

325

AUSTRALIAN BROADCASTING COMMISSION

THE SCIENCE SHOW

WEDNESDAY, 14 APRIL 1982

LIVING WITH THE NEW BIOLOGY

The Hon. Mr. Justice M.D. Kirby  
Chairman of the Australian Law Reform Commission

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IN VITRO FERTILISATION

Tonight we are going to examine the challenge to our legal system presented by rapid advances in medical science and technology. We will do so by taking four areas of development. These are:

- . in vitro fertilisation (to so called 'test tube babies');
- . genetic counselling (the problem of preventing or dealing with severe genetic abnormalities, mental and physical);
- . genetic engineering (the mystery world of DNA and manipulation of basic forms of life); and
- . human tissue transplantation.

Let us take first in vitro fertilisation. The first test tube baby was Louise Brown born in July 1978. Since her birth, a steadily growing number of such babies have been born, many of them in Australia. We are amongst the leaders of the technology and this is a matter of pride. The pictures of the smiling parents and their offspring evoke natural human sympathy — especially because of the struggle these people have had to enjoy the pleasures and responsibilities of parenthood and family life.

In vitro fertilisation is a set of techniques which involves using human sperm and human eggs. It allows conception to take place outside the human body, on a piece of glass — hence 'in vitro'. A couple of weeks ago the Victorian Attorney-General announced the establishment of an interdisciplinary committee to examine legal and social implications of the technique. The Chairman of the committee is my colleague, Professor Louis Waller, the Victorian Law Reform Commissioner. Though the inquiry is a Victorian one, the problem is national, indeed international. The IVF technology has now spread to the Royal North Shore Hospital of Sydney. The issues raised by the technology go well beyond our country. They affect humanity.

According to public opinion polls, the majority of Australian people support the in vitro program. Some ask : who could possibly oppose the technique that simply overcomes a physical obstruction and may bring parenthood to more than 30,000 couples?

It is now increasingly realised that there are problems to be addressed:

- . Some commentators, particularly those starting from a traditional religious point of view, are absolutely opposed to the new techniques:
  - .. They are seen as 'laboratory procreation' — a dehumanised, unnatural manufacture of man as if he were a mere product : the elevation of the scientist to God-like power. This, roughly, is the reason that led Pope Pius XII to condemn the technique as absolutely illicit.
  - .. Other opponents point out that IVF requires masturbation to produce the sperm. It is said that this admittedly widespread practice is evil. In the absence of married love at the time of conception, it is thought that no good can come of it.
  - .. Other opponents fear the process of freezing of the human embryo — a technique utilised because of the wastage of embryos in the process of fertilisation — will all too readily lead on to experimentation with embryos and foetuses. The spectre of the foetal farm, developed to provide tissue for the relief of adult diseases, is one that horrifies some observers, but not others.
  - .. If embryos are frozen and not needed for future use, should they be discarded or would this act involve killing a form of human life?
  - .. Other opponents of the whole program simply say that, whatever your religion, there are better things to be done with the scarce medical dollars that would bring help to more fellow citizens. According to these people, this is an exotic, extremely expensive program benefitting relatively few.
- . Even amongst those who positively support the IVF technology, there is now an increasing recognition of the need to consider particular social and legal consequences. Take the following, for example:
  - .. Should IVF be available only to married couples or also to single people, such as, say, a lesbian woman who wanted a child?
  - .. Should we permit surrogates, ie if a woman cannot carry a baby full-term, should her sister be permitted to do so? If so, who is the true mother? Who, if either of them, has the say in abortion decisions?
  - .. What happens to the law of incest? Could a daughter carry the child of her parents?
  - .. Should parents be able to chose the gender of the embryo they select?

- .. Should it be lawful to retain a frozen human embryo for hundreds of years as is said to be technologically possible? If so, what is to happen to the distribution of property? Is the child's identity one of our generation or the generation into which he is born?
- .. In the case of frozen embryos, what is to happen on the death or divorce of the donors?

These may sound exotic questions. Looking at the smiling babies we may prefer to put them out of our minds. But unless we provide the answers and the laws, we may be delivering our society to the Brave New World which Huxley wrote about 50 years ago this year.

#### GENETIC COUNSELLING

Let me turn to the issue of genetic counselling. So far, all of the 'test tube babies' have been genetically normal. But what about the position of people who have, or are likely to have, genetically abnormal children? A very high proportion of people who seek genetic counselling are couples who have already produced an abnormal child or know of one in the family. Genetic counselling involves doctors telling such people:

- . whether a pregnancy should be undertaken at all;
- . whether ante-natal diagnosis of abnormality (such as by the procedure of amniocentesis) would be useful;
- . whether alternatives such as artificial insemination by anonymous donor should be used to avoid the risk of passing on genetic defects.

There are a lot of ethical problems here and most of them have to be faced by doctors, in the surgery, with only the vaguest guidance from the law:

- . Should disclosure of a genetic defect be made to the parents or the child? At what age does the child with a genetic disorder become a separate patient entitled to separate, private advice?
- . What are the limits of disclosure to third parties? For example, should a doctor tell a prospective spouse of the risks of genetic abnormality?
- . What is the extent of the doctor's duty of frankness about mental disorder or retardation in a baby? If the doctor paints too pessimistic a picture, will the child be rejected by its parents and placed in an institution with consequences even worse than the genetic abnormality itself?
- . What is the duty of a doctor who himself disapproves of abortion to advise pregnant women, especially those of mature years, to have amniocentesis, to test against the risk that the child may be mentally retarded or suffer other grave disabilities?

- . Should every woman, or every woman over a given age, be entitled as of right to the amniocentesis test? Just in economic terms, would this not be much cheaper than keeping a retarded child in institutions for many years?
- . Does the State which will otherwise have to fund the support of grossly disabled people have a legitimate interest to encourage abortion in such cases or is this the slippery path to unacceptable eugenics?

The legal situation in respect of the birth of grossly retarded and malformed children is only now being developed:

- . Murder can include wilful failure to take necessary action. Yet the recent trial and acquittal in England of Dr. Leonard Arthur, who put a grossly retarded child in a corner and gave only sedatives until it died, shows how reluctant juries are to convict doctors in such circumstances.
- . Doctors sometimes admit to causing the death of a grossly handicapped baby by giving it an injection at birth.<sup>1</sup> There can be little doubt that such positive action amounts to homicide. But it may be hard to detect. Some moral philosophers say it is quicker and kinder than murder by neglect — leaving the child to die for want of nourishment.
- . In America, there is already flourishing litigation surrounding this topic. Women sue doctors to recover the cost of maintaining a retarded child, because the doctor failed to advise amniocentesis. Some of these claims have succeeded. Will this risk force even opponents of abortion in the medical profession to advise the need for counselling of this kind, especially among women over 30 or 35?
- . In America, actions have even been brought successfully by children against their parents claiming 'wrongful pregnancy', 'wrongful birth' and in one case 'wrongful life'. In essence, the claim is that parents ought to have had the ante-natal tests and not submitted the child to such a life of woe. A similar case in Britain recently in the Court of Appeal failed. It was held that the common law of England did not recognise a cause of action against doctors for allowing the child to be born deformed.<sup>2</sup> Yet if a foetus is life and is owed duties by parents and doctors, are there ever cases where the mental retardation or physical disabilities are so gross that the birth should not be allowed to occur? If so, what are the precautions we would introduce against the misuse of the power to terminate life? Are we content to leave these decisions to be made by hospital committees or the unguided discretion of doctors on the spot?

## GENETIC ENGINEERING

A third issue relates to genetic engineering. This is an expression that includes a number of techniques that involve scientific manipulation of the most basic forms of life. The life form may be plant, animal or human life. Without going into how they do it, scientists have been able by genetic engineering to achieve the cloning of plants and animals such as frogs and mice. Lately a good deal of attention has been given to the material that contained the genetic information of all living cells, the so-called DNA.<sup>3</sup> Scientific techniques are now available to enable recombination between molecules of DNA derived from different species of organisms. This technique of manipulating basic living matter is called recombinant DNA. There is a great deal of hope that experiments in this area will prove tremendously helpful in tackling pathology in human beings, including some forms at least of cancer. Furthermore, use of genetic engineering can have great economic consequences. New forms of plant life (and possibly new forms of animal life) could be bred. New energy forms may be developed. In a world of burgeoning population, food shortages and energy scarcity, genetic engineering may come to our rescue.

But here too problems arise:

- . Some people just take a fundamentalist view that interference in the natural order is unacceptable and dangerous and may lead to consequences and risks we cannot perceive. According to this view we should just leave well alone.
- . Some of the scientists involved in the early DNA experiments saw potential hazards. These included the possible production of new and highly pathogenic organisms which could escape from containment into the population spreading epidemics beyond our control. Subsequent research appears to have indicated that this risk is much less than was at first feared. Just the same, there are risks where experiments use genes derived from dangerous pathogens. Large-scale industrial genetic engineering may involve dangers to the environment, such as the escape of an unexpected virus or the spread of a fungus whose dangerous properties had not been contemplated.
- . There is a further problem in medical treatment involving DNA. Doctors, anxious to help their patients, might be tempted to press on with experiments that involve the use of genetic engineering before it has been properly tested. In 1981 in the United States, Professor Martin Cline injected bone marrow containing genetically engineered DNA into two patients. He did this without getting permission under voluntary guidelines. He has been reprimanded. Following criticism that the reprimand was too lenient, he has been 'fined' nearly \$200,000 by the

withdrawal of Federal research grants in that amount. He had tried unsuccessfully to treat people suffering from beta thalassaemi with cloned beta-globin genes which he had engineered in the laboratory.<sup>4</sup> A Nobel Prize if he had succeeded. Ignominy and rebuke on failure.

Professor Cline's case has raised questions about the effectiveness of voluntary guidelines on this form of genetic experimentation. In Australia until recently there was nothing more than a set of rules drawn up by the Australian Academy of Science. Late last year the Federal Government established an advisory committee on recombinant DNA. The Chairman is Dr. Nancy Millis of Melbourne University. But questions remain:

- . Given the risks of the kind of problems that can occur if genetic engineering goes wrong, should we have more rigorous legislative control? Is a reprimand from a voluntary committee an adequate sanction against the medical or scientific adventurer? With great profits to be made potentially out of genetic manipulation, do we need more legislation to protect the community against the risk that things go wrong?
- . The committee established comprises scientists and industrials. Every one of them has a Ph.D. Will the community's general interest be adequately protected by the scrutiny of such a committee? Is there any risk that such a committee of enthusiastic scientists and technologists may not be adequately sensitive to community opinion and needs?
- . Even if there have been few accidents or mistakes so far, does the kind of potential risk of error with genetic engineering require more serious legislative sanctions? Is the criminal law needed to prevent the enthusiastic Dr. Clines of this world from taking risks with basic life forms that may endanger the species, however well motivated they may be?
- . Can lay legislatures ever hope to cope with problems of this kind? Sir Gustav Nossal, in a recent lecture to the Australian Academy of Science, urged that:

Bio-technology is moving so rapidly that if we have a Royal Commission or introduce legislation now about recombinant DNA or in vitro fertilisation ... or anything else of this nature, the ground will have shifted before we have got through the mechanics; the action will have moved to the next level. It is much better to use soft-edged measures depending on human judgment and decency, such as strong ethics committees including outside lay members to monitor research and treatment in laboratories and hospitals. In any case, the genie is out of the bottle and cannot be put back.<sup>5</sup>

Is this an admission of the ultimate defeat of our lawmaking institutions? Has the scientist and medical technologist gone beyond the wisdom of the whole community? Are we, the citizens and patients inevitably caught up in the chariot of science, liable to be taken wherever it goes? This is something our democracy has so far refused to acknowledge. But the crunch question must soon be answered.

Even if, as a society, we conclude that there is nothing much we can do to regulate the scientist, there will again be problems of detail to be sorted out:

- . The Commonwealth Government is proceeding with its Plant Variety Rights Bill currently before Federal Parliament. The aim is to introduce a system where plant breeders can obtain exclusive property rights for commercial exploitation of new plant varieties.<sup>6</sup> Already petitions have been presented to Parliament protesting, claiming that life forms are 'a common heritage to all'.<sup>7</sup>
- . In the United States a narrow 5:4 decision of the Supreme Court held that patent rights could be secured in bacteria developed to combat water-borne oil spills.<sup>8</sup> Should it be possible to patent life forms and if so under what circumstances? Can men and companies own life?
- . Should cloning of human beings ever be permitted? A recent US report said we could have it within 10 to 20 years. The number of children in Australia who are named after their parents indicates that there is, at the very least, a risk that some people would think they should donate a clone of themselves to posterity. Is the law to stand idly by whilst this development occurs?

#### HUMAN TISSUE TRANSPLANTS

I finally turn to human tissue transplantation. This is a subject that was referred to the Law Reform Commission. The legislation based on the Commission's report is gradually being adopted throughout the country. That project, which brought together people of differing disciplines and the general community shows what can be done to address the kinds of problems I have been discussing.

Surgical transplantation of tissues and body parts from one human being to another was not readily possible until recently. Then developments of medical techniques which overcame the natural tendency of the body to reject transplantation, opened up a marvellous new field by which skin, blood, bone marrow, kidneys, corneas, hearts, glands, livers, lungs and so on can be transplanted from one human being to another. There is no doubt about the beneficial aspects of this medical technology. It can, for example, restore sight. It can release people from the thrall of a dialysis machine to enjoyment of a nearly normal life. Success rates are high.



What are the issues that were revealed in the Law Reform Commission's inquiry? They included:

- . Opting out. First, should we introduce a regime under which everybody is deemed to be a donor unless in his lifetime he has opted out of the system? This is the legal regime now in force in France and other countries. It is said to face up to the fact that we live in a death-denying society (where people will not contemplate their death). Often the most useful tissues and body parts are taken from people at their death — frequently from young victims of fatal motor car accidents. Such people would never contemplate a donation. Yet, if they were asked, they would probably concur in making their body parts available to someone who could be helped, rather than having them buried or burned. As against the French system, it is urged that we should be concentrating on encouraging people to make a gift. Interference in the integrity of the human body is feared. So too is the possibility that occasionally a doctor may be tempted to use less than the most vigorous effort to sustain a potential donor, where his tissues could be of great help to a most worthy recipient. The first question is whether Australia is ready for an 'opt out' system. The Law Reform Commission did not think so. It proposed a much simplified 'opt in' system, limiting the ways in which consent must be secured, particularly in urgent cases.
- . Definition of death. The second issue is the definition of death. The issue arises in this context because much of the tissue that could be used would come from young people who have suffered 'brain death' in a motor care accident but are otherwise healthy. In these case an artificial respirator may keep blood circulating through the body. If beating of the heart and circulation of the blood marks the difference between 'life' and 'death', obviously such people, artificially sustained, are still alive. Medical experts now accept that death may be defined in terms of the irretrievable loss of function of the brain. This definition was also accepted by the Law Reform Commission and for all legal purposes.
- . Children's donations. A matter upon which the Commission divided was the third issue. Should young people ever be able, say young people under the age of 16, to donate a non-regenerative tissue to their brother or sister in need? Sir Zelman Cowen and Sir Gerard Brennan dissented on this score. They said the law should never permit such donations because it would allow undue pressure to be placed upon a young person in a family crisis when the law should protect him from pressure and temptations to bravado. The majority of the Commissioners thought that the law had little to offer in a family crisis of this kind except to ensure that proper procedures were followed, that the child donor understood fully what he was doing and that the donation was approved by a committee headed by a judge. This quandary illustrates the way in which people of good will can differ on subjects of this kind.

- Sale of body parts. A fourth issue upon which the Law Reform Commission was unanimous was that we should persist with the gift of body parts and not encourage the development of the American system of selling blood and other organs. The Commission proposed that sale should be forbidden except in a very limited case approved by the Minister. Body parts of the human being are deserving of special respect and not susceptible to the same treatment as automobile parts. If sale were permitted, there could be temptation for the poor to offer their organs to the rich. Traffic of this kind was thought distasteful. But Dr. Peter Swan of the Australian National University has criticised us, claiming that market forces should be permitted to sort out problems of this kind. According to Dr. Swan, if a poor person wants to sell a kidney or a cornea, he should be permitted to do so, as he is in South America, Asia or parts of the United States.
- Coroners' cadavers. Fifthly, an issue arose as to whether it should be possible to retain specially useful body parts from coroners' cadavers after a post-mortem is conducted. Should it be necessary to return all the body parts to the body? Or should it be possible and legitimate to keep specially useful organs such as the tiny pituitary gland which can be used to produce serum to combat dwarfism and other maladies. At the time of our report, this practice was being followed in Australia, without lawful authority. Should it now be legitimised? If so, what rules should be introduced to ensure that the medical technologists who take the organs do so under proper conditions? Should they have to inform relatives? If we permit the pituitary to be taken, are we on the path towards organ farming as predicted by the recent film 'Coma'? — Are we on the way to 'neomorts' and 'bioemporium'?
- Other issues. The Law Reform Commission postponed other issues of transplantation such as IVF and the use of foetal tissue in transplants. Should aborted foetuses become part of the property of the State and be available for transplant use as a source of spare parts?

#### HOW CAN THE LAW COPE?

The dazzling advances of scientists and technologists seem to have gone beyond the comprehension of ordinary people. The 'time cushion' that used to exist, within which lawmakers could prepare legal regulation to state society's standards, has virtually evaporated. Scientific and technological discoveries tumble out of the minds of these modern wizards. Slow-moving legal institutions find it hard to catch up. Occasionally the law is called on to provide a response. Instruments such as the Law Reform Commission are sometimes called into activity to help Parliament cope with the pressures of change. This is not an issue confined to the medical profession. It is the problem of adapting democratic institutions developed in the age of the long bow and the horse-drawn cart to the world of interplanetary flight, computers and bio-technology.

The Law Reform Commission offered assistance in the area of transplants, in the report that is now being implemented gradually throughout the country. The Commission is currently working on two aspects of the impact of the computer on the law : the development of new laws for the protection of individual privacy in computerised personal information systems and the development of new laws to permit the admission of computer evidence in courts of law. But these efforts represent a puny social response to a terribly important, little-recognised and broad-based challenge to our democratic institutions. Unless we can adapt our lawmaking procedures from their current mediaeval form, we must face the fact that increasingly our society will forfeit its control over social values long held dear. Scientific experimentation and technological developments will haul us along where the scientist and the technologist take us. Our opportunity to evaluate these changes and assert human concerns will, in part at least, be lost.

In the field of medical technology, we already have a few illustrations of what can happen, without any suggestion of evil or impropriety on the part of those involved. A scientific discovery may occur in an instant of time. Working out the legal and social consequences tends to take a great deal of time, particularly with the miniscule resources we are inclined, as a society, to devote to the effort. In the field of medical science, marvellous advances have been made in our century for the relief of pain and the treatment, cure and prevention of disease. We have, and should maintain, an optimistic spirit about the enormous value of medical science. But we should also be capable of providing the guidance and ground rules which the medical scientists themselves seek. This is not an appeal for a backward-looking, anti-science, Luddite approach to medical developments. I would have no part of such an attitude. It is, instead, an appeal for machinery to provide prompt social consideration of scientific advances. Unless interdisciplinary machinery can be developed, capable of consulting the experts and the general community and helping Parliament with the social and legal implications of medical developments, we must sadly face up to the inability of our democratic institutions to respond to the challenge of science. That may be a conclusion you will reach after this seminar. You may believe that the problems are:

- . too difficult and intractable to be addressed;
- . too sensitive ever to be considered by parliaments comprising elected members, timorous of the special interest group and the passionate minority voice;
- . too technological to be fully comprehended by the layman, whether in Parliament, the Cabinet or in the judiciary;
- . too inevitable to be withstood and therefore virtually above the law and legal regulation.

All of these are conclusions of despair. I remain an optimist that our system of government, which we have so carefully nurtured and developed over 800 years, can adapt to the age of mature science and technology. But if this is to happen we will need new institutions. We will need more dialogue between scientists and the community and scientists and lawmakers. We will need more occasions such as this where thoughtful people come together to offer their views. We will need the support of the media and the interest of at least a few politicians who see more closely than most nowadays do that the great engine of our time is science and technology.

My chief point is a simple one. Science and technology is advancing rapidly. If democracy is to be more than a myth and a shibboleth in the age of mature science and technology, we need a new institutional response. Otherwise, we must simply resign ourselves to being taken where the scientists' and technologists' imagination leads. That path involves nothing less than the demise of the Rule of Law as we know it. It is for our society to decide whether there is an alternative or whether the issues posed by modern science and technology are just too painful, technical, complicated, sensitive and controversial for our institutions.

FOOTNOTES

1. See eg Dr. P. Huntingford, Melbourne Herald, 20 March.
2. McKay v. Essex Area Health Authority & Anor, Times Law Report, 20 February 1982, 21. See also S.C. Hayes and R. Hayes, Mental Health Law Policy and Administration, 1982, 44. The US case is Park v. Chessin, 46 NY 2d 401 (1978).
3. Deoxyribose Nucleic Acid.
4. New Scientist, 26 November 1981, 587.
5. G. Nossal, 1982 Lemberg Lecture, Australian Academy of Science, delivered at University of New South Wales, 27 January 1982, as reported AMA Gazette, March 1982, 24 ('The Genie is Out ...').
6. Statement by Mr. P. Nixon, Minister for Primary Industry, at the conclusion of the 113th Meeting of the Australian Agricultural Council, Adelaide, 8 February 1982, mimeo.
7. See eg Commonwealth Parliamentary Debates (The Senate), 17 March 1982, 850.
8. Diamond v. Chakrabarty, 447 US 303 (1979).
9. Interest is beginning. See eg D.E. Fisher, 'The Use of DNA and the Law in Australia', (1982) 56 Australian Law Journal 6.