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BALLARAT LAW ASSOCIATION

MEDICO-LEGAL DINNER 1982

SOVEREIGN HILL, BALLARAT VICTORIA 3 JULY 1982

REFLECTIONS ON THE LAW AND DEFORMED BABIES

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

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THE A.M.A. AND THE TREATMENT OF MINORS

During the week past much publicity has been given in Australia to a submission compiled by a legal officer of the Australian Medical Association (N.S.W. Branch) for the national Association and endorsed for delivery to the Law Reform Commission of Western Australia. The submission arises out of a reference to that State law reform agency from the Attorney-General for Western Australia, Mr. Medcalf. That reference, in turn, arises from discussions at the Standing Committee of Federal and State Attorneys-General in Australia. That Committee agreed that the Law Reform Commission of Western Australia should examine a number of matters dealing with the provision of medical services for minors. Upon receipt of the final report of the Western Australian Commission, it is hoped to develop reform suitable for adoption on a uniform basis throughout Australia. There are many important and vexed issues in the terms of reference to the West Australian Commission. They include:

- * the special needs of minors in respect of drug dependence and termination of pregnancy
- * the age at which minors may consent to their own medical treatment
- * the extent to which the views of parents, guardians and others may override the wishes of minors in medical treatment.
- * the provision of goods and services, including contraceptive services to minors
- * protection for the privacy of minors in a medical relationship
- * withholding of medical services to a minor.

About each of these topics, it would be possible to have a thoughtful discussion. However, I want to single out for consideration an issue which is surely one of the most difficult of those listed and which has attracted, already, a degree of public attention. I refer to the problem of what should be done by medical practitioners, parents and others in the tragic event of the birth of a child grossly deformed physically or mentally retarded to a serious degree. The AMA submission addresses the question of the rights and obligations of physicians, hospital staffs, parents and society where the decision is made to withhold consent for the treatment of such children. Specific examples quoted are severely retarded or severely deformed infants whose parents refuse surgical correction of such disabilities as a lethal gastro-intestinal or genitourinary anomalies, without which surgical correction the child will shortly die.

In the course of its submission, the AMA endorsed the British Medical Association statement contained in its 'Handbook of Medical Ethics' published by that Association. Included in that statement are the following guidelines:

'Adult patients must make their own decisions, but for an infant the parent must ultimately decide. The responsible physician must help the parents to understand the choices...The doctor must find a just and humane solution for the infant and the family, to which consultation with hospital colleagues, general practitioners, nurses and social workers may contribute'.

After cautioning about the development of eugenics and the possible exaggeration of fears on the part of parents in this predicament, the AMA submission gets to its main points:

'The AMA is of the opinion that the dangers of enacting legislation on the legality of the withholding of consent for treatment are far too great and complex to be overcome, no matter how limited the legislative provision. Each case must be individualised and no rules are suitable for all cases. Drawing legislative distinctions between medical omissions and commissions leading to death, is sometimes unsatisfactory. Failing to perform an operation on a Downs Syndrome 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 to such a child; at least not with a similar level of confidence.

The dilemma of whether medical treatment of severely malformed infants should take place or whether doctors are ever justified in letting them die is one of great concern to the medical profession. It is the A.M.A.'s view that in certain circumstances, where doctors and parents agree that prolonging life would only prolong the baby's distress, it should be given no treatment other

than to make it comfortable and allowed to die. Surely when it is deemed to be in the best interests of the child that its life should not be prolonged, the ability to refuse to prolong its life should exist.'

I want to discuss these views. I want to caution that present Australian law would not necessarily protect doctors and parents who agreed together that a child born mentally or physically disabled should be allowed to die. Although the AMA has urged no legislation on this 'painful' subject, present criminal law is already relevant. I am inclined to think that it would be preferable to develop legislation which:

- . asserts the main criterion of the 'best interests of the child';
- . lays down minimum procedural requirements to ensure that the decision once made is based on appropriate, specialist medical opinion; and
- . states general criteria on which the decision would be made - so that variations between doctors and hospitals can be reduced and greater consistency, uniformity and principle secured in such a vital decision affecting life and death.

BEST INTEREST OF CHILD

In most Australia States the crime of murder includes a wilful omission with intention to kill. Recent cases in England have stressed that it is not for doctors and parents to agree not to treat a child, simply because it is retarded or physically disabled. Whatever may be the debates in our community about abortion of an unborn foetus, we are here dealing with a legal person - a human creature born into this world and entitled, indubitably to the full protection of the law. There can be no doubt about that proposition, whatever doubt and debate may exist about the legal rights of the unborn. Once the child is born, it is legally as much a person as you or I. The law will protect and defend it - perhaps especially so because such a child cannot defend itself. Recent cases in England have made it plain that it is a mistake to approach the dilemma of what to do when a child is born grossly mentally or physically retarded, by the criterion of the best interests of the parents, saving distress of the family, saving costs to the State or relieving the doctors and hospital staff of emotional trauma. The sole question is: what is in the best interests of the child. In answering that question, the views of doctors and parents can only be factors to be weighed - admittedly terribly important factors - but not determinative of whether the child should live or not.

SHIFT IN LAW: 'DEMONSTRABLY AWFUL' LIFE

Although cases involving the problem of mentally or physically deformed children rarely come to the notice of the law in Australia, that is not to say that there is no law on the subject governing doctors, parents and indeed everyone concerned. In a recent case in England (Re B. (a minor) Times Law Reports 10 August 1981, 15), where doctors and parents had agreed that a mentally retarded child should not have an operation that would have prolonged its life, the Court of Appeal intervened, on the application of a social worker, to order that the operation should be performed.

However, the courts are not unaware of the emotional and financial tragedy which these situations involve. Even in the case just mentioned, there was an almost imperceptible shift in the law. One of the English judges suggested that, if the child's life had been proved to be likely to be 'demonstrably awful', a different decision might have been reached. That this might amount to opening the door to the possible development of future court rulings about the circumstances in which operations should or should not be done 'in the best interests of the child'.

NEED FOR NEW LAWS

I cannot agree with the A.M.A. assertion of the danger of enacting any legislation on the legality of withdrawing treatment for such babies 'no matter how limited the legislative provision'.

The fact has to be faced that there is legislation already in place. The Crimes Acts and Criminal Codes of Australia are not silent on this topic. They talk of 'wilful omissions with intent to kill' sometimes amounting to murder. Yet it is acknowledged that this is what is happening in hospitals with the concurrence of doctors, parents and, quite possibly, the majority of the community. Unfortunately, this is another case where the law in its generality in the statute books is not being observed in practice.

ISSUES FOR LAW REFORM

Nor is it satisfactory to ignore problems of this kind, leaving the decisions as important as life and death to unstructured and unguided discretion even of skilled doctors. It is particularly unsatisfactory because parents faced with such dilemmas were often going through a severe emotional crisis of guilt and self reproach, which would prevent a balanced decision and could lead them to surrender their judgment entirely to the medical professionals. Whilst professional judgment will always be important in such cases, the life or death decision should not depend upon the moral code of a particular doctor or the chance factor of whether a child was born in one hospital or another.

The AMA says there should be no legislation on this. But there is criminal legislation. Decisions are being made deliberately to withhold treatment that would normally be given to a baby as a matter of urgent routine. The intention is admitted to be to allow the baby to die. It should not depend upon a particular hospital or doctor involved nor even upon the parents as to whether the child should die. No one would dream of asserting that, like the Spartans of old, parents today could decide that a healthy child who was unwanted for some reason should be put out to die. Mental retardation and physical disabilities vary in degree. The assessment of whether a life will be demonstrably awful is not always easy to make at birth. The personal value systems of particular doctors, hospitals and parents vary enormously. Though it may be easier to make difficult professional decisions without the guidance of rules, where matters of life and death are concerned, this is not the usual way of our legal system.

PROCEDURES FOR REFORM

The work of the Australian Law Reform Commission in its project on human tissue transplantation shows that it is possible for the community to face up to difficult medical and legal dilemmas of this kind. Legislation based on the Law Reform Commission's report has been introduced in three jurisdictions and is likely to be introduced in three more this year. This shows that it is possible to promote a dialogue between lawyers, doctors and the concerned community to develop sensitive rules to deal with difficult medico-legal problems. No one would propose that criminal prosecutions against doctors or nursing staff or parents would normally be appropriate in the painful cases of malformed babies. But legislation could and in my view should be designed to ensure greater consistency and proper procedures in cases of this kind.

Unlike the AMA, I believe there should be legislation, because the current legislation is not, apparently, adequate, clear or being observed. It is destructive of respect for the Rule of Law for any notion to develop that a private, often hurried and stressful conversation between doctors and parents can waive the criminal law. No one is suggesting police or officials should intervene in these painful decisions. Obviously the parents and the doctors must have a vital part to play in the ultimate decision. But, as it seems to me, the law should do three minimum things at least:

- * it should bring clearly to the mind of doctors, parents and all involved that the sole criterion for action is the 'best interests of the child' not the convenience of society, parents, the family or anyone else.
- * it should lay down minimum procedures to be followed in hospitals in cases of this kind. A similar approach was taken in the report on human tissue transplants, requiring second opinions and appropriate expertise to assure against conflict of interests; and

* it should seek to lay down at least certain general criteria for the decision. Doctors, after all, do have criteria by which they make the decision to advise allowing the child to die. So the criteria exist. I am informed that there are certain well-established signs by which most of these decisions are made in practice. For the guidance of doctors and for the information of the community and to promote consistency and uniformity in these decisions, such criteria should be spelt out and identified. Obviously the AMA and the Royal Colleges would have a vital role to play in doing this. Criteria governing decisions of life and death should not be secret. In secrecy lies the opportunity for uncertainty, confusion and idiosyncratic personal judgments.

OTHER MEDICO-LEGAL ISSUES

The issue of treatment of deformed and retarded babies is only one of many medico-legal issues which will have to be faced in the decades ahead. Amongst the others are:

- * human tissue transplants
- * the definition of death
- * euthanasia generally in the case of pain
- * the 'right' to heroin for cancer treatment
- * the living will i.e. the right to make a will forbidding extraordinary medical care for terminal illness
- * in vitro fertilization
- * use of genetic engineering in medicine
- * fairness to patients in clinical trial of new drugs
- * computerisation of medical records

It is important that Parliaments should have the assistance of interdisciplinary advisory bodies including doctors and lawyers working together. But it is just as important in all of the sensitive matters I have mentioned, to ensure frank and thorough consultation with the community before any laws are developed.