware of any other existence and may not therefore have any idea of how badly his life compares with anything else, as he has no idea of what anything else is.
- B. Because of this problem, people sometimes resort to an entirely different test—the substituted judgement test. This test supposedly asks what the infant, were he able to express a preference, would desire as being in his best interests. However, there are problems with this, in that the infant has never been able to express any opinion previously so we have no grounds to assess what his judgment would have been.

- C. Who is in the best position to make such decisions? Some are suspicious of leaving it up to the courts on the grounds that the courts will be unduly led by the medical profession and will give too much discretion to the doctor. So if it is not to be courts, and if doctors do not have the final say, then who should decide? Should it be the parents? One would think that the parents should play a central role, but then there is always the possibility that, in some cases at least, the parents may not be sufficiently protective of a child whom they may regard as a burden.
- D. The following have identified the following possible decision-makers:
  - 1. Doctors: Those who see the decision to be made as primarily a medical one should have no problem with doctors making the decision. Others, however, object that to give doctors exclusive power to decide would be to subsume an ethical dilemma within the medical sphere. Leaving the matter to doctors might also encourage medical paternalism. However, the practice now of involving the whole medical team in treatment and decisions as to its withdrawal reduces previous fears as to abuse of power.
  - 2. Parents: Parents are the most intimately connected with the infant. Bear in mind, however, that it is not necessary for the parents to care for the child: the state can take over care. Arguments are often advanced on the basis of family privacy, as in the Baby Doe line of cases in the 1980s in the United States, which emphasised the parental responsibility to care for one's child, so long as the route chosen was within accepted medical standards. Recent decisions, both in the United States and the United Kingdom, have seen a strengthening of the hand of the parents.
  - Parents and doctors: The Australian approach is to allow doctors and parents to make decisions and this is also effectively the British approach.
  - 4. Ethics committees: These have the merit of distancing the decision from those most affected and whose self-concern may dominate. They were in vogue in the United States in the aftermath of the Baby Doe decisions, when government was refusing federal aid to hospitals that did not have an investigatory structure to deal with potential cases of child neglect. One advantage they have is that they allow for objectivity in decision-making.
  - 5. Law: Finally, these decisions may be resolved by the courts. Again, this allows for consistency and, one might argue, objectivity. But the law is a very formal way of resolving issues and may also be something of a blunt instrument. The prospects of litigation do not necessarily help families at a time when they are facing morally and emotionally difficult decisions.

### Summary

We have discussed the ethical issues involved in reproduction from the perspective of the embryo to that of the world. In the next lecture we will close our discussion of ethical issues in reproduction.

#### FOR GREATER UNDERSTANDING



### Questions

- 1. Compare the arguments of Peter Singer and Helga Kuhse to those outlined by law in both the United Kingdom and the United States. List the arguments one by one. Consider the implications for future legislation.
- 2. Consider the legal implications faced by the decision-maker in every case of withholding medical care. Are they different for newborns and the elderly? Why or why not?

# **Suggested Reading**

Lantos, John D. *Lazarus Case: Life-and-Death Issues in Neonatal Intensive Care*. Baltimore, MD: Johns Hopkins University Press, 2001.

### Other Books of Interest

Broberg, Gunnar, and Roll-Hansen, Nils (eds.). Eugenics and the Welfare State: Sterilization Policy in Denmark, Sweden, Norway, and Finland. East Lansing, MI: Michigan State University Press, 1996.

Burleigh, Michael. *Ethics and Extermination: Reflections on Nazi Genocide*. New York: Cambridge University Press, 1997.

Quill, Timothy E. A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life. Baltimore, MD: Johns Hopkins University Press, 1996.

Selden, Steven. *Inheriting Shame: The Story of Eugenics and Racism in America*. New York: Teachers College Press, Teachers College, Columbia University, 1999.

## Lecture 14: Science As a Father

The Suggested Reading for this lecture is Mark A. Rothstein's Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era.

#### Introduction

In the final lecture of this course, we will bring together some of the themes that we've been thinking about and ask some fundamental questions about where these new developments in reproductive technology have been taking us. Does assisted or so-called artificial reproduction have a negative effect on our identity? And if it does, then perhaps we should ask ourselves whether these developments in reproduction that we've been looking at will actually contribute to human happiness as much as we thought, or whether there is a dark side to them.

### I. The Importance of Identity

- A. We gave an example of a woman who learned as an adult that she had been conceived as a result of artificial insemination by a donor and had a great deal of anger at the anonymous donor. Identity is very important to us, and traditional notions of identity may be confused once we start resorting to artificial reproductive techniques.
- B. Many others manifest their feelings with curiosity about artificial insemination by a donor (AID). Many of us will recall the account of a woman who spent a great deal of time and energy on trying to track down the donor who was used to conceive her. She succeeded to the extent of finding out that it was one of a small number of medical students at a particular university in California, and then the trail went dead. Perhaps it was just as well for the medical students in question; they might not have appreciated the prospect of reunions with their unknown offspring. This sometimes happens when adopted children contact their birth mother: the response is not the warm welcome that they might have wished for.
- C. If identity is that important, how can it be reconciled with the practice of anonymising donors of gametes. Until very recently, it had been the rule that sperm donors in artificial insemination programmes would not have their identity revealed to the recipients or the resulting offspring. This is now changing in some countries, where the practice of what are called "open donations" is becoming more common.
  - In an open donation system, the child will have the right to know who
    his or her father is. This knowledge might result in contact between
    the two, or it may just satisfy curiosity.
  - 2. The AID example is an interesting one, and an important one too, but the issue has ramifications in other forms of artificial reproduction where donated materials are used, or where a surrogate mother is involved. How much do we need to know about ourselves?

D. Of the facts from the past that shape our sense of identity there is perhaps none more important than family: who our parents were, where they came from, who their parents were, and so on. This is not just a matter of sentiment—although it may be—it is also a matter of hard scientific interest, for this is information about our genome, about our genetic inheritance.

# II. Who Was My Father?

- A. Genetic information is very important. Knowing who one's biological father is may be important information at a social and emotional level; knowing one's genetic inheritance (and in particular knowing information about genetically influenced conditions) may be important for the decisions about one's own health. As we become increasingly aware of the link between genetic attributes and a range of illnesses, information about parentage takes on a greater importance.
- B. Is this knowledge of parentage something to which we have a right? One has to be careful in talking about rights, because people mean different things by rights language and the recognition of a right can encourage the belief that a particular claim should be given absolute protection. Rights, of course, have to coexist with other rights. This is something that is recognised in the United Nations Convention of the Rights of the Child, which asserts, quite boldly, that the child has the right to know his parents.

### III. What Is Best for the Child? The Parents?

- A. As far as the parents are concerned, there is evidence that the open information schemes are popular with those who use them, and indeed most of them, at least in the United States—where they are optional—came into existence in response to demand.
  - Elsewhere they have become popular as a voluntary option, as in New Zealand, where most programmes now proceed on an open donor basis.
  - 2. In some countries donor identity release is required by law to be open: this is the case in Sweden, Austria, and the Netherlands.
  - Where donor identity is required by law, this tends to have happened in recognition of what is seen as a child's right, and established under the United Nations Convention on the Rights of the Child.
- B. It is interesting to note that even if there are parents who are willing to tell children of their origins, there are many parents who have used artificial insemination who do not wish to do so.
  - A recent study in the United Kingdom, for example, found that amongst a group of artificial insemination parents canvassed, only 5 percent had told their near-adolescent children of the fact that they had been conceived in this way.
  - Other European studies had revealed a similar picture: in the Italian group studied, no parents had told the children, and amongst Spanish parents only 4 percent had done so. In the Netherlands the

- picture was markedly different. There, 23 percent of the parents had told their children.
- C. And how do the children feel if they are told by parents that they were conceived through artificial insemination?
  - There is some information on this, but not a great deal. Part of the problem here is that many children are not told, and therefore the samples will be small.
  - However, studies in New Zealand and Sweden indicated that in the samples with which they were concerned, young children tended to be rather matter of fact about the whole thing.
  - 3. A recent study carried out in California, which looked at parents and children in an open donor programme, reached similar conclusions about the feelings of children who had been informed of the fact that they had been conceived in this way.
- D. There have been studies carried out on the feelings of adults who were conceived through artificial insemination. A recent study points to difficulties such as feelings of mistrust, feelings of being cut off from the rest of the family, a sense of abandonment by the donor, and, most importantly, feelings of frustration and loss at not being able to contact the donor or find out more information about him. It is possible that they would not have experienced such feelings had they been told when they were much younger and grown up with the information.

#### IV. What of the Donor?

- A. We should also wonder what the effect on donors might be.
- B. An obvious reaction might be not to donate, as evidence indicates that a major inhibiting factor to participating in a donation programme is fear of identification. The giving of a sample anonymously is very different from the giving of a sample that might result in a child.
- C. It is significant, perhaps, that in the Netherlands, once open identity donation was introduced as the norm, the supply of sperm donors went down from 900 to 300, then the number of sperm banks dropped by 50 percent, and the waiting list for treatment went up to two years.
- D. Some critics of open donation have also pointed out that there might be an issue of the right of a donor to know his children. What if a donor found out this information and contacted the family—that, one can imagine, could be extremely awkward.
- E. This brief discussion of identity and artificial insemination shows just how morally complex are many of the issues to which assisted reproduction gives rise.
- F. We should not expect it to be otherwise; human reproduction is a complex matter fraught with emotional implications. Looking back over the discussion, there are several broad themes that may be identified:
  - 1. The issue of risk.
  - 2. The Issue of dignity.

3. The issue of control or regulation.

#### V. Risk

- A. Risk is a major preoccupation, and rightly so. There is always going to be some risk in science, as in any other activity. Some of this risk will be acceptable, some will not. The main risks we see are those of bringing into existence unforeseeable biological hazards, or of causing physical, psychological, or emotional damage to others, particularly to children.
- B. As far as the first of these is concerned—the risk of biological damage—we see a generalised fear that interventions in the natural will somehow disturb our human ecology, and that the human genome will be changed in a way that we shall have cause to regret.
- C. The danger of this is slight at present; a far more pressing danger could be found, for example, in other fields (in xenotransplantation, which transplants organs between animals and humans, dangerous infections might come into existence as a result).
- D. A great deal of the anxiety over the natural is focused at present on human reproductive cloning.

### VI. Human Dignity

- A. Dignity is better than autonomy as a yardstick against which we measure developments in reproductive science. It suggests that there are values other than personal fulfillment and self-determination. Pinning all one's moral colours to autonomy can lead one to a sterile position where the sole test of whether anything is right is whether somebody wants it badly enough.
- B. As we have seen in this course, many of these issues involve a balancing of social interests against the interests of others. A position that gives pre-eminence to autonomy would not let sufficient attention to be paid to social interest.
- C. For this reason, although we must respect choice and encourage the making of autonomous choices in reproduction, we have to do so with one eye on what these choices mean for society as a whole.
- D. In practice, what this is going to mean is that procreative liberty cannot always be achieved.

# VII. Control or Regulation?

- A. How do we control all of this? Can we actually control science or will we be forever chasing after it, wondering about the ethical implications of what science has done?
- B. There is no simple answer to this. We shall not be able to ensure in advance that science goes in the direction that we want it to go. Much of our ethical effort will be after the event and therefore possibly too late.
- C. But what we can do is make efforts to ensure that scientific experimentation is carried out within a clear and open structure of ethical review, and we should try to ensure that mechanisms are in place to protect those within the scientific or medical world who see abuses and can

- bring them to public attention. That means good systems of monitoring scientific misconduct in general.
- D. We need to acknowledge that the preservation of values—and particularly the value of human dignity—in the face of big science can only be done realistically on an international level. This means cooperation through the agencies that we already have in place—international medical associations (for example, the WHO, UNESCO, and other UN bodies). This cooperation is vital if we are to prevent abuses.

## Summary

Ultimately, we need to remind ourselves that concern over human reproduction is only really worth it if the life that is reproduced is worth living. And that is something which should direct us to the many other pressing issues of bioethics such as fairness and justice, big issues that still wait for us to address them successfully.

#### FOR GREATER UNDERSTANDING



# Questions

- 1. What does the future hold in bioethics? Are we looking toward a future envisioned by Aldous Huxley or as seen in the life-giving fields of *The Matrix*?
- 2. Are genetic materials subject to copyright by scientists? Is the material of life a commodity?

# Suggested Reading

Rothstein, Mark A., ed. *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era.* New Haven, CT: Yale University Press, 1997.

# Other Books of Interest

Engelhardt, H. Tristram. *The Foundations of Bioethics*. 2nd ed. New York: Oxford University Press, USA, 1996.

Purdy, Laura M. Reproducing Persons: Issues in Feminist Bioethics. Ithaca, NY: Cornell University Press, 1996.

Wolf, Susan, ed. *Feminism and Bioethics: Beyond Reproduction*. New York: Oxford University Press, USA, 1996.

### **COURSE MATERIALS**

## Suggested Readings:

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- Davis, D.S. Genetic Dilemma. New York: Routledge, 2001.
- Fenwick, Lynda Beck. *Private Choices, Public Consequences: Reproductive Technology and the New Ethics of Conception, Pregnancy, and Family.* New York: Dutton, 1998.
- Gosden, Roger. Designing Babies: The Brave New World of Reproductive Technology. New York: W.H. Freeman, 1999.
- Horowitz, Irving Louis. *Taking Lives: Genocide and the State Power*. New Brunswick: Transaction, 1997.
- Huxley, Aldous. Brave New World. New York: HarperCollins Publishers, 1998.
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- Mulkay, Michael. *Embryo Research Debate: Science and the Politics of Reproduction*. Cambridge: Cambridge University Press, 1997.
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- Pence, Gregory E., ed. Flesh of My Flesh: The Ethics of Cloning Humans: A Reader. Lanham, MD: Rowman & Littlefield, 1998.
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- Solinger, Rickie, ed. *Abortion Wars: A Half Century of Struggle, 1950–2000.*Berkeley: University of California Press, 1998.
- Warren, Mary Ann. Gendercide: The Implications of Sex Selection. Lanham, MD: Rowman & Littlefield, 1985.