JOINDER OF ISSUE AT THE FRONTIERS OF BIOMEDICINE: A REVIEW ESSAY ON "GENETICS, ETHICS AND THE LAW", BY GEORGE P. SMITH, II*

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I. INTRODUCTION

Genetics, among all the areas of the new bio-medical technology, raises some of the most complex, difficult, fundamental and value-laden conflicts in its ethical and legal perspectives. These conflicts have been exhibited in incidents such as public outcry over the danger of recombinant DNA research or objection to "in vitro" fertilisation. Such incidents have often given rise to governmental or professional regulation of particular activities, but there has been a lack of a comprehensive and consistent approach to the totality of the inter-related issues involved.

Some of the causes of this deficiency may be unavoidable. For instance, although the underlying values or principles involved are often not novel, the context in which they are raised and the degree of potential impact of a decision both immediately and in the future, often are. Further, assessing the potential impact of a decision in terms of either predicting its risks or benefits, or, when these are predictable, weighing them, can be fraught both with uncertainties and value-laden judgements. It may even be that such factors mean that the issues raised by modern genetics are different in kind, and not just in degree, from those faced by individuals and society in the past. In addition, there is the problem of a lack of consensus in the community as to what the governing principles should be. As attaining such a consensus would seem to be impossible in a modern pluralistic society, it has been suggested that we should focus on consensus as to decision outcomes, rather than on agreement as to the principles on which these decisions are based.[1]

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1 S. Toulmin, "The Tyranny of Principles" (1981) 11(6) *Hastings Center Report* 31.

However, accepting that there are some problems which are unavoidable, what is needed is a framework within which there is potential for a comprehensive and interconnected discussion and exegesis of the subject matter of genetics, ethics and the law, which accommodates, highlights and helps to solve particular difficulties. Does the text *Genetics, Ethics and the Law* meet these requirements?

The principal matters listed in the table of contents, 1. Changing Values and Perceptions; 2. Implementing a Negative Eugenics Programme; 3. The Vagaries of Informed Consent; 4. Wrongful Life and Wrongful Birth — An In-Depth Consideration; 5. The New Biology and a Programme for Positive Eugenics; 6. The Legal Response; 7. The Scientific Methods and the New Biology: An Overview; 8. The Bioethical Conundrum: A Consideration in Microcosm; and 9. Science and Religion: Compatabilities and Conflicts, comprise the necessary framework. However, the potential this offers is not always realised. The reasons for this failure vary in different parts of the text and are of differing degrees of importance. Some relate to matters of substance and others to matters of form. A discusson of these matters constitutes the remainder of this review essay.

II. MATTERS OF SUBSTANCE

1. Definition of Medical Research

Genetic procedures, like other medical interventions, can be classified into four categories; therapy/non-research (that is, "practice"[2]), non-therapy/non-research, therapy/research or non-therapy/research. The legal and ethical requirements for any given medical intervention may vary depending on which of these categories is applicable.[3] Smith does not address the issue of which genetic procedures constitute therapy and which do not. He also appears to incorrectly assume that all procedures constitute medical research.

Further, on many occasions when discussion of legal and ethical aspects of genetic research is appropriate, the focus is on medical experimentation in general, rather than genetic research in particular. This approach probably results from presuming that principles relevant to medical research in general apply directly to genetic research. While this may be true in many instances, there is not nearly enough in-depth analysis of how genetic research may differ from other forms of medical research and why, therefore, some legal and ethical principles relevant to the latter may not be applied without modification to the former. For instance, simply seeking a person's consent to participate as a research subject does not usually carry any serious risk of harm to the person approached. This may not be true when that person has been selected as a potential subject because he is a member of a family which is afflicted by an inherited genetic disease. Approaching such a person may constitute harm to him if this made him aware that he might develop some incurable, genetically transmitted disease (for

2 See The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, "The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research", D.H.E.W. Publication No (OS) 78-0012, Washington 1978. Reproduced in Appendix J of Smith.

3 See M. A. Somerville, "Clarifing the Concepts of Research Ethics: A Second Filtration" (1981) 29(2) *Clinical Research* 101.

example, Huntington's chorea) of which he would otherwise have been unaware. Although the person may regard having such knowledge as a benefit, because he may wish to avoid reproducing and the risk of passing on the disorder, the suffering that living with this knowledge involves, and which could have been avoided, should be neither ignored nor minimized as a harm.

2. Benefit to Society vs. Harm to the Individual

Smith places strong emphasis on benefit to society as a justification for certain courses of conduct, often without adequate consideration of the harm to the individual which may be involved in the proposal being espoused. Risk to the individual (and the the community) must always be considered and the anticipated benefit to the individual or the community must outweigh the risk, before one can justify carrying out an intervention which is potentially harmful to the individual. Further, the harm, or risks of harm, involved in some interventions may be of such a nature that those inverventions may be absolutely unacceptable no matter how much benefit they promise. The approach adopted by Smith does not appear to follow this type of decision-making model.

Community benefit is readily seen as justifying genetic interventions, even mandatory ones. For example, it is proposed that "societal problems such as population control, the cost of supporting the handicapped, and the general welfare of the population favor the trend toward mandatory genetic screening."[4] In comparison, the harm which could arise from such a programme due to the infringement of individual rights, is either readily dismissed or not considered. On other occasions, individual rights are recognised and overridden, rather than dismissed: "The state's interest in improving the quality of a population's genetic pool in order to minimize suffering, to reduce the number of economically dependent persons, and possibly, to save mankind from extinction arguably justifies the infringement of individuals' civil liberties."[5] Similarly, it is proposed that "[p]erhaps less hesitancy [concerning sterilising mentally incompetent persons] would be encountered if the courts were to be convinced that the incompetent — if fully aware of his own mental state — would not want to burden society with other defective individuals such as himself. Thus, a societal standard of the greatest benefit or good would be made more significant than the fundamental right of individual procreation and the general public welfare served."[6]

These last two statements are typical of the impression given by the book as a whole with respect to how conflicts of individual and societal rights should be resolved. The author's choice is always in favour of society. It is, of course, a value judgement whether one agrees with this choice of hierarchy and, in any given situation, there will be arguments for and against which should be explored. The danger is adopting an invariable rule of preference applicable to all situations.

In many parts of the book, especially where the extensive footnotes are read in close conjunction with the text, both sides of an issue are exposed. But a problem remains.

4 Smith, 19.
5 *Ibid.*
6 *Id.*, 37.

Too often one is left uncertain as to the author's choice among conflicting principles, or approaches, or course of conduct. Although, in a controversial area such as genetics, one should on the whole avoid dogmatism, it would be useful to know the author's predilection, even if it is only tentative and subject to revision in the future. An analogy can be drawn to the physician's advice to the patient concerning what he, the physician, would choose to do if he were in the same circumstances as the patient. This advice is not determinative of the patient's choice, but is a factor the patient will take into consideration in making up his own mind. Similarly, it would have been useful to take the author's opinion into consideration, but this was often not possible because it was not expressed.

Another problem arises because the text does not always spell out the full ramifications of what is being proposed. Take, for instance, the following statement:

> In *Buck* v. *Bell*, Justice Holmes stressed that "it would be better for all the world . . . if society can prevent those who are manifestly unfit from continuing their kind." Perhaps world conditions have become so complex and resources so valuable that society now has a compelling interest in restricting reproduction by those, who although not "manifestly unfit" themselves, perpetuate human suffering by giving birth to genetically defective offspring.[7]

Buck v. *Bell*[8] concerned the issue of the compulsory, sexual sterilisation of an institutionalised mental patient, who was incompetent to consent to the procedure herself. There is much current debate whether the carrying out of such interventions on incompetent persons can be justified and, if so, when and who may authorise them. I suggest that the better view is that some of these interventions can justifiably be undertaken, provided they are subject to strict substantive and procedural safeguards such as those recently proposed by the Law Reform Commission of Canada.[9] The important point is that all these decisions must be taken from the most comprehensive view of the "best interests" of the incompetent person, by a decision-maker who is disinterested (in the sense of free of conflict of interest) but not uninterested, and, to the extent that it is possible, to promote the incompetent person's participation in human love, warmth, sexuality and fullness of experience. But very different considerations, principles and issues are involved when the proposal is to sterilise a mentally competent person, who is capable of giving or withholding consent to the intervention and who is not institutionalised. Smith fails even to distinguish these two situations, let alone explore their differences or the general ramifications for individuals or society of allowing the involuntary (non-consensual) sterilisation of those competent to refuse consent.

It should be pointed out here that being incompetent, mentally ill or retarded, or institutionalised are differentiating factors giving rise to a different decision analysis with respect to the sexual sterilisation of mentally incompetent persons as compared with those who are competent. In making these distinctions no implication is intended that one group of persons has more or less rights than the other. It is simply that these factors are relevant in reaching a decision in a given case of how best to implement

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7 *Id.*, 21.

8 274 U.S. 200 (1927).

9 *Sterilisation: Implications for Mentally Retarded and Mentally Ill Persons*, Working Paper No. 24, Minister for Supply and Services, Ottawa, 1979.

principles of respect for each individual person, beneficience (protection of that person from harm and futherance of his well-being), and justice.[10]

3. Informed Consent

The requirements imposed by the doctrine of informed consent can only be dealt with satisfactorily by structuring the issues involved.[11] Failure to do this can lead to confusion. For example, confusion can arise in a case involving a failure to obtain consent as to whether battery or negligence is the appropriate cause of action. It can also be present in relation to the requirements of the law with respect to the patient's understanding of information or as to the required scope of disclosure of information to the patient and how this scope is affected by doctrines such as "therapeutic privilege". Furthermore, there may be confusion as to how consent requirements vary for medical research as compared with "practice".[12] It is impossible to canvass even these issues here, let alone all the relevant issues raised by consent, and many of them have been discussed elsewhere.[13] However, one example will be given of the precision needed in addressing these matters which is not always displayed in *Genetics, Ethics and the Law.* Smith states that "[t]he patient must be made to understand that to which he is consenting."[14] Although a court may adopt such a standard of subjective understanding by a patient, it is suggested that it is unlikely that it would do so. One reason would be that if the patient claimed he did not understand, then despite the fact that the reasonable patient in the same circumstances would have understood and the physician did not know that this patient did not understand, the court would be forced to find that the patient's consent was invalid, unless it chose not to believe his testimony. On the other hand, a purely objective standard of understanding of information by the patient (that is, he will be deemed to have understood the information if a reasonable man in the same circumstances would have understood it) may be unfair to him. Therefore, it is suggested that the test used by the law to determine whether the requirement of understanding of information by the patient is fulfilled, should be whether the reasonable physician in those circumstances would have thought that this patient apparently understood the information he was required to be given. That is, a test of "apparent subjective understanding" on the part of the patient should be adopted.[15]

In short, as the above example demonstrates, there is a great deal of nuance which needs to be examined with respect to many health law issues and which is not always to be found in Smith's text. When this failure occurs in combination with a failure to structure the issues being dealt with, it is especially likely to result in statements which could clearly be challenged in terms of their accuracy, at least as far as they purport to constitute the only available analysis of a given situation. For instance, to make a

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10 See note 2 *supra.*

11 See M. A. Somerville, "Structuring the Issues in Informed Consent" (1981) 26 *McGill L. J.* (4) 740.

12 See M. A. Somerville, "Special Issues in the Consent Forum: Therapeutic/Non-therapeutic Procedures" to be published in *Health Law in Canada,* 1982. For the distinction between research and "practice" see note 2 *supra,* and note 3 *supra.*

13 See note 11 *supra.*

14 Smith, 35.

15 See M. A. Somerville, "Consent to Medical Care" Study Paper, Protection of Life Series, Law Reform Commission of Canada, Ottawa, 1979, 16.

general statement based on the *Kaimowitz* case,[16] "that one who is involuntarily committed to an institution is, from a legal standpoint, incapable of consenting to a surgical intervention (psychosurgery)",[17] is at best confusing and at worst wrong. It is true that the court held that, in the circumstances presented in *Kaimowitz,* the involuntarily institutionalised patient could not consent to experimental psychosurgery. The reasons the court gave for its decision were varied, but included the following: the fact that research was involved; that little was known about the consequences of the proposed procedure; that there was a high-risk/low-benefit ratio; and that the patient's consent may have been subject to unavoidable coercion because of "his mental condition, the deprivation stemming from involuntary confinement, and the effects of the phenomenon of 'institutionalisation'."[18] None of these reasons, except possibly the last, need apply to a non-research, therapeutic, general (non-psychosurgical) medical intervention on an involuntarily institutionalised patient. In fact, the court recognises this and the judgement contains a passage which refutes the existence of any rule prohibiting general surgery (as opposed to psychosurgery) on involuntarily institutionalised patients. In the words of the court: "We do not agree that a truly informed consent cannot be given for a regular surgical procedure by a patient, institutionalised or not. The law has long recognized that such valid consent can be given. But we do hold that informed consent cannot be given by an involuntarily detained mental patient for experimental psychosurgery for the reasons set forth below."[19]

It is worth pointing out here that institutionalised, involuntarily committed patients need special protection, sometimes even from those seeking to do them good by imposing treatment on them. But this protection cannot be established by a blanket denial of an involuntarily committed person's right to consent to medical treatment. In fact, such a denial may detract from protection of the involuntarily committed person or, more precisely, his ability to protect himself through the exercise of his individual rights of autonomy and inviolability. This is so because these rights carry the power to refuse treatment, as well as to consent to it. If these rights are not recognised with respect to the power to consent to treatment, neither, in all likelihood, will they be with respect to the power to refuse treatment. Another area of controversy and current debate concerns the rights of involuntarily committed persons to refuse treatment and that has been raised almost, it seems, without recognising it.

Further, it could not be expected that in-depth treatment would have been given to the complex conflict that can arise between different *needs* of the patient (that is, the patient's needs as perceived by the medical profession, his needs as he, himself, perceives them, and, sometimes, his actual needs) and between these "needs" and *rights* (the patient's rights as perceived by the law and, sometimes the community's right to protect itself). Nevertheless, at least brief reference should have been made to these

16 Unreported but summarised 42 U.S.L.W. 2063 (July 31, 1973). Published in W. M. Gaylin, J. S. Meister & R. C. Neville (eds) *Operating on the Mind (The Psychosurgery Conflict)* (1975) Appendix, 185.

17 Smith, 44.

18 *Kaimowitz,* note 16 *supra*, 197.

19 *Id.,* 195.

issues as they are raised by Smith's statement that an involuntarily committed person is unable to consent to surgery.

Among the most disturbing statements in the text are those concerning the necessity of obtaining the patient's consent to participate in medical research or the scope of disclosure of information required when medical research is involved. For instance, in relation to research carried out on aborted foetuses, it is proposed that "the mother, herself, should have no particular concern with experimentations [sic] performed on disorganized fetal tissue and hence, should not be requested to give her consent to such acts."[20] With respect to the required scope of disclosure of information to the patient, it is claimed that "[t]here are no decided cases which resolve the conundrum of whether it is necessary to disclose to the patient that an experiment is being conducted and the very nature of the experiment itself."[21] Even if an American court has not yet faced this issue, it seems impossible to believe that it would not require such disclosure, as its Canadian counterpart has already done.[22] This requirement could be adopted through case law, by recognising that such a disclosure is the common practice of competent researchers in the same circumstances. The highly detailed H.S.S. (Health and Social Services)[23] and F.D.A. (Food and Drug Administration)[24] regulations could be introduced as evidence of such a practice.

One source of the problems found in the chapter on consent is that this area has changed rapidly in very recent times and yet there is often reliance upon older cases or references which no longer exhibit current approaches or attitudes. This earlier material is relevant, informative and interesting, but the way in which it is used reflects one of the difficulties I had with the book as a whole; namely that certain segments almost seem to have been written in a different era to other segments, and the distinction as to which segments have a place in history and which in the present time is not always made obvious. The clearest example of the use of an outdated source occurs in relation to the Declaration of Helsinki. The original 1964 version of the Declaration is cited in the text and reproduced in Appendix D, whereas the current version is the 1975 one.

4. "Wrongful Birth" and "Wrongful Life"

There is a lengthy discussion of "wrongful life" and "wrongful birth" actions, which is also inadequately structured. Again, some surprising and certainly debatable suggestions are made. For instance, one argument given in support of recognising "wrongful life" suits runs as follows:

> Parents and the medical profession, knowing of the risk of incurring liability for wrongful life, will become much more conscious of the child's right to a healthy mind and body and be less hampered with notions of the sanctity of human life. This will reap benefits for society in that such concern by parents and medical practitioners will greatly decrease the number of persons dependent on society for their support and existence. The debate between existence with defects and non-

20 Smith, 41.
21 *Id.*, 40.
22 See *Haluska* v. *University of Saskatchewan* (1966) 53 D.L.R. (2d) 436 (Sask. C.A.).
23 45 C.F.R. Part 46; 46 Fed. Reg. 16, 8366-8389, January 26, 1981.
24 21 C.F.R. Part 50; 45 Fed. Reg. 106, 36386-92, May 30, 1980.

> existence will become a matter of the past as recognition of the right to exist without defects becomes accepted.
> This type of approach places a burden of some dimension upon the medical profession. For example, a doctor — because of the very real danger of a lawsuit — may elect to take one of two options. He may either abort all borderline cases in an effort to immunize himself from suit or, resign from the practice of pediatrics [sic obstetrics].[25]

Despite the language used in this statement, it does not seem that Smith intends that a physician should be able to impose mandatory abortion with impunity. Rather, it appears that what is meant is that when the foetus is, or might be, defective, the physician should advise the woman and recommend that she have an abortion.

Although, as Smith recognises, "wrongful birth", "wrongful life" and "prenatal torts" (tort liability for prenatal injury to the foetus which includes preconception or post conception tortious injury to the parents which results in injury to the child) are all related, there are different considerations pertinent to each. Perhaps the most important distinctions between these causes of action are the identity of the plaintiff or plaintiffs and the nature of the damage alleged.

In "wrongful birth" cases the plaintiff parent alleges that but for the defendant's negligence[26] he or she would not have become the parent of the child. Thus, the child itself constitutes the damage to the parent and the amount of this damage must be quantified. An alternative to this "birth as damage" approach is that the birth of the child is simply the event giving rise to, or the occasion of, the damage suffered by the parent. That damage can take various forms, including economic loss to the parent for having to support the child, loss of opportunity to work because of needing to care for the child, or emotional injury to the parent due to his or her life-style or feelings being adversely affected by the birth of the child. One difficulty with this alternative, "birth as the occasion of damage", approach, is the traditional, and to some degree present, reluctance in the law to award compensation for the type of damage just described, when that damage stands alone (that is, it is not directly connected with physical injury to person or property, or at least a risk of such injury). This difficulty is avoided by

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25 Smith, 82. If, as appears likely, the word paediatrics has been mistakenly used for the word obstetrics, this represents an interesting Freudian slip.

26 For instance, negligence in performing a sterilisation operation, or an abortion, or in supplying contraceptives, or in advising the plaintiff-parent regarding reproduction when, but for the negligent advice, the parent would either not have conceived a child or not have continued an existing pregnancy. Sometimes actions based on a wrongful conception claim are distinguished as "wrongful pregnancy" cases. See B. M. Knoppers, "Physicians Liability and Prenatal Diagnosis", 1982, 18 *C.C.L.T.* 169, 173. Further, it should be noted that there is also a possibility of tort liability for "wrongful avoidance of birth". Such liability could arise if a healthy foetus were aborted, or sterilisation were recommended and carried out, on the basis of a positive finding of a genetic defect or trait which was in error due to negligence.
It is interesting to note that a "wrongful birth" case has just been decided in the South Australian Supreme Court, without identifying it as such (*F. v R.* No. 926 of 1978, Judgement No. 6082, May 5, 1982). The female plaintiff was subject to a properly performed but unsuccessful tubal ligation and as a result, conceived and gave birth to a child. There was an unavoidable risk of the sterilisation failing of which the plaintiff was not informed. The female plaintiff was awarded $10,000 for pain and suffering and $250 "under the Beck and Fanelly principle". The male plaintiff was awarded $250 for loss of consortium. The female plaintiff's damages were awarded for the pain and suffering of both the "wrongful pregnancy" which involved a caesarian section for delivery of the child and the second sterilisation operation. It is expressly stated that the court "cannot find that the care of the child has been a matter which sounds in damages".

adopting the "birth as damage" approach, which regards the birth of the child as a form of physical injury to the parent and as constituting the damage. Then, the factors listed above (which constitute the damage in the "birth as the occasion of damage" approach) are taken into consideration in quantifying the amount of that damage. On the other hand, an argument favouring an analysis based on a "birth as the occasion of the damage" approach stems from "wrongful life" suits. "Wrongful birth" and "wrongful life" actions should be treated consistently when this is possible. Regarding the birth of the child only as the event giving rise to damage may help to overcome the difficulty in "wrongful life" suits that, when life itself is characterised as the damage, without that damage there would be no plaintiff who could claim. The approach of seeing birth simply as the event giving rise to damage tends more towards recognising the experience the child undergoes in living a *damaged life,* rather than life itself, as the damage. The problem still remains, however, that in "wrongful life" suits the only alternative to damaged life would be no life at all, and not undamaged life as in pre-natal tort cases. This is discussed below.

The formula employed to establish causation in "wrongful birth" cases may vary depending on whether a "birth as damage", or a "birth as the occasion of damage", approach is used. Pursuant to a "birth as damage" approach, the test for causation-in-fact will be, "but for" the defendant's negligence would the child have been born; for causation-in-law, was the birth of the child a reasonably forseeable consequence of the defendant's breach of duty? Unless there is a set-off for benefit derived from the birth of the child, the plaintiff-parents will receive damages assessed on the basis of the full cost of caring for the child and not, for instance, merely the difference between caring for a damaged child as compared with a "normal" one.[27] In comparison, under a "birth as the occasion of damage" approach, although the full cost of rearing the child may also be recovered, because the heads of damage tend to be more discreet and identified, it may be easier to argue that the damage suffered by the parents should be restricted to their having had a damaged, rather than a "normal" child, when this is the case. If this approach is adopted, the test for causation-in-fact will be, "but for" the defendant's negligence would the plaintiffs have had a "normal" rather than a damaged child, and for causation-in-law, was the birth of a damaged rather than a "normal" child a reasonably forseeable result of the defendant's breach of duty. When causation is

27 The recent case of *Robak* v. *U.S.* (658 F. 2d 471 (1981)) is interesting in this respect. The court awarded the parents damages for the wrongful birth of their severely damaged child. The mother had contracted rubella during the pregnancy and the physician failed to advise her of the risks of the child being born deformed as a result of her illness. If the mother had known, she would have had an abortion. The court expressly refused to set off the costs of rearing a normal child against the damages awarded to the parents for rearing the damaged child. A causation based analysis which employed a "birth as damage" approach, was used to explain this result: "but for" the negligence of the defendant, the child would not have been born at all, rather than would not have been born damaged. Consequently, the parents' damage consisted of the birth of the child and was quantified as the full cost of rearing it and not just the additional costs incurred because it was damaged, rather than undamaged.

established under this test, the defendant will only be liable for the difference in cost between raising a "normal" and a damaged child.[28]

An alternative way in which the cost of rearing a normal child may be excluded from recovery as damages, and which will be applied whichever approach is used, has already been mentioned above. Benefits derived by the plaintiffs from the negligent act of the defendant will be available for set-off against the damage incurred. Consequently, when the child is healthy, the final amount assessed as damages may be minimal or nominal, or the benefits conferred on the plaintiff-parent by having the child may be viewed as exceeding the damage caused. But it should be recognised that failure to recover damages because a "benefits" rule has been applied, is not due to the plaintiff-parent having no justifiable claim. Rather, in the court's view, the parent suffered no "net damage". However, when the child is damaged, this is usually not the case. Hence, an amount ranging from the additional expenses incurred in caring for a damaged child as compared with a "normal" one, up to the full cost of rearing a damaged child,[29] can be recovered.

In summary, either differences in formulation of the test used to establish causation, or the application of a "benefits set off" rule, or both factors in combination, can explain how courts are able to award damages in "wrongful birth" cases where the child is damaged and, quite consistently in terms of the law, not to do so where it is healthy.

In "prenatal tort" cases, the plaintiff can either be the injured child or the parents. The child's claim is that but for the wrongful act or omission of the defendant he would have been born without the injury of which he complains. The parents' claim is similar, but their damage consists of the injury that the child's injury causes to them, such as medical expenses which they incur on behalf of the child,[30] or, possibly, a claim for negligently inflicted nervous shock.

In "wrongful life" actions the plaintiff is the child and the nature of the alleged damage is life itself. In other words, the child alleges that but for the negligence of the defendant he would not have been born and that having been born constitutes more harm to him than not having been born. Smith argues that such causes of action should be recognised and, in fact, in one recent case this has occurred.[31] Such recognition involves accepting a "quality of life" principle which may be in conflict

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28 Arguably, damages would be assessed in this way when the parents would still have had a child "but for" the negligence of the defendant (that is, the defendant's act is not causally related in law to their having a child), however, "but for" the negligence of the defendant they could have avoided having a damaged child (that is, the defendant's act is causally related to their having a *damaged* child). The issue of whether the parents would have had another child if their damaged child had been aborted, rather than born, was not addressed in assessing damages in *Robak* v. *U.S.*, note 27 *supra*. It also needs to be considered that in some cases the parents may have an "extra" child because they had a damaged child. In such cases it would seem their damage consists of the full cost of rearing the damaged child. I wish to note that, although I think the analysis I have pursued here is necessary, there is something inherently objectionable in it. I would suggest that this is the characteristic of "reification" that it displays, the treating of persons as things or objects.

29 See *Robak* v. *U.S.*, note 27 *supra*, where such an award was made. It seems in this case, that there were no compensating benefits arising from the birth of the child which could be set-off against the damage the parents suffered.

30 A. I. Ogus, *The Law of Damages* (1973) 279-80.

31 *Curlender* v. *Bio-science Laboratories*, 165 Cal. Rept. 477 (1980), appeal denied 2 Civ. 58192 (Sept. 4, 1980).

with a "sanctity of life" or vitality principle.[32] This conflict occurs because the former principle, in stark contrast to the latter, necessarily recognises that life may be of such poor quality that it constitutes a damage to be alive (that is, it may be better to be dead than alive).

It is only recently that systems of law based on the common law or civil law models have been faced with the issue of whether their traditional adherence to a strict "sanctity of life" principle needed modification in some circumstances, by allowing a "quality of life" criterion to operate. This issue has been raised mainly by, and in the context of, modern medical advances. It is as yet far from resolved, one of the major difficulties being to find a suitable limiting device governing when, and the extent to which, a "quality of life" principle should be applied. The fear is that any recognition of this principle by the law could open up dangerous precedents subject to far-reaching abuse. Consequently, although such a change in the law may be justified in some circumstances, its wider implications need to be carefully researched. For instance, the latent (or, even more so, the overt) recognition of a "quality of life" principle, through recognition of a "wrongful life" action, could have precedent-setting effect with respect to issues related to euthanasia, particularly in the context of defective newborn babies.

"Wrongful life" suits also raise complex issues concerning how we, as individuals and as a society, view some of our most important, intimate, personal, human relationships. One such issue is whether a child should be prevented from suing its parents on the basis of a "wrongful life" action, assuming that such actions are otherwise potentially available. This is a particularly difficult issue, especially when the parents knew that they might conceive or give birth to a damaged child (as opposed to the situation where they ought to have known this as reasonable parents), but decided to take this risk. Smith would seem to favour children being able to sue their parents for "wrongful life"[33] and even suggests that "[a] decision to carry a genetically defective fetus to term would be an example"[34] of "negligent fetal abuse".[35] But surely this approach could not be applied to parents who have been subject to some tortious or non-tortious conduct which might affect their offspring (for instance, they have been exposed to mutagenic chemical compounds), or who are carriers of some genetic defect, who decide to conceive a child and who are opposed to abortion for religious reasons. It is suggested that in all cases, the parents' right not to have their reproductive decisions interfered with should give them immunity from a "wrongful life" action by the child. However, the child should be free to sue any other wrongdoer for a prenatal

32 See E.W. Keyserlingk, "Sanctity of Life or Quality of Life" Study Paper, Law Reform Commission of Canada, Ottawa, 1979.
33 Smith, 80.
34 *Id.*, 38.
35 *Ibid.*

(including a pre-conception) tort which caused him to be born in a damaged state,[36] or, possibly, in a "wrongful life" action for causing him to be born.

"Wrongful life" actions may also raise difficult causation problems. For instance, if the alleged fault is negligent post-conception genetic screening, but the parents would not have considered abortion even if they had been given the correct information from this screening, then "but for" the fault of the defendant, the damage which the child alleges (his "wrongful life") would, on the balance of probabilities, still have occurred. Hence, the defendant's fault is not the cause-in-fact (and thus, necessarily, not the cause-in-law) of the child's damage. In contrast, negligent genetic screening of the parents prior to conception, or after conception where the parents would have considered abortion, will, in all probability, give rise to a finding of causation. This is true because "but for" the negligence of the defendant the child would not, on the balance of probabilities, have been conceived or born, (that is, there is causation-in-fact) and this result was a reasonably forseeable consequence of the breach of duty (that is, there is causation-in-law).

In all three cases postulated above, there is the loss of a chance for the parents to act with the knowledge which they would have had available "but for" the negligent act of the defendant. However, in the latter two cases this chance carried a greater probability of avoiding the birth of the child, and hence of avoiding the damage of which the child complains, than in the former. The more probable it is that had the chance which was lost been available the damage would have been avoided, the more likely it is that the law will regard the loss of the chance as the cause of the child's damage. Thus consideration of the loss of a chance can be relevant in establishing causation in "wrongful life" actions, but this notion of loss of a chance should be distinguished from the doctrine of "la perte d'une chance" (loss of a chance) as it has been developed in French law. There are analytical insights to be gained from comparing the two. The usual approach when using the French doctrine is to regard the loss of a chance as the damage itself.[37] Such an analysis avoids the necessity of proving the causal link between the wrongful act and a final damaging result, because the same event (causing the plaintiff to lose a chance to which he was entitled) constitutes both the defendant's wrongful act and the plaintiff's damage. Hence, the question of whether, if the chance had been present (as it would have been but for the defendant's negligence), the outcome would, on the balance of probabilities, have been

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36 *Cf.* Congenital Disabilities (Civil Liability) Act 1976 (England and Northern Ireland). This Act grants immunity from suit to the mother (s.1(1)), except with respect to injury caused to the child by the mother driving a motor vehicle (s.2), but allows a suit by the child against the father. In fact, the father has less immunity from suit by the child than any other person. Section 1(4) provides:

> In the case of an occurrence preceding the time of conception, the defendant is not answerable to the child if at that time either or both of the parents knew the risk of their child being born disabled (that is to say, the particular risk created by the occurrence); but should it be the child's father who is the defendant, this subsection does not apply if he knew of the risk and the mother did not.

The Act covers preconception and prenatal tort actions, but, probably, would not be interpreted to include "wrongful life" actions. As the child's right of action is derivative from a potential tort liability of either parent (s.1(3)), if "wrongful life" actions were held to be comtemplated by the Act, they would only lie for cases such as negligent genetic screening of the parents or foetus. It may be worth considering whether a derivative liability approach, such as this, could function as a suitable limiting device in "wrongful life" actions.

37 See G. Boyer Chammard and P. Monzein, *La Responsabilité Medicale* (1974) 92-105.

different, is irrelevant.[38] In "wrongful life" actions that is not the case because the damage the child complains of is having been born, and not simply losing a chance not to be born. Consequently, in order to prove causation, the child must show that the loss of the chance that his parents should have had of acting with the knowledge to which they were entitled, on the balance of probabilities, caused him to be born. In this respect it is worth noting that the defendant's wrongful act need not be the sole cause of the plaintiff's damage, it is enough if it is a "proximate"[39] or contributing[40] cause.

If "wrongful life" actions are to be allowed, there is a need to propose some principles on which courts may rely in deciding whether or not to entertain an action in any given circumstances. One possible approach, which has already been mentioned, would be to make a "wrongful life" action at the suit of the child contingent on a breach of duty to one or both parents.[41] Another criterion could be that where the defect is intrinsic to the child himself or herself, such as a genetic defect,[42] the claim should be more readily entertained that when it is extrinsic, such as having been born an "adulterine bastard"[43] or into disadvantaged circumstances.[44] The reason for suggesting such a distinction is that when the nature of the damage alleged is life itself, the injuring aspect of that life must be inextricably connected to having life. To the extent that having life can be disconnected or detached from the injury that life is said to constitute, life, itself, is not the injury. Rather, the surrounding circumstances (for instance being illegitimate), constitute the injury.

5. "Birth Technology" and Eugenics

Smith discusses positive eugenics, A.I.D. (artificial insemination by donor), "in vitro" fertilisation and embryo implants in some detail. The question of access to "birth technology" by unmarried parents is raised, but is not dealt with in depth. The broader ramifications of this question encompass difficult issues of discrimination, which become even more difficult when the persons seeking to use the "birth technology" are regarded by society as "deviant" in some way. For instance, should access to birth technology be restricted to married couples? If so, should a married couple, where the husband is a transsexual, be provided with A.I.D. because they are married, or denied it on the basis of sexual orientation? Is being married a necessary, but insufficient, claim to having access to "birth technology" in that we should require prospective parents to be married and heterosexual? Once we apply some criteria of choice in deciding on who should have access to birth technology, are there other criteria which should be introduced, including some general test of "fitness to parent"?[45]

Only one question will be raised with respect to positive eugenics. Even if we are able to say that negative eugenics can be justified, that is, we can identify which

38 Irrelevant, that is, to establishing causation, but not irrelevant in quantifying the damage which flowed from the loss of the chance.
39 See *Robak* v. *U.S.*, note 27 *supra*, 477.
40 See *McGhee* v. *National Coal Board* [1972] 3 All E.R. 1008 (H.L.).
41 See note 36 *supra*.
42 *Curlender* v. *Bio-science Laboratories*, note 31 *supra*.
43 *Zepeda* v. *Zepeda* 190 N.E. 2d 849 (1963), cert. den. 379 U.S. 945 (1964).
44 *Williams* v. *State*, 223 N.E. 2d 343 (1966).
45 See M. A. Somerville "Birth Technology, Parenting and 'Deviance' " (1982) 5 *Int. J. Law Psychiatry* (2).

negative traits we wish to avoid and justify taking steps to suppress these, can we assume that we are also able to choose desirable characteristics for future generations? Is positive eugenics possible in the sense of its having a reasonably predictable and acceptable risk/benefit ratio and, if not, is it justifiable? On the other hand, is it any worse to try to determine the genetic fate of future generations by responsible, rational choice, than to leave it to pure chance? One factor which is relevant in answering this last question is that the degree of risk which a person or a society will tolerate as acceptable is greater when that risk is imposed by chance, rather than by deliberate choice.[46]

6. Regulation of Medical Research

Smith gives priority, in most of the text, to the rights of, and benefit to, society as the overriding value. In contrast, he opts for an individual right in relation to the regulation of medical research, that of self-regulation by the researcher in genetic engineering. However, this stance is not as inconsistent as it may seem at first glance. Although priority is given to the individual researcher's right to carry out research, Smith sees this approach as promoting societal good, which takes precedence over risks of individual harm (and it would seem over risks of societal harm) which may result from giving an unfettered right to carry out unreviewed, unapproved biomedical research. Smith argues for his position as follows:

> In the final analysis, the private researcher charts the course of scientific investigation. He will determine the balance between freedom of scientific inquiry and concepts of what is socially good; he will determine whether his research should be totally utilitarian, providing the greatest good to the greatest number even if it may compromise the rights of some individuals, and how his research should accommodate the competing interests of each subgroup in society. The system of self-regulation would be workable, of course, if scientists accepted the fundamental principle that their research must promote the social good by seeking to minimize human suffering for the greatest number; that principle would provide adequate ethical guidance for research decisions. This general standard appears to favor independent scientific study since the research scientist determines both the definition of the social good that the experimentation will promote and the beneficiaries of that research. The standard is based on a broader conception, however, in that it seeks to minimize mental, physical, social and spiritual suffering throughout the human community. The standard therefore, would allow a scientist to undertake in utero or in vitro fetal research in order to produce children free from debilitating recessive hemophilic or sickle cell genes because successful research

46 It is worth noting that the degree to which a risk is imposed by chance of choice may be somwhat concealed. The further removed the choice creating the risk is from the event in which the risk crystallises in damage, the less likely it is that choice, rather than chance, will be identified as the source of the risk. This is particularly true when the choice giving rise to the risk leaves the selection of victims to chance. (See, generally, G. Calabresi, *The Costs of Accidents* (1970).) Thus, in a given situation involving risk, some of the risk may be imposed by chance and some by choice. Whether the conduct in question will be regarded as acceptable, as far as its risk creation aspects are concerned depends upon the balance of the chance/choice and risk/benefit ratios. The acceptability of any given risk will be assessed, first, by taking into account both the probability and seriousness of the risk, plus other factors of which the social utility of the risk-taking conduct is one example. Secondly, the source of the risk, whether chance or choice, will affect its acceptability. If the risk is imposed by choice, its acceptability may also depend upon how well concealed this fact is.

> ultimately would benefit parents and prospective parents and their offspring by eliminating suffering and also would benefit society by making available for others research resources otherwise allocated to maintain the genetically defective.[47]

Such a view was once common, but it is increasingly (and, one would have hoped, universally) recognised that researchers should not be the sole arbiters of whether their research is ethically acceptable. This contemporary approach brings assessment of the scientific and ethical factors invovled in research into line, because researchers have never been the sole judges of the scientific validity of their own research. In many cases, requirements for ethical review of research protocols by committees with trans-disciplinary and community representation have now been formalised.[48]

Further, to the extent that it needs stating, because there are implications in the text to the contrary, the ethical acceptability of any given medical research intervention is not simply a matter of relativity. It is not true that the research is ethically valid provided the good sought to be achieved by the ends pursued outweighs any harm (which includes risks of harm) comprised by the means used. Rather, requiring that the hoped for benefit of the ends outweighs any harm caused by the means used, is a necessary but insufficient criterion of ethical acceptability, as it could be that some research which promises great benefit is inherently ethically unacceptable because of the means involved.[49]

A final quote crystallises my reservations about the general approach to substantive issues suggested in *Genetics, Ethics and the Law*. Smith writes: "When a physician seeks to implant an ovum into another woman, he should obtain permission from the donor for the transfer or implant. But, what if the donor woman has strong religious or other objections to in vitro fertilization that would have led her to refuse permission if she were told that her ova were to be used for that purpose?"[50] This question is not answered, except to say that "[t]hese dilemma may be upon us rather quickly".[51] But, the use of the world "should" in the phrase "should obtain permission", rather than *must,* exemplifies the general failure of the text to recognise and give sufficient weight to the rights of individuals. Secondly, the fact that the question posed is unanswered may suggest that in such cases the woman's ova could be used for "in vitro" fertilisation not only without her consent, but even where it is known she would

47 Smith, 133.

48 See, for example, H.S.S. regulations, note 23 *supra*; F.D.A. regulations, note 24 *supra*; Medical Research Council of Canada, *Ethics in human experimentation,* Report No. 6, Ottawa, 1978.

49 Cases in which the means are regarded as inherently unacceptable could be analysed in terms that the benefits sought in the ends, do not outweigh the risks of harm of the means. However, the point is that, in the cases contemplated, such an analysis should not even be available as a potential justification. One reason for adopting this approach is that the weight given to harms and benefits, the assessment of the probability of their occurrence, and, even, what will be identified as a harm or benefit, all have a large component of subjective value judgement. Thus, the use of these criteria, because they are subject to distortion, may give rise to unacceptable decisions, even those taken in "good faith", let alone those decisions in which there is abuse of decision-making power. Consequently, in some cases, the safe-guard needed will be to prohibit any possible justification of certain means through relating them to the potential good of the ends sought. It remains, of course, a value judgement as to which cases fall within this class of unjustifiable means. See M. A. Somerville, "Does the Aim of Human Medical Experimentation Affect Its Legal or Ethical Validity?" (1979) 3(2) *Legal Medical Quarterly* 83.

50 Smith, 167.

51 *Ibid.*

object. This is to accept that ends do sometimes justify means, even when, as here, those means contravene individual rights and could bring the medical profession, the research community and the activity of medical research itself, into serious disrepute and could destroy public confidence in the integrity of researchers and the activity of research. The failure to recognise such implications leads to the final point this passage raises. Accepting, for the moment, the hierarchy of values espoused in the text, namely, that benefit to the community is the overriding aim, there seems to be a total lack of insight that it may sometimes be necessary to protect individual rights (e.g. of autonomy or self-determination regarding participation in medical research), in order to promote the good of the community (e.g. the community's interest in having research carried out).

III. MATTERS OF FORM

In terms of form the book is cumbersome to use because the very extensive footnotes are placed at the end of each chapter rather than at the foot of each page. Further, it is sometimes difficult to determine what is intended to be the exact relevance of a particular footnote to the statement in the text to which it refers. Perhaps both these problems could have been overcome by incorporating more of the material presently in the footnotes, into the text.

Finally, there are numerous typographical and type-setting errors. For instance, one assumes that the following passage can only be explained as such an error:

> It has been suggested that the more certain we are that the benefits of experimentation with human fetuses will accrue only to society or to other fetuses and the more the still-living abortus alone will be damaged or suffer pain or injury, the more we should approve the research. The closer socially beneficial experimentation comes to bestowing some benefit also on the research subject, the more it deserves moral condemnation.[52]

IV. CONCLUSION

In conclusion, the very controversial and topical issues discussed in *Genetics, Ethics and the Law* need in depth and on-going consideration by a broad spectrum of people. Despite the manifest shortcomings of the book, which have been outlined above, its value lies in the effect it will have in stimulating strong reactions for or against the attitudes it espouses, which is one way of furthering the discussion which must take place.

52 *Id.*, 65-6, n.112.