

Human Rights Commission

LEGAL AND ETHICAL ASPECTS OF THE MANAGEMENT
OF NEWBORNS WITH SEVERE DISABILITIES

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PREFACE

This is the tenth of a series of Occasional Papers published and distributed by the Human Rights Commission. It was prepared within the Commission by Dr Helen Ware of the Legal and Projects Branch in response to a request by the Australian College of Paediatrics that the Commission promote consideration of ethical and legal issues surrounding the treatment of newborns with severe disabilities.

The final draft of the paper was edited in Dr Ware's absence by an informal working party made up of Mr Douglas Cohen, Senior Vice President of the Australian College of Paediatrics, Professor Robert Hayes of the Australian Law Reform Commission, Dr Helga Kuhse of the Centre for Human Bioethics at Monash University and Dr Kathy MacDermott of the Commission.

This paper is intended to provide an analytic review of issues relating to the care of newborns with severe disabilities, with particular emphasis on the human rights involved. These derive from the International Covenant on Civil and Political Rights, the Declaration of the Rights of the Child and the Declarations on the Rights of Disabled Persons and Mentally Retarded Persons.

The Commission would be glad to receive comments on the paper or issues raised in it. It would also be glad to have an opportunity to participate in Seminars or other activities which address the issues, and particularly the human rights issues, associated with newborns with severe disabilities. Its purpose is to raise key issues and arguments associated with this subject in order to encourage a public discussion which will in turn assist the Commission in deciding what action it should take in this context. It is not intended as a set of guidelines for parents, doctors or any of the other people who may be involved in the area.

**LEGAL AND ETHICAL ASPECTS OF THE MANAGEMENT
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INTRODUCTION

In 1983 the Human Rights Commission was invited by the Australian College of Paediatrics to join with it in promoting discussion of legal and ethical issues related to deciding whether life-sustaining treatment should be given to infants with major disabilities. These issues clearly concern a core area of human rights: the value placed upon life.

2. The Human Rights Commission was set up by the Commonwealth Government in 1981 to promote and protect human rights in Australia. The Commission works under the Human Rights Commission Act 1981 (Cwlth), the Racial Discrimination Act 1975 (Cwlth) and the Sex Discrimination Act 1984 (Cwlth). The rights which it was established to protect and promote are set out in four United Nations documents and two Acts of the Commonwealth Parliament. The four United Nations documents are annexed to the Human Rights Commission Act and are: the International Covenant on Civil and Political Rights, the Declaration of the Rights of the Child, the Declaration on the Rights of Mentally Retarded Persons and the Declaration on the Rights of Disabled Persons. The two Acts are the Racial Discrimination Act and the Sex Discrimination Act, and these rely for much of their validity on, respectively, the International Convention on the Elimination of All Forms of Racial Discrimination and the International Convention on the Elimination of All Forms of Discrimination Against Women. Under the Human Rights Commission Act, responsibility lies with the Commission for ensuring that the laws and programs of the Commonwealth - including those of the A.C.T. - are not in conflict with the human rights set out in the four documents annexed to it. Specifically, the

Commission's functions include looking into acts or practices of the Commonwealth which may conflict with a human right and trying to bring about a settlement, or alternatively reporting to the Attorney-General on legislation which should be amended. The Commission is also given the power under its Act to undertake research and educational programs on behalf of the Commonwealth for the purpose of promoting human rights.

3. In the Discussion Paper which follows, issues relating to giving life-sustaining treatment to infants with major disabilities are considered in the context of a number of specific human rights which are in each case set out in part or in full. (The full text of each right is given in Appendix C.) The laws of the A.C.T. which are relevant are also considered. Because of the Constitutional distinction between Commonwealth and State powers, the laws of the individual States cannot be considered here. However, it might well be expected that if it were shown that the legal provisions in the A.C.T., which are similar to those in the States, appear to be in conflict with human rights requirements, then it might well be desirable to look also at the relevant State legislation.

The Concern

4. In Australia each year some 2,000 children are born with severe disabilities.¹ There are also some 800 perinatal deaths due to congenital abnormalities². With some of the most severely impaired of infants the question arises as to the most appropriate management. Nowhere in the world is life-sustaining treatment applied to every single birth. If, for example, a baby is born without a brain or with a vestigial brain it is allowed to die, even though with modern technology it would be possible to keep such infants alive by mechanical or other means. Equally some hospitals have an unwritten rule that, given the risk of severe disabilities, infants who are excessively premature will not be treated with every technical aid available.

3.

5. Decisions as to treatment or non-treatment where the probable or inevitable consequence of non-treatment is death raise complex legal and ethical questions. These questions overlap, but are not identical with, questions arising in relation to older children who have become severely disabled. This paper does not address that second set of questions.

6. The current legal position is that it simply is not clear whether parents or a doctor could be prosecuted if they did not initiate or withdrew treatment. The law is clear that murder and manslaughter can result from omissions to act as well as from actions. In the United Kingdom Dr Arthur (see Appendix A: **1981**) was charged with murder after he had given a painkilling drug, which also sedates and depresses appetite, to a Down's Syndrome child whose parents had rejected it. The charge was later reduced to attempted murder. Dr Arthur was acquitted but the precedent remains.

DEFINITIONS AND PROBLEMS OF DEFINITION

7. Problems similar to those affecting legal interpretation also affect the ethical and even practical interpretation of decisions regarding life sustaining treatment. A number of useful distinctions have been made in relation to acts and situations which often arise in this context; but such distinctions are really only useful so long as they remain clear. Unfortunately, a number of the distinctions which follow have developed grey areas of uncertainty which affect their usefulness.

8. Voluntary, Non-Voluntary Euthanasia. Euthanasia is defined as the bringing about of gentle and easy death, especially in the case of incurable and painful disease. Voluntary euthanasia is contrasted with non-voluntary euthanasia. In voluntary euthanasia, the person who dies does not consent to his or her death because he or she is not asked;

because he or she is asked and chooses to go on living; or because the person who is not capable of being consulted dies. The latter situation is of course that situation of the newborn; and it is because of the impossibility of directly consulting the wishes of the child that some reject the idea of infant euthanasia. Unlike the distinctions which follow, this distinction raises few grey areas of meaning. The problem it does raise is the difficulty of establishing, in the case of those who are not capable of deciding, what, taking all the relevant factors into account would be in the child's best interests.

9. **Active and Passive Euthanasia.** Both active and passive euthanasia result in death: the distinction between them is that between actively initiating a course of events (e.g. giving a lethal injection) that leads to death and not intervening in a course of events which has already started and which will, without some intervention, lead to death e.g. turning off a respirator to let a patient die of a pre-existing ailment. The grey area associated with this distinction emerges when the distinction is made to apply to ethics rather than fact. That is, while it has often been argued and assumed that 'letting die' is ethically superior to active euthanasia, it can and has been argued that there are circumstances in which the reverse is true first making the point that, in terms of intention, there may in fact be no distinction between euthanasia and letting die Dr Helga Kuhse goes on to argue that

Whilst the Administration of a lethal injection would bring a swift and painless death for the patient, letting die may be neither swift nor painless. In the much-discussed Johns Hopkins case (again involving a Down's Syndrome infant with an intestinal obstruction), the dying process took 15 days. The suffering involved in this is difficult to justify indeed., and it seems clear that in a case such as this a quick and painless injection would better serve the interests of the infant³.

10. Treatment and Non-Treatment. 'Non-Treatment' is a term which has different meanings and connotations to different physicians. Some refer to non-treatment only as the withholding of surgery. To others, it means ordinary feeding and comfort, appropriate analgesia but no surgery, oxygen, intravenous fluids or antibiotics. Others, in addition, would either withhold feedings or sedate the child heavily and institute demand feeding only.

11. Where limited sustaining treatment is given, there will be an indefinite, sometimes prolonged, period of deterioration and possible suffering for the infant and an indefinite prolonged period of psychological strain to parents, physicians, and nurses as these parents wait and wish for the infant to die.

12. When virtually all treatment is withheld, nutritional support is reduced, large doses of sedatives are given and feeding is only instituted on demand, there is an abbreviated period of waiting for the infant to die. However, this cannot properly be described as 'letting nature take its course'. The grey area here, then, is not ethical but practical: it is unlikely that the meaning of non-treatment can be sufficiently clarified to act as the basis of an ethical choice.

13. Intention to Palliate (ease pain) and Intention to Kill. The distinction which is being made by this pair of terms does not lie either in the medication being given, which can be the same in both cases, or in the result for the patient, which can also be the same. The distinction in fact lies in the intention of the physician concerned - and of the parents who have consented to his actions - and whether his or her intention was to relieve suffering or to hasten death. Because the same act can be motivated by different intentions, and because intentions may be difficult to establish after the fact, this is a distinction which some have not regarded as meaningful. The

Law Reform Commission of Canada has, however, proposed the following amendment to their Criminal Code based on such a distinction:

A physician should not be prevented from undertaking or ceasing to administer palliative care and measures intended to eliminate or to relieve the suffering of a person for the sole reason that such care or measures are likely to shorten the life expectancy of that person.⁴

14. Ordinary and Extraordinary Means. The distinction between ordinary and extraordinary means is tied to the distinctions between treatment and non-treatment and between active and passive euthanasia. That is, it sets up an opposition between kinds of treatment which may be regarded as routine and those which may be regarded as extreme, heroic or even experimental. This opposition may in turn form the basis of a distinction between kinds of life-sustaining treatment which may or may not be applied to infants with severe disabilities. The problem is that, as in the case of treatment vs non-treatment, definitions of extraordinary vs ordinary means of sustaining life can vary to the point where the terminology may cloud rather than clarify issues.

EURDER AND MANSLAUGHTER IN THE A.C.T.

15. The Human Rights Commission has a mandate to look at Commonwealth law and to recommend that any inconsistencies between that law and human rights be removed. The laws of the Australian Capital Territory are Commonwealth laws and accordingly are considered here. While the law regarding murder and manslaughter varies between the A.C.T. and the States and again among the States themselves, all are sufficiently similar for conclusions in one case to be relevant to the other cases.

16.

murder and manslaughter are set out in the Crimes Act, 1900 (NSW) in its application to the Australian Capital Territory (the A.C.T). Section 18(1) of the Act Provides:

- (a) Murder shall be taken to have been committed where the act of the accused, or thing by him omitted to be done, causing the death charged, was done or omitted with reckless indifference to human life, or with intent to kill or inflict grievous bodily harm upon some person, or done in an attempt to commit, or during or immediately after the commission, by the accused, or some accomplice with him, of an act obviously dangerous to life, or of a crime punishable by imprisonment for life.
- (b) Every other punishable homicide shall be taken to be manslaughter.

17. Some elements, pertinent to the position of a doctor in relation to a severely disabled neonate, .required under s.18 and the common law to prove murder in the A.C.T are

- (1) the death of a human being;
- (2) that the act or omission of the accused caused the death;
- (3) that such act or omission was done or omitted with:
 - (a) intent to kill; or
 - (b) intent to cause grievous bodily harm; or
 - (c) knowledge that death or grievous bodily harm would be the probable consequence of the act or omission (the High Court ruled in 13 v. Crabbe,⁵ 26 March 1985, unrecorded, that it was this rather than reckless indifference to the consequences of the act or omission which was necessary to constitute murder); and
- (4) that such act or omission is malicious or without lawful cause or excuse.

18. To prove manslaughter, the following elements would need to be established:

- (1) the death of a human being;
- (2) that the act or omission of the accused caused the death; and

- (3) that the act or omission of the accused causing death was unlawful.

19. It is manslaughter to kill by criminal negligence, which may arise where the accused omits to take the steps he/she is under obligation to take either at common law or by statute. Hence in R v. Instan⁶, the accused was convicted of manslaughter when her neglect accelerated her aunt's death: the accused took no steps to obtain medical aid, or give or obtain nursing assistance when the aunt contracted gangrene.

20. In the A.C.T., as in the States, the crimes of murder and manslaughter are tried by judge and jury. This means that in addition to the legal elements of the alleged offence, the reaction of a jury to the facts in each case will have a significant impact on the decision reached.

21. Prediction of criminal responsibility in cases arising from the non-treatment of infants with, or at risk of having, grave disabilities, remains highly uncertain. In a recent article on 'Extremely Premature Infants - the Legal Framework for Life and Death Decisions',⁷ Professor Robert Hayes has made an assessment of how the jury system might operate under the broadly similar procedural provisions in the Australian States and Territories. As such his assessments are relevant insofar as they may relating to jury trials in the A.C.T. Professor Hayes has emphasised that the material which follows represents his own personal assessment; many other lawyers may, no doubt, disagree.

22. Professor Hayes' discussion takes the form of a broad assessment of the response that a jury might be expected to make in certain situations. It must be emphasised that it is never possible to pre-determine a jury's decision, nor to anticipate accurately a jury's response, particularly given that the

circumstances of each case will differ. The following hypothetical examples do, however, reflect certain trends that are developing in this area:

- (a) THE INFANT IS BORN IN SUCH A CONDITION THAT THERE IS NO POSSIBILITY OF INDEPENDENT LIFE. IT CAN ONLY BE SUSTAINED THROUGH ARTIFICIAL SUPPORT SYSTEMS. ONCE LIFE SUPPORT IS REMOVED, DEATH WILL OCCUR.

It would be difficult to satisfy a jury beyond a reasonable doubt that the parental and medical decision-makers had deliberately (murder) or through gross negligence (manslaughter) caused the death of a living being...

- (b) THE INFANT IS BORN IN SUCH CIRCUMSTANCES (E.G. EXTREME PREMATUREITY) THAT THERE IS A POSSIBILITY OF INDEPENDENT BUT POSSIBLY SEVERELY DISABLED LIFE, WHICH IN THE SHORT TERM CAN ONLY BE SUSTAINED THROUGH ARTIFICIAL SUPPORT SYSTEMS.

It would be difficult to satisfy a jury beyond a reasonable doubt that the parental and medical decision-makers intentionally caused the death through their deliberate failure to take reasonable measures in fulfilling their duty of care (murder), or made a gross departure (manslaughter) from the standard of care to be expected of such decision-makers.

- (c) THE INFANT IS BORN WITH SUCH A CONDITION (E.G., ACUTE BRAIN DAMAGE, AND INTESTINAL OBSTRUCTION) THAT THERE IS THE POSSIBILITY OF INDEPENDENT BUT SEVERELY DISABLED LIFE, BUT WHERE MAJOR SURGERY IS NEEDED IN ORDER TO MAKE POSSIBLE THAT INDEPENDENT EXISTENCE.

It is possible to draw an ethical distinction according to whether the treatment merely inevitably prolongs a dying process and whether it prolongs living, even if the life that is prolonged is of a quality that many would consider it not worth living. But as Pope Pius XII has said, the burden of the treatment cannot be ignored.

- (d) THE INFANT IS HEALTHY ON BIRTH AND WOULD ENJOY A RELATIVELY NORMAL LIFE SPAN WITHOUT THE NECESSITY FOR ANY MAJOR ATYPICAL INTERVENTION, BUT WITH SOME PHYSICAL OR MENTAL ABNORMALITY WHICH ON ANY REASONABLE INTERDISCIPLINARY ASSESSMENT WOULD THROUGHOUT HIS LIFE BE:

- (A) A SEVERE HANDICAP: HE OR SHE WOULD BE COMPLETELY DEPENDENT ON CARE PROVIDERS, AND WOULD LIVE IN AN INSTITUTION; OR

- (B) A MODERATE HANDICAP: THE PARENTS MIGHT BE ABLE TO COPE, BUT ON THEIR DEATH, ONLY INSTITUTIONAL LIFE WOULD BE POSSIBLE; OR
- (C) A MILD HANDICAP: WITH SUPPORT AND TRAINING A RELATIVELY INDEPENDENT LIFE IN, E.G., A GROUP HOME, WOULD BE POSSIBLE.

(A) If the parents reject the child, medical decision-makers would require the authorisation of a legal guardian before they could lawfully proceed with care. If the decision is made to deny care. and the infant dies. they might commit murder. although the parents would most probably be charged only with manslaughter. The jury is likely to acquit the parents.

(B) and (C) These must remain as areas of agony where it would be entirely inappropriate to attempt prediction.

INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS

23. The question remains whether criminal law provisions in the A.C.T. and the practices of doctors and hospitals under federal jurisdiction currently provide the appropriate protection to the human rights of neonates born with severe deformities. Not only is the law itself not clear in its applications to all individual situations, but there are also questions as whether the law and current practices are themselves in conflict, and whether either or both are in conflict with human rights as set out in the six United Nations documents which Australia has signed. To clarify these questions it is necessary to start with an examination of those sections of each document which relate to the human rights of infants with severe disabilities.

24. Article 6. Article 6 of the International Covenant on Civil and Political Rights (ICCPR) provides in paragraph 1 that

Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

The remaining paragraphs of Article 6 deal with the crime of genocide and limitations upon capital punishment. There are four points to be noted about the right to life provision of Article 6.

- (1) it is not absolute: only arbitrary deprivation of life is completely ruled out;
- (2) it is confined to human beings;
- (3) it is clear that the framers of the Article were not thinking of issues relating to active or passive euthanasia but of despotic and murderous governments, of capital punishment and genocide. The only reference to younger persons is the provision of Paragraph 5 that the death sentence shall not be imposed for crimes committed by persons under the age of eighteen nor upon pregnant women;
- (4) there is little indication as to how the law is expected to protect the right to life where this requires a positive input such as the provision of special medical services for infants born prematurely.

25. **Human Beings and Persons.** The second point raised under Article 6 raises in turn the question of what it means to be human. There are, broadly speaking, two answers to that question. First, it is possible to define a human being in physical terms, as Aristotle's definition of a being having two legs and no wings or, more recently, as a being having a certain number of chromosomes. There are obvious problems with any kind of definition based on numbers of limbs or organs. If the definition of a human being is made in terms of genetic characteristics, then some deformed infants with major chromosomal disorders would be excluded. Some of these infants do appear to lack basic human characteristics. Some, for example, are incapable of communication beyond a cat-like meowing or of developing forethought or of survival beyond two or three years. Glanville Williams has suggested that an infant lacking physical human characteristics is not protected by the law of murder or manslaughter.⁸

26. A second answer to the question of what it means to be human is a definition couched in terms of abilities, like self-consciousness, or the ability to take part in relationships, or the ability to make moral choices. According to this definition, a human being is someone who is able to act in certain intellectual ways which are considered to be characteristically human. To distinguish in discussion between this definition and a physical one, the physical definition is said to isolate 'human beings' and the definition by ability to isolate 'persons'. One of the effects of using this concept of persons is that it does not make for a distinction between a fertilised ovum, a fetus, and a new born.

27. Jonathan Glover, the author of Causing Death and Saving Lives⁹ is one of a growing number of philosophers who argue that, speaking exclusively from the point of view of the rights of the child, there is no moral difference between not conceiving a child, and painlessly aborting a fetus or killing a new born baby. There may be side effects, such as the impact upon the parents and upon society which make a difference but there is no difference for the 'child' because in each instance the child had no means of knowing what was happening or of desiring to live. The child, that is, was not yet a person, not yet able to act in certain intellectual ways considered to be characteristically human.

28. Most people are familiar, whether they agree with it or not, with the argument that abortion and infanticide are morally equivalent. The claim that not conceiving should be added to the list is much less familiar. Yet, from the viewpoint of the child in each case the end result is the same: a sentient, self-conscious being or person never comes into existence. Very few people would consider it to be morally wrong to wait a year to conceive if thereby the risk of a deformed infant would be reduced. Opinions are divided as to the morality of 'replacing' a defective fetus by abortion followed by a new conception. The

extreme case comes when there has been an actual birth and the infant can be seen to be severely impaired - say with no legs or arms or no stomach. If at the parents' request such an infant is instantly and painlessly killed and replaced the following year by a normal birth to the mother Glover would argue that the sum of human welfare has been increased and that morality has been well served by the avoidance of pain and suffering to the deformed infant and the creation of the normal infant. This is the ultimate form of the quality of life argument - that the creation of a new worthwhile life is to be preferred to the maintenance of a highly imperfect life. Thus in the case of Siamese twins where only one can survive the operation should be designed to save the more nearly normal twin. In Glover's view the reason for not killing severely handicapped adults is that they have autonomy and can be assumed to have a will to live unless they have shown otherwise. The side effects of killing adults are also likely to be much graver for friends and relations and for society as a whole.

29. Many other philosophers and theologians have questioned whether infants are persons with full rights. 'Of course babies are not yet, in the full sense, free or choosing beings who clearly have rights. They are, perhaps, only potential or dispositional persons and enjoyers of rights.'¹⁰

30. Richard McCormick, the Catholic moral theologian, argues that not all infants are persons. He argues that the duty to preserve the life of a newborn child with severe disabilities is determined not only by whether or not they entail grave hardship, but also by the quality of the life thus saved. In his view, in the Judeo-Christian tradition, life is not a value to be preserved in and for itself: it's a relative good - a value to be preserved insofar as the higher, spiritual purposes of life are attainable. The duty to preserve physical life, as well as the limits of that duty, are based on the possibility of attaining to these higher values. Consequently,

'life is a value to be preserved only insofar as it contains some potentiality for human relationships'.¹¹ Thus the criterion for deciding which efforts must be made and which efforts need not be made to sustain a defective newborn's life are 'the potential for human relationships associated with the infant's condition'. If this potentiality is totally absent, or if it would be totally undeveloped or utterly subordinated to the mere effort for survival, human life 'has achieved its potential' and no treatment is obligatory. The baby may be allowed to die.

31. Warren Reich, another Catholic moral theologian takes a much more conservative view of the limits of the duty to sustain life, relying exclusively on the distinction between ordinary and extraordinary means. He argues that qualitative aspects of the use of some medical treatments in terms of pain, hardship, futility of treatment, or the extremely adverse condition of the survivor may diminish the obligation to treat. Whilst negative duties can be absolute there are limits to positive

obligations. Taking the case of spina bifida babies with some mental retardation he says

as regards those infants who can be expected to experience at least a minimal self-consciousness and freedom of will and who therefore will be striving to achieve moral (or moral-religious) self-realization, the duty to preserve life may be limited by the excessive hardship that would foreseeably be experienced by the patient if his entire striving to discover moral meaning in life were to be totally submerged in or utterly strained by the mere effort to survive and by the suffering that accompanies that effort.¹²

32. Thus Article 6 is not a simple caveat; it raises questions about what it means to be human and what it means to live a human life which require considered and sensitive reflection. Considered answers to such questions are recorded in the decisions of landmark cases such as that of the United States Supreme Court in 1973 in Roe v. Wade¹³, where it was

pointed out that 'the unborn have never been recognized in the law as persons in the whole sense' and that in general legal rights have been contingent upon live birth. Accordingly the Court ruled that as far as legal rights are concerned it is viability or the potential to live outside the mother's womb which is crucial. 'Viability', it observed, is usually placed at about seven months (28 weeks) but may occur earlier, even at 24 weeks. The issue of what it means to live a human life arises again in the context of Article 7 which protects the individual from torture or cruel, inhuman or degrading treatment or punishment. That is, to apply life-sustaining treatment to newborns with severe disabilities might in some cases be regarded as inhuman or degrading treatment by honest and fair people in the community.

33. Article 7. Article 7 of the ICCPR provides that

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.. In Particular, no one shall be subjected without his free consent to medical or scientific experimentation.

Proponents of the view that in some cases the quality of life is so poor that death would be preferable argue that there are circumstances in which prolonging the life of severely defective infants does constitute torture or inhuman treatment. Examples would include those cases where the infant will never be able to survive without being attached to a machine, where breathing without a respirator will always be impossible, or where the absence or malfunction of digestive organs means that the infant can only be fed intravenously. Another example would be Tay-Sachs disease where the infant is subject to a progressive increase in spasticity and dementia usually leading to death at age three or four.

34. The Saikewicz case is of particular relevance here.¹⁴ Saikewicz was 67 years old but he had an IQ of 10 and a mental age of under three years and could not speak. He developed leukemia and his guardian argued that since he could not

understand why painful treatment should be imposed upon him such treatment would, in effect, constitute torture. The Massachusetts Supreme Court accepted this reasoning and backed up the decision not to treat on the grounds that imposing prolonged pain where the person could not understand the reason for it and would not experience a prolonged return to painfree life constituted inhuman treatment. Given Saikewicz's mental age this case would appear to have clear implications for infants who are at risk of being subjected to prolonged painful treatments with no ultimate prospect of moving on to a life without pain.

35. The second part of Article 7 deals with the question of free consent to medical or scientific experimentation. This provision clearly has its roots in horror at so called 'medical experiments' carried out in the Second World War concentration camps. Viewed in an absolutist or literal light it would appear to rule out all experimentation on children and other persons without the capacity to consent on their own behalf since no provision is made for substitute consent. Many writers in this area have drawn the distinction between ordinary means which are obligatory and extraordinary means which are not. In terms of the International Covenant on Civil and Political Rights this distinction would appear to parallel that between experimental and non-experimental treatment, although the Covenant does not address the issue as to whether there are circumstances in which the individual can be obliged to accept non-experimental medical treatment for his or her own good.

36. In guiding the families and physicians of patients Pope Pius XII stated that they are not obliged in conscience to consent to or to use extraordinary means to preserve life. Under 'extraordinary' means are included not only highly complex but also highly expensive and inconvenient treatment.¹⁵

37. In the case of Karen Ann Quinlan, an adult woman in a chronic and persistent 'vegetative' state, the Supreme Court of New Jersey, in a unanimous decision in 1976, became the first court in the United States to recognise (explicitly) that life, whatever its form, nature or content, is not necessarily to be considered as always being good and not always to be prolonged as long as possible. The Court ruled that, as Ms Quinlan's guardian, her father could authorise her artificial life support systems to be switched off and that 'a death resulting from such an act would not come within the scope of the homicide statutes proscribing only the unlawful killing of another'. On the basic point of medical responsibility the Court concluded that

Physicians distinguish between curing the ill and comforting and easing the dying, that they refuse to treat the curable as if they were dying or ought to die, and they have sometimes refused to treat the hopeless and dying as if they were curable many of them have refused to inflict an undesired prolongation of the process of dying on a patient in irreversible condition when it is clear that such "therapy" offers neither human nor humane benefit. We think these attitudes represent a balanced implementation of a profoundly realistic perspective on the meaning of life and death and that they respect the whole Judeo-Christian tradition of regard for human life. No less would they seem consistent with the moral matrix of medicine, "to heal", very much in the sense of the endless mission of the law, "to do justice n.16

38. A case directly involving a child was that of Stephen Dawson, a six-year old Canadian boy blind with atrophied nerves, partly deaf, incontinent, unable to hold a spoon to feed himself, unable to stand, walk, talk or hold objects and with no method of Communicating with the environment or indicating whether in pain Subject to frequent seizures despite medication he had to be restrained by splints to keep his elbows straight so that he could not chew on his hands and tear at his face. His parents, who maintained that he was in pain, refused permission for life-saving surgery to unblock the shunt draining excess cerebro-spinal fluid from his head. The Public Trustee

for British Columbia took the case to the Supreme Court after the Provincial Court had found in favour of the parents' right to refuse treatment. The Provincial judge held that treatment constituted an 'extraordinary surgical intervention' which would serve 'only to prolong a life inflicted with an incurable condition'. The judge also held that the shunt revision would constitute a violation of Stephen's right not to be subjected to cruel and unusual treatment under s.12 of the Canadian Charter of Rights and Freedoms. In the Supreme Court Mr. Justice McKenzie reversed the decision giving custody of Stephen to the Public Trustee so that the shunt operation could be performed. In comparing the two judgements it is clear that the central difference between the two judges was in their opinion as to whether it was possible to lead a life of such suffering that 'non-existence is the better alternative'. This is clearly a philosophical rather than a legal question. Judge McKenzie was also influenced by the fact that in the absence of the operation Stephen's death was unlikely to be immediate but might well prove to be long-drawn out and painful.

39. 'In this case, the court must decide what its ward would choose, if he were in a position to make a sound judgement'.¹⁷ The problem is how can anyone evaluate what a newborn severely defective child would want. In re B¹⁸ Templeman L.J. said that the test was

whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die. There may be cases, I know not, of severe proved damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion, but in the present case ... I have no doubt that it is the duty of this court to decide that the child must live.

would be making a contract as against the obligation to save a drowning man. Perfect duties resting on rights override imperfect duties not resting on rights. Respecting people's right to autonomy and to work out their own lives has the consequence that one cannot use people as a means to the benefit of others. For those who do not distinguish between autonomy and the potential for autonomy, this would mean that one cannot kill an infant because the death of that infant would be of benefit to the remainder of the family or to society as a whole (say because of the extraordinary cost of keeping such a child alive). However, this would leave open the question of the infant's positive right to be kept alive at whatever cost. This is a very real issue in Australia today where at least one infant has died as the direct consequence of a shortage of respirators and the staff to service them. This issue will be discussed further in relation to Principle 4 of the Declaration of the Rights of the Child, which includes the child's 'right to adequate ... medical services'.

46. Article 23. Paragraph 1 of Article 23 states that 'the family is the natural and fundamental group unit of society and is entitled to protection by society and the State' and paragraph (2) recognises 'the right of men and women of marriageable age to marry and found a family.'

47. Both the protection due from the State to the family unit and the right to found a family involve the right of parents to take a major part in making decisions regarding the application of life-sustaining treatment to infants with severe handicaps.

48. To date little research has been done of the opinions of parents of children with severe disabilities, or of the views of those children who have reached adult age and are able to articulate their experiences. Two studies from South Wales indicate that 'siblings of ... spina bifida children [are]

almost four times more likely to show evidence of maladjustment than the siblings of ... control children'; that 'the mothers of children with spina bifida have higher stress scores than the mothers of children with psychiatric problems, brain disorder and physical handicaps'; and that 48% of 77 parents of Down's Syndrome children 'were prepared to accept the idea that not all handicapped children should be kept alive at all costs' .26,27 Almost half of the parents of Down's Syndrome children who accepted active or passive euthanasia qualified their acceptance by a proviso relating to the severity of the disability affecting the infant concerned. Most 'would not accept that a Downs Syndrome child, without additional problems, could be considered as 'very severely handicapped'²⁸.

49. Two letters from parents of children with spina bifida give further access to the kinds of issues with which parents of infants with severe disabilities are forced to grapple, perhaps for the duration of their childrens' lives or their own:

When my two year old son was born the team of doctors in charge thought his outlook was good and so operated immediately (they told me that if they did not operate he might not die but survive in a worse state). A year later we knew he would not only never walk but never even sit unsupported. Meanwhile he receives from physiotherapists, doctors, social workers and all his family an immense amount of loving care. I think we all carry a double wish: that he will grow and prove intelligent and able to cope with life; and at the same time that he might die painlessly should life prove intolerable. One day I think I am a moral coward for not being prepared to solve it by drastic means myself; the next I reproach myself for insufficient courage and optimism in thinking of the future.

There is certainly a good case for leaving spina bifida children unoperated at birth.

Could the medical profession not produce some generally agreed guiding advice for future parents, suggest, in fact, a national policy? At the moment the fate of a spina bifide baby seems to depend to some extent on chance factors (which hospital you are in perhaps); considering

the numbers born and the severity of the handicap, this may well add to the confusion and bitterness felt by some parents.²⁹ What is abortion if not a form of euthanasia? Why can one kill perfectly good babies and yet if they are actually born (but turn out wrongly) insist they live, even to the extent of operations, incubators and oxygen tents; then place them in hellish institutions for the rest of their lives? Or confine their mother to a living hell? What kind of morality is this?³⁰

50. Both of the above letters were written by parents who loved their children but had severe doubts as to whether they should have been killed or allowed to die at birth. Not long after they were published another mother of a severely handicapped child killed the child and committed suicide because she could bear neither to go on caring for him nor to commit him to an institution. She and her husband had agreed that all three would die together but she had forestalled him apparently on the grounds that he, at least, had a right to some contentment in life.

51. Other parents, perhaps those with less severely affected children, have far more positive experiences. A mother of a ten year old with spina bifida reported

our son has taught us, his family, to reevaluate our goals in life, to appreciate the many gifts we took for granted, and to become a far closer family and more tolerant of the problems of others. He has given to us and the many people he meets a special gift of love.

There are also people who were candidates for non-treatment in infancy who are now outstanding adults such as Sondra Diamond, a Canadian psychologist with severe cerebral palsy who also survived 60% burns as a teenager. However, such individuals would all appear to come from

exceptionally supportive family backgrounds (whether of a biological or a foster family). One of the unanswered questions relates to the fate and perceptions of those severely disabled individuals who are brought up in institutions because there is no supportive family available.

52. Given the profound influence severely disabled children have on the family, and conversely the influence the family can have on the severely disabled child, the right of parents to participate fully in decisions regarding that child cannot be divorced from the responsibility to take decisions based on the welfare and interests of the child. Current legal practice focuses on consent - to treatment or to non-treatment - as the mechanism through which decisions regarding the child are articulated. Consent provisions divide responsibility between parents and medical practitioners in a fairly clear-cut way.

53. Consent. Any doctor who wishes to undertake the care of a child at law must have the consent of the parents or guardian. In discussing the question of treatment or non-treatment, it is often overlooked that a doctor has no independent powers of decision-making in relation to his patient. He or she must put what he or she wants to do before the persons with the power to consent and those persons must then decide whether they wish to say yes or no. The legal issue is not 'should we, as doctors, treat this infant' but rather 'should we advise the parents to consent or withhold consent to treatment'.

54. Legally, it is the persons with the power to consent - the parents - who are alone responsible for making the difficult decision to say yes or no to intervention, even if that decision is regarded by others as a cruel, irrational, unfair, discriminatory or ignorant one. In certain circumstances, the

decision can be taken away from the parents and placed before a politically accountable Minister of State or an impartial and independent Judge but it cannot be resolved legally by hospital staff seeking to take the law into their own hands.

55. The consent rule means that parents must be in close communication with the medical staff treating their child, that they must be informed immediately about any problems posing a threat to the child's capacity for independent existence, that they must be given full information about the problems and the course of treatment proposed, and that their consent should be sought for every step that is taken, particularly for a step involving intervention and the introduction of artificial life-prolonging techniques.

56. The legal obligation of securing consent arises both to meet the appropriate standard of care (negligence) and to avoid liability in battery (trespass to the person), and in the context of handling of personal information to meet the duty of confidence imposed by law on those holding confidential information.

57. The Mechanics of Obtaining Consent. The following summarises the legal guidelines:

- (a) All factors relating to treatment which could influence the parents' decision to participate must be disclosed.
 - (b) The test of what information should be given to parents is judged by reference to what a 'reasonable patient' would want to know before making the decision to submit to treatment.
 - (c) The person seeking to obtain consent should take reasonable steps to ensure that he or she has been understood and that this understanding is apparent.
 - (d) Care should be taken not to intimidate parents or otherwise coerce them into appearing to give consent.
 - (e) The issue of consent is a particularly complex one when the patient is incapable of giving valid consent because of age or mental disability. Third party
-

consent can be given by parents or legally appointed guardians. Consent is not required if emergency treatment is necessary to preserve the life of the patient. It is extremely doubtful whether valid third party consent can be given for procedures which are not essential for the preservation of life or health such as the donation of blood or human tissue, cosmetic surgery or non-therapeutic sterilisation.

58. One problem raised by current legal provisions surrounding consent is that the chances are very high that neither the parents concerned nor the medical practitioner has any direct experience of the day to day problems awaiting both parents and child; and while a number of medical practitioners can and do have the benefit of knowing what parents think of decisions long after those decisions have been made, they may be influenced by extra-medical considerations and by the fact that they will not themselves be responsible for watching over the lives of children with severe disabilities. Parents, on the other hand, are often asked to take decisions at a time when they are themselves in need of counselling or support. Because of these restrictions on their respective abilities to evaluate fully the best interests of the child, many parents and medical practitioners would, it has been argued, benefit from the responsible involvement of a hospital ethics committee. The role of such an expert body in safeguarding the rights and best interests of the mentally retarded person is recognised in the Declaration on the Rights of Mentally Retarded Persons, which calls for an evaluation by 'qualified experts' whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights...

59. Upon considerations such as these, a working party set up by the Australian College of Paediatrics argued in Its Report on 'Non-intervention in Children with Major Handicaps - Legal and Ethical Issues'³¹ that hospital ethics committees should 'assist with the decision making process whenever an objective opinion was required,

whether this was for social, medical, legal or humanitarian reasons^{1.32}. Such assistance has been discussed as likely to take two forms: the formulation of broad guidelines for decision-making and active intervention in the decision-making process.

60. In fact provisional guidelines have been drafted by the working party of the Australian College of Paediatric Surgeons and are set out in its Report³³ (see Appendix D). Some discussion of intervention is warranted here.

61. In an unpublished article on ethics committees and professional accountability, Professor Robert Hayes makes a series of distinctions which are relevant to any discussion of the rights of the family to protection and to privacy in its decision-making process and to the need for provision for intervention when such intervention is clearly in the best interests of the child. He argues that:

- (1) informed parental decisions about their extremely premature or disabled infants, taken on the advice of conscientious health teams, ought to be respected by the legal system in our society;
- (2) where the parents are simply paralysed by indecision or temporarily unable to cope, so that an informed response will not be immediately forthcoming, the problem should be resolved through support and counselling, not through the intervention of an ethics committee; and
- (3) there must be a capacity for strangers to intervene in family affairs where this is in the best interest of the child.³⁴

While the hospital ethics committees might play a useful role in screening parents from direct intervention in their decision-making process by strangers wishing to interfere in the doctor-patient relationship (for example, local government

officers, government appointees, persons involved in fundamental religious groups or just individuals professing an interest), they might themselves become mechanisms of arbitrary interference with the rights of the family to privacy and to protection. If powers are to be afforded to hospital ethics committees as to decisions regarding life sustaining treatment, great care will have to be exercised in relation to the procedures governing the selection of committee members and the definition of the powers of the committee. As Professor Hayes. argues, the committee should not be permitted to interfere with a decision that another person is legally entitled to make, is equipped to make, and wishes to make, [nor should it] ... be able to authorise a course of conduct which might deprive a person of his or her existing rights.³⁵

DECLARATION OF THE RIGHTS OF THE CHILD

62. There are three principles which are of special relevance to the severely impaired newborn child.

Principle 2

The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity. In the enactment of laws for this purpose, the best interests of the child shall be the paramount consideration.

Principle 4

The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.

Principle 5

The child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition.

63. Joseph Fletcher S.T.D. is a professor of medical ethics and one of the very few authors who has examined the implications of the Declaration of the Rights of the Child for the treatment of severely defective newborns. In his view the Declaration

neither faces the issue nor closes it off. It says that each child is to be treated and cared for according to his 'particular condition. Principle Five leaves the problem hanging there, without explaining what 'the best interests of the child' are (Principle Two). And yet the Declaration uses exactly the language that a responsible clinical ethic would use: 'particular condition'.³¹⁾

64. What the Declaration does not resolve is the question whether it can ever be in the child's -'best interests' to be allowed to die. It does, however, make it quite clear that the child's interests are the decisive factor and that it would never be acceptable to let the child die in the interests of the family or of society. (This does not, however, resolve the issue of how resources are to be allocated in a society with children with many needs.)

65. Fletcher's own view is that there is such a thing as a life not worth living and that, for that reason, not all severely deformed infants should be kept alive. He quotes Cardinal Jean Villot, Vatican Secretary of State who told the International Federation of Catholic Medical Associations in 1970 that life is precious, 'But for all that, a medical man does not have to use all the techniques of survival offered by a constantly creative science'.

66. He also quotes the working party of the Newcastle Regional Hospital Board Chaired by the Lord Bishop of Durham and with Monsignor Loftus as a prominent member which stated that 'The doctor has no ethical obligation to treat cases in which the likely benefits are very dubious. Thus in the present state of medical knowledge the policy of selection for the treatment of spina bifida is in our opinion justified'. Their conclusion

was based upon a consensus that prevention of suffering comes before the preservation of life and that if it can be foreseen that pain for the child will outweigh the happiness then it is justifiable not to practise aggressive treatment.

67. Another aspect of the Rights of the Child which has received little attention is the right to adequate medical services. A premature baby of 900 grammes has already died in Sydney because a respirator was not available. This child was not deformed but doctors had to make the decision whether to remove a 700 grammes infant already on a respirator who had a much poorer prognosis; having decided not to do this the heavier child was doomed. It is understood that State Ministers of Health are currently trying to reach an agreement as to the birthweight at which it is reasonable to mandate aggressive treatment and hence to require the provision of respirators and the staff to service them.

68. The Sydney case raises the issue of resource allocation in relation to the child's right under Principle 4 to adequate pre-natal and post-natal care and medical services. Given Australian conditions, does Principle 4 assure a right of access to a respirator? Or, taking the case of an infant with major disabilities who requires sophisticated life-sustaining treatment, does that infant have a right to such treatment if the cost of treatment is of the order required to purchase a respirator which could then be made available to a number of premature infants with a more promising prognosis? Or, more broadly still, should priority in the allocation of resources go to ante-natal treatment where treatment may arguably give the greatest benefit to the largest number of children?³⁷

69. In a medical system in which there are limited resources, in which the treatment of one may be at the expense of treatment of others, the right to treatment cannot realistically be considered in absolute terms.

DECLARATION ON THE RIGHTS CT DISABLED PERSONS

70. The most relevant paragraphs of the Declaration are

3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age which implies first and foremost the right to enjoy a decent life, as normal and full as possible.

6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthetic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.

9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subject, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialised establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

At first examination paragraph 6 might appear to rule out any discriminatory treatment of disabled infants such as non-selection for aggressive treatment. However, the addition of positive rights and especially the 'right to enjoy a decent life, as normal and full as possible' complicates the issue. What happens where there is no prospect of a decent life or of normal enjoyment of life? Similarly with the right to live with one's family - what if the family rejects the infant and there is no option but an institution? If there is no prospect of providing the child with the minimum conditions to which she or he is entitled, can it ever be in the interests of the disabled infant to cease treatment? Take the case where the parents of a

spina bifida infant refuse permission for a shunt operation. Certainly the State can step in and have the child declared a ward, authorize the operation and arrange for institutional care. However, many thoughtful and dedicated persons who have laboured to save large numbers of spina bifida children would argue that institutional life for the more severely affected constitutes inhuman treatment and denies respect for their human dignity.

71. It should be noted in this context that paragraph 9 of the Declaration on the Rights of Disabled Persons stipulates that where institutionalisation is

indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

The fact that institutional life may in fact be described in some cases as 'inhuman treatment' raises yet again the issue of thoughtful and appropriate allocation of resources. Should life-sustaining treatment be provided where life-maintaining services cannot be

72. The reported opinions of individuals who might well themselves have been candidates for non-treatment in infancy very widely: Everett Koop, the Surgeon General of the United States, has argued that none of the infants he operated upon who is now adult has committed suicide or wished to be dead.³⁸ On the other hand, John Lorber of the United Kingdom, who has perhaps the most extensive experience of caring for children with spina bifida of anyone, reports having had a number of adolescent patients attempt suicide as well as a number of mothers of such children. Another British surgeon has stated:

The question often occurs to me when talking to parents of a newborn baby with a severe handicap, what I would answer if the child when he came of age should ask me, 'Why did you let me live?' My possible answers, legality, my lack of courage, sound hollow. I could certainly not plead

ignorance. The only answer which I could find morally defensible would be, 'Your parents believed they could bring you up to be emotionally whole, though physically crippled.'³⁹

73. There may well be a structural reason why American surgeons appear to take a much more optimistic view of the matter. In the United States severely deformed infants are only likely to survive where they have parents who are both able and willing to pay for very expensive treatments ⁴⁰ Koop himself has said that he had never faced a clinical situation where financial costs were a constraint. In contrast, in Britain all infants have an equal right to treatment, irrespective of parental income, but overall health budgets impose clear constraints.

DECLARATION ON THE RIGHTS OF MENTALLY RETARDED PERSONS

74. The Declaration on the Rights of Mentally Retarded Persons has many similarities with the Declaration on the Rights of Disabled Persons. Two distinctive features of the Declaration are that the same rights as other human beings are only guaranteed 'to the maximum degree of feasibility' (paragraph **I**) and that there is a special provision for the 'right to a qualified guardian when this is required to protect his personal well-being and interests' (Paragraph 5). Finally Paragraph 7 provides that:

Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to test-riot or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

75. The classic case of discrimination against intellectually impaired infants concerns the decision not to operate upon an intestinal obstruction in the case of a Down's Syndrome infant where there would be no question not to operate in the case of a normal infant:

Baby B was referred to ... [the MD] at the age of 36 hours with duodenal obstruction and signs of Downs Syndrome. His young parents had a ten-year old daughter, and he was the son they had been, trying to have for ten years; yet, when they were approached with the operative consent, they hesitated. They wanted to know beyond any doubt whether the baby had Down's Syndrome. If so, they wanted time to consider whether or not to permit the surgery to be done. Within 8 hours a geneticist was able to identify cells containing 47 chromosomes in a bone-marrow sample. Over the next three days the infant's gastrointestinal tract was decompressed with a nasogastric tube, and he was supported with intravenous fluids while the parents consulted with their ministers, with family physicians in their home community, and with our geneticists. At the end of that time the B's decided not to permit surgery. The infant died three days later after the withdrawal of supportive therapy. 41

Such a practice has been widespread in the United Kingdom and the United States (although it may be less common since the introduction of the Baby Doe regulations). Dr Arthur was charged with attempting to murder a mentally retarded mongol baby who had been rejected by his parents. The doctor had ordered a course of 'non-treatment' for the baby, prescribing a pain killing drug which also sedates and depresses appetite. Dr Arthur was acquitted possibly because the jury felt that even in helping the baby to die (by sedation which prevented it from demanding food) the doctor was showing full concern for its life given that its parents had abandoned it.

76. There are two ways of examining what is meant by that 'maximum degree of feasibility' which qualifies the rights of mentally retarded infants. One is to pursue the implications of

the concept of personhood, of mental and moral capacity and ability to relate to others, in relation to human rights in general (see paragraphs 23-29 above). The other is to look at the provisions of paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons, which states that:

Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

77. The provisions of paragraph 7 would appear to imply that the decision not to operate upon a Down's Syndrome baby, where an operation upon a normal baby would be a matter of routine should only be made by the parents (1) based upon a medical evaluation made by qualified experts, (2) within legal safeguards and (3) subject to the right of appeal. To be consistent with the Declaration of the Rights of the Child the decision could only be made on the basis of the child's own welfare. This means that in cases in which the parents have abandoned the child, one factor which would have to be considered by, say, a hospital ethics committee, would be the less favourable prognosis for a child with no parents willing to care for it. (No one is suggesting that where the parents want the operation, the operation should not be performed.)

Principle 2 of the Declaration of the Rights of the Child would also suggest that any decision should involve consideration of available fostering and institutional provisions where these are likely to be required. This is where there is a possibility of strengthening the State's responsibility for the positive rights of the mentally retarded. If institutional conditions are so

'demonstrably awful' that counsellors consider death a preferable fate, then clearly the State has a responsibility to improve institutional conditions to provide for the rights of the mentally retarded. Casting the responsibility back on the State also helps to resolve many of the problems associated with the extraordinary burdens placed upon some parents and especially mothers of retarded children who also have physical impairments.

78. It should be noted that between the two extremes of mental age of under 1 and one of over 16 (i.e. an adult intelligence) it does not necessarily follow that the more retarded the individual the more unhappy or unpleasant life is likely to be. Lorber has argued that above a certain level the more intelligent his spina bifida patients are the more they suffer because they have a greater understanding of what is happening and a greater appreciation of what they are missing.⁴² One insoluble problem in examining the rights of the severely retarded lies in knowing what they would choose, e.g. the Saikewicz case where the court said it was necessary to decide what a competent person would wish if he found himself in Saikewicz's situation, i.e. with leukemia and an IQ of 10.⁴³

RELEVANT TECHNICAL AND SOCIAL DEVELOPMENTS

79. Even fifty Years ago the question of the rights of severely deformed neonates was largely a non-issue because such children did not survive simply because the technology to keep them alive was not available. Today it is possible to keep infants alive even if they have no brains, no bowels or no limbs. The question then arises as to whether it is desirable to keep all such children alive.

80. Public debate over the treatment of severely impaired infants has to date been muted in Australia, although in the United States and the United Kingdom - where the ethics of the behaviour of physicians is much more open to public scrutiny and comment - such debate has been widespread. Such debate forms part of a wider concern over the relative status of 'sanctity of life' considerations when weighed against 'quality of life' considerations. Concern with the quality of life inevitably becomes more of an issue as life expectancy rises and merely staying alive absorbs a lesser proportion of individual resources and attention.

81. A parallel social development has been a shift in the power balance between physicians and parents. In the past the family doctor often 'played God' and told the parents that the child had been still-born, when, in fact, it had been born alive but severely deformed and had been allowed or helped to die at birth. Today doctors consult with parents and conditions in delivery wards are such that decisions and practices are much more open to public scrutiny than when births usually occurred at home or in small cottage hospitals.

82. Another major social factor relates to the availability of abortion and of aminocentesis which makes it possible to detect genetic defects at about the 20th week of pregnancy. To note the connection between the availability of abortion in cases of deformity of the fetus and concern about the management of deformed neonates is not necessarily to accept the slippery slope argument that abortion should be outlawed because it inevitably must lead to infanticide. A range of views exist in the community from Tooley and other philosophers who argue that both abortion and infanticide are acceptable in some circumstances through those, probably the majority, who accept abortion but not infanticide, to those who would accept neither practice. Thus Ramsey wrote to the New York Times following the Supreme Court decision allowing abortion:

Ineluctably we pass from abortion to infanticide because many of the reasons alleged to justify permissive abortion have equal force in justifying the killing of neonates in hospital nurseries⁴⁴.

However, there is one clear difference between abortion and infanticide in the contemporary debates infanticide is only seriously proposed where the infant is severely deformed, whereas abortion is supported on a wide range of grounds. Once the infant is born the demand for children to adopt is such that a child is most unlikely to be globally 'unwanted' in Australia unless it is deformed. Indeed, adoption is no longer restricted to 'normal' babies and the adoption of Down's Syndrome infants is not uncommon.

83. Another highly relevant social development is the trend towards 'normalisation' of life and away from institutionalisation for persons with disabilities. When the severely deformed were shut away in institutions there was less questioning as to whether some lives were worse than death. Equally, the insistence upon a right to a 'normal' life inevitably raises the question as to the fate those for whom any kind of normal life is never going to be a realistic possibility. An adult with a mental age of less than two years cannot lead a normal life even in the absence of any physical impairment.

84. An associated development relates to changes in the roles commonly adopted by women in Australian society. It is clearly extremely difficult, if not impossible, for a woman to be in paid employment outside the home and to provide full care for a severely impaired child. Men are not expected to take on such burdens⁴⁵ and women are increasingly questioning the extent to which their lives should be devoted to the care of others without any opportunity for self-fulfillment. Women now require greater scope for choice. Normalisation should not depend upon the unpaid labour of women.

THE POSITION OF THE MEDICAL PROFESSION IN AUSTRALIA

85. In 1982, the Australian Medical Association declared that:

failing to perform an operation on a Down's Syndromic child for a correctable defect is simply letting nature take its course. However, the same could not be said of a doctor failing to provide nourishment for such a child⁴⁶

This echoes the judgment of the British Medical Association that selective treatment is appropriate and that doctors can best judge when to withhold treatment 47

86. In 1981-82 Singer, Singer and Kuhse⁴⁸ surveyed obstetricians and paediatricians in Victoria concerning their beliefs and practices in treating of infants born with severe handicaps. Overall, 87 obstetricians and 111 paediatricians responded. Out of the combined total of 198, only 2 paediatricians felt that in all circumstances every possible effort should be made to sustain life and 90% of obstetricians and 76% of paediatricians had directed upon at least one occasion that less than maximum efforts should be made to preserve the life of an infant (see Table 1).

87. In 1983 the Australian College of Paediatric Surgeons convened a working party to report on non-intervention in children with major handicaps. The report of that working party is given below in Appendix D.

TABLE 1: Questionnaire used in survey of attitudes to treatment of newborn infants with major handicaps.⁴⁹

QUESTION	OBSTETRICIANS (n = 87)		PAEDIATRICIANS (n = 111)	
	Yes	No	Yes	No
1. In the course of your medical practice have you ever had cases in which decisions have had to be made whether or not to continue the treatment of a severely handicapped infant?	78 (88.5%)	9 (11.5%)	100 (90.1%)	11 (9.9%)
2. Do you believe that in all circumstances every possible effort, including the use of both ordinary and extraordinary means, should be made to sustain life?		87 (100%)	2 (1.8%)	109 (98.2%)
3. If you answered yes to Question 2, would you describe your belief as based primarily on				
(a) secular ethical principles?			1 (0.9%)	
(b) ethical principles depriving from religious views?			1 (0.9%)	
(c) Other? please specify.				
4. Where a decision has to be made whether or not to continue treatment, do you discuss what should be done with *				
(a) another doctor or doctors?	75 (86.2%)		101 (90.9%)	
(b) the parents?	77 (88.5%)		100 (90.1%)	
(c) nursing staff?	48 (55.2%)		94 (84.7%)	
5. In deciding whether or not to continue treatment, do you think it important to distinguish between ordinary and extraordinary means of prolonging life?	71 (81.6%)	16 (18.4%)	86 (77.5%)	25 (22.5%)

QUESTION	OBSTETRICIANS (n = 87)		PEDIATRICIANS (n = 111)	
	Yes		Yes	No
6. Have you ever directed that maximum efforts should be made to preserve the life of an infant? Has this happened (a) several times (b) occasionally (c) once or twice (d) never (e) no answer				
7. Do you believe that there can ever be circumstances in which it is right to take active steps to terminate the life of an infant, i.e. steps that go beyond the withdrawal of life-support systems?#		60 (68.9%)	44 (39.6%)	61 (54.9%)
8. Do you see a need for change in the law relating to the treatment of severely defective infants?@	22 (25.2%)	59 (67.8%)	50 (45.0%)	50 (45.0%)

* The totals exceed the number of respondents because many respondents ticked more than one option. 4 Six paediatricians (5.4%) did not answer this question.

@ Six obstetricians (6.9%) did not answer this question.

49. P. Singer, H. Kuhte and C. Singer, 'The treatment of newborn infants with major handicaps' (1983) Medical Journal of Australia 275.

CONCLUSION

88. This paper is a discussion paper designed to stimulate debate on a major human rights issue. It is not intended to propose solutions to these vast problems. As Dr Lorber concluded when describing his philosophy: 'selection for treatment is offered as the best but not a good solution to an insoluble problem. From a strictly legal point of view there are currently three options:

- (1) leave matters as they are
- (2) enforce the law to the full, perhaps by some equivalent to the American Baby Doe regulations. (These regulations, imposed by the Federal Government of the United States, require all hospitals receiving funds to display notices stating that withdrawing care from handicapped infants is a violation of federal law. A toll-free number for direct complaints to Washington is provided. See Appendix A.)
- (3) change the law.

89. The disadvantages of (1), leaving matters as they are would be:

- (a) that it is bad policy to have a criminal law which is regularly flouted by men and women of good intent seeking to do their best;
- (b) that it is undesirable that the survival of an individual severely defective but viable infant should be a matter of almost random chance depending upon the hospital, the doctor, the parents and even the season of the year;
- (c) that if some infants are to be selected for non-treatment society should be aware that such choices are being made and there should be public debate as to the criteria upon which the choices are based.

90. Enforcing the law to the full without exception by some equivalent to the Baby Doe Regulations (2) is likely, as a senior representative of the Australian College of Paediatrics has recently pointed out, 'to produce more problems than it solves.'⁵¹ One major problem is:

That the autonomy of individual patients or parents of paediatric patients might be eroded and the rights and powers afforded by the common law denied. Where strangers (for example, social workers, persons involved in fundamental religious groups, local government officers, government appointees, or persons plucked from the community) are able to intervene to upset personal or parental decisions regarding treatment and thus to interfere in the doctor-patient relationship in a very basic way, then professionalism is indeed under threat.⁵²

In a specifically human rights context such a development would raise serious problems in relation to the rights of the family to privacy and to protection, discussed above under Articles 17 and 23. These rights would be seriously infringed by developments in Australia paralleling those in the United States, such as hospital posters advertising the provision of toll-free 'hot lines' for anonymous informers who wish to interfere in or have revoked decisions reached by parents.

91. If it is ultimately decided to change the law (3), there are a number of different ways in which such changes might be made. The law might specify the medical conditions under which the implementation of the decision not to treat (or even to hasten a painless death) would not constitute an offence, or it might make a more general provision leaving the decision in an individual instance to the treating physician with the agreement of a hospital medical ethics committee. The parents' role would also obviously need to be specified. Appendix B sets out draft model legislation which has been proposed in the

United States. It makes it quite clear that the welfare of the child in question shall be the only decisive criterion. It also seeks to clarify that for a child suffering from an irremediable condition there is a legal entitlement to 'the administration of whatever quantity of drugs may be required to keep such a child free of pain' (section 10).

92. If it is decided either to enforce the law to the full or to change the law, then governmental action will be required and such action should be clearly informed by human rights considerations. This is why the Commission has decided to issue

this discussion paper and to open up the debate as to the nature of human rights criteria which are applicable in this situation.

REFERENCES

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- 13 Roe v. Wade 410 USSCR 113 (1973)
- 14 Superintendent of Belchertown State School v. Saikewicz, Massachusetts Supreme Judicial Court, 370 NE 2d 417 (1977).
- 15 Pius XII, 'Prolongation of life', (1985)4 The Pope Speaks. 395-7.
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- 21 In the Matter of Eichner, New York Appellate Division, Second Department; 27 March 1980.
- 22 See the Commission's discussion of this matter in Its Report No. 11, Human rights of the terminally ill, AGPS, Canberra, 1985, p.3.
- 23 In pe Quinlan, 355 A 2d 647 (1976).
- 24 Griswold v. Connecticut, 381 U.S. 479 at p. 495 (1965).
- 25 Dudgeon v. United Kingdom, (1981)4 EHRR 149.
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THE SCENE IS .SET.:
 RELEVANT DEVELOPMENTS IN AUSTRALIA
 AND OVERSEAS'

- 1970 Ramsey, the American theologian, publishes 'Feticide/Infanticide upon request' arguing that if abortion on the grounds of defect is justified then so is infanticide (1970) 39 Religion in Life 170).
- 1971 Lorber, the British paediatrician, Publishes 'Results of Treatment by Myelomeningocele' arguing that the prospects for some spina bifida babies are so grim that they should not be treated at all (1971) 13 Developmental Medicine: Child Neurology Supplement 279).
- 1973 The Supreme Court says in Roe v. Wade that the privacy provisions of the U.S. Constitution protect the woman's right to an abortion in the first months of pregnancy (410 USSCR 113 (1973)).
- 1973 Tooley publishes his revised paper 'A Defence of Abortion and Infanticide' in J. Feinberg (ed.), The Problem of Abortion, Wordsworth Publishing Co., Belmont, Calif., 1973.

- 1973 Duff and Campbell publish 'Moral and Ethical Dilemmas in the Special Care Nursery' ((1973) 289 Pew England J. Med. 890) showing that 43 out of 299 deaths in the nursery resulted from decisions not to treat.
- 1974 Testimony before the Senate Health Sub-Committee on Medical Ethics suggests that three quarters of all American physicians admit to the regular practice of passive euthanasia (United States Senate, Health Sub-Committee on Medical Ethics, 93rd Congress, 2nd Session, 26, 1974).
- 1974 Florida Congressman Sackett introduces a Death with Dignity Bill proposing that persons incapable of rational thought should be allowed to die by withdrawing all medical treatment.
- 1975 Robertson publishes 'Involuntary Euthanasia of Defective Newborns : A Legal Analysis' ((1975) 27 Stanford Law Review 213-69).
- 1975 Sonoma Conference on Ethical Issues: 17 out of 20 expert panalists declare that some severely defective infants 'Should be killed under certain conditions' (reported Pediatric News (April 1977) 32).
- 1976 In pe Quinlan the New Jersey Supreme Court authorised the guardian and parents of a young woman in a persistent vegetative state to remove her from a respirator relying upon a constitutionally protected privacy right that is 'broad enough to encompass a patient's decision to decline medical treatment under certain circumstances' (70 NJ, 10;355 A 2d 647 (1976)).

- 1977 The Anglican Church of Canada, Task Force on Human Life publishes Dying: Considerations Concerning the Passage from Life to Death arguing that 'the only way to treat such defective infants humanely is not to treat them as human'.
- 1977 A U.S. National Survey of 267 pediatric surgeons and 190 pediatricians showed that 80% of pediatric surgeons and 50% of pediatricians thought that there were some newborn infants whose lives should not be saved despite the availability of effective life-saving resources. (Shaw and Manard, 'Ethical Issues in Pediatrics Surgery', (1977) 60 Pediatrics 588).
- 1979 Christopher Derkacs, a 23 month old child with Down's Syndrome, died of a respiratory illness in hospital in Perth. It was alleged that life-saving treatment had been withheld from him. A coroner's inquiry delivered an open finding due to lack of evidence. (West Australian 27.12.1979).
- 1979 The Lancet, (24 November 1979) publishes an anonymous article on the 'Non treatment of Defective Newborn Babies' arguing that some children allowed to live would be fully justified in censuring the medical experts who ensured their survival.
- 1980 The Californian Appeals Court recognises an action for wrongful life on the grounds that the handicapped child would have been better off if allowed to die at birth (Curlender v. Bio-Science Laboratories 106 Cal. App. 3d811, 165 Cal. Rptr 477 (1980)).

- 1980 Fitzhardinge and Bennett-Britton question 'Is Intensive Care Justified for Infants less than 801 grams at Birth?' ((1980) 14 Pediatrics Research 590).
- 1981 Siamese twins are born in Illinois joined at the waist and with only one abdomen and bowel and three legs. The obstetrician orders palliative care but no feeding. A nurse feeds them and complains to the authorities. A charge of attempted murder against the obstetrician is dropped because no one was willing to testify against him. (Robertson, 'Dilemma at Danville'. (1981) 11 Hastings Centre Report, 5.8).
- 1981 The English Vacation Court decides that a Borough Council can intervene to ensure an operation on a Down's Syndrome infant (Baby Alexandra) with a potentially fatal intestinal blockage (Be B (Minor) Time 8.8.1981, (1981) 1 WLR 1421).
- 1981 A Derby jury finds Dr Leonard Arthur not guilty of the attempted murder of a Down's Syndrome infant (John Pearson) given a pain killing drug which also sedates and depresses appetite when his parents rejected him.
- 1982 The Supreme Court of Indiana upholds the parents' right to authorise the withholding of food from a severely mentally retarded child (Baby Doe). (The child died before the case could be heard by the Federal Supreme Court.)
- 1982 Baby Doe regulations are imposed by the Federal Government of the U.S. All hospitals receiving federal funds must display notices stating that

withdrawing care from handicapped infants is a violation of Federal law and giving a toll-free number for direct complaints to Washington. Federal Judge Gerhard Gesell disallows the regulation at the request of the American Academy of Pediatrics and the American Hospital Association on the grounds that it had been introduced without sufficient public discussion. A similar regulation has since been reintroduced.

- 1983 Mr Justice McKenzie in the Supreme Court of British Columbia rules that parental refusal of consent to an operation for the removal of a blockage in a life-sustaining shunt for Stephen Dawson should be overruled. Stephen was a seven year old who was blind, partly deaf, incontinent and could not stand, walk, talk or hold objects or demonstrate whether he was in pain.
- 1983 The Annual Scientific Meeting of the Australian College of Paediatrics holds a session on 'Non-intervention in children with major handicaps' following issue of the ACP Working Party Report on the topic.
- 1983 The Canadian Law Reform Commission issues a report on Euthanasia, aiding suicide and cessation of treatment, recommending that a physician should not incur any criminal liability if he decides to discontinue or not initiate treatment for an incompetent person when that treatment is no longer therapeutically useful and is not in the person's best interests.
- Nor would a decision be reasonable which would force a newborn or adult to undergo an exceptional series of operations or treatments resulting in great suffering, only to end up with a medically unacceptable quality of life. (LRCC Ottawa (1983) 25-8).

1984

The Medical Journal of Australia publishes 'The Right to Live and the Right to Die', Dr Cohen's discussion of the ACP Working Party Report and the Baby Doe controversy and suggests that the Human Rights Commission should take up the issue.

PROPOSED LEGISLATION'

AN ACT Relating to the administration of euthanasia to certain severely defective children suffering from an irremediable condition; creating new sections; and providing penalties.

BILL ENACTED BY THE LEGISLATURE OF THE STATE OF _____

NEW SECTION. Section 1. Authorisation of euthanasia. Subject to the provisions of this Act it shall be lawful for a qualified physician, or his professional medical agent, as authorised by a qualified physician's written statement, to administer euthanasia to a qualified child for whom the child's parent or guardian previously has made a written declaration voluntarily requesting euthanasia for the qualified child and which declaration is lawfully in force at the time of administering euthanasia.

NEW SECTION. Section 2. Definitions. The definitions set forth in this section shall apply throughout this Act unless the context clearly requires otherwise.

(1) "Physician" means a registered medical practitioner legally licensed and qualified to practice medicine in this state.

(2) "Qualified physician" means the specific physician in charge who will either administer or authorise the administration of euthanasia and who previously has received written approval for this specific administration of euthanasia from at least five of seven members of a professional medical ethics committee of this state.

(3) "Professional medical ethics committee" means a committee created pursuant to section 3 of this Act.

(4) "Euthanasia" means the painless and quick inducement of death and may be accomplished by removal of medical treatment, by positive act, or by any painless and quick means.

(5) "Qualified child" means any severely defective child under the age of eighteen years² in respect of whom two physicians, one of them a medical Specialist in the particular

1. A. Morris, 'Law, morality and euthanasia for the severely defective child', in M. Koh, (ed), Infanticide and the value of life, Prometheus, New York, 1978.

2. The author reports that this page limit was inserted in error and asks that it not be regarded as part of the proposed legislation.

area in question, have certified in writing that the child clearly appears to them to be suffering from a severe, incurable, and irremediable condition.

(6) "Irremediable condition" means either (a) a serious physical illness, including serious genetic defects, serious birth defects, or other physical impairment, which is diagnosed as severe and incurable and which is expected to cause a child severe distress or pain and to render him incapable of the rational or functional existence needed to enjoy the most minimal amount of human goods necessary to constitute ordinary human life in its most minimal sense, or (b) a condition of brain or genetic damage or deterioration such that what would be a child's normal mental or genetic faculties are so severely and irreparably impaired to such an extent that the child has been rendered incapable of leading a rational existence.

(7) "Declaration" means a witnessed declaration in writing made by a qualified child's parents-to-be or parents or parent if the other parent is dead or unknown, or legal guardian, substantially in the form set forth in this Act.

NEW SECTION. Section 3. Professional medical ethics committee - Rules governing. (1) The director of the department of (Social and Health Services) of this state shall, in consultation with the medical association of physicians in this state, adopt rules for the selection and operation of professional medical ethics committees. There shall be a number of such committees sufficient to carry out the purposes of this Act.

(2) Each committee shall have seven members representing persons of diverse backgrounds and occupations, such as attorneys, social workers, theologians, and others, but in no event shall any committee have more than three physicians among its membership.

(3) The duties of the committee shall be to review the diagnoses of the two physicians who have examined a child and all individual circumstances of each child's specific case on its own merits solely as those merits relate to that child (except for fully known conditions or diseases, for which as a category - such as anencephaly - there is no reasonably possible medical remedy and in which event the committee may establish a policy governing each category of condition or disease instead of dealing with each case within the category), and after considering all the individually pertinent dimensions - scientific, medical, ethical, and others - the committee shall determine whether the administration of euthanasia would be in the better interests and welfare of the child. The committee shall make this ultimate decision without consideration of, or reference to, the interests or welfare of any person or matter other than the highest individual welfare of the particular child in question.

(4) The director of the department of (Social and Health Services) of this state shall also promulgate rules for determining who may or may not sign a declaration by way of attestation, for regulating the care and custody of written declarations and of written approvals or disapprovals of professional medical ethics committees, for appointing, with their consent, hospital physicians having responsibility in relation to qualified children who are subject to euthanasia, and for the prescribing of any matter he may think fit for achieving the purposes of this Act.

NEW SECTION. Section 4. Declaration made in advance. Subject to the provisions of this Act, a declaration shall come into lawful force and effect immediately after having been executed and shall remain in lawful force and effect unless revoked.

NEW SECTION. Section 5. Mode of revocation. A declaration may be revoked at any time by destruction, by notice of cancellation shown on its face, or by any other clearly communicated act of revocation, effected, in any way, by the declarant or to his order.

NEW SECTION. Section 6. Duties and rights of physicians, nurses, and professional medical agents. (1) Before causing euthanasia to be administered to a qualified child, the physician in charge shall make such (a) that a valid written declaration exists and (b) that a valid written approval of the professional medical ethics committee exists for the administration of euthanasia in the specific case, and if the physician should determine that the professional medical ethics committee or the parent's or guardian's motivation or desire for euthanasia is supplied by any reason, or combination of reasons, other than solely for the sake of the child, then the physician shall not cause euthanasia to be administered.

(2) Euthanasia shall be deemed to be administered by a physician if it is prescribed by the Physician in charge and by his written order euthanasia is administered to a qualified child by the physician's professional medical agent or nurse.

(3) No person shall be placed under any duty by this or any other Act or by contract or by any statutory or other legal requirement, to participate in any way in ^{any} aspect of treatment or euthanasia authorised by this Act to which such person has a conscientious objection.

NEW SECTION. Section 7. Protection for physicians, nurses, and professional medical agents. (1) A physician or a nurse or a physician's professional medical agent who, acting in good faith, causes euthanasia to be administered to a qualified child in accordance with what a reasonable person would believe to be

a valid written declaration and a valid written approval by the relevant professional medical ethics committee shall not be guilty of any offense.

(2) Physicians, nurses, or physician's professional medical agents who have taken part in the lawful administration of euthanasia as set forth in this Act or in accordance with subsection (1) of this section shall be deemed not to be in breach or violation of any professional obligation, oath, or affirmation.

NEW SECTION. Section 8. Offenses. (1) It shall be an offense punishable on information or indictment by a sentence of life imprisonment for any person wilfully to conceal, destroy, falsify, alter, or forge a declaration with intent to create the false impression that a parent or guardian desires, or does not desire, euthanasia for his child; it shall equally be an offense punishable on information or indictment by a sentence of life imprisonment for any person wilfully to conceal, destroy, falsify, alter, or forge any document or writing with the intent to create the false impression that a professional medical ethics committee has approved, or has refused to approve, euthanasia in the case of any child; and it shall equally be an offense punishable on information or indictment by a sentence of life imprisonment for any person wilfully to conceal, destroy, falsify, alter, or forge any document or writing with the intent to create the false impression that the physician in charge has authorised a nurse or any other professional medical agent to administer euthanasia to any child.

(2) Any person signing a declaration of any document in writing indicating that a professional medical ethics committee has, or has not, approved euthanasia, and who signs by way of attestation and wilfully puts his signature to a statement that he knows to be false shall be deemed to have committed the crime of perjury and shall be subject to its punishments.

NEW SECTION. Section 9. Insurance policies. No policy of insurance that has been in force continuously for one year shall be vitiated or legally impaired in any way by the subsequent administration of euthanasia to the insured.

NEW SECTION. Section 10. Administration of drugs. To remove doubt it is hereby declared that a child suffering from an irremediable condition shall be entitled to the administration of whatever quantity of drugs that may be required to keep such child free of pain.

NEW SECTION. Section 11. Forms of declarations. Declarations required under this Act shall be made in substantially the following style.

FORM

Declaration made _____ 19 ____, by
 _____, guardian or parent(s) of
 _____, a qualified child.

I (we) declare that I (we) voluntarily subscribe to the matters now set forth : It has been clearly determined that my (our) child, who is named above, is suffering from a severe, incurable, and irremediable condition, as defined by the Severely Defective Children's Euthanasia Act of 19 _____, which condition has been clearly and fully explained to me (us), and it has been determined by five members of the professional medical ethics committee that it would be in the better interests of my (our) above-named child to have euthanasia, which committee decision has been clearly and fully explained to me (us). In light of the above, but exclusively on the basis of my (our) independent consideration and judgement of the question, and after consultation with others, and solely because I (we) deeply believe that euthanasia is in the better interest of my (our) above-named child, I (we) do hereby request and authorise the administration of euthanasia to my (our) child, at the earliest convenient time and circumstance.

 Parent Or Guardian

 Parent or Guardian

We testify that the above-named declarant(s) voluntarily signed this declaration in our presence, and appeared to us to appreciate its full significance. We do not know of any pressure being brought to bear upon the declarant(s) to make this declaration, and we believe it is made by his/her (their) own wish and solely on behalf of the better interests of his/her (their) above-named child. So far as we are aware, we are entitled to attest to this declaration, and we do not stand to benefit by the death of the above-named child.

 Witness

 Witness

_____ 19 _____, by
and _____ who are about to
become parents.

After full discussion with my (our) attending physician, Dr _____, I (we) believe myself (ourselves) to be fully informed about the forthcoming birth of my (our) child(ren) and recognise that occasionally children are born who have severe defects or irremediable conditions, as that latter term is defined in the Severely Defective Children's Euthanasia Act of 19 _____, which defect or irremediable conditions disable newborn children from ever having the basic capabilities of enjoying the minimal goods that constitute a bare minimum of ordinary human life - an example of this type of newborn is one that is anencephalic. Because I (we) believe that it is in the better interests of severely defective newborns, such as anencephalic newborns referred to above not to survive, I (we) hereby request and authorise that if our child, or if any of our children now about to be born, should be anencephalic or clearly of any equally severe and equally disabling disease or condition as such disease or conditions previously have been determined by the professional medical ethics committee, then no active steps should be taken by anyone, and in particular that no resuscitatory techniques should be used, to prolong the life or lives of my (our) child(ren) so afflicted or to restore them or any one of them to consciousness.

Parent-to-be

Parent-to-be

•We testify that the above-named declarant(s) voluntarily signed this declaration in our presence and appeared to us to appreciate its full significance. We do not know of any pressure brought to bear upon the declarant(s) to make this declaration, and we believe it is made by his/her (their) own wish and solely on behalf of the better interests of their child(ren) about to be born.

Witness

Witness

NEW SECTION. Section 12. Short title. This Act may be cited as the Severely Defective Children's Euthanasia Act of 19 _____

NEW SECTION. Section 13. Severability. If any provision of this Act, or its application to any person or circumstance is held invalid, the remainder of the Act, or the application of the provision to other persons or circumstances is not affected.

NEW SECTION. Section 14. Captions and section headings. Captions and section headings used in this Act shall not constitute any part of law.

APPENDIX C

THE INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS

ARTICLE 6

1. Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

2. In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgment rendered by a competent court.

3. When deprivation of life constitutes the crime of genocide, it is understood that nothing in this article shall authorize any State Party to the present Covenant to derogate in any way from any obligation assumed under the provisions of the Convention on the Prevention and Punishment of the Crime of Genocide.

4. Anyone sentenced to death shall have the right to seek pardon or commutation of the sentence. Amnesty, pardon or commutation of the sentence may be granted in all cases.

5. Sentence of death shall not be imposed for crimes committed by persons below eighteen years of age and shall not be carried out on pregnant women.

6. Nothing in this article shall be invoked to delay or to prevent the abolition of capital punishment by any State Party to the present Covenant.

ARTICLE 7

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

2. Everyone has the right to the protection of the law against such interference or attacks.

ARTICLE 23

1. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

2. The right of men and women of marriageable age to marry and to found a family shall be recognized.

3. No marriage shall be entered into without the free and full consent of the intending spouses.

4. States Parties to the present Covenant shall take appropriate steps to ensure equality of rights and responsibilities of spouses as to marriage, during marriage and at its dissolution. In the case of dissolution, provision shall be made for the necessary protection of any children.

DECLARATION OF THE

RIGHTS OF THE CHILD Principle 2

The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity. In the enactment of laws for this purpose, the best interests of the child shall be the paramount consideration.

Principle 4

The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.

Principle 5

The child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition.

DECLARATION ON RIGHTS OF DISABLED PERSONS

3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age which implies first and foremost the right to enjoy a decent life, as normal and full as possible.

6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.

9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subject, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialised establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

DECLARATION OR RIGHTS OF MENTALLY RETARDED PERSONS

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.

5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

Non-intervention in children with major handicaps

Legal and ethical issues

*Report of a Working Party, March, 1983**

AUSTRALIAN COLLEGE OF PAEDIATRICS

MEMBERS OF WORKING PARTY

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1. INTRODUCTION

It is the misfortune of some children to be born with malformations that are so complex that it is impossible for them to survive for more than a very limited time without medical or surgical intervention. Fifty years ago, almost all of these children died. With the development of modern technology, some form of surgery has been devised to alleviate, in various degrees, the condition of a majority of these children. This has created a number of new problems and new responsibilities for the medical profession, for the legal profession and for society in general.

Because of the major problems relating to varying community and medical attitudes and opinions and to differing hospital policies, it is desirable that *uniform* guidelines should be provided by the Australian College of Paediatrics for the guidance of its members in decision making relating to the management of children with major handicaps. Whilst there is a need for uniform guidelines, it is desirable that any such guidelines should allow some flexibility. Such guidelines should conform, as far as possible, to legal, medical and ethical standards currently obtaining within the community.

Euthanasia is defined as the bringing about of gentle and easy death, especially in the case of incurable and painful disease.

Euthanasia may be voluntary or non-voluntary, active or passive.

Voluntary euthanasia is contrasted with non-voluntary euthanasia using as the criterion the fact that the subject did or did not consent to his death. In the case of an infant or child, euthanasia can only be non-voluntary.

Active euthanasia is contrasted with passive euthanasia, the difference between the two concepts being one of action as opposed to omission or inaction. Passive euthanasia is described as "letting nature take its course" and therefore is not identical with acts of omission. Whilst the law recognises a distinction between acts and omissions, it does not provide a definite answer to the commission/omission controversy. Active euthanasia, which in an infant or child could only be non-voluntary, is the deliberate bringing about of a rapid and easy death of the subject. In law, it is not different to any other homicide and would be treated as such.

The College believes that it is highly improbable that any Australian Government would move to make any form of active euthanasia legal.

3. EXTRAORDINARY MEANS TO PRESERVE LIFE It does not seem possible to make a consistent and rational distinction between ordinary and extraordinary

* This document attempts to present a consensus view and therefore the views expressed in the document do not necessarily reflect the views of all individual members of the working party or of the individual members of Council of the Australian College of Paediatrics.

Registrar, Australian College of Paediatrics.

2. EUTHANASIA

means to preserve life, or to distinguish between failure to use extraordinary means to preserve life and passive euthanasia.

The Law Reform Commission of Canada does not attempt such distinctions; it prefers revision of the appropriate sections of the Criminal Code in order to define the legal parameters of the refusal or cessation of medical treatment. It rejects the decriminalisation or legalisation of compassionate murder or aiding suicide, but sets out the following points:

- (a) Any reform having to do with human life must begin by admitting a firm presumption in favour of life.
- (b) The guiding principle for medical decision making is not life in itself as an absolute value but the patient's overall welfare.
- (c) If treatment can reasonably be applied to preserve a person's life or health, it should normally be assumed that this person's choice, if he could express it, would be to receive treatment and not to refuse it. Nevertheless, it would be regrettable and absurd if, because a person is incompetent, his attending physician were legally obliged to continue or to undertake useless treatment.
- (d) The law must recognise what is now a medical and scientific reality. It must admit that the cessation or non-initiation of treatment which offers no chance of success, is a good decision and one based on sound medical practice.

4. PALLIATIVE CARE

- (a) Whilst accepting that, in certain situations, it may be justifiable to cease or interrupt medical treatment, it must, at the same time, be accepted that there is always a requirement to keep the patient comfortable and free from pain.
- (b) The law should not prevent a physician from ceasing to administer specific treatment which is no longer seen to be contributing to an acceptable quality of life; or from undertaking palliative care intended to relieve suffering simply because such care is likely to shorten the life expectancy of the child.

To recognise this principle is not equivalent to legalising active euthanasia.

5. PASSIVE EUTHANASIA AND COMPASSIONATE MURDER

It is not our intention to make any firm recommendations at this stage in this sensitive and contentious area. This in no way implies any lack of recognition of its importance. On the contrary, the working party was very much aware of the need for clarification of these important issues. Indeed, this is one of the central points that would need to be dealt with by the proposed Medical Intervention Advisory Board referred to in the final section of this document. At this stage, we will do no more than make certain comments for the guidance of paediatricians and other non-medical practitioners involved in this difficult area of patient and parental care and, in due course, to assist the deliberations of the proposed Medical Intervention Advisory Board.

Sir Macfarlane Burnet² argues vigorously for the right to die and, in some circumstances, the right to let die. "Compassionate infanticide is already standard practice where the product of birth is such as to justify the term 'monstrous', that is, where there is a gross and physically

disturbing malformation such as anencephaly or severe spina bifida. Where there is no possibility of effective surgery, it is not infrequently dealt with by allowing the infant to die under sedation."

Professor John Lorber³ of the University of Sheffield who has been associated with both the aggressively active and, more recently, with the much more selective and conservative management of spina bifida, has stated in unequivocal terms that society is indulging in hypocrisy if it thought that the Court should inevitably come down on the side of life in the case of the newborn with major malformations. He points out that more than 300 spina bifida babies are allowed to die in Britain every year. In the 1950's and 1960's aggressive efforts were made to sustain these babies. Now, according to Lorber, most of those grown to adulthood languish in nursing homes, frequently unloved, unvisited, unhappy and a costly burden to themselves and society.

Whilst acknowledging the truth of MacFarlane Burnet's assertion, it is important to emphasise that, at law, infanticide — compassionate or otherwise — is homicide and that euthanasia, the killing of a human being, is also equatable with homicide — either murder or manslaughter.

Under the New South Wales Crimes Act, "Murder shall be taken to have been committed when the act of the accused or the thing by him omitted to be done, causing the death charged, was done or omitted with reckless indifference to human life or with intent to kill or inflict grievous bodily harm upon some person."

The position in other States is similar. Manslaughter can conveniently be defined as other unlawful killings.

It should be noted that it matters not that the death of the subject was caused by an omission: the question is — did action or inaction of the accused cause the subject's death?

Paediatricians should be quite clear, therefore, that passive euthanasia may fall within the legal definition of homicide.

The proposal that a charge of compassionate murder be introduced as a lesser offence than murder or manslaughter has gained only limited acceptance. It was carefully considered and rejected by the Canadian Law Reform Commission on a number of valid grounds.

Arising from all this, a number of important points need to be made concerning the process of developing guidelines and their force at law.

- (a) Guidelines should be developed which are consistent with the rights and liabilities which the legal system creates.
- (b) Guidelines cannot purport to authorise conduct which is unlawful.
- (c) If, however, reasonable people believe guidelines produce a rational and appropriate result, but are nevertheless contrary to the current legal description of rights and liabilities, then the process of law reform must be set in train.
- (d) It should be remembered that no legal rule or set of guidelines will ever produce a perfect result in every case.
- (e) It should be remembered that adherence to guidelines can never insulate the paediatrician from the possibility of legal action although it may lessen the

NON-INTERVENTION IN CHILDREN – LEGAL AND ETHICAL ISSUES

likelihood of prosecution against him being successful.

- (0) In formulating guidelines, it is therefore necessary to analyse carefully the legal rules governing decision making about medical treatment of seriously handicapped children and to ask whether in the vast run of cases the rules are proving impractical or are out of touch with social needs and expectations.

Finally, two important points need to be emphasised. Firstly, a doctor need not undertake any procedure which conflicts with his own reasonably based views on what is medically appropriate but may refer a patient to another practitioner. In other words, if he has reservations about intervention or non-intervention because of the severely handicapped state of the child, he meets his duty of care to the child and to the parents by referring the child to another doctor.

Secondly, it should be realised that there are effective inbuilt checks and balances in the present legal system. In the unlikely event of a charge of homicide being brought against either parents or doctor in the type of case which we are considering, it is for a jury to assess whether gross negligence was shown either by parents who conscientiously withheld consent for treatment or by the paediatrician in any of his acts of omission or commission. It is difficult to imagine any jury convicting in the situations typically raised to illustrate the dilemmas and agonies of decision making in this area where parents and doctor have acted honestly and in the interests, as they perceived them, of the child and the rest of the family. **6. CONSENT**

It would seem appropriate to set down the framework of rules determining consent as these are basic to decision making on life and death issues for severely handicapped children.

The obligation of securing parental consent arises in the context of treatment, both to meet the appropriate standard of care and to avoid liability in "trespass to the person". The case law is unclear on certain aspects of these matters and there has been little by way of legislative intervention to clarify the situation.

The Mechanics of Obtaining Consent

The following summarises the legal guidelines as to what information the healthcare professional must impart.

- (a) All factors relating to treatment which could influence the parents' decision must be disclosed.
- (b) The test of what information should be given is judged objectively by reference to what a "reasonable" person would want to know before making the decision to consent to treatment.
- (c) The person seeking to obtain consent should take reasonable steps to ensure that he has been understood and that this understanding is apparent.
- (d) Care should be taken not to intimidate parents or otherwise coerce them into appearing to give consent.

7. OVERVIEW OF POSSIBLE LEGAL SANCTIONS

The possible legal sanctions for inappropriate decision making about intervention in children with major disabilities can be set out in tabular form, as follows:

MEDICAL ISSUE	LEGAL ISSUE	CIVIL SANCTION	CRIMINAL SANCTION	OTHER AVENUES
Doctor not obtaining consent of parents. Parents withholding consent to treatment with death subsequently ensuing.	Trespass to the person of the child in question. Did this "cause" death and were they guilty of "gross negligence"?	Action on its behalf for damages.	Prosecution against Child made a ward of the court, or placed under <u>der. so</u> that treatment desired	by the doctor can go ahead.
Doctor "letting nature take its course" without seeking the concurrence of the parents, allowing preventable death.	Did this "cause" death, and was he guilty of "gross negligence"?		Criminal prosecution of the doctor for manslaughter,	Child made a ward of the court, or placed under ministerial guardianship, on the initiative of a stranger seeking authority for active intervention by another doctor on behalf of the child.
Active death-making by the doctor, with or without the complicity of the parents.	'Causation' and 'intention to kill'?		Prosecution of the doctor for murder, and of the parents, if actively involved, as accessories.	Child made a ward of the court, or placed under ministerial guardianship, to enable his removal from the "care" of the treating doctor, and if necessary, his parents.

8. FUTURE LEGISLATION

The Australian College of Paediatrics supports the Law Reform Commission of Canada which suggests the following fundamental rules on which any reform of the law should be based.

- (a) It is essential that any reform be sensitive to the intrinsic limits of criminal law.

- (b) The solutions proposed must retain a great deal of flexibility if they are to be adapted to the specific circumstances of each case and are not to impede

the continuing evolution of science medicine and society.

It is best to seek solutions which, wherever possible, fit harmoniously into the existing socio-judicial context and do not represent a radical upheaval of all the basic principles and institutions of our law.

The law should protect all citizens equally. The law is also intended to provide additional protection for those who are weaker or whose rights may be more readily violated or ignored.

(Despite the principle referred to here, the law should not preclude the paediatrician from taking into account, in his decision making process, variations in severity of disease processes and variations in life expectancy of patients — see section 9).

9. SOCIO-ECONOMIC CONSIDERATIONS — COSTS AND LOGISTICS

There is an increasing disparity between our ability to do things and our ability to pay for what we do. Allocation of available resources is becoming increasingly important and must always be considered. Therefore, decisions must be made as to who is going to get the available resources.

Not only has modern technology become incredibly expensive but we must also consider the socio-economic consequences of survival of infants with genetic diseases and continuing handicaps. In the 1940's, for example, most children with Down's Syndrome died within the first five years of life. Now, a majority of such children can be expected to survive for 30 to 40 years.

Severely disabled children must be supported and cared for either by the family or by the State. The impact on the economy and also on patient, family, siblings, and society in general must receive careful consideration. It must also be realised that the large amount of Money and the utilisation of specialised staff, equipment and facilities may jeopardise the care of other children or other worthy causes for which funding is not then available.

10. DECISION MAKERS

Infants and children with non-correctable major handicaps are totally unable to express their wishes regarding treatment. The decision must be made by someone else. The difficulty lies in determining who this someone else should be and on what criteria the decision should be based. By whom should the decision be made?

(a) Court or Committee

One possible approach would be the "judicialisation" of the decision making process. In this situation, any decision as to the continuation or cessation of treatment for an incompetent person would necessarily be the subject of a judicial or quasi-judicial decision by a Court or Administrative Agency.

Or these decisions could be made by an appropriate Hospital Committee which would determine the conditions under which treatment should be either halted or not initiated.

The *Australian College of Paediatrics* does not deny the essential role of judicial decision making in settling disputes. A judicial decision is obviously necessary when there is any real conflict.

However, one would not wish to overburden the Courts

by referring to them each and every decision regarding the cessation of treatment for the incompetent.

One would also not wish to judicialise the decision making process which should be based more on consensus than confrontation.

(b) Parents Alone

"It is sometimes argued that the parents alone should make the decision.

Whilst recognising that this course is legally valid and that parents or next of kin must be involved as fully as possible in the decision making process, there are a number of major objections to leaving the decision to the parents alone.

Firstly, making such a decision may create feelings of guilt and anxiety, and it seems inhumane to impose this additional burden on the suffering parents. Secondly, it has been argued that parents may be subject to a conflict between their own interests and those of the child. Since the latter are paramount it is important, so it is argued, that parents *alone* should *not* make the decision.

Thirdly, parents would be making such an important and emotive decision at a time when their judgement may be seriously impaired; and in any case it may be difficult for them to conceive the ultimate effects of their decision on the affected child, on other members of their family or on themselves.

(c) Consensus

The desirable course is for a decision to be arrived at after proper discussion between the parents and the attending physician having taken into account the views of the nursing staff involved and those of senior and experienced colleagues. By following this course, the danger of placing undue emphasis on the paediatrician's judgement is avoided.

In many cases the parents and paediatrician may be assisted to achieve consensus by hearing the views of *the* family members and friends, social workers, and members of the clergy.

11. THE DECISION FOR OR AGAINST INTERVENTION OR CONTINUATION OF TREATMENT⁶

First and foremost, the right of the child to live is paramount provided that survival is consistent with an acceptable quality of life, even if this quality falls well short of normal physical and intellectual standards.

The decision regarding non-intervention or cessation of treatment will also be influenced by what, if any, medical or surgical measures are available and their likely outcome; by whether such measures are curative or merely palliative; and by whether they can properly be regarded as established or still unproven. These are medical questions which can usually be resolved by consultation between experienced paediatricians and paediatric surgeons. Whether such procedures would, even if successful, offer hope of producing an acceptable quality of life is a very different matter. The notions both of "acceptable" and "quality" like the notion of "a life not worth living" all relate to value judgements on which there are no experts with exclusive competence in our type of society. At the two extremes, the answer is quite clear cut. There are still a number of conditions such as anencephaly that

are not amenable to treatment; or in which palliation could only be of very temporary benefit.

At the other extreme, there are many instances in which surgery and appropriate supportive measures can offer either complete cure or palliation with a satisfactory quality of life. In such circumstances, it is our clear responsibility to offer such children every available facility to ensure their survival. In such instances one should not and would not be influenced by the fact that the provision of such treatment might require multiple operations, prolonged use of expensive and complex life support systems, transporting the child a considerable distance, and prolonged hospitalisation. Were the parents to refuse or even to wish to defer permission for operation or other appropriate measures in such circumstances, one should make every effort to convince them to the contrary but, if such approval were still not forthcoming, the decision should be taken out of their hands. In other words, the right of the child to live and to enjoy the possibility of a reasonable quality of life would prevail.

However, between these two clear and definable extremes, there exists a grey area where decisions are much more difficult and where there may be a sharp division of opinion between those concerned in the decision making process.

12. PRIVACY AND PUBLIC DEBATE — THE ROLE OF HOSPITAL ETHICS COMMITTEES

It is eminently proper and desirable that informed public debate should be encouraged on the various complex and contentious issues that are involved in establishing the criteria of acceptable quality of life. Organisations and individuals should be encouraged to assist in the formulation of principles and guidelines that will assist the decision making process, and ensure that the decisions made are likely to have support of a majority of the community.

It would be unfortunate however if such exercise of free speech should lead to frequent litigation in individual situations.

Litigation by persons not involved other than by a commitment to some general thesis, however worthy or even admirable, would probably make the decision making process unworkable; it would certainly add to the agony of decision making — it could add little to its wisdom. The objections to litigation by individuals and organisations not directly involved are strengthened by the publicity likely to be given to such interventions by the mass media. The deeply tragic features of such cases and the contentious nature of decisions which must be taken pose great temptations for the media. Sensationalised reporting of individual cases could however harass and impede the judgement of those charged by the community with the duties of compassionate decision making. It would assault the privacy of parents and families at a time when their burdens were already almost too much to bear; combined with litigation by persons or organisations not directly involved, the result could be disastrous.

The distinction between informed public debate and the need for privacy in individual instances is particularly relevant to the role of Hospital Ethics Committees in this context. Whilst much of the work of such Committees is bound up with considerations devolving around the propriety of various research projects, their responsible involvement in the ethical aspects of non-intervention in children with major handicaps should be perceived as an

appropriate and proper role. This would seem the appropriate Hospital Committee to assist with the decision making process whenever an objective opinion was required, whether this was for social, medical, legal or humanitarian reasons.

13. MEDICAL INTERVENTION ADVISORY BOARD

The Australian College of Paediatrics recommends the setting up of a Medical Intervention Advisory Board representing a wide range of expertise and community opinion necessary to its important decision making role. Such an Advisory Board should include members of the medical, legal and other professions known to have a special interest, involvement or experience in this complex subject, as well as community representatives who were both interested and willing to give a significant amount of their time to this important task.

It is desirable that such an Advisory Board should be autonomous and that it should have the powers and protection of a Royal Commission if it is to operate effectively. The Terms of Reference should include:

- (a) consideration of submissions relating to all aspects of non-intervention in children with major handicaps from any interested individual or organisation;
- (b) the provision of uniform guidelines relating to management of children with major handicaps;
- (c) to advise regarding deficiencies or any other problems seen to exist in the present legislative processes in this context;
- (d) to continue to review relevant information available on this subject and to assess those legal, social, socio-economic and ethical problems that may arise as societies' attitudes on these matters continue to evolve.

It would be a matter for Government decision whether such a Board should be set up *de novo* or whether its functions should be assumed by an already existing body, such as the Human Rights Commission or the Australian Law Reform Commission.

14. PROVISIONAL GUIDELINES

Pending the formulation of guidelines as envisaged above, the College recommends to its members the following general principles to assist them in their ethical decision making in regard to severely handicapped newborns.

- (a) The doctrine of informed consent is basic to the doctor-patient relationship and the guidelines set out in Section 6 of this document should be scrupulously observed.
- (b) Decisions should wherever possible be arrived at by consensus of parents and medical attendants, having paid due regard to the views of other interested parties (Section 10).

The agreement of an experienced Medical Officer not directly concerned in the management of the patient should be sought in all possibly controversial decisions relating to the life or death of the handicapped newborn.

The management of the hospital concerned should be informed of all such decisions, either directly or via the Hospital's Ethics Committee.

- (c) The overriding principle in all such cases must always be the best interest of the child.
- (d) The law must be respected and these guidelines must not be construed as giving the paediatrician licence to disobey the law (Section 5).
- (e) If the paediatrician finds himself in serious conflict with the parents of a handicapped newborn about the right course to follow, it is ethically correct for him to refer the patient to another doctor (Section 5).

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