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Consistent with the Commission's commitment to full equality between men and women, care has been taken throughout this volume to use gender-neutral language wherever possible.

Royal Commission on New Reproductive Technologies

Commission royale sur les nouvelles techniques de reproduction

NEW REPRODUCTIVE TECHNOLOGIES:

Ethical Aspects

Research Studies of the
Royal Commission on
New Reproductive Technologies

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Preface from the Chairperson

As Canadians living in the last decade of the twentieth century, we face unprecedented choices about procreation. Our responses to those choices — as individuals and as a society — say much about what we value and what our priorities are. Some technologies, such as those for assisted reproduction, are unlikely to become a common means of having a family — although the number of children born as a result of these techniques is greater than the number of infants placed for adoption in Canada. Others, such as ultrasound during pregnancy, are already generally accepted, and half of all pregnant women aged 35 and over undergo prenatal diagnostic procedures. Still other technologies, such as fetal tissue research, have little to do with reproduction as such, but may be of benefit to people suffering from diseases such as Parkinson's; they raise important ethical issues in the use and handling of reproductive tissues.

It is clear that opportunities for technological intervention raise issues that affect all of society; in addition, access to the technologies depends on the existence of public structures and policies to provide them. The values and priorities of society, as expressed through its institutions, laws, and funding arrangements, will affect individual options and choices.

As Canadians became more aware of these technologies throughout the 1980s, there was a growing awareness that there was an unacceptably large gap between the rapid pace of technological change and the policy development needed to guide decisions about whether and how to use such powerful technologies. There was also a realization of how little reliable information was available to make the needed policy decisions. In addition, many of the attitudes and assumptions underlying the way in which technologies were being developed and made available did not reflect the profound changes that have been transforming Canada in recent decades. Individual cases were being dealt with in isolation, and often in the absence of informed social consensus. At the same time, Canadians were looking

more critically at the role of science and technology in their lives in general, becoming more aware of their limited capacity to solve society's problems.

These concerns came together in the creation of the Royal Commission on New Reproductive Technologies. The Commission was established by the federal government in October 1989, with a wide-ranging and complex mandate. It is important to understand that the Commission was asked to consider the technologies' impact not only on society, but also on specific groups in society, particularly women and children. It was asked to consider not only the technologies' scientific and medical aspects, but also their ethical, legal, social, economic, and health implications. Its mandate was extensive, as it was directed to examine not only current developments in the area of new reproductive technologies, but also potential ones; not only techniques related to assisted conception, but also those of prenatal diagnosis; not only the condition of infertility, but also its causes and prevention; not only applications of technology, but also research, particularly embryo and fetal tissue research.

The appointment of a Royal Commission provided an opportunity to collect much-needed information, to foster public awareness and public debate, and to provide a principled framework for Canadian public policy on the use or restriction of these technologies.

The Commission set three broad goals for its work: to provide direction for public policy by making sound, practical, and principled recommendations; to leave a legacy of increased knowledge to benefit Canadian and international experience with new reproductive technologies; and to enhance public awareness and understanding of the issues surrounding new reproductive technologies to facilitate public participation in determining the future of the technologies and their place in Canadian society.

To fulfil these goals, the Commission held extensive public consultations, including private sessions for people with personal experiences of the technologies that they did not want to discuss in a public forum, and it developed an interdisciplinary research program to ensure that its recommendations would be informed by rigorous and wide-ranging research. In fact, the Commission published some of that research in advance of the Final Report to assist those working in the field of reproductive health and new reproductive technologies and to help inform the public.

The results of the research program are presented in these volumes. In all, the Commission developed and gathered an enormous body of information and analysis on which to base its recommendations, much of it available in Canada for the first time. This solid base of research findings helped to clarify the issues and produce practical and useful recommendations based on reliable data about the reality of the situation, not on speculation.

The Commission sought the involvement of the most qualified researchers to help develop its research projects. In total, more than 300

scholars and academics representing more than 70 disciplines — including the social sciences, humanities, medicine, genetics, life sciences, law, ethics, philosophy, and theology — at some 21 Canadian universities and 13 hospitals, clinics, and other institutions were involved in the research program.

The Commission was committed to a research process with high standards and a protocol that included internal and external peer review for content and methodology, first at the design stage and later at the report stage. Authors were asked to respond to these reviews, and the process resulted in the achievement of a high standard of work. The protocol was completed before the publication of the studies in this series of research volumes. Researchers using human subjects were required to comply with appropriate ethical review standards.

These volumes of research studies reflect the Commission's wide mandate. We believe the findings and analysis contained in these volumes will be useful for many people, both in this country and elsewhere.

Along with the other Commissioners, I would like to take this opportunity to extend my appreciation and thanks to the researchers and external reviewers who have given tremendous amounts of time and thought to the Commission. I would also like to acknowledge the entire Commission staff for their hard work, dedication, and commitment over the life of the Commission. Finally, I would like to thank the more than 40 000 Canadians who were involved in the many facets of the Commission's work. Their contribution has been invaluable.

Patricia A. Baird

Patricia Baird, M.D., C.M., FRCPC, F.C.C.M.G.

Introduction

Given the range and complexity of issues on which the Royal Commission on New Reproductive Technologies was asked to make recommendations, it was vital that it find a common way for Commissioners with varying backgrounds and life experiences to approach the technologies — an ethical framework for decision making was needed. The first paper in this volume of studies presents the ethical framework the Commission adopted: a modified ethic of care and a set of guiding principles that were used as a prism through which to view the technologies. The volume then goes on to explore some of the ethical issues raised by the development and use of new reproductive technologies.

How new reproductive technologies are used or not used will impinge upon deeply held views about the nature of reproduction and of relationships between individuals and between society and individuals. Moral reasoning and ethical analysis are essential in providing guidance in the complex areas of both public policy making and private decision making about the technologies. The ethical questions generated by the technologies must be answered in light of clearly outlined and explicit values and principles, so that Canadians can understand why and how the Commission came to its recommendations.

The importance and centrality the Commission has given to consideration of the ethical aspects of the technologies are symbolized by the decision to put this volume first in the series of volumes that present the Commission's research. The ethical issues and positions set out in the papers in this volume provide a context for the findings that follow in subsequent volumes, just as the Commission's ethical framework set the context for the reasoning leading to the recommendations in the Commission's Final Report.

The Studies

Will Kymlicka's clear and salient arguments for the Commission's adoption of an ethical framework with explicit guiding principles provide a cornerstone not only for this volume, but for all the research volumes and for the Commission's Final Report as well. As Dr. Kymlicka notes, the spelling out of the ethical principles used in reaching conclusions about matters in the Commission's mandate is an extension of the less clearly delineated role of ethical thinking found in many earlier inquiries into new reproductive technologies. A consideration of how these inquiries dealt with ethical aspects, a review of public input to this Commission on ethical issues, and a wide reading of the bioethical literature led Dr. Kymlicka to the conclusion that adopting a set of guiding principles is the most promising way to come to sound and caring public policy related to new reproductive technologies. Indeed, the emphasis on connectedness found in the ethic of care and the inclusive aspects inherent in the ethical framework outlined are particularly well suited to address the complexity and diversity of ethical challenges generated by new reproductive technologies, which have many and varied implications for the individuals and groups touched in one way or another by the technologies.

The adoption of this approach — an ethic of care framework and eight guiding principles — does not guarantee clear answers or resolve all moral disputes; it is not a magic formula. Rather, this approach facilitates a process of deliberation, reflection, and discovery that ensures a broader consideration of the questions and of the people involved. Through the reasoned and balanced application of this ethical framework, Canadian society can examine how the values it generally upholds — such as individual autonomy, equality, and a balancing of individual and collective interests — can be applied to emerging issues.

One of the key prerequisites of individual autonomy is the ability to make informed choices. Françoise Baylis makes the case that health care practitioners are morally obliged to give patients and research subjects adequate information so that they can make informed choices about participating in medical interventions. She enumerates and explains 10 categories of information that, at the very least, should be made available to the patient or subject. She discusses the obstacles to be overcome before informed choice can become a reality for Canadians facing decisions about their involvement with various new reproductive technologies.

Medicalization is a process whereby a type of behaviour or a physical condition previously thought to be outside the arena of health care intervention becomes, in time, regulated by health care institutions and professionals or by an authoritative definition of health and technological solutions. In the context of women's reproductive health, some critics have viewed medicalization as putting limits on the informed choice that Dr. Baylis emphasizes, and, therefore, on individual autonomy. The assessment by Michael Burgess and colleagues of medicalization as it

applies to the development of new reproductive technologies shows how analysis of a socio-medical phenomenon can lead to insights into both the positive and negative aspects of treating infertility as a medical condition. For instance, funding treatments through the health care system can increase access to services, thereby bringing social benefits to those who need them, but it may also mean that non-medical alternatives are devalued and made less desirable than a technological solution. The authors also show that the insights gained from this kind of analysis may be relevant in making public policy decisions about funding of treatments.

Prenatal diagnosis is cited by some critics as an example of how the medicalization of women's reproductive health — in this case of pregnancy — could remove choice from women by pressuring them to have the testing and to terminate the pregnancy if a serious disorder is detected. As Dorothy Wertz points out, however, because of the nature of prenatal diagnosis and the potential for termination that is involved, every aspect of the prenatal diagnosis process has been the object of intense scrutiny by practitioners, biomedical ethicists, and interested scholars. This has resulted in extensive ethical reflection internationally on the implications of the availability and use of prenatal diagnostic procedures and the need for non-coercive, non-directive counselling and choice. Dr. Wertz looks at the factors that parents consider in choosing to have prenatal diagnosis and deciding whether to terminate if the findings indicate a disorder. She notes that such decisions are made in a social context, and partly on the basis of what impact affected children would have on their own and their family's quality of life. The great majority of people think prenatal diagnosis should be available for serious disorders, and most favour leaving decisions regarding its use, and a subsequent termination if it shows a disorder, in the private sphere. Dr. Wertz also warns of the potential for misuse of prenatal diagnostic technology — for example, for sex selection — but also for prenatal paternity testing, tissue typing for organ or marrow donation, mandatory testing, and wrongful birth and wrongful life cases.

The final two studies in this volume describe the mechanisms and structures currently in use in this country to assess the ethical implications of research proposals or of new medical technologies. John Dossetor and Janet Storch examine the composition, function, and operations of two kinds of ethics committees: institutional ethics committees and research ethics boards. Their review provides an informative and useful guide to how ethical review is conducted in a practical sense in individual hospitals and clinics, as well as at the provincial and federal levels. It is clear from their work that integrated ethical review at a national level is needed, and that new reproductive technologies in particular have far-reaching social and ethical implications that need to be considered before implementation. This finding has particular importance for the Commission's recommendation for the establishment of a National Reproductive Technologies Commission, one of

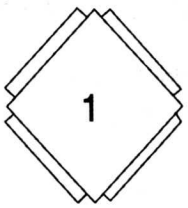
whose functions would be ethical review of research trials and proposed medical treatments.

The need for consideration by Canadians of the ethical issues associated with new reproductive technologies is not limited to this country's borders. Pran Manga addresses the significant moral implications for Canada of worldwide developments with regard to the technologies, particularly in developing countries. Dr. Manga believes that Canada has an opportunity to play a leading role in the development of international ethical guidelines and regulations for new reproductive technologies that would support human rights and oppose discrimination against women in developing countries. He makes the point forcefully that a first step is to ensure that Canadian practices are beyond reproach, so that Canada is in a position to act as a leader and exemplar.

Conclusion

Commissioners wanted to ensure that their ethical decision making was as wisely based as possible, and that their reasoning was made explicit and clear to those reading the report. They came to their recommendations with three considerations in mind: a clearly specified ethical framework; a conviction that medical practices should be evidence-based; and an understanding of the social values and attitudes of Canadians. However, if Commissioners concluded after ethical analysis that a technology or practice was ethically unacceptable, they made their recommendations in light of that conclusion, even if evidence showed a practice was effective.

The ethical framework used by the Commission could also guide the body it has recommended to be set up to ensure ongoing monitoring and policy making regarding new developments in reproductive technology. This approach to decision making would help ensure that how Canada deals with new reproductive technologies could, indeed, withstand scrutiny from other countries worldwide, and that Canada could fulfil a role as an international leader in this area.



Approaches to the Ethical Issues Raised by the Royal Commission's Mandate

Will Kymlicka

Executive Summary

In this study, the author examines how ethical issues have been approached by previous international inquiries into new reproductive technologies (NRTs), by academics working in the field of bioethics, and by intervenors at the Commission's public hearings.

The paper argues that it is important for the Commission to adopt a consistent approach to its ethical deliberations. Two possible approaches are considered: one involves adopting a comprehensive "ethical theory," such as utilitarianism or natural law; the other involves adopting a set of "guiding principles," such as respect for autonomy or protection of the child's best interests.

The strengths and limitations of each approach are discussed. The author argues that guiding principles offer a more promising route for evaluating public policy related to NRTs, because they are less controversial than comprehensive ethical theories and easier to apply to concrete policy issues.

Based on a review of the international inquiries, the Commission's public hearings, and the bioethics literature, the paper develops a preliminary set of seven widely shared guiding principles that could inform the Commission's deliberations.

This paper was completed for the Royal Commission on New Reproductive Technologies in October 1991.

While the author argues that the guiding principles approach is promising, he emphasizes that it cannot resolve all moral disagreement. He reviews some of the areas in which guiding principles will be controversial or indeterminate, and suggests various ways in which these disagreements can be handled. Particular attention is paid to the valuable role that public education and accountability can play in promoting informed debate about the ethical implications of NRTs.

Introduction

New reproductive technologies (NRTs)[1] raise a number of important moral issues. It is not always easy to distinguish moral issues from other kinds of issues, such as matters of personal taste or social etiquette. Different societies distinguish these different realms in different ways. But as Mary Warnock puts it, "it seems likely that in any society, at any time, questions relating to birth and death and to the establishing of families are regarded as morally significant."[2] It is the presence of these irreducibly moral issues that accounts for much of the public interest in NRTs and for the establishment of the Royal Commission on New Reproductive Technologies (RCNRT).

It is important, therefore, for the Commission to adopt a clear and consistent approach to its ethical deliberations. Many previous inquiries have been criticized for failing to do so. This paper considers two such approaches: one involves adopting a comprehensive "ethical theory," such as utilitarianism, natural law, or the ethic of care; the other involves adopting a set of "guiding principles," such as respect for individual autonomy, protection of the child's best interests, and respect for human life. While each approach has its strengths and limitations, this paper argues that the latter approach provides a more promising base for informed debate and public consensus.

Before considering these two approaches in more detail, it will be useful to consider how others have approached the ethical issues raised by NRTs. The following two sections, therefore, provide an overview of the approach taken by other inquiries into NRTs, in Canada and internationally, and the approach taken by Canadians in their interventions to the RCNRT public hearings.

As the following two sections indicate, a similar pattern emerged in both the international inquiries and the public hearing interventions:

- a number of inquiries/intervenors stated nothing at all about how their ethical conclusions were reached;
- of those that did explain their approach, only a few endorsed a particular comprehensive ethical theory, while the rest chose instead to rely on a set of guiding principles;

- of those that endorsed guiding principles, a few simply stated the very general principle that everyone's rights and interests need to be considered, while the rest endorsed a diverse range of more specific principles, including principles of autonomy, respect for human life, non-commercialization, beneficent use of technology, and protection of the child's best interests.

Ethical Discussions in the International Inquiries

Many international inquiries emphasize the importance of ethical issues. The mandates for these inquiries often explicitly mention ethical issues, and it is not uncommon for reports to begin by stating that the basis for public concern about NRTs is the challenge they pose to our traditional moral conceptions.

However, there was no agreement on how ethical issues should be approached. The following summary focusses on 35 inquiries from Great Britain, Australia, the United States, and Canada. These are listed in an appendix. (The number in brackets refers to the number of the inquiry as it is listed in the appendix.) To keep the summaries concise and unbiased, only those theories or principles explicitly identified and endorsed in the relevant report are cited. As will be apparent, these inquiries differ in the ethical approach they endorse, and in the level of attention they pay to ethical issues.

Canada: The 10 Canadian reports examined for this paper fall into five groups:

1. One provided no discussion of its approach to ethical deliberations [1].
2. Four stated that their general aim was to protect the rights and interests of all parties, including society, without endorsing any particular theory or set of principles for identifying or balancing these rights and interests [2,5,6,8].
3. Two stated that they sought to avoid ethical issues [7,9]. Of these, one report nonetheless endorsed the following basic principles: human dignity should be respected, NRTs should only be used for therapeutic purposes, the child's best interests should be protected, and commercialization should be prohibited [9].
4. Two endorsed the ideals of "autonomy, beneficence, and justice" as their guiding principles [3,4].
5. One stated that it was guided by these "fundamental social values": non-commercialization, non-discrimination in access, informed consent, and protection of the child's best interests. It

asserted that fundamental social values are embodied in the law and can be identified by examining the law [10].

United States: The seven American inquiries examined for this paper fall into three groups:

1. Four did not discuss their approach to ethical deliberations [1,2,4,5].
2. Two endorsed the principles of "autonomy, beneficence, and justice" [3,7].
3. One stated that its aim was to balance the rights and interests of children, parents, and society, without endorsing any particular theory or set of principles for identifying or balancing these rights and interests [6].

Great Britain: The seven British inquiries examined for this paper fall into four groups:

1. Four did not discuss their ethical theory [2,3,6,7].
2. One did not endorse any particular ethical theory, except to say that it rejected utilitarianism and felt that moral argument involves, at least in part, an appeal to moral sentiment [1].
3. One endorsed natural law as the appropriate ethical theory for evaluating NRTs. However, since the members of this inquiry could not agree on how to interpret the requirements of natural law, their recommendations were instead based on three "subsidiary principles": unity of marriage, protection of human life, and informed consent [4].
4. One claimed that "respect" is the fundamental moral notion and that all moral beings are owed respect. It did not endorse any theory of how to interpret that notion [5].

Australia: The 11 Australian inquiries examined for this paper fall into seven groups:

1. One did not provide any account of its ethical deliberations [10].
2. One stated that its fundamental principle was that the child's best interests must be paramount [2].
3. Four appealed to "community standards" or "community sentiments" as the basis of their ethical deliberations. Three of these tried to apply community sentiments directly; i.e., they based their acceptance or rejection of a particular NRT on the level of public acceptance of that NRT [1,8,9]. The fourth, however, appealed to community sentiment more indirectly. It attempted to identify some general community standards that are applied in many areas of social life and that could provide guidance in the case of NRTs. These more general community

standards were said to include the principles of respect for the child's best interests, respect for human life, the non-commercialization of reproduction, and equal access to health care. These principles were seen as flowing from the more general principle of respect for human dignity [7].

4. One appealed to the idea that the rights and interests of all must be considered, without endorsing any particular theory or set of principles for identifying or balancing these rights and interests [5].
5. Two relied primarily on the principle of respect for personal autonomy, although this had to be balanced with the principle of respect for the child's best interests and/or protection of the common good [4,11].
6. One relied primarily on the principle of respect for human life, including potential human life [3].
7. One stated that its basic principle was to improve the health and well-being of the members of the community [6].

Ethical Discussions in the Public Hearings

As with the international inquiries, the ethical implications of NRTs were obviously of great concern to many public hearing intervenors. Most intervenors made at least some mention of these implications, and a number of intervenors made them the focus of their presentations. There was general agreement that ethical issues are important and deserve more study and debate than they have received so far. There was no agreement, however, about how the RCNRT should approach these issues.

In some cases, intervenors simply stated their ethical beliefs without giving any reasons for those beliefs. In other cases, however, the intervenors attempted to give a more systematic or theoretical account of their moral reasoning. They discussed the ethical theory or guiding principles upon which their beliefs were based and had suggestions about how the RCNRT should approach its ethical deliberations. Of these, a few intervenors recommended that a specific ethical theory be adopted by the Commission for its deliberations. For example, one intervenor recommended a "natural law" framework, while another endorsed a strict libertarian framework. There were also a few passing references to the "ethic of care" and to utilitarianism, although it is not clear whether these were being recommended as a comprehensive framework for public policy on NRTs. These (and other) theories are discussed in detail below.

However, most intervenors who discussed their ethical reasoning did not endorse a particular ethical theory. Instead, a number of intervenors

appealed to "guiding principles," which were felt to be consistent with many different ethical theories and hence more likely candidates for public consensus. Approximately 75 intervenors proposed one or more guiding principles. Not surprisingly, these proposed guiding principles varied from sector to sector. The following is a brief summary of the principles that were endorsed most frequently within each sector.[3] As with the international inquiries, only those principles that were explicitly identified as such by the intervenor are noted.

1. Medical community: Most medical intervenors, particularly those representing professional organizations, endorsed the following three principles: autonomy, beneficence, and justice.[4]
2. Family, religious, and pro-life groups: The most frequent principles endorsed by this sector were respect for human life from the moment of conception, and protection of the family as the proper environment for the child.
3. Women's groups: The most frequent principles endorsed by women's groups were respect for women's reproductive autonomy; non-discriminatory access to NRTs regardless of class, race, sexual orientation, or disability; and non-commercialization of reproductive materials or services.
4. Alternative and community health and social services: The three most frequently endorsed principles within this sector were respect for individual choice; cost-effective health care, including public health promotion and disease prevention; and public participation and accountability for reproductive health care policy decisions.
5. Cultural/ethnic groups: The most frequently endorsed principle in this sector was equal (non-discriminatory) access.
6. Legal and human rights groups: The most frequently endorsed principles in this sector were informed consent, and protection of the child's best interests.
7. Groups and individuals representing people with disabilities: Intervenors from this sector focussed on principles of equality and individual autonomy.

No coherent pattern of principles could be detected in the remaining sectors (labour groups, concerned citizens, consumers, industry), partly because so few intervenors from these sectors endorsed a set of guiding principles.

It can be seen from this brief sketch that two distinct approaches to ethical issues have been taken by public hearing intervenors and international inquiries (insofar as they explicitly discussed their ethical reasoning). A few of the intervenors and inquiries endorsed a particular comprehensive ethical theory, while most chose to rely on a set of guiding principles. The next two sections discuss in more detail the option of

adopting an explicit ethical theory for the Commission's work. The final two sections of the paper consider the option of adopting a set of guiding principles.

Six Ethical Theories

Many of the international inquiries have been heavily criticized for failing to adopt a clear ethical theory and for their lack of theoretical sophistication in the field of bioethics. Indeed, an entire issue of the *Journal of Medicine and Philosophy* is devoted to critiques of the ethical reasoning of government bioethics commissions around the world (including Canada).[5]

Adopting a comprehensive ethical theory, and then rigorously applying it to the various ethical issues raised by particular NRTs, is said by these critics to be important for two reasons: it would ensure consistency among all the recommendations, since they would all be derived from a single ethical perspective, and it would promote informed debate, since readers who disagreed with the recommendations would be able to determine exactly where the disagreements arose (e.g., whether they arose at the level of fundamental moral perspective, in the application of that perspective, from different empirical assumptions, etc.). However, the critics do not agree on which ethical theory should be adopted or on how competing ethical theories are to be evaluated in the attempt to choose the most appropriate one.

At least six major ethical theories can be found in most moral philosophy or bioethics textbooks in Canada:

1. *Utilitarianism*: Utilitarianism is the view that the morally right action or policy is the one that creates the "greatest happiness for the greatest number" of people in society — i.e., the one that maximizes human well-being. There are many versions of utilitarianism, depending on how human "happiness" or "well-being" is defined and on whether the instruction to maximize well-being is supposed to be applied by individuals in their everyday decisions, or just by institutions and governments.

   All these versions, however, are *consequentialist*, in the sense that an action or policy is judged by its potential impact on everyone's interests, not on its intrinsic qualities. For example, utilitarians believe that there is nothing intrinsically right or wrong about experimenting on people without their consent. If such experimentation would maximize human well-being in society by generating valuable knowledge, then it is morally justified. Many utilitarians believe, however, that allowing people to experiment on others without their consent would undermine

social trust and cooperation, and that this negative consequence would outweigh the benefits of increased knowledge.

2. *Deontology*: Deontologists believe that certain acts and policies are intrinsically wrong, regardless of the possible good consequences that might come from them. For example, many deontologists believe that people have intrinsic moral rights over their bodies, and these rights constrain what medical researchers can do to them in the name of the greater good. Deontological theories are often formulated in terms of rules prohibiting actions that can be said (and known), before the fact, to be wrong.

   There are many versions of deontology, depending on which actions and policies are said to be intrinsically wrong and on how absolute these prohibitions are said to be. For example, most deontologists agree that lying and torturing are intrinsically wrong, and so cannot be done even to bring about great *benefits* to others, but some deontologists believe that they may be permissible if done to avoid great *harm* to others. In explaining why certain actions are prohibited, most contemporary deontologists appeal to the idea that anyone who acts in these ways fails to show respect for others as rational agents. Since the injunction to always respect people as rational agents comes from Immanuel Kant's *categorical imperative*, deontological theories are sometimes referred to as "Kantian" theories of morality.

3. *Natural law*: Proponents of natural law believe that morality is based on the natural order of things, and that moral goodness does not consist in transcending or escaping the natural order, but in its perfection. Principles of morality can be discerned in the basic tendencies of the natural order, including the desire of all living things for self-preservation, the desire of all animals (human and non-human) for procreation and family life, and, above all, the inclination of humans to reason and act in accordance with rational principles. Each of these natural tendencies gives rise to natural law duties regarding respect for life, protection of the family, and respect for rational autonomy. Behaviour that conflicts with or frustrates human beings' determinate and rational human nature is morally wrong. There are many different versions of natural law theory, depending on what actions and policies are identified as consistent with human nature and human reason (a common example of impermissible action is euthanasia).

   Natural law is commonly equated with the doctrines of the Roman Catholic Church, since the Church is perhaps the most consistent defender and interpreter of the natural law tradition.

However, it is important to note the difference between natural law and divine law. Knowledge of divine law is said to be received through divine revelation; but knowledge of the principles of natural law is said to be universally accessible to human reason, even by those who are unaware of the teachings of the Church or who have not received divine revelation. While the Church's general teachings are based on both natural and divine law, it only appeals to natural law in its public policy recommendations, since it believes that public policy in a pluralistic country should be based on principles that stand independently of religious belief. For this reason, natural law underlies that part of the Catholic theology that is said to be accessible to all on the basis of their natural powers of perception and reason.

4. *Contractarianism*: Contractarianism is the view that morality can be understood as an agreement or social contract between the members of a society regarding how best to regulate their common affairs. Generally speaking, contractarians do not believe that there has been, or should be, an actual contract among the members of society. Rather, contractarians believe that morality can be understood *as if* it were a social contract, and that the best way to determine whether a proposed moral rule is justified is to ask whether each person in society *could* agree to it.

   There are many versions of contractarianism, depending on how this hypothetical agreement is understood. In the real world, there are often substantial differences in bargaining power between the weak and the strong, or the healthy and the infirm. If the stronger members of society are allowed to take advantage of their greater bargaining power, then they will demand special privileges while according few, if any, rights to the weak and vulnerable (e.g., infants, people with disabilities, the demented).

   For one strand of contractarianism, these inequalities between the strong and the weak are the unavoidable consequence of viewing morality as a social contract, rather than as a matter of natural law (see the mutual advantage theory of morality, discussed below). Most contractarians, however, believe it is unfair for differences in knowledge, bargaining power, or threat advantage to influence the terms of the social contract. Consequently, they ask not what people would agree to given their present inequalities in bargaining power, but rather what people would agree to if they were negotiating from a position of equality. Other contractarians ask what people would agree to if they were motivated by benevolence rather than self-interest.

These forms of contractarianism tend to emphasize principles of egalitarian justice and respect for individual autonomy.

5. *The ethic of care*: The four previous theories can all be described as belonging to the "rights/interests" model of moral reasoning; that is, they all start with a fairly general theory of human interests or human nature, and then seek to deduce abstract moral principles of justice or human rights from it. Proponents of the ethic of care believe that this model is primarily a male model of moral reasoning, which needs to be either replaced or complemented with the more female "ethic of care." This ethic emphasizes the importance of being sensitive to the needs of unique individuals in each case, rather than trying to find universal principles of right conduct that will apply to all cases. It also emphasizes the importance of attending to responsibilities and the preservation of social relationships, rather than focussing on competing rights.

   There are many versions of the ethic of care, depending on whether it is meant to supplement or replace principles of justice and rights, and on how our responsibilities are to be enforced. For example, some proponents of the ethic of care say that once we focus on the importance of relationships, rather than competing rights, public policy should treat the pregnant woman and her fetus as a single unit and not restrict the woman's rights in the name of the fetus. Others, however, argue that a concern for relationships and responsibilities suggests that the law should impose a "duty of care" on pregnant women to protect the fetus.

6. *Mutual advantage*: All of the theories listed above believe there are such things as moral reasons, which are irreducible to, and may conflict with, prudential reasons (i.e., self-interest). According to these theories, we are morally obligated to show respect and concern for others, whether or not this promotes our personal goals and desires.

   For proponents of the mutual advantage theory of morality, however, there are no such things as irreducibly moral reasons or values. According to this view, I only have a reason to do something if the action satisfies a desire of mine. If respecting others does not satisfy a desire of mine, then I have no reason to do it. This means there are no general moral rules that every person must obey, regardless of their personal goals.

   However, it may be in each person's interests to obey certain rules (e.g., against theft and injury), so long as everyone else also obeys them. Adherence to these rules requires some short-term sacrifice of personal goals but promotes one's long-term interests by providing protection from injury and creating the conditions

of stable cooperation. As a consequence, a set of social rules will evolve that are mutually advantageous, and mutual advantage theorists often describe these as "moral" rules. However, it may not be to the advantage of the strong to accept rules that require them to protect or assist the weak. Indeed, where differences in power are sufficiently great, mutual advantage theories may justify the enslavement of the weak and vulnerable.

Since the idea that morality is just a strategy for promoting one's long-term self-interest was developed at length by Thomas Hobbes, mutual advantage theories are often called "Hobbesian" theories of morality. However, it is important to note that Hobbesian theories are arguably not theories of *morality* at all. For many people, to look at things from the "moral point of view" is to adopt the perspective that human beings, just in virtue of their humanity, have intrinsic worth and are owed some degree of respect and concern, regardless of their bargaining power. Hobbesians deny that we have any reason to adopt this point of view. But in rejecting the moral point of view, and in denying that there are irreducibly moral reasons, mutual advantage theorists are not so much offering an alternative account *of* morality as an alternative *to* morality.

While these are the six most common theories in contemporary moral philosophy, there are other theories available for consideration. With the exception of the natural law tradition, these six theories are generally perceived as being secular theories of ethics. There are other more explicitly theological theories that could be considered, however. Moreover, while these six theories have dominated Western moral discourse, there are important ethical and religious traditions, including Islam, Hinduism, Buddhism, Confucianism, et cetera.

The contrast between secular and religious ethics in the West may be overdrawn, particularly in the context of debates regarding public policy. For, as noted in the discussion of natural law, it has been a staple of Catholic (and Protestant) moral argument for centuries that civil authority in pluralist countries must be exercised in accordance with principles that can be defended independently of any particular religious belief. Consequently, most religious writers on NRTs distinguish between arguments directed primarily at the members of their own community of faith, which are often explicitly theological, and those that appeal to the broader public. The latter adopt a "public" language and framework that are consistent with their religious beliefs but not dependent on them.

For example, the Catholic Church argues that masturbation is immoral, a claim that is often defended by appeal to biblical injunctions against "spilling one's seed." Therefore, the Church insists that its members not engage in forms of artificial insemination that involve masturbation, and some Catholic doctors will not provide that service.

However, the Church does not seek to prohibit other people from providing artificial insemination by husband (AIH) involving masturbation. Moreover, this is not simply a tactical decision to avoid a public dispute that the Church would likely lose. Rather, the Church believes it would be wrong to prohibit others from using such forms of AIH, since it would violate their freedom of conscience, which is itself a great value. Individuals of different faiths should be free to pursue their religious beliefs, so long as they do not harm others or undermine the common good.

But we misinterpret Catholic ethics if we put the injunction to avoid masturbation on a par with the injunction to avoid abortion of fetuses with genetic anomalies. The former injunction is addressed to members of the community of faith, but the latter is (also) addressed to the broader public and is intended to guide public policy. The Catholic Church believes that it has a moral responsibility to the larger community to defend human rights and the common good, and that this responsibility requires setting aside its particular religious beliefs and adopting instead a public language. When Catholics argue against abortion of fetuses with genetic anomalies, therefore, they are not appealing to their religious beliefs or asking that society be sensitive to their religious beliefs. They are appealing to a public language and asking that society consider the moral status of the fetus in a non-sectarian way.

Thus, secular ethics are an important part of, rather than entirely distinct from, religious ethics. As noted above, Catholics have generally adopted the public language of natural law. Protestants and Jews have generally adopted the public language of deontology. However, as discussed below, these categories are not clear-cut, and one can find adherents of different religions relying on different secular theories.

Moreover, these secular ethical theories are, to a large extent, developments of religious traditions. For example, one fundamental basis of Judeo-Christian ethics is the idea of *agape*, or love. God loves all his children and has instructed people to "love thy neighbour as thyself." This instruction to love thy neighbour is the basis for Jewish ethics, and Christ's teachings can be seen as attempting to extend this idea. *Agape* is reflected in Christ's golden rule — do unto others as you would have them do unto you. (A similar golden rule can be found in the Jewish tradition.) It is generally agreed that this idea of love for all God's children is the precursor of the idea, found in five of the six theories, that we should show equal concern for all members of the community.

The golden rule has become secularized in the form of Kant's categorical imperative (treat other people as ends in themselves, never only as a means), or in the more general idea that from the moral point of view each person matters and matters equally. The moral impulse is the same, but its source has changed; that is, our obligation to love others is no longer seen as deriving from the fact that we are all God's children, but rather from the fact that we are all human beings. It is respect for our

shared humanity, rather than respect for our divine creation, that underlies secular morality.

This helps explain why it is possible for religious theorists to adopt secular theories when engaged in public policy arguments. Both theists and secularists believe that all human beings deserve respect and consideration because of their distinctive capacities for consciousness and reason. Theists believe that the reason *why* humans deserve this respect is that our distinctive capacities were given to us by God, and they allow us to participate in the Divine. For secular theorists, these capacities are important in and of themselves, independent of any divine creation. Consequently, theists and secular theorists disagree about the *source* of our obligation to respect human beings, but do not necessarily disagree about the *content* of that obligation — that is, they can both agree that morality requires respect for each person's rationality and concern for their conscious well-being. This is why secular theories about respect for persons are consistent with, but not dependent on, religious beliefs.

Given Canada's increasingly multicultural population, it might also be useful to consider some of the major Eastern ethical traditions. However, as there have been few suggestions in the Canadian context that these ethical traditions should provide the basis for public policy, they will not be examined here. When adherents of these traditions have entered public debate, it has been mainly to seek greater sensitivity by medical professionals and the health care system to their distinctive needs and beliefs.

Difficulties with Adopting an Ethical Theory for the Commission's Work

As noted above, some people believe it would be useful if government commissions such as the RCNRT adopted a comprehensive ethical theory and then rigorously applied it to the various ethical issues raised by NRTs. This section will consider two practical difficulties with this: consensus on a theory is unlikely to be achieved, and, even if consensus is achieved, the theory may not in fact yield useful answers to the issues facing the RCNRT.

The relative merits of the various theories have been the subject of debate for centuries, and it seems inevitable that reasonable people will continue to disagree. Some people take the persistence of disagreement as evidence that there is no one right answer to moral issues. For example, according to Mary Warnock, "It cannot be too strongly emphasised that in questions of morality, though there may be better and worse judgments, there is no such thing as a correct judgment."[6] Even those who believe there are right answers must admit these answers can be difficult to discover. Moral philosophers have not yet discovered a knockout argument for or against these different theories. While new theories are developed

(e.g., the ethic of care), they do not refute earlier theories, in the way that Copernicus is thought to have provided a decisive refutation of Ptolemy.

There have been various attempts to refute ethical theories on the basis of logic (e.g., trying to show that a theory is self-contradictory) or sentiment (e.g., trying to show that a theory violates our everyday intuitions about what is right and wrong). But the fact that these theories have maintained adherents for centuries suggests that they are not obviously illogical. And while it is not difficult to show that some theories (e.g., utilitarianism) violate some of our everyday moral intuitions, this is not a conclusive argument, for not everyone shares the same intuitions, and in any event, it seems that each of these theories has some counter-intuitive implications. Thus, neither logic nor sentiment is capable of providing a conclusive argument for or against a particular ethical theory.

An additional difficulty is that even if everyone did adopt a particular theory, it is unlikely that they would all agree on how to interpret it. The hard work is not done even if a theory has been selected, since there is no clear, direct, uncontroversial path from the ethical theory to conclusions regarding NRTs.

It is rarely possible to draw a clear and direct line from the very general concepts of *agreement*, *utility*, *care*, etc., found in the ethical theory, to the nuts and bolts of particular ethical decisions. There is no magical formula for applying any of these theories. Even if we decide that morality is a matter of maximizing utility, for example, how do we know what will maximize utility? Should utility be measured in terms of subjective preferences, or are there objective standards by which we can judge some interests to be more important or urgent? Or if we define morality in terms of natural law, which natural dispositions should we respect? Most proponents of natural law emphasize that one of the human dispositions to be respected is the human quest for intellectual growth and scientific development. But when is technical progress a manifestation of our natural dispositions, and when is it a violation of them?[7]

Again, if we define morality in terms of ethical caring, what counts as ethical caring? Many proponents of the ethic of care argue that it requires shifting away from a preoccupation with conflicting rights toward a concern for the responsible maintenance of relationships, especially with dependants. But what counts as the irresponsible severing or neglect of a relationship? If we decide that morality is a matter of agreement, what kinds of agreement count? Most contractarians say that morally relevant agreements must be reasonable agreements. But what counts as reasonable?

This is not to deny there are better and worse interpretations of *utility*, *nature*, *care*, or *agreement*. However, just as reasonable people continue to disagree about which ethical theory to adopt, so they will continue to disagree about which interpretation of these theories is best. There is nothing in the structure of the various theories that guarantees everyone will interpret them in the same way. On the contrary, there is every reason

to believe that utilitarians will continue to disagree over what promotes utility; contractarians, over what is reasonable; natural law proponents, over what is natural; proponents of the ethic of care, over what is responsible; et cetera.

So the quest to select a particular ethical theory is not likely to be very helpful. There may be a more useful approach. Rather than taking the time to resolve the (unresolvable) philosophical differences among these various theories, it may be more profitable to build instead on their points of agreement. In particular, it may be possible to get proponents of different theories to agree on a set of lower-level principles — while the different theories are implacably opposed at the theoretical level, they tend to converge more often at the practical level.

There is a substantial body of literature, particularly in the field of applied ethics, on the role of mid-level principles. Precisely because concepts such as *nature*, *agreement*, or *care* are so hard to interpret and apply, theorists who work in the field of applied ethics often need to derive a set of more concrete, mid-level rules or principles from their preferred ethical theory. For example, many utilitarians recognize that it is impossible to determine what will maximize utility in a particular context (partly because there is no agreement on the definition of utility). So they seek to identify mid-level principles that focus on more specific and tangible human interests, such as people's desire for autonomy and the need to prevent harm. Decision makers can then follow these principles directly, without having to understand (let alone measure) what promotes utility in the abstract and aggregate. According to utilitarians working in the field of applied ethics, the best we can do to promote overall utility is in fact to ignore overall utility, and instead focus on protecting certain specific important interests (e.g., through rules requiring informed consent and safe practices). This is often called *rule-utilitarianism*, since it instructs people to obey a set of mid-level rules, rather than aim directly at the maximization of utility.

Similar moves to derive mid-level principles are made by proponents of other ethical theories. Indeed, it turns out that proponents of different theories often generate similar principles. The kinds of rules endorsed by rule-utilitarians are often closely related to the kinds of dispositions endorsed by proponents of natural law, which are related to the kinds of agreements endorsed by contractarians and to the kinds of relationships endorsed by proponents of the ethic of care. For example, all these theories seem to converge on principles emphasizing respect for individual autonomy and protection of the child's interests.

Why would theories that disagree at the theoretical level converge on the same mid-level principles? One reason is that they do not entirely disagree at the theoretical level. With one exception,[8] they all share a commitment to what we can call the "moral point of view." That is, they all believe there is such a thing as a moral perspective on issues, which is

distinct from a prudential (self-interest), scientific, or aesthetic perspective, and which is defined by some notion of respect for persons.

From a prudential point of view, some people's lives may not matter to us, particularly if they are too weak or too distant to either harm or benefit us. From an aesthetic point of view, some people's lives may not matter, particularly if (as with Nietzsche) we think that only a few people are capable of genuine greatness in thought or action. But from a moral point of view, all people matter in and of themselves. It matters how well their lives go, and if our decisions affect their well-being, then we must take that into account. Adopting the moral point of view, therefore, requires that we sympathetically attend to people's interests and circumstances, try to understand how things look from their point of view, and give due weight to their well-being. Adopting the moral point of view requires that we "put ourselves in other people's shoes," and ensure that our actions are acceptable from their point of view as well as our own.

The idea that we must sympathetically attend to other people's well-being is sometimes said to be distinctive to the ethic of care, but this idea is in fact shared by all of these theories. Despite their many differences, utilitarians, contractarians, care theorists, and others all agree to the following claims that define the moral point of view:

1. Moral reasoning requires that we sympathetically identify with the situation of others and consider their views and interests alongside our own. This consideration is due to others by virtue of our shared humanity.
2. This process of empathizing with others is more difficult the further others are from us (in terms of social status, natural talents, racial/ethnic background, etc.).
3. To fully consider the situation of distant others, we must overcome or extend our natural inclination to sympathize with those who are closest to us and seek to adopt a more generalized concern and attentiveness.

These claims can be found in every major moral theory, secular or religious, and underlie "justice" theories, such as those of Mill and Rawls, as much as "care" theories, like those of Gilligan or Baier.[9]

This shared commitment to the moral point of view helps explain why there is a convergence on principles of respect for autonomy and protection of the child's interests. Once we put ourselves in other people's shoes, it is only natural that we will see the importance of respecting their points of view and of protecting those who are vulnerable. Thus we arrive at principles of autonomy and protection of the child's interests.

It seems that when practical decisions must be made, each theory relies less on the philosophical nuances that distinguish it from all the others and more on the basic moral impulse it shares with all the others; i.e., the basic impulse to put ourselves in other people's shoes, understand

their perceptions, and give due weight to their interests. The subtle distinctions among the theories, while the subject of heated philosophical debate, are relatively minor when compared with this central moral impulse that they all share, particularly at the level of practical decision making. The quest to select an ethical theory, then, may ultimately be unnecessary. For when we try to apply a theory, we end up relying on mid-level principles that all theories share.

A major concern with the RCNRT's adoption of a particular ethical theory is that it may alienate unnecessarily a broad range of people who might otherwise agree with the Commission's reasoning and recommendations. There will be many people who do not share any given theory preferred by the Commission and who cannot be persuaded to adopt it. Therefore, they might automatically reject the Commission's recommendations, even though they may well agree with the mid-level principles that actually generate the conclusions.

In summary, there are three important reasons why adopting an ethical theory might not be appropriate for the Commission:

1. There are deep disagreements about the relative adequacy of different theories, disagreements that are hard to resolve, or even to characterize. Selecting a particular theory is likely to alienate a substantial portion of the population.
2. There is a large gulf between endorsing a comprehensive theory and arriving at practical conclusions on specific NRT-related issues. Theories are not formulas that can generate clear answers to difficult issues. They have to be interpreted before they can be applied, and these questions of interpretation can be as difficult and controversial as the question of which theory to adopt. Therefore, adopting a particular ethical theory may not bring us any closer to resolving the disputes within the Commission's mandate.
3. Given the difficulty of interpreting and applying ethical theories in a rigorous way, most applied ethicists rely instead on a looser form of argument appealing to mid-level principles rather than to fundamental theoretical concepts. To a large extent, these mid-level principles can be derived and applied without undergoing the difficult and potentially divisive task of adopting an ethical theory.

Guiding Principles

If the Commission decides to base its ethical deliberations on guiding principles, which principles should it adopt, and where do they come from? Three sources of guiding principles will be examined: the RCNRT's public

hearing interventions, the international inquiries, and the bioethics literature.

Public Hearing Interventions

The public hearings provide a helpful starting point for identifying guiding principles. Seventy-five intervenors endorsed one or more guiding principles, representing a wide range of sectors and interests. These interventions provide not only a rich source of potential principles, endorsed with the specific Canadian context in mind, but also a preliminary indication of the extent to which a consensus on principles is possible.

At first glance, it may seem that the public hearings do not provide much support for the claim that a consensus on guiding principles is possible, for, as discussed earlier, intervenors from different sectors did not agree on the appropriate principles for managing NRTs. However, it is easy to exaggerate the extent of this disagreement. While different groups endorsed different principles, these principles are largely complementary rather than competing. For example, the family sector emphasized the child's interests, the alternative health sector emphasized accountability, and women's groups emphasized the principle of the non-commercialization of reproduction. But these three principles are quite consistent with each other, and indeed it is clear from their recommendations that all three sectors share all three principles. While intervenors from the family sector did not explicitly include accountability and non-commercialization among their guiding principles, their proposals to establish a national monitoring agency and to ban the selling of genetic material reveal that, in fact, they do accept these principles.

In other words, while different sectors emphasized different principles, they might not oppose each other's principles. Moreover, there was always some overlap among the sectors. For example, while the principle of autonomy was advanced most forcefully by women's groups, and the principle of respect for human life was advanced most forcefully by family groups, there were also some women's groups who emphasized respect for life and some family groups who emphasized respect for autonomy.

This suggests that beneath the apparent diversity of principles endorsed in the public hearings, a core of shared principles can be identified. A re-examination of the interventions suggests that the following seven principles received considerable support from a broad range of sectors:[10]

1. individual autonomy;
2. appropriate use of resources;
3. non-commercialization of reproduction;
4. equality;

5. respect for human life;
6. protection of the vulnerable; and
7. accountability.

These principles are examined in turn below.

1. *Individual Autonomy*

The principle of autonomy states that people should be free to choose how to lead their lives, particularly with respect to their fundamental personality-defining commitments (e.g., work, family, sexuality). Of course, this is not an unqualified principle. One's freedom of choice does not include the freedom to harm or coerce others, or to undermine social stability. Moreover, some restrictions must be placed on people for their own good, in circumstances where they lack the information or competence necessary to make reasonable decisions. However, it is a defining feature of modern culture that individuals are seen as having the right (and the responsibility) to decide what kind of life they want to lead, and what kind of person they want to be.

As with most of the guiding principles, the principle of autonomy has a number of implications for the management of NRTs. Minimally, the protection of autonomy generates a requirement of "informed consent" to medical procedures. If a woman is to have autonomous control of her person, then others can't intrude on her body without her consent. The active promotion of autonomy might also generate a requirement of "informed choice." Autonomy requires access to, and information about, a wide range of options. It might also require the provision of psychosocial counselling to help patients deliberate effectively about these options.

In the public hearings, the principle of autonomy was invoked in various ways. Some intervenors focussed on informed consent, some on informed choice. Some focussed on providing more information or options, others focussed on removing social pressures. While most intervenors felt that reproduction was a fundamental personality-defining commitment, some explained this in terms of the importance of family life (medical; alternate health), while others tied it to the importance of being able to control one's body (women's).[11] Some intervenors also noted that medical professionals have a right to autonomy — for example, a right to refuse to provide treatments that violate their conscience.

2. *Appropriate Use of Resources*

The principle of the appropriate use of resources states that decisions about the provision of new services or technologies must be made in accordance with clearly defined health care priorities, recognizing that there are competing needs and scarce resources. The term "appropriate use of resources" comes from the Canadian Nurses Association's brief,[12] but it seems to capture an ideal identified in different ways by other intervenors. Some intervenors talked about "matching health care resources to health

needs," or ensuring that resource decisions promoted "the greatest good of the greatest number." In each case, the underlying idea is that society must (re-)establish a sense of its health care priorities and not allow these priorities to be distorted by the allure of high technology.

This principle has both negative and positive implications for funding. Negatively, the principle implies that technology should not be publicly funded if it does not promise substantial health benefits. Positively, it implies that health care procedures should be provided if they are beneficial, since one of the responsibilities of governments is to promote the health and well-being of their citizens.[13]

In the public hearings, this principle was interpreted in various ways. For most intervenors, it was seen as requiring rigorous and ongoing cost-benefit evaluation of technology. For some intervenors (particularly women's groups), it was also seen as requiring greater attention to the full range of women's reproductive health care needs. Intervenors from the alternative health sector often argued that the principle of the appropriate use of resources will lead, in turn, to various "public health principles," such as the principle of prevention. Prevention was seen by many intervenors as a neglected and cost-effective response to health care needs, which should take precedence over high-technology therapies. There was a general belief that NRTs have not yet been adequately evaluated in terms of their contribution to the meeting of genuine health needs.

3. *Non-Commercialization of Reproduction*

The principle of non-commercialization states that it is inappropriate for decisions involving human reproduction to be determined by the profit motive. Therefore, the buying and selling of reproductive materials (e.g., human embryos, fetal tissue) or reproductive services (e.g., commercial surrogacy) is inappropriate.

The prohibition of commercialization is said to be important for a number of reasons. Commercialization could lead to exploitation of the poor. Commercialization of childbearing could also harm children, by promoting the view that children are commodities. Commercialization of gametes, embryos, and fetal tissue would show disrespect for human life. More generally, introduction of the profit motive into the sphere of reproduction is degrading. According to Elizabeth Anderson,[14] commerce is appropriate for the exchange of things that are to be "used," but not for objects or services that are to be "respected" or "admired." Since the human capacity for reproduction and the genetic materials that it creates should be respected — and not merely used — introduction of the profit motive is degrading.

In the public hearings, this principle was interpreted in various ways. Some intervenors distinguished between "payment for services" and "compensation for expenses," and argued that the latter was acceptable while the former was not. Others, however, argued that any financial exchange was unacceptable, and that compensation for expenses was a

screen behind which payment for services could be made. There was also some dispute about whether the existence of commercial sperm banks or private *in vitro* fertilization (IVF) clinics constituted inappropriate commercialization. There was near-unanimous agreement, however, that the buying and selling of embryos, fetuses, and children was unacceptable, as was the creation of commercial surrogacy agencies.

4. *Equality*

The principle of equality states, at a general level, that every member of the community is entitled to equal concern and respect, and that, at a more specific level, every member of the community should have equal access to basic public services, such as health care and education. Equality, therefore, is really two distinct principles.[15] The first is the principle of moral equality, which is more or less equivalent to the "moral point of view" — the view that the well-being of each person matters and matters equally. This precludes any social practice based on the assumption that some people's lives are worth less than others. Secondly, there is the principle of equal access to basic public services, such as health care or education.[16] In our society, it is generally assumed that equal access to basic services is required by, and part of, the principle of treating people with equal respect.

There are different ways of interpreting these principles. Minimally, respect for equality requires that laws discriminating against certain groups should be repealed. The principles of equality preclude any legal system that creates first- and second-class citizens. However, respect for equality may also require active steps to ensure that (1) all members of society are treated with equal respect throughout society (e.g., educational programs against racism, sexism); and (2) all members are equally capable of accessing public services (e.g., special outreach programs for remote communities or minority cultural and linguistic groups).

While everyone agrees about the importance of eliminating legal discrimination, there is less agreement about the necessity of positive measures to promote equality. Libertarians and others on the right wing of the political spectrum argue that removing legal barriers is sufficient to ensure equality, and that positive measures to promote particular groups are unfair, divisive, and restrictive of individual freedom. Those on the left wing of the political spectrum argue that the mere removal of legal barriers does not create genuine equality in social status, economic opportunities, or access to services, and that positive measures are required to overcome entrenched barriers or prejudices facing disadvantaged groups.

In the public hearings, the principle of equality was invoked in a number of contexts. Some intervenors representing people with disabilities focussed on the most general principle of moral equality and argued that certain uses of NRTs (e.g., using prenatal diagnosis to identify and abort fetuses even in cases where the fetus has only a mild handicap; non-medical sex selection) should be prohibited as inconsistent with the

moral equality of persons. Educational programs promoting greater tolerance for people with disabilities and more sensitive prenatal diagnosis counselling were also justified in terms of promoting this general idea of equality.

Most intervenors, however, focussed on the principle of equal access to health care and argued that the current provision of NRTs infringed this principle in various ways. Some intervenors emphasized economic and geographic barriers to equal access and argued that NRTs deemed to be legitimate medical treatments should be publicly funded (including travel grants). Others focussed on the screening of prospective patients for parental suitability. Some saw all such screening as discriminatory, since people capable of natural conception are not assessed for their parental suitability. Others simply objected to the practice of excluding whole groups of people on the basis of their marital status or sexual orientation, rather than examining each person on his or her own merits. Yet others objected to the arbitrary and capricious manner in which such decisions were made, and to the fact that doctors had no training or qualification to judge parental suitability. There was also concern that prejudice against women with disabilities, or women of colour, was limiting their access to NRTs.

5. *Respect for Human Life*

This principle states that human life deserves respect at all stages of its development. It is widely agreed that all forms of human life (and indeed human tissue more generally) should be treated with sensitivity, not callousness or indifference. While the law does not treat embryos and fetuses as full members of the community, they are closely connected to the community, in virtue of both their genesis (i.e., having been created by members of that community) and their future (i.e., their potential to become members of that community). Thus, there are restrictions on how embryos and fetuses should be treated.

There has been much dispute about what kind of respect is owed to embryos and fetuses at what stages of development. Some endorse a principle of graduation, according to which the embryo/fetus deserves more respect as it develops, up until viability or birth, at which point it becomes a full member of the moral community. According to this view, various forms of research are acceptable on early embryos that are not acceptable on fetuses. Others argue that the embryo/fetus should be treated as a full member of the community from the moment of conception, so that non-therapeutic experimentation is never justified.

However, even those who defend the principle of graduation impose some limits on the kinds of experimentation that can be performed. Some argue that research should be limited to the surplus embryos from *in vitro* fertilization infertility treatments (i.e., embryos should not be created solely for research). Others argue that embryo/fetal research should only be conducted for certain purposes (e.g., to improve infertility treatment, but

not to test new pharmaceutical drugs). Many people believe that there should also be limits on the way these forms of human life are collected, stored, exchanged, and disposed of. These restrictions are said to be necessary to ensure that the embryo/fetus is treated with dignity and respect.

In the public hearings, this principle was interpreted in various ways. Intervenors from the family, religious, and pro-life sectors argued that respect for human life prohibits any non-therapeutic experimentation on living embryos and fetuses. These intervenors also opposed the use of fetal tissue from deliberately aborted fetuses. Other intervenors, including some from the medical community, defended the principle of graduation, and argued that tightly controlled forms of embryo and fetal tissue research were consistent with respect for human life. As we have seen, there was general agreement from many sectors that respect for human life is inconsistent with the commercialization of genetic material.

6. *Protection of the Vulnerable*

This principle states that the welfare of those who are less capable of looking after themselves deserves special consideration. The most common example concerns the welfare of children. Since children cannot look after their own needs, parents must have the power to make decisions for them. However, these powers are not "rights" in the traditional sense. Rather, they are trusts, to be exercised for the benefit of the child, and the state has the authority to intervene where that trust is violated.

The widespread commitment to this principle reflects society's view that children are not the property of their parents, but rather are independent but vulnerable members of the community. While society's conception of the needs of children has changed over the years, it is generally agreed that children need not only the basic necessities (e.g., food), but also emotional nurture, and a sense of rootedness and family lineage. Consequently, promotion of the child's best interests is tied, in most cases, with the promotion of stable family formations.[17]

Historically, the principle of protecting the child's interests has been applied to decisions regarding the treatment of children who are already in existence; in the context of NRTs, some people have extended the principle to questions of conception. It has been argued that access to assisted conception should be denied to "unsuitable" parents (e.g., single women, lesbian couples), since it is not in the child's best interests to be born into such a family environment. However, this extension of the principle may conflict with another long-standing legal principle, namely, that a child is never wronged by being brought into existence.[18]

The principle of protecting the vulnerable applies to some adults as well. For example, society must ensure that adults who are temporarily or permanently unable to make competent decisions, or who are in desperate straits, are not taken advantage of.

In the public hearings, the principle of protecting the vulnerable was raised in various contexts. One issue concerned the legal status of children conceived with the use of sperm from anonymous donors. It was generally agreed that such children should have the same legal status as children born through natural conception and should be recognized as the legitimate offspring of the social parents. It was also generally agreed that the child should have access to non-identifying information regarding the donor, particularly if it might assist in the child's health care. A more controversial issue concerned the child's access to information regarding the identity of the donor. Some intervenors argued that the child had an important interest in having access to such information when he/she reached the age of majority, just as adopted children seem to benefit from having access to information about their birth parents. Others were less sure of these benefits.

The most controversial issue, however, concerned the screening of NRT patients for parental suitability. Some family-sector intervenors appealed to the child's interests to justify excluding all but legally married couples from access to NRTs. Intervenors from other sectors, however, argued that there was no evidence that children born into other family forms were thereby disadvantaged.

7. *Accountability*

The principle of accountability states that the public has the right, and the responsibility, to regulate and monitor the provision of NRT services and NRT-related research, so as to ensure that the various principles listed above are respected. This is, to some extent, a shift from the traditional principle of professional self-regulation, in which the public had little role to play in either the development or enforcement of codes of medical practice. Of course, even in the old model, professional organizations were obliged to act "in the public interest." However, the implications of NRTs are so profound that the public can legitimately demand to play a more active and participatory role in their regulation.

Again, this principle has a number of implications. Minimally, it implies the need for public oversight of NRT developments. The public has a right to know what kinds of NRT procedures and research are being done, and to be assured that these practices are in fact following the rules. The principle may also require greater public input into the planning and managing of NRT services and research. A wide range of groups and points of view should be represented when policies are made.

In the public hearings, this principle was interpreted in various ways. There was extensive support for some kind of a national regulatory or advisory body to oversee NRTs. Given the pace of NRT development and the difficulty in foreseeing all the outcomes or consequences of NRTs, it was widely felt that a permanent body should be established. There was also great emphasis on increased public participation in NRT decision making, particularly by women and consumers, although intervenors representing

minorities, people with disabilities, and various community health groups also wanted representation.

Despite the initial appearance of moral disagreement, it seems there was considerable consensus on these seven principles in the public hearing interventions.[19] An examination of the international inquiries and the bioethics literature shows that similar sets of principles have been useful in deliberating about NRTs.

International Inquiries

As noted above, many international inquiries have endorsed a set of guiding principles, while only a few have endorsed a comprehensive ethical theory. A superficial glance at the range of principles endorsed by these inquiries might suggest little congruence on the choice of guiding principles (see the section entitled "Ethical Discussions in the International Inquiries"). However, on closer inspection it can be seen that, like the public hearing intervenors, most inquiries share a core set of principles, despite their differences in focus or emphasis. Among the inquiries that stated their guiding principles, almost all endorsed principles regarding protection of the vulnerable, autonomy, and respect for human life. There was also substantial support for principles of non-commercialization and equal access.

In fact, of the seven principles listed above, the only principle that does not appear frequently in the international inquiries is the principle of accountability. However, if we examine the recommendations of these inquiries, it becomes apparent that this principle too is at least tacitly endorsed. Perhaps the single most common recommendation in the international inquiries concerns the establishment of some system of public monitoring of NRT services and related research. The authors of the reports may have felt that the principle of accountability was too obvious to mention. However, in many ways, the recommended systems of accountability are a break from the tradition of professional self-regulation, where there was little public input into either the development or enforcement of the rules governing the provision of health care services. Therefore, it may be worth stating the obvious: the social and ethical implications of NRTs are such that some form of public accountability is needed alongside the traditional mechanisms of professional self-regulation.

While there is considerable consistency between the tentative list of seven guiding principles and the international inquiries, none of the inquiries has endorsed precisely the same set of principles. Most reports endorsed some but not all of the seven principles. This is primarily due to differences in focus and mandate, rather than disagreements about moral values. For example, it is not surprising that inquiries concerned with fetal tissue transplants did not discuss the child's best interests, or that inquiries concerned with artificial insemination did not discuss respect for the human embryo/fetus. The proposed list of principles is more

comprehensive than those of most inquiries, but then the RCNRT has the most comprehensive mandate. Moreover, it is important to note that only a few inquiries have rejected any of the seven principles on the list.[20]

Bioethics Literature

This tentative list of principles is also consistent with the principles commonly enunciated in bioethics texts. As was noted above, those who work in the field of applied ethics, including medical ethics, have increasingly focussed on mid-level principles rather than comprehensive ethical theories, which are seen by many as too abstract to serve as useful guides for action.[21] A survey of bioethics texts reveals that the following principles constitute the core of bioethics: beneficence (and non-maleficence), justice, informed consent, respect for human life, honesty, and confidentiality.[22]

There are differences between this list and the list proposed above. It is important to remember, however, that the discipline of bioethics originally evolved to aid individual doctors deal with individual cases that raised difficult moral dilemmas. So it was, and largely still is, directed primarily at helping doctors deal with their patients or research subjects rather than with public policy questions. This explains the presence of principles of personal conduct, such as honesty or non-maleficence. While it is surely right that ethical doctors will not lie to or harm their patients, these principles are not specifically relevant to most public policy debates. Even the principle of justice, which seems to have a broader scope, was initially confined to questions of fairness in research.

The RCNRT, however, is faced with much broader questions of health care policy. Here the issue is not so much the principles by which doctors should be guided when treating individual patients, as the principles by which society should be guided when managing and funding the provision of NRTs inside and outside the health care system. This requires a different, and more comprehensive, set of principles. For example, the question is not just how a doctor can ensure the informed consent of an individual patient (the principle of informed consent), but how society can manage the provision of NRTs inside and outside the health care system to promote the autonomy of all citizens (the principle of autonomy). Likewise, the question is not just how doctors can ensure that therapies will benefit a particular patient (the principle of beneficence), but how health care priorities should be set by society (the principle of the appropriate use of resources). Similarly, the question of justice is not just how researchers select their experimental subjects, but rather how society can ensure there is no discrimination or unfairness in access to health care services.

Some steps have been taken toward making bioethics more relevant to public policy issues. For example, the principle of informed consent has been expanded into a more general principle of autonomy. However, this transition from doctor/patient-centred to policy-centred principles is far

from complete. There is not yet a well-established set of bioethical principles dealing with such policy-oriented issues as the status of the child, the role of commercialization, or the nature of public accountability. Instead, there is continuing attention to such doctor/patient-centred principles as "honesty" and "non-maleficence," which apply regardless of the policy decisions made by governments. No matter how NRTs are managed, it is true of course that doctors should not lie to or harm their patients or research subjects.

There is, then, a certain gap between the proposed list of principles, intended to guide public policies, and the standard set of bioethical principles, which are intended to guide individual professionals. However, it seems safe to say that insofar as bioethicists are moving toward policy-oriented principles, they are increasingly endorsing the same principles as those listed above. Moreover, it is important to note that while bioethicists have not yet endorsed the full set of principles listed above, neither have they rejected any of them.

Thus, there is evidence from a variety of sources — public hearing interventions, international inquiries, and the bioethics literature — that suggests not only that ethical deliberations can be based on guiding principles, but also that it is possible to achieve consensus on the proposed list of principles as at least a first step in ethical deliberations about NRTs. Further support can be found in various international covenants, such as the International Covenant on Civil and Political Rights.[23]

The fact that consensus is possible on these principles does not show that they are valid or adequate to the task. The existence of this consensus may just reflect that some groups have been able to impose their interests or views on society. The ultimate test of this list of principles is to examine them in the light of the moral point of view, to see whether they show due concern for the interests and perspectives of all those who are affected by NRTs. If we consider these principles from the moral point of view, are there other important human values that deserve protection but are not currently mentioned? As more is understood about the interests of those affected by NRTs, perhaps adopting the moral point of view will lead to the addition of more principles. The possibility that there are further principles cannot be ruled out. However, the fact that this set has received extensive support from such a wide range of intervenors, representing many different sectors, as well as from a wide range of inquiries by bioethicists, suggests that they may capture the most fundamental moral values relevant to NRTs.

Applying the Guiding Principles

Identifying the guiding principles is only the first step. The next step is to apply the principles. Each guiding principle identifies a legitimate

interest that may be applicable to many groups that are affected by NRTs. To apply the principles properly, therefore, we need a list of the individuals and groups who are potentially affected by the use of these technologies (the "stakeholders").

Based on the public hearings, it seems there are eight major groups that are potentially affected by NRTs:

1. women;
2. children;
3. embryos/fetuses;
4. people with disabilities;
5. racial and ethnic minorities;
6. gays and lesbians;
7. health care providers; and
8. patient and donors.

This list of stakeholders can be used in tandem with the list of guiding principles to provide a consistent approach to ethical deliberations. Using these two lists, the Commission can consider how various policy options affect the legitimate interests of each of the affected parties, and thereby arrive at morally responsible recommendations.

Of course, this is not a magical formula for resolving all moral disputes. There will be disagreements over the interpretation of the guiding principles, and over their relative priority in cases of conflict. Indeed, some critics of *principlism* have argued that this apparent consensus on guiding principles will dissolve once people begin to apply them. The rest of this section will discuss some potential sources of disagreement and suggest some mechanisms for coping with them.

It is certainly true that there are disagreements about how to interpret these shared principles. One of the most serious of these concerns the principle of respect for human life. While most people share a commitment to respecting human life as a general principle, they disagree about what form of respect, and what level of protection, is owed to human life at its various stages of development.

This disagreement reflects differing views about how human life acquires its distinctive moral status. Every moral theory must have some account of when (and why) human life acquires the status of personhood, and of what form of respect is owed to human life that does not have that status. There is a wide range of answers to these questions in moral philosophy. The following criteria have all been proposed for assessing when human life acquires moral status (or when its moral status increases): conception, syngamy, implantation/primitive streak, sentience, quickening, viability, birth, and rationality.

People disagree over which of these various "marker events" is relevant in assessing the moral status of the embryo or fetus. Moreover, there are also disagreements over whether it is the actuality or the potentiality of the embryo or fetus that has moral relevance. For example, some international inquiries argue that sentience is the key marker event in acquiring moral personhood. But some of these reports argue that it is the *potential* for sentience that matters, and that the embryo acquires this potentiality when it develops the primitive streak at 14 days. (This is distinct from arguing that the embryo acquires moral status at 14 days because that is when its individual identity is fixed.) Others argue that it is the *actual* possession of sentience that determines personhood, and that the fetus acquires this capacity at around 40 days or later. So two people can agree on which of the seven criteria to adopt, and still disagree about when the embryo or fetus acquires its moral status. People may also invoke different criteria when assessing the moral status of *in vitro* and *in utero* embryos.

This generates a bewildering array of possible answers to the question of the moral status of the embryo or fetus, and it is far beyond the scope of this paper to try to resolve this debate. A rigorous analysis of these different criteria and of the potentiality argument would be required. Of course, it is possible that consensus will not be possible on this issue. If so, the commissioners may have to agree to disagree and let the public know that there are deep and perhaps irresolvable disputes on this question. If such fundamental disagreements exist, they should not be minimized.[24]

However, the existence of this moral disagreement does not invalidate the usefulness of the "guiding principles" approach, for it is still important that there is general consensus on the principle that human life deserves respect, and that this respect places limits on NRT-related procedures and research. For example, this consensus would help explain and justify any recommendations the RCNRT might wish to make concerning the establishment of a system of accountability for embryo research.

Moreover, the statement of guiding principles can help promote a more informed public debate on the ethical implications of NRTs. If some disagreements are unavoidable, then it will help promote public debate if readers can identify as clearly as possible the precise location of the disagreement. If they are told that disagreements over embryo experimentation reflect disagreements over what forms of respect are owed human life at its different stages of development, then they will have a clear idea of what kinds of arguments they need to consider and discuss.

The existence of a consensus on guiding principles will be less useful if irresolvable moral debates arise about the interpretation of every principle. But it is possible that there will be few moral disagreements over the interpretation of these principles — much of what gets called moral disagreement can in fact be traced to factual disagreements.

The public hearings revealed that people disagree about a wide range of facts regarding NRTs. For example, disagreements about whether *in vitro*

fertilization deserves public funding as an appropriate use of resources often reflect different empirical assumptions about its comparative success rates and about the effectiveness of prevention. Disagreements about whether increased availability of *in vitro* fertilization promotes or diminishes women's autonomy often reflect different empirical assumptions about the sorts of pressures to have children that women face from friends, family, NRT providers, and society at large. Disagreements about whether prenatal diagnosis (PND) promotes discriminatory attitudes toward people with disabilities often reflect different empirical assumptions about the motives and actions of PND-users and providers. In many of these cases, people agree on the values, but disagree on how the provision of particular NRTs will in fact affect those values.[25]

In cases such as these, there are disagreements about the ethical implications of NRTs without there being any disagreement on moral values. The solution to these disagreements, therefore, lies in empirical research as much as in moral philosophy. If people disagree on the facts about how NRTs are being provided, or about what impact they are having on various groups in society, then the RCNRT can try to find more reliable or conclusive evidence.

Unfortunately, the facts are not always available. This leads to a second source of disagreement — namely, how should we act in conditions of uncertainty? Or, put another way, upon whom does the burden of proof lie? Do we allow NRTs until they are proven harmful? Or do we not allow NRTs until they are proven beneficent?

As various commentators and international inquiries have noted, there is a fundamental disagreement in society over this question of the burden of proof.[26] To some extent, this disagreement reflects an underlying difference in views about technology. In the absence of sufficient facts about particular NRTs, people draw on their more general attitudes concerning the impact of technology on society. Proponents of NRTs often display optimism regarding the benefits of technology and our capacity to control it responsibly. For them, the burden of proof is on those who would curtail technological development. Opponents of NRTs, on the other hand, are often technological pessimists, who feel that society puts itself at long-term risk when it employs technology to solve current problems. As a result, they put the burden of proof on those who would introduce new technologies to show that the benefits will outweigh the harms.

This points to the importance of different general attitudes toward technology. One manifestation of these different attitudes is the "slippery-slope" debate. Opponents of NRTs sometimes argue that adopting certain NRTs is the first step on a slippery slope toward eugenic reproductive policies, a Brave New World, or greater male control of women's reproduction. They argue that we should not take the first step unless we have conclusive evidence that we can and will avoid subsequent steps down the slope. Proponents of NRTs, however, respond that society has proven its ability to use technologies responsibly and prevent abuses,

and that many existing technologies that were initially opposed for slippery-slope reasons are now generally accepted. They argue that the potential abuses are far-fetched and indeed too remote to warrant serious consideration; therefore, we should not block progress from an irrational fear of worst-case scenarios.

These slippery-slope arguments arise in many areas of the RCNRT mandate, and it is important to determine how they should be evaluated. But it is also important to note that the slippery-slope argument is effective precisely because it appeals to shared values.[27] The slippery-slope argument claims that seemingly beneficial first steps should be avoided because they inevitably will lead to results that we all acknowledge are horrendous. If there were no agreement about what counted as morally bad outcomes, there would be no room for slippery-slope arguments. Everyone agrees it would be unacceptable if the use of NRTs led parents to view their children as commodities, or led society to be intolerant of human imperfections. People simply disagree about whether NRTs are likely to have that effect, and as to where the burden of proof lies. Is it incumbent on proponents of NRTs to prove that society will avoid the slippery slope? Or is it incumbent on opponents to prove that society will fall down that slope?

Here is another source of disagreement about the ethical implications of NRTs that does not reflect a difference in moral values. It may be difficult for the RCNRT to resolve this conflict, since it is likely that differences in general attitudes toward technology (unlike specific beliefs about a particular NRT) are relatively difficult to dislodge. However, it may be possible to diminish the conflict. One reason for some groups' pessimism about the impact of NRTs on shared values and their desire for conclusive evidence that NRTs are benign before they are introduced is that these groups do not feel they have any control over the future direction of technological development. They want NRTs stopped now, since this may be their only chance to stop them. Conversely, one reason for some groups' optimism is that they do have some control over the rate and direction of NRT development. In other words, differences in attitudes toward technology may reflect differences in social power. If some groups feel *they* are powerless to prevent society from falling down the slippery slope, they are more likely to feel that *no one* in society can stop that development.

Insofar as this is true, the RCNRT can try to eliminate this disagreement over the burden of proof by proposing the establishment of an advisory or regulatory body, with representation from a wide range of societal interests and viewpoints. This might give each group in society confidence that it will be involved in evaluating the evidence about the implications of NRTs as it is collected, and that it will be able to act effectively should its interests or values turn out to be harmed by future NRT developments.

This raises a further area of possible study by the RCNRT. It may be worth considering what kinds of regulatory or advisory bodies can give

everyone in society the confidence that the ethical implications of NRTs are being systematically monitored from a range of different perspectives.

To summarize this section, then, the existence of a consensus on certain guiding principles does not mean that all moral disagreement will disappear. People will disagree about the interpretation of these principles for a variety of reasons, including different views of the moral status of the embryo and fetus, different factual beliefs, and different assumptions about the likely impact of technology on society. However, the existence of these disagreements does not undermine the viability of the guiding principles approach. Many disagreements can be resolved or accommodated through the provision of more information, or the establishment of a public oversight body.

It is also important to remember that some ethical disagreements do not need to be resolved to make public policy recommendations. For there are not only moral constraints on the RCNRT's recommendations, there are also a number of legal, social, and economic constraints. Certain policies that may be desirable in principle may be impossible in practice, given these constraints.[28] Some options will be more appropriate or feasible in the light of Canada's legal, political, economic, and cultural context, and existing institutions and practices. Once these constraints are taken into account, the kinds of moral conflicts that arise may change and become more manageable. As the feasible range of recommendations becomes clearer, we might discover that some seemingly intractable problems will not arise, and that most problems that do arise can be resolved on the basis of relatively uncontroversial guiding principles.

There are a variety of reasons to hope that disagreements over the interpretation of guiding principles can be resolved or contained. If they can, then the guiding principles approach provides a more promising basis for consensual public deliberation than the ethical-theory approach.

This suggests an alternative account of where previous inquiries into NRTs have gone astray. As noted above, previous inquiries have often failed to adopt a clear and consistent approach to ethical issues. Some critics suggest that this failure is tied to the absence of a comprehensive ethical theory. It may be the case, however, that the shortcomings of previous inquiries stem from the inadequacy of their guiding principles, or the inadequate way these principles were applied.

It is interesting to note that many critics of previous inquiries have not considered the option of adopting guiding principles. The only alternative to adopting an ethical theory, some people assume, is to rely on subjective whims or public opinion polls. This false dichotomy seems to have been accepted by Mary Warnock. In answering critics who complained about the lack of an ethical theory in her report, Warnock said: "Every sentence ... had to be argued over. To reach agreement on conclusions was difficult enough. To have arrived at an agreed line of *argument* would have been impossible."[29] This is a powerful warning about the difficulties in arriving at a shared ethical theory. But her alternative is surely

unacceptable, if she means that public inquiries cannot hope to give any moral reasoning at all for their recommendations. If the RCNRT report is to be persuasive, and is to promote public debate, then it must give reasons for its conclusions. But these reasons need not be arguments "all the way down," i.e., down to the first principles of an ethical theory. Rather, the reasons can appeal to a set of mid-level principles that are consistent with various theories. This option is largely ignored in the debate between Warnock's critics and supporters.

It might be argued that we need an ethical theory to have confidence in our mid-level principles. In fact, if anything, the direction goes the other way. Our confidence in a particular ethical theory will largely depend on whether it makes room for the various mid-level principles to which we are already strongly committed. For example, if an ethical theory denies that the child's interests deserve special protection, then we are much more inclined to reject the theory than to renounce the principle of protecting the vulnerable. Indeed, this is precisely why most people reject mutual-advantage theories as an account of morality. Since the mutual-advantage theory cannot explain our commitment to principles of protecting the vulnerable and respecting human life, it does not warrant serious consideration as an account of morality.

The public expects that the RCNRT will give reasons for its recommendations. And, of course, these should be good reasons. But people do not need to subscribe to a particular ethical theory to evaluate what counts as a good reason. For example, the fact that a particular policy will promote the child's interests is clearly a good reason for endorsing that policy. The public and policy makers accept this as a good reason, even though they may not understand specific theories. Anyone who doubts whether promoting the child's interests counts as a moral good lacks the most basic ethical sensibilities — they have failed to understand what it means to look at things from the moral point of view.

This brings us back, once again, to the "moral point of view." The public has expressed a concern that NRTs be examined from a moral point of view, as well as from a purely medical, scientific, legal, or economic point of view. They will want evidence that the Commission has considered their interests and the interests of their children and of future generations with empathy; that the Commission has considered the fate of the weak and marginalized, in addition to the legitimate interests of the more vocal or powerful; and that the Commission has done what it can to put itself in the shoes of all those who are affected by NRTs, and that it will take those impacts into account in its recommendations.

This, indeed, is the real problem with the previous inquiries. The flaw of the Warnock Report is not that it failed to endorse an ethical theory, but rather that it failed to consistently adopt the moral point of view. It did not fully consider the impact of NRTs on women or the disabled or children. Instead, it adopted a narrow medical point of view on various issues.[30]

Both ethical theories and guiding principles are attempts to spell out the requirements of this moral point of view to provide more determinate guidance. This paper has argued that guiding principles offer a more promising avenue for spelling out the moral point of view in the context of public policy making for NRTs, since they are more practical and less controversial. However, whichever approach is taken, the ultimate test of the RCNRT's ethical deliberations will be whether the Commission shows a sincere commitment to understanding and protecting the well-being of all those who are touched by NRTs.

Conclusion

The RCNRT's mandate raises a number of moral issues, and indeed it is the presence of these moral issues that largely explains why the Commission was established. It is important, therefore, for the Commission to adopt a clear, consistent, and pragmatic approach to its ethical deliberations. Many previous inquiries in Canada and elsewhere have been criticized for failing to do so.

This paper has considered two such approaches: one involves adopting a comprehensive ethical theory; the other involves adopting a set of guiding principles. The former approach has difficulties in the context of public policy making. It is unlikely that most citizens (or commissioners) will endorse a single theory. Moreover, a specific theory does not provide much direct guidance for resolving practical ethical issues.

The guiding principles approach is promising. Examination of the public hearings, international inquiries, and bioethics writings suggests that consensus is possible on a specific set of guiding principles. While such a consensus would not eliminate all disagreement about the ethical implications of NRTs, it would provide useful guidance for the Royal Commission and public deliberations on a wide range of issues. The set of principles can serve as a source for policy objectives and as a screen against which potential policy recommendations are tested. By testing all its recommendations against the same explicit and comprehensive set of principles, the Commission can ensure that its ethical deliberations are thorough and consistent.

Appendix. List of Canadian and International Inquiries

Canada

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2. Law Reform Commission of Canada. *Crimes Against the Foetus.* Ottawa: Law Reform Commission of Canada, 1989.
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4. Medical Research Council of Canada. *Guidelines on Research Involving Human Subjects.* Ottawa: Medical Research Council of Canada, 1987; *Guidelines for Research on Somatic Cell Gene Therapy in Humans.* Ottawa: Medical Research Council of Canada, 1990.
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7. Law Reform Commission of Saskatchewan. *Tentative Proposals for a Human Artificial Insemination Act.* Saskatoon: Law Reform Commission of Saskatchewan, 1981.
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United States

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Notes

1. Throughout this paper, the term "NRTs" is used to refer to all the technologies, procedures, and health care policies listed in the RCNRT's mandate. Thus, it refers not only to infertility treatments, but also to prenatal genetics, fetal tissue research, and various alternatives to these technologies and procedures.

2. M. Warnock, *A Question of Life: The Warnock Report on Human Fertilisation and Embryology* (Oxford: Basil Blackwell, 1985), viii.

3. For an explanation of how intervenors were assigned to "sectors," or communities of interest, see *What We Heard: Issues and Questions Raised During the Public Hearings* (Ottawa: Royal Commission on New Reproductive Technologies, September 1991), 7.

4. According to some critics, it has become a "ritual incantation" for professional medical groups to endorse these three principles. See K.D. Clouser and B. Gert, "A Critique of Principlism," *Journal of Medicine and Philosophy* 15 (1990): 219-36.

5. "Symposium on Bioethics Commissions," *Journal of Medicine and Philosophy* 14 (4)(1989).

6. Warnock, *A Question of Life*, 96.

7. This difficulty is illustrated in the Church of England's report on NRTs (Church of England, Board for Social Responsibility, *Personal Origins: The Report of a Working Party on Human Fertilisation and Embryology* (London: CIO Publishing, 1985)), listed in the appendix. While the members of the report's task force agreed on a natural-law framework, they were deeply divided on how to interpret the idea of natural law. In particular, they were divided on the question of whether natural law requires us to be active stewards or passive recipients of our genetic inheritance. Similar internecine disputes can be found among proponents of all the major ethical theories.

8. The one exception is the mutual-advantage theory. As we have seen, it denies there is such a thing as the moral point of view (or, more accurately, it denies we have any reason to adopt that point of view). Since this theory is best seen as a rejection of morality, I will henceforth concentrate on the other five theories.

9. For further discussion and references, see W. Kymlicka, *Contemporary Political Philosophy* (Oxford: Oxford University Press, 1990), chaps. 1-3, 7. The centrality of this moral point of view to the entire Western moral tradition makes it difficult to determine exactly what distinguishes the different theories. For example, Rawls is sometimes categorized as a contractarian, but calls himself a deontologist, while others insist that his approach is utilitarian. The Protestant theologian Paul Ramsay calls himself a deontologist, but he invokes some aspects of natural law, while others insist he is a teleologist. The Catholic philosopher Richard McCormick endorses natural law, but adds various deontological components to his theory, while others insist he is a utilitarian. Similarly, many people believe that the ethic of care is a variant, rather than rejection, of traditional rights/interests theories. While proponents of each theory are often keen to sharply distinguish their preferred theory from all the others, many observers have concluded that the six theories are not really competitors, but rather are interrelated in complex ways and tend to blur into one another.

Things get even muddier if we move beyond the six "pure" types of ethical theory and consider the various "hybrid" forms of moral theory. Given that each of these theories is said to have some counter-intuitive implications, it is not uncommon for moral philosophers to try to combine the more attractive elements of different theories into a new hybrid theory. Thus we find theorists who say that we should combine utilitarianism with deontology, or the ethic of care with the ethic of justice. There are 720 ways of combining these six pure types, and while not all of these combinations are plausible, or even coherent, a thorough search of the literature would reveal that most of them have been endorsed by at least one moral theorist. Rather than six sharply distinguished theories, what we actually find in the literature is a continuum of theories, each blending into the next, sharing certain key features, but varying in their philosophical nuances. There is as much disagreement on how to characterize the differences among these theories as on how to evaluate them.

10. The number of intervenors who endorsed each principle is listed below, by sector:

1. individual autonomy: 12 women's, 6 medical, 1 consumer, 6 alternative health, 2 legal, 2 family, 2 disability;
2. appropriate use of resources: 4 medical, 5 women's, 5 alternative health, 1 citizen, 2 family, 1 labour, 1 disability;
3. non-commercialization of reproduction: 4 women's, 1 culture, 1 legal;
4. equality: 4 medical, 7 women's, 1 legal, 1 labour, 1 alternative health, 3 disability, 2 culture, 1 consumer, 2 family;
5. respect for human life: 15 family (including 2 pro-life medical groups and 5 pro-life women's groups), 3 medical, 1 labour, 1 disability, 1 alternative health;
6. protection of the vulnerable: 6 family, 1 alternative health, 2 women's, 2 citizen, 1 legal; and
7. accountability: 5 women's, 3 alternative health, 1 culture.

These numbers indicate the number of intervenors who *explicitly* endorsed the relevant ideal as a guiding principle for the management of NRTs. The extent of implicit support for these principles is much higher. As noted earlier, only 75 of the 296 intervenors identified any guiding principles. Moreover, not all of these 75 intervenors were trying to identify a comprehensive list of such principles. Some were just bringing attention to principles they thought were particularly important, or that were potentially overlooked. Consequently, the numbers cited above cannot be taken as an accurate gauge of the real support for these principles. For example, while 31 intervenors explicitly endorsed the idea of individual autonomy as a guiding principle for the management of NRTs, it does not follow that other intervenors were hostile to, or in any way less committed to, this ideal. Indeed, none of the intervenors rejected this principle. In fact, few intervenors rejected any of the principles listed above. (The one exception is the qualified support for commercialization among some citizens, consumers, and medical intervenors.)

Other principles endorsed in the public hearings included:

- cultural sensitivity [culture];
- honesty [medical];
- confidentiality [legal, consumer];

- the "seventh-generation" principle [women's];
- freedom of religion and conscience [medical]; and
- right to a safe working environment [labour].

11. This could be an important difference, since a generalized principle of reproductive choice may support "individual consumerism," including the right of men to have access to commercial surrogacy or to donate sperm. Such rights are not entailed and indeed may conflict with the right of women to control their bodies. See C. Overall, *Ethics and Human Reproduction: A Feminist Analysis* (Boston: Allen and Unwin, 1987), 169-70. This raises the possibility that the principle of autonomy could conflict with the principle of non-commercialization. Libertarians believe that to have autonomous control over something one must have the right to engage in commercial exchanges regarding that thing. Most people, however, deny that autonomy presupposes commercialization. For example, no one thinks that the right to vote includes the right to sell one's vote.

12. Canadian Nurses Association, "New Reproductive Technologies: Accessible, Appropriate, Participative" (brief to the Royal Commission on New Reproductive Technologies, Ottawa, 20 September 1990), 10. The CNA actually uses the term "appropriate use of technology," but emphasizes that this principle "is broad and refers to the appropriate use of all health care resources." I have changed the label to better reflect this broad meaning.

13. Intervenors from the medical community sometimes describe this as the "principle of beneficence." However, this is somewhat confusing since, traditionally, that principle has been used in the more narrow context of doctor-patient relationships. The term "appropriate use of resources" seems more appropriate for the public policy context. See the discussion under "Bioethics Literature" below.

14. E.S. Anderson, "Is Women's Labor a Commodity?" *Philosophy and Public Affairs* 19 (1990): 71-92.

15. A related principle is that of equality of opportunity — i.e., the principle that no one should be disadvantaged by their social background (their class, sex, racial, ethnic, or religious background) in their ability to participate in and contribute to the economic, political, and cultural life of the community. Therefore, everyone should have roughly the same opportunities to succeed in life, and no one should be precluded from competing for a particular job or political office. This principle was rarely raised during the public hearings. However, a few women's groups argued that the reason that NRTs are perceived as threatening to women is that women do not yet have genuinely equal opportunity to participate in the political, economic, scientific, and health care systems. In this view, promoting equal opportunity for women throughout society is needed to ensure that women have an equal ability to control the development and use of the technologies.

16. Some writers prefer the term "equity" in health care. This reflects the belief that equality of health status is impossible, given the fact that some factors affecting health are beyond social control, while equality of access is insufficient, given the fact that different people face unequal health risks. Thus, a more appropriate goal, it is said, is equity in opportunities for health. Since the language of equal access is more familiar and was explicitly invoked by both intervenors and international inquiries, I will continue to use it.

17. In some interventions and international inquiries, it is unclear whether recommendations regarding promotion of the family were entirely derived from the need to protect the child's best interests, or whether they had an independent rationale. See, for example, the following inquiries: Queensland, Special Committee Appointed to Enquire into the Laws Relating to Artificial Insemination, *In Vitro* Fertilization and Other Related Matters, *Report* (Brisbane: The Committee, 1984), 40; New South Wales Law Reform Commission, *Artificial Conception Report 1: Human Artificial Insemination* (Canberra: The Commission, 1986), 18, 20.

18. On the potential conflict between restrictions on access based on the child's best interests and the traditional rejection of the idea of "wrongful life," see the reports of the Ontario Law Reform Commission, *Report on Human Artificial Reproduction and Related Matters* (Toronto: Ministry of the Attorney General, 1985), 196-97; Law Reform Commission of Saskatchewan, *Tentative Proposals for a Human Artificial Insemination Act* (Saskatoon: LRC, 1981), 2-13; and J. Glover, *Ethics of New Reproductive Technologies* (De Kalb: Northern Illinois University Press, 1989), 51.

19. There is some overlap among these seven principles. For example, the principle of the appropriate use of resources is often connected to the principle of accountability. Similarly, the promotion of autonomy is often seen as requiring equal access to NRTs. It may be possible to combine these related principles, although perhaps at the price of losing sight of important issues. Conversely, it may be possible to divide some of these principles into even finer-grained categories. For example, while most people agree that the requirement of informed consent flows from the principle of autonomy, some feel it is sufficiently important to be considered a separate (albeit derivative) principle. It is partly a matter of judgment when it is appropriate to either combine or disaggregate principles. However, the seven principles seem to capture important and relatively distinct ethical ideals.

20. The main exception is the rejection of the principle of non-commercialization of reproduction by Australia's National Bioethics Consultative Committee in its recent reports on surrogacy. According to the NBCC, the distinction between "commercial" and "altruistic" surrogacy is "very confused," since the exchange of money does not preclude the existence of an altruistic motive, and the absence of money does not preclude the existence of some other form of inducement or pressure. See *Surrogacy: Report 1* (Canberra: NBCC, 1990), 9-10.

The principle of non-commercialization is also rejected by the Ontario Law Reform Commission. It argues that various forms of natural reproduction depend on the existence of a commercial exchange (e.g., paying doctors to repair tubal damage). See *Report on Human Artificial Reproduction and Related Matters*, 171.

21. However, this trend is not unanimous. See Clouser and Gert, "Critique," for a critique of this tendency toward "principlism."

22. For a representative sample, see R.T. Francoeur, *Biomedical Ethics: A Guide to Decision-Making* (New York: John Wiley and Sons, 1983); T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 3d ed. (New York: Oxford University Press, 1989); T.A. Mappes and J.S. Zembaty, *Biomedical Ethics*, 3d ed. (New York: McGraw-Hill, 1991); and J.E. Thomas and W. Waluchow, *Well and Good: Case Studies in Biomedical Ethics*, rev. ed. (Peterborough: Broadview Press, 1990).

23. United Nations, *International Covenant on Civil and Political Rights* (General Assembly Resolution 2200A (XXI), 16 December 1966). See the discussion in the

Queensland Report, which appeals to various international covenants to support a similar list of principles: Special Committee Appointed to Enquire into the Laws Relating to Artificial Insemination, *In Vitro* Fertilization and Other Related Matters, *Report* (Brisbane: The Committee, 1984), 40-63.

24. It is worth noting that this disagreement about the moral status of the embryo and fetus arises *within* each of the six ethical theories. That is, proponents of the same ethical theory can disagree about the moral status of the embryo, and proponents of different ethical theories can agree on the status of the embryo. If we re-examine the six theories discussed earlier, we note that many of them employ phrases such as "respect for persons." Thus, each theory requires some account of "personhood"; that is, each framework needs some account of when (and why) human life has the status of personhood and what form of respect is owed to human life that does not have that status. However, there are many such accounts, and one can combine different accounts of personhood (and of due concern for non-persons) with different ethical theories.

It is sometimes said that utilitarians are committed to the view that the fetus only acquires moral status at birth, whereas deontologists and proponents of natural law are committed to the view that the embryo acquires status at its conception. This is inaccurate. Many utilitarians argue that the embryo acquires moral status when it is capable of feeling pain and pleasure, and some have even argued that potential embryos prior to conception have moral status, since they would, if conceived and born, contribute to the overall good.

Conversely, the natural law tradition gives various answers to the moral status of the embryo. The current position of the Catholic Church is that the embryo acquires personhood upon conception, or, at least, that we cannot rule out that possibility. However, other proponents of natural law, including the Catholic Church prior to 1859, have argued that the embryo/fetus is presumed not to have become a person until later (e.g., after quickening). Some recent Catholic ethicists have considered the possibility that implantation should be taken as the attainment of personhood, since this is when genetic identity is definitively established.

The British inquiry that adopted the natural law perspective disagreed on the moral status of the embryo. Some members felt that the embryo bears the image of God from conception; other members thought that the embryo/fetus only becomes a human being when it comes to possess the essential human capacities for reason and morality, and that these capacities "cannot take form in an embryonic body which has not yet reached the appropriate stage of differentiation and development" (*Personal Origins*, 30). A similar range of views about the definition of personhood can be found among proponents of contractarianism or the ethic of care.

Given that there is no unique connection between ethical theories and theories of personhood, adopting an ethical theory would not resolve the debate over the moral status of the embryo/fetus.

25. According to M. Benjamin, factual disagreements often become perceived as moral disagreements: "Many disagreements do not, despite an initial appearance to the contrary, turn on conflicts of moral values ... As research in negotiation has revealed, to formulate these disagreements or to allow them to remain formulated as if they are so rooted [in conflicting moral principles] is to place gratuitous obstacles in the way of arriving at mutually satisfying accommodation" (*Splitting the*

Difference: Compromise and Integrity in Ethics and Politics (Lawrence: University Press of Kansas, 1990), 16).

26. On the importance of different assumptions about the burden of proof and different expectations about the impact of technology on society, see M.J. Charlesworth, *Life, Death, Genes and Ethics: Biotechnology and Bioethics* (Crows Nest, NSW: Australian Broadcasting Corporation, 1989), 24-33; and British Columbia, Royal Commission on Family and Children's Law, *Ninth Report: Artificial Insemination* (Vancouver: The Commission, 1975), 7.

27. For the dependence of slippery-slope arguments on shared values, see D. Lamb, *Down the Slippery Slope: Arguing in Applied Ethics* (London: Croom Helm, 1988), 5.

28. For example, people may disagree about whether a law criminalizing the non-medical provision of artificial insemination by donor or non-commercial surrogacy arrangements is *in principle* acceptable. However, they may agree that it is *in practice* unworkable, given the legal reality that such laws might be unenforceable and counter-productive. Other disputes over principles may be rendered otiose by existing economic or social constraints. In these cases, differences in principle may not need to be resolved in order to deliberate about the practical recommendations, once we take into account social, legal, and economic constraints. For a discussion of the various moral and non-moral constraints on public policy regarding NRTs, see T.H. Murray, "So Maybe It's Wrong: Should We Do Anything About It? Ethics and Social Policy," in *Ethical Issues at the Outset of Life*, ed. W.B. Weill and M. Benjamin (Boston: Blackwell, 1987).

29. Warnock, quoted in M. Lockwood, "Warnock Versus Powell," *Bioethics* 2 (1988), 188.

30. I discuss the limitations of previous inquiries, and elaborate on the guiding principles approach, in W. Kymlicka, "Moral Philosophy and Public Policy: The Case of NRTs," *Bioethics* 7 (1993): 1-26.

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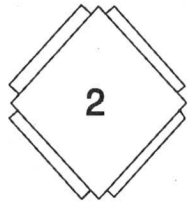

Assisted Reproductive Technologies: Informed Choice

Françoise Baylis

Executive Summary

Based on the principle of respect for persons, health care practitioners are morally obliged, says the author of these papers, to give autonomous patients and research subjects adequate information so that they can make informed choices about participating in a medical intervention. In the context of assisted reproductive technologies (ARTs), she outlines the methodology and the requirements to meet this obligation. The objective, she says, is "for infertile couples to retain control over their participation in therapy or research, and for them to make choices in accordance with their objectives and values."

After a general overview to establish the framework of the discussion, the author goes on to discuss informed choice in the context of five ARTs — *in vitro fertilization* and embryo transfer, preconception agreements, oocyte donation for clinical purposes, embryo freezing for subsequent transfer, and preimplantation genetic diagnosis.

She itemizes ten categories of information that should minimally be made available to the patient or subject. These include his or her current medical status; the nature and objectives of the proposed intervention, alternative interventions, and adjunct interventions; the nature and probability of known and possible consequences; the

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qualifications of the team members; the costs involved; and any other information that may help him/her to make an informed choice. In addition, there should be statements that s/he may ask questions now and later; that s/he may refuse to participate without jeopardizing access to health care; and that consent and refusal are revocable.

Drawing on current research, the author describes each procedure and its potential harms, benefits, and inconveniences (from a social, psychological, emotional, and practical as well as a medical and surgical perspective); the choices open to participants at various stages; and its success rate. In many cases she also describes the situation as it applies to specific clinics, such as what information they routinely give to participants; the costs of specific interventions; and the legal background.

Part 1. Assisted Reproductive Technologies: Informed Choice

This paper, the first of six contained in this publication, provides a general overview of the requirements of informed choice with respect to assisted reproductive technologies (ARTs). In particular, this overview details the framework for subsequent papers on informed choice and (i) *in vitro* fertilization and embryo transfer (IVF-ET); (ii) preconception agreements; (iii) oocyte donation for clinical purposes; (iv) embryo freezing for subsequent transfer; and (v) preimplantation genetic diagnosis.

The key elements of a morally valid choice[1] (consent or refusal) are intentionality, understanding, and voluntariness.[2] A morally valid choice is an *intentional* choice by a competent person — a choice "willed in accordance with a plan."[3] Second, it is a choice made with some *understanding* of the nature and foreseeable consequences of alternative courses of action or inaction. Third, a morally valid choice is a choice that is *not subject to controlling influences* such as "force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion."[4]

In this paper, intentionality is not discussed. It is simply held that ARTs should be available only to those with the capacity to make intentional choices about whether to authorize or to refuse a non-coital method of reproduction and/or associated intervention(s). Understanding, the second element of a morally valid choice, though not discussed *per se*, is the focus of this and subsequent papers, each of which critically addresses issues concerning appropriate disclosure.[5] Voluntariness, the third element of a morally valid choice, is discussed briefly at the end of this first paper and is sometimes referred to in subsequent papers when non-disclosure or false disclosure potentially undermines voluntariness.

The focus of this and subsequent papers having been specified, it must be noted at the outset that these papers are purposely limited in at least two ways. First, informed choice is discussed only with reference to

heterosexual couples who are in a stable ongoing relationship.[6] This is not to suggest that homosexual couples or single persons should be denied access to ARTs.[7] It is simply that the possible impact of different social arrangements on the decision-making process is beyond the scope of this and subsequent papers,[8] except as concerns oocyte donation for clinical purposes and preconception agreements.

The second constraint on the discussion of informed choice is the presumption that both partners should actively participate in the decision-making process. With many of the ARTs, there are serious known and potential harms for women. Their free and informed choice regarding the use of these technologies is therefore of the utmost concern. Nevertheless, it is important to remember that infertility is often a couple's problem, and although some of the proposed interventions do not present a risk of physical harm for men, they may present a risk of psychological or other harm. For this reason, it is deemed that the consent or refusal of both partners is required as regards the general nature and objective(s) of the intervention, in addition to which there must be independent consents or refusals from each partner for the specific harms that s/he may be exposed to.

Effective Communication and Disclosure

The principle of respect for persons stipulates that persons may not be used solely as means to ends, but must be respected as ends in themselves. This principle requires that we treat individuals capable of self-determination as autonomous agents. For this reason, health care practitioners and researchers are required (morally obliged) to inform *autonomous* patients and subjects about available options and their anticipated consequences so as give them a fair opportunity to make an informed choice.

Informed decision making for both research and therapy is a process that generally begins with disclosure of relevant information and culminates with a choice to authorize or to refuse a particular intervention. In the interim, the prospective research subject or the patient presumably tries to understand and assess the information disclosed, then weighs the consequences associated with each option so as to make a choice that is consistent with his/her life goals, objectives, values, beliefs, or other factors.

If a decision is made to authorize a particular intervention, a consent form (preferably one that summarizes in point form the relevant matters discussed)[9] is signed.[10] Ideally, this signed form attests to the fact that a process of the kind just described — a process that acknowledges the personalities, values, beliefs, abilities, and interests of patients and subjects, and promotes their active participation in decision making — has taken place. Too often, however, the consent form seems to be a substitute for continuing open communication, and the disclosure process is reduced to "a mechanical recitation of procedures, interventions and risks."[11]

To avoid this, infertility clinics typically use several means of communication in concert to relay relevant information in written, oral, audiovisual, and experiential form.[12] There are information sheets, brochures, and kits regarding specific ARTs; there are group information sessions with presentations by various members of the team; there are assessment appointments and counselling sessions that allow for private conversations with physicians, researchers, nurses, counsellors, and others; and, in some instances, there are even opportunities for "trial runs." For example, during the physical examination, a vaginal ultrasound can be performed to get a baseline monitoring of the woman's pelvis and to familiarize the woman with this technology (see Appendix).

Effective communication, however, requires more than well-orchestrated disclosure strategies. If the objective is for infertile couples to retain control over their participation in therapy or research, and for them to make choices in accordance with their objectives and values, then of equal importance is the ability of staff members to interact effectively with prospective candidates. The secretaries who are the initial contact persons, the "infertility nurses," the lab technicians, the physicians, researchers, and counsellors are all responsible to varying degrees for giving couples information, support, and understanding in order for them to make choices compatible with their wishes:

> The effective communicator uses vocabulary that the patient [or subject] can comprehend; speaks in gentle direct tones at about the same rate of speech used by the patient [or subject]; breathes deeply and calmly; stands or sits straight and relaxed; and is accessible to eye contact by the patient [or subject] ... [In addition, s/he] must have positive regard for the patient [or subject] and say what is honest and appropriate to the circumstances.[13]

Methodology aside, at least ten discrete items of information should be disclosed in order for patients or prospective research subjects to make informed choices about whether to authorize or to refuse the interventions required for one or more of the ARTs:[14]

1. a description of the patient's or subject's current medical status (i.e., diagnosis and prognosis);
2. information about the nature and objective(s) of the proposed intervention, along with similar information about available alternatives and adjunct interventions;
3. information about the nature and probability of the known and possible consequences (i.e., benefits, harms, and inconveniences) of the various options (i.e., the proposed intervention, alternative interventions, and the option of no intervention);[15]
4. information about the qualifications and experience of the various team members;

5. information about the costs involved;
6. additional information that may assist a prospective patient or subject to make an informed choice;
7. a statement that the subject or patient may ask questions now and later;
8. a statement that confidentiality will be respected;
9. a statement that the patient or subject may refuse to participate without jeopardizing access to health care; and
10. a statement that consent and refusal are revocable. In principle, the patient or subject may withdraw his/her consent or overturn his/her previous refusal without jeopardizing access to health care.

Each of these aspects of disclosure is considered in turn.

1. A description of the patient's or subject's current medical status (i.e., diagnosis and prognosis)

The communication process should not begin with the assumption that patients or subjects understand their current medical status. Although many couples who consider using ARTs have a history of infertility problems and probably have already spoken with a number of physicians, nurses, and counsellors, they may not understand their medical situation. Some couples will be well informed, but others will know only that they have been unable to conceive. Meanwhile, each couple faces a particular set of circumstances: there are different causes of infertility, one or both partners may be infertile, the couple may be at risk for a particular genetic disorder, and so on. Such factors influence (if not determine) the suitability of a particular intervention (whether therapy or research). For this reason, a review of the diagnosis and prognosis should be undertaken with couples seeking to avail themselves of ARTs.

2. Information about the nature and objective(s) of the proposed intervention, along with similar information about available alternatives and adjunct interventions

Nature

Typically, information given to patients and subjects about the nature of a proposed intervention and available alternatives is limited to descriptions of the different stages of the various interventions and the means necessary to achieve each of these stages. For example, IVF-ET is usually described as a five-step process that involves controlled ovarian hyperstimulation, oocyte retrieval, semen collection, IVF, and embryo transfer. By comparison, gamete intra-fallopian transfer (GIFT) is described as a four-step process that includes controlled ovarian hyperstimulation, oocyte retrieval, semen collection, and gamete transfer to the fallopian tube(s).

In explaining controlled ovarian hyperstimulation, the drugs that are used to stimulate follicular growth, suppress ovarian function, and induce ovulation are identified. In describing oocyte retrieval, the use of transvaginal follicular aspiration or laparoscopy is explained. With semen collection, the topic for discussion is masturbation and the need to abstain from ejaculation two to three days before producing a semen sample.

Much more information, however, is required for an adequate understanding of the nature of a particular ART. For example, couples should be aware of the impact an ART cycle is likely to have on daily living. The social, psychological, and practical aspects of the intervention are as important as the medical aspects. Moreover, couples should understand that ARTs are elective, not necessary interventions. Finally, couples should appreciate that not all available ARTs are "therapy." The last of these points merits further comment.

In this and subsequent papers, infertile couples interested in availing themselves of ARTs are described either as patients or subjects. The reason for this is that although some ARTs are therapy, some are clearly research and some are non-validated practice.[16] This is owing to differences in objectives, target populations, safety and efficacy, and professional consensus.[17] Knowing whether a particular ART is clinical practice, clinical research, or non-validated practice is relevant to one's understanding of the nature of the intervention.

The objective of clinical research is to develop or contribute to generalizable knowledge. Research may eventually benefit a particular patient or a class of patients, but this is not the primary objective. By comparison, the objective of a non-validated practice is to benefit an individual patient using a new or different device, drug, or procedure, and the objective of clinical practice is to benefit an individual patient using an established therapy.

As such, the target population for research is a group of (1) subjects with a specific disease or disorder; (2) subjects who are at risk for a specific disease or disorder; (3) subjects with a "related" disease or disorder; and (4) subjects who are healthy volunteers. By comparison, non-validated practice and clinical practice are provided exclusively to individual patients with, or at risk for, a specific disease or disorder.

These similarities between clinical practice and non-validated practice aside, in other respects non-validated practice more closely resembles research than therapy. Consider, for example, the issue of safety and efficacy. With clinical practice, there is strong evidence regarding safety and efficacy based on prior laboratory, animal, and human research. With clinical research and non-validated practice, however, there is no (or limited) evidence regarding safety and efficacy.[18] Also, with clinical practice there is a "professional consensus" as to the therapeutic merits of the treatment. With clinical research, on the other hand, there is honest professional disagreement about the relative therapeutic merits of alternative interventions. The aim of the research is to resolve this dispute.

Somewhat similarly, with non-validated practice there is honest belief on the part of some members of the profession about the therapeutic merits of the new drug, device, or procedure. In time, this may give rise to honest professional disagreement.

In sum, non-validated practices are distinct from therapy, owing to the absence of reliable data about safety and efficacy and the lack of professional consensus regarding the therapeutic merits of the intervention. Non-validated practices are also distinct from research, in that typically they are not structured as scientifically and ethically sound research projects.

This being said, where do ARTs fit along the research-therapy continuum? Some ARTs used in particular circumstances are probably best described as clinical practice: their objective is to benefit infertile couples; there is reasonable evidence of safety and efficacy; and there is some measure of professional consensus as regards their therapeutic merits.

Other ARTs are clinical research. Their primary objective is to generate and validate new knowledge; the target population is infertile and fertile individuals as well as gametes and embryos; evidence of safety and efficacy is lacking; and there is no professional consensus as regards the therapeutic merits of the intervention.

Finally, some ARTs can properly be described only as non-validated practice. Their objective is to benefit infertile couples; there is no (or limited) evidence of safety and efficacy; but there is honest belief, on the part of some members of the profession, regarding the therapeutic merits of the proposed intervention.

Infertile couples interested in ARTs must be apprised of the "status" of each available intervention. Is it clinical practice, clinical research, or non-validated practice? In particular, couples need to understand that although a specific intervention may be intended as "therapeutic," it does not follow that the intervention is "therapy." For example, knowledge about safety and efficacy, as well as professional consensus concerning the therapeutic merits of the intervention, may be lacking — both of which are characteristic traits of therapy.

Objective(s)

In addition to understanding the nature of an intervention, couples must also understand its objective(s). At present, it is widely assumed that the objective of all ARTs is to help women get pregnant, or more generally to help couples have one or more of "their own" children. For this reason, the success or failure of infertility programs is typically measured by pregnancy and take-home-baby rates.

This narrow objective may be appropriate for specific medical interventions, but it is not appropriate for infertility programs. The objective of a good program should be to help infertile couples move beyond their present state of infertility into parenthood *or* into a way of life where

the couple has come to terms with not having biological children. This broader objective should be the ultimate goal of an infertility program, and infertile couples should be invited to share this goal.

Another legitimate objective for infertility programs is to ensure that infertile couples have a positive and helpful medical encounter whether or not pregnancy and a child result. A positive encounter is one in which the couple retains control over the decision-making process, is treated with respect by staff members, and is given adequate emotional and moral support. On this point it is appropriate to quote the British Columbia IVF Program:

> As a program, we do not see a successful outcome after one of the new reproductive technologies as being measured only in terms of pregnancy ... A significant number of patients, ... although they do not conceive, do end up with some degree of resolution of their problem which does empower them to continue with their lives in a more meaningful way.[19]

3. Information about the nature and probability of the known and possible consequences (i.e., benefits, harms, and inconveniences) of the various options (i.e., the proposed intervention, alternative interventions, and the option of no intervention)

For prospective patients and subjects to assess whether, for *them*, the benefits of a particular ART outweigh the harms, they must be given relevant information about (1) the extent and likelihood of the anticipated short- and long-term benefit(s); (2) the seriousness and frequency of the anticipated short- and long-term harm(s) and inconvenience(s); (3) the possibility of unanticipated short- and long-term benefit(s), harm(s), and inconvenience(s); and (4) the precautions that will be taken to avoid the short- and long-term harm(s) and inconvenience(s), thereby maximizing the benefit(s).

Second, for prospective patients and subjects to determine whether the benefit-harm ratio of a particular ART is acceptable to them, as compared with the benefit-harm ratio of an alternative ART or the option of no intervention, similar information must be provided about available alternatives. Third, for prospective patients and subjects to compare the benefit-harm ratio of a particular intervention at one clinic with the same intervention at another clinic, they must be given appropriate comparative data.

In all cases, the disclosed information should be as accurate and as current as possible. In particular, overly optimistic success rates should be studiously avoided, and potential harms and inconveniences should be identified clearly. Moreover, only data relevant to the population group of which the prospective patient or subject is a member should be presented. These data should accurately reflect that clinic's experience, not the experience of others.

To elaborate briefly on these last points, it is widely known that

> success rates for a given procedure, particularly as it is being developed and refined, may vary considerably from center to center, and even

> within the same center from month to month. Such differences may result from subtle variations in the technique of performing the procedure, differences in patient [or subject] populations, the degree of training of physicians or laboratory personnel, and the number of patients [or subjects] being treated [or involved in research].[20]

Couples are asked to weigh a certain chance of benefit against a certain chance of harm and inconvenience. The benefits, harms, and inconveniences to which they will be exposed, if they choose to proceed, are those of the clinic they will be attending for the population group of which they are members. Thus, it is imperative that prospective patients and subjects be given the most recent data from the clinic they are considering attending as it pertains to the population group of which they are members.

The only legitimate exception to the general rule about providing local data are new clinics that have no data of their own to cite. In these instances, data from the clinic(s) where the team members trained may be relevant. When the information disclosed is not specific to the clinic, this must be stated clearly so that couples know the data provided do not reflect the clinic's experience and are presented only for illustrative purposes.

Finally, data from other clinics generally should be provided in addition to (not instead of) local data. This is important so that couples may compare the probabilities of benefit, harm, and inconvenience for different clinics. Some couples may be willing to trade off a lower success rate for proximity, shorter waiting lists, or other considerations, whereas other couples may not.

In subsequent papers, due to space limitations, only the potential benefits, harms, and inconveniences of the proposed intervention are discussed in detail.

4. Information about the qualifications and experience of team members

It is uncommon for physicians and researchers to present prospective patients and subjects with their credentials and a summary of relevant work experience. The assumption is that physicians and clinical researchers have met the standards of the profession and are duly licensed to practise medicine and engage in research. This aspect of adequate disclosure is of particular importance with ARTs, however, because many of these interventions are novel, and their success rates depend a great deal on the experience and expertise of team members. ART candidates need to know this and, accordingly, need to know the qualifications and experience of team members.[21]

In addition, expertise may vary tremendously with different ARTs. For example, a clinic may have much expertise with IVF-ET but very limited expertise with embryo freezing. When this is the case, such discrepancies must be disclosed. To do otherwise would be to seriously undermine the validity of any consent or refusal obtained.

5. Information about the costs involved

The Canadian health care system is administered by the provinces because health is a provincial responsibility under the constitution. The Constitution Act, 1867 section 92, subsection 7, gives the provinces responsibility for

> the Establishment, Maintenance, and Management of Hospitals, Asylums, Charities, and Eleemosynary Institutions in and for the Province, other than Marine Hospitals.

The federal government, however, has an active role in health care because it provides funding for hospital and physician services as well as surgical-dental services performed in hospitals. The criteria for reimbursement outlined in the Canada Health Act (1984)[22] are public administration, comprehensiveness, universality, portability, and accessibility.

Although coverage for hospital and medical care is supposed to be universal, the only province that pays the full cost of an ART cycle (excluding drugs) is Ontario, provided the "service" is hospital-based. In all other provinces and at IVF Canada (a private clinic in Ontario), the cost of physician-related procedures, laboratory work, and required hospital stays must be borne by the couples. This fact must be disclosed to prospective participants.

In addition to the actual costs for the intervention(s), there is also the cost of drugs, time missed from work, and, if the clinic is not nearby, travel, food, and accommodation. These costs apply to all ART candidates, including Ontario residents, and must be clearly explained.

6. Additional information that may assist the specific patient or subject to make an informed choice

For research in Canada, the standard for disclosure was established in *Halushka v. University of Saskatchewan.*[23] The prospective research subject is to be informed of all foreseeable potential consequences. For therapy, the relevant legal cases are *Hopp v. Lepp*[24] and *Reibl v. Hughes.*[25] In *Hopp v. Lepp*, the court stipulated that the physician must disclose the nature of the procedure, the gravity of the procedure and any material risks. Furthermore, the physician must answer all questions asked by the patient. In *Reibl v. Hughes*, the court explicitly introduced the "reasonable patient" standard. The physician must disclose any information that "would reasonably be expected to affect the patient's decision," and the test for adequate disclosure is whether a reasonable patient in similar circumstances would have consented to treatment if undisclosed risks had been disclosed.

With these cases the court established that what is relevant to adequate disclosure is what a reasonable volunteer subject or patient in similar circumstances would need to know in order to make an informed choice. What a reasonable researcher or physician in similar circumstances would disclose is all but irrelevant. This requirement to attend to the specific needs of the patient or subject clearly speaks to the importance

of providing all prospective ART candidates with as much additional information as possible to assist them with the decision-making process.

As a general rule, any information that may elicit a refusal must be disclosed.

7. A statement that the subject or patient may ask questions now and later

In *Hopp v. Lepp*, the court explicitly discussed the importance of answering questions asked by the patient. Assuredly, patients and subjects must be given ample opportunity to ask questions about issues of particular importance to them. Physicians, researchers, and other team members, for their part, must make every effort to encourage prospective candidates to ask questions, particularly in areas where problems with disclosure are common (namely, potential harms associated with drugs, limited pregnancy and take-home-baby rates, and failure to distinguish between therapeutic and research procedures). Members of the health care or the research team should also ensure that their answers to direct questions satisfy patients' or subjects' need for information.

The purpose of disclosure is to empower patients and subjects to make informed choices consistent with their values and wishes. This objective can be achieved only in a supportive and interactive environment in which patients and subjects are free to ask questions as they arise (i.e., both *before* and *after* a choice has been made to proceed or not to proceed with an ART). To be precise, consent *should not* end the dialogue, and refusal, at the couple's discretion, *need not* end the dialogue.

8. A statement that confidentiality will be respected

Infertile couples need to be reassured that personal medical information will not be disclosed without their permission. This promise of confidentiality must be explicitly qualified, however, given that personal medical information may be used in ways that go beyond the more traditional doctor-patient relationship.

For example, the common practice of team medicine requires the disclosure of personal medical information to members of the health care team. In addition, there may be chart reviews for medical education, quality assurance, and possibly research. Also, because ARTs are novel interventions, there is a need (if not an obligation) to publish clinical and research findings to make them available to a wider community. Thus, couples need to know that several persons may have access to their records. They should be assured, however, that personal medical information will not be disclosed indiscriminately and that their names and other identifying information will remain confidential. A blanket promise of confidentiality creates false expectations and should be avoided.

Maintaining confidentiality within the limits described above is not usually a problem. Conflicts may arise, however, in various instances when, for example: (1) an HIV (human immunodeficiency virus) test is required and a person tests positive, and (2) there is a medical or scientific

breakthrough with a new ART. In the first instance, care must be taken to explain to prospective candidates that there is a legal obligation to report HIV seropositivity or acquired immunodeficiency syndrome (AIDS) to the appropriate public health authorities.[26] In the second instance, care must be taken to ensure that there are no indiscriminate breaches of confidentiality for reasons of gratuitous publicity or self-aggrandizement.

A separate but equally important concern has to do with the use of gametes and embryos from anonymous donors. Current practice in many clinics is to promise anonymity. In light of current changes regarding access to information by adoptees, however, this may be a promise that will become impossible to keep. Children conceived through ARTs may be given access to records about their genetic heritage, and promises made to gamete and embryo recipients and donors should be qualified accordingly.[27]

9. A statement that the patient or subject may refuse to participate without jeopardizing access to health care

This and the next point are relevant to concerns about the potential for coercion. Infertile couples are a vulnerable population who are in a dependent relationship with those who potentially have the power to help them overcome their infertility. In the minds of some couples, to refuse an ART is to risk the perception by health care practitioners that they are unwilling to go the last mile and are therefore undeserving of medical attention and effort. In assessing the benefit-harm ratio of authorizing or refusing to authorize an ART, couples must be able to leave concerns about jeopardizing access to health care out of the equation.

10. A statement that consent and refusal are revocable. In principle, the patient or subject may withdraw his/her consent or overturn his/her previous refusal without jeopardizing access to health care

Couples must be free to consent to or refuse an ART in the belief that either choice is revocable. From a pragmatic perspective this raises an interesting point about the possible need to introduce policies to deal with reversals of refusals. Typically, the withdrawal of consent is easy to deal with. The couple simply withdraws from the infertility program. The revocation of a previous refusal, however, signals a willingness to join an infertility program; of critical importance in this instance are policies governing change in such decisions. The fact that an initial refusal followed by a subsequent consent could result in several months or years of delay (because of waiting lists) may serve as a subtle form of coercion and is to be avoided.

Freedom from Coercion

Both the proponents and the opponents of ARTs often raise concerns about the potential coercion and exploitation of women who agree to the ARTs and of women who donate their ova and embryos for therapeutic or research purposes. These concerns are both legitimate and serious.

This being said, it is important to distinguish "the twin harms of coercion and exploitation — harms that are commonly conflated, but can usefully be distinguished."[28] Held defines coercion as "the activity of causing someone to do something against his [or her] will."[29] In general, coercion

> involves the imposition of external control using physical, emotional or moral force (either in the form of a threat or an offer) in order to achieve a specific end. With exploitation, on the other hand, there is no presumption as to how the end is obtained, but some benefit is gained at the expense, and possibly without the knowing cooperation, of another.[30]

This distinction is important. Coercion, by definition, precludes voluntariness and thus undermines free choice. By comparison, exploitation may occur with or without the voluntary participation of the person being exploited and thus does not, of necessity, undermine the decision-making process. Exploitation is not discussed here. Of concern, however, are the overt, covert, and insidious exercises of power that limit free choice.

For example, what pressure does society exert by virtue of what it teaches men and women about infertility? What pressure do health care professionals exert on infertile couples? And what pressure is there from spouses, family members, and friends?

At the very least, overt coercive manoeuvres initiated by health care practitioners can be curtailed with the introduction of clear ethical (and, if necessary, legal) directives about adequate disclosure, substantial understanding, and freedom from controlling influences. The introduction of ethical (and perhaps legal) constraints, however, does not address the concerns of those who argue that women are not "really free" to choose or to refuse an ART.

At some level this claim cannot be denied. Women are the product of their environment and have been socialized in ways that cause them to hold certain beliefs about the importance of their fertility. This criticism of ARTs, however, is in certain respects true of many other areas of decision making. More generally, we are all, to some degree, constrained by external circumstances and the influence of others. The critical question is this: at what point does the constraint or influence undermine free choice?

To insist that women are necessarily incapable of making free and informed choices about ARTs is to treat women as children. It is appropriate to be concerned about and to want to change the conditions under which women are asked to make decisions about their reproductive health. Legitimate concern does not require the elimination of choice, but rather the introduction of measures to ensure the opportunity for *free and informed* choice.

From a certain feminist perspective, this response may seem to fail to recognize the fundamental problem of sexual inequality. It naively

supposes that efforts to promote "adequate disclosure," "substantial understanding," and "freedom from controlling influences" will effectively reduce (if not eliminate) the coercion of women despite the imbalance of power between the sexes.

In response, it can only be said that while it is true that ARTs may lead to the coercion of individual women, they do not *inevitably* do so. The potential for coercion (in contrast with the potential for exploitation) very much depends upon the information provided, the way in which it is disclosed, and the manner in which the decision to authorize or refuse an ART is sought. Thus, universal condemnation of ARTs as inherently coercive seems unfounded, particularly as there are ways and means of ensuring that appropriate ethical (and perhaps legal) constraints are introduced and not subverted.

Conclusion

In subsequent papers, the specific requirements of informed choice for IVF-ET, preconception agreements, oocyte donation for clinical purposes, embryo freezing for subsequent transfer, and preimplantation genetic diagnosis are examined critically. Significantly, however, these papers do not address the ethics of these technologies of assisted reproduction — this is beyond the scope of the contracted papers. For purposes of discussion, the working assumption is that the technologies are morally acceptable, provided they are practised in a morally acceptable way, a *sine qua non* of which is that there be informed choice. This being said, many of the points made with respect to adequate disclosure may reflect a certain bias.

Notes

1. For many, "informed choice" translates to "informed consent." This is not surprising given the nature of the relationship between health care practitioners and patients, and between researchers and prospective research subjects. The practitioner or researcher is asking the patient or prospective research subject to empower him/her to act in a specified, agreed-upon manner in relation to the other's person. To focus on informed consent, however, is to promote the health care practitioner's or researcher's choice. On the other hand, to speak of informed choice by autonomous decision makers is to legitimize both informed consent and informed refusal. The objective of the dialogue with the prospective patient or subject is to elicit a choice (a consent or a refusal).

2. R.R. Faden and T.L. Beauchamp, *A History and Theory of Informed Consent* (Oxford: Oxford University Press, 1986).

3. Ibid., 243.

4. Nuremberg Code (1948), in J. Katz, *Experimentation with Human Beings* (New York: Russell Sage Foundation, 1972), 205.

5. An important debate that is not explored in this and subsequent papers is whether those who are responsible for disclosure are also responsible for determining whether there is sufficient understanding on the part of prospective candidates in order for them to make informed choices. Of critical importance in this regard is what constitutes a reasonable attempt to check for understanding and how much understanding is sufficient. On this last point, many agree that full understanding is neither possible nor required. The critical issue is the threshold beyond which there is sufficient understanding. As Faden and Beauchamp argue in *History and Theory of Informed Consent*, no sharp demarcation line can be drawn on conceptual grounds, but a decision as to where to draw the line is required on moral and political grounds.

6. Care must be taken in defining "a stable ongoing relationship." The objective in using this label instead of simply referring to married or common-law couples is to avoid some of the complicating issues that might arise with couples who are married but separated. For example, the claim that both partners must consent to the nature and objectives of a particular ART would not apply to couples that have separated.

7. Most professional bodies that have examined the ethical, social, political, and legal aspects of ARTs recommend that access to ARTs be restricted to heterosexual married or cohabitant couples. For example, Australia, France, Japan, and Singapore limit IVF-ET to married couples, whereas Austria, Denmark, Finland, and the United Kingdom allow cohabitant couples access to IVF-ET. Only the United States and the United Kingdom permit single women to avail themselves of ARTs. For more information, see J.G. Schenker and D.A. Frenkel, "Medico-Legal Aspects of *In Vitro* Fertilization and Embryo Transfer Practice," *Obstetrical & Gynecological Survey* 42 (1987): 405-13.

8. Presumably most of the concerns relevant to heterosexual couples will be relevant to homosexual couples. There may be significant differences, however, between couples and single persons.

9. Some consent forms are extremely succinct and do little more than name the intervention(s) that is(are) to be authorized and provide some brief general statement about potential benefits and harms. Other consent forms list the main points of discussion, describe the known potential short- and long-term benefits, harms, and alternatives, and provide additional information relevant to an adequate understanding of the proposed intervention. Clearly this type of consent form is preferable if the objective is to promote informed choice.

10. A recent trend in business, which has developed in response to increasing litigation, is to have customers sign *either* consent *or* refusal forms. In this way, there is a record of the fact that a certain offer has been made regardless of whether the offer is accepted or rejected. Worthy of note in this regard is the fact that certain health care facilities are now adopting a similar policy in requiring a signed written record of both consents and refusals.

11. J. Arboleda-Florez, "Reibl v. Hughes: The Consent Issue," *Canadian Journal of Psychiatry* 32 (1987), 67.

12. There are data to suggest that combining oral and written presentations increases comprehension (T.M. Grundner, "How to Make Consent Forms More Readable," *IRB: A Review of Human Subjects* 3 (August-September 1981): 9-10).

Since some people are more visual and experiential than others, it seems reasonable to suppose that including these means of communication along with written and oral presentations would further enhance comprehension.

13. J.E. Sieber, "Informed Consent as Respectful Communication," *Forum on Medicine* 2 (1979), 485.

14. This section is a modified, expanded, and annotated version of earlier work by F. Baylis in Canadian Fertility and Andrology Society and Society of Obstetricians and Gynaecologists of Canada, Combined Ethics Committee, *Ethical Considerations of the New Reproductive Technologies* (Toronto: Ribosome Communications, 1990).

15. At issue are two distinct considerations: (1) What *are* the potential benefits, harms, and inconveniences (short-term and long-term) of the various options? (2) What *is the probability* that any of the potential benefits, harms, and inconveniences will manifest themselves?

16. In the literature the term non-validated practice is used sparingly. Terms used more commonly to describe interventions that are (1) not undertaken in the context of a randomized clinical trial and (2) not widely accepted as therapy (because reliable information about safety and efficacy is not available) include experimental therapy, novel therapy, innovative therapy, and innovative practice. Non-validated practice, however, is a more accurate description of non-research interventions characterized by clinical equipoise. Other terms are misleading because they erroneously suggest that the intervention more closely resembles therapy than research.

17. The discussion that follows is a summary of a presentation by F. Baylis, "ECMO: Therapy, Research, or Non-Validated Practice," The Hospital for Sick Children, Toronto, 10 January 1991.

18. With non-validated practice, if the device, drug, or procedure is new, there is likely to be no (or limited) evidence about safety and efficacy. On the other hand, if the device, drug, or procedure has been tested and approved for use in a different population, or for a different purpose, there may be good evidence about safety but still no (or limited) evidence about efficacy.

19. Personal communication, Christo Zouves, Medical Coordinator, British Columbia In Vitro Fertilization Program (letter April 2, 1991).

20. Canadian Fertility and Andrology Society et al., *Ethical Considerations of the New Reproductive Technologies*, 3.

21. A summary of the minimum personnel requirements is provided by the American Fertility Society, "Revised Minimum Standards for In Vitro Fertilization, Gamete Intrafallopian Transfer, and Related Procedures," *Fertility and Sterility* 53 (1990): 225-26.

22. This Act (R.S.C. 1985, c. C-6) replaced the Hospital Insurance and Diagnostic Services Act (R.S.C. 1970, c. H-9) and the Medical Care Act (R.S.C. 1970, c. M-8).

23. *Halushka v. University of Saskatchewan et al.* (1966), 53 D.L.R. (2d) 436-46 (Sask. C.A.).

24. *Hopp v. Lepp*, [1980] 2 S.C.R. 192-212.

25. *Reibl v. Hughes*, [1980] 2 S.C.R. 880-929.

26. In all Canadian provinces and both territories AIDS is a reportable communicable disease; not all provinces or territories, however, require the reporting of ARC (AIDS-related complex) or HIV seropositivity. See D.G. Casswell, "Disclosure by a Physician of AIDS-Related Patient Information: An Ethical and Legal Dilemma," *Canadian Bar Review* 68 (1989), 256.

27. This issue will be addressed in the paper on oocyte donation for clinical purposes.

28. F.E. Baylis, "The Ethics of *Ex Utero* Research on Spare 'IVF' Human Embryos," Ph.D. dissertation, University of Western Ontario, 1989, 103-104.

29. V. Held, "Coercion and Coercive Offers," in *Coercion*, Nomos Vol. 14, ed. J.R. Pennock and J.W. Chapman (Chicago: Aldine, Atherton, 1972), 50-51.

30. Baylis, "The Ethics of *Ex Utero* Research on Spare 'IVF' Human Embryos," 104.

Appendix. Effective Communication[1]

Initial Contact

The secretary who answers the first telephone call from an emotionally fragile couple anxiously seeking out their last chance for a biological pregnancy is an important member of the team. The infertility secretary must be well oriented and well trained. S/he must understand not only infertility but also available treatments and procedures. To be sure, the secretary is not responsible for disseminating medical information. S/he must have a basic understanding of ARTs, however, if s/he is to appreciate a couple's concerns and be able to relay these concerns without delay to appropriate medical personnel.

If a couple has specific concerns, it is common for a nurse, rather than a physician, to respond. The role of the infertility nurse is more independent than many other nursing positions. The nurse must thoroughly understand the importance of the team approach and be able to provide clear, *consistent* and accurate information. Unlike many compliance-oriented medical situations, infertility treatment and research requires the *interactive* participation of staff and infertile couples.

Information Booklet

Because of the complexity of most ARTs, it is essential that couples receive written information about ARTs before their initial visit. Surprises on an initial visit not only increase stress levels, but they take away from the couple's much-needed sense of control.

The information booklet should provide a comprehensive summary of the available options, a detailed description of the medications used, and an honest discussion of the anticipated benefits and harms. In particular, program statistics and drug costs must be clear.

The information booklet should be written below the 7th or 8th grade reading level. "The reading level can be reduced by: (1) using shorter and simpler sentences, (2) improving organization of the information, (3) using more familiar terminology, and (4) defining technical terms in layman's language."[2] This last point is particularly important because if "confusion regarding terminology exists, meaningful communication may be blocked."[3] Also, for couples who choose to proceed with one of the ARTs, it is worth remembering that the women will be awake (sometimes lightly sedated) for many of the procedures and will overhear a number of medical terms. For them to feel part of the team they need to understand the terms being discussed among team members. Commonly used terms such as follicle, oocyte, estradiol, LH, and LH surge should be explained in the information booklet.

Group Information Session

A group information session is an important part of the introductory process and should be available to all couples who have upcoming appointments. These sessions should be held in the evening to accommodate couples who work during the day.

Representatives from each area of the medical team should participate in these meetings (laboratory, psychology, nursing, medicine, social work) to answer questions and address concerns in their area of expertise. At this meeting, couples should be encouraged to comment and ask questions.

Among the issues that should be discussed at the group information session are semen collection and analysis, ovarian hyperstimulation and the associated risks, insemination, fertilization, embryo transfer, and the possibility that not all eggs will fertilize and that not all embryos will be transferred. Also, adjunct interventions available at the particular clinic, such as embryo freezing, oocyte donation, and embryo research, should be described. In addition, practical issues should be disclosed that may help the couples fully appreciate the nature of their commitment if they choose to proceed. This includes information about inability to work during an active treatment cycle, accommodation options, insurance coverage for drugs, and so on.

Assessment Day

The objective of this appointment is to provide the couple with more specific information about the program and the ART they are considering, in order for them to determine whether they wish to proceed with an ART cycle. At the outset, the couple should understand that the appointment is not for the staff to decide whether they are eligible for an ART. (Usually this is done with the prescreening of the original referral.) Rather, the planned series of meetings is for the couple to decide whether to participate. The appointment should include the following stages: a videotape presentation, nurse interview, mental health (or social work)

interview, physician interview and physical, and meeting with the program coordinator to sign consent forms.

(a) Videotape

A taped overview of the program — including procedures, medications, risks, and expectations — provides the couple with a consistent introduction to the program (the tape is especially useful for couples who are unable to attend the group information session). In addition to information about the program, the video presentation can be used to provide the couple with an overview of the rest of the assessment day.

(b) Nurse Interview

This interview allows the couple to raise private concerns, update their medical history (which should have been completed and forwarded to the office before the assessment day), and begin to develop a relationship with the infertility nurse. The infertility nurse is a key member of the team. In many ways, s/he may be regarded as the manager of the ART cycle for those couples who decide to proceed.

(c) Mental Health (Social Work) Interview

In some programs, couples respond to psychological questionnaires prior to their assessment day visit, and this appointment is used to explain the test results. In other cases, the mental health professional (social worker) takes a history and addresses present concerns such as semen collection and fear of injections. In either case, this visit serves as a reference point for couples who proceed through the program. Occasionally relaxation therapy is recommended at this time and follow-up appointments are arranged.

(d) Physician Interview and Physical Examination

The physician meets the couple in the treatment room so that the couple has an opportunity to see the room in which they will be spending a great deal of time if they choose to proceed with an ART. At this time a routine physical is performed, specific concerns are addressed, and the procedure of "measuring the uterus" takes place. This procedure serves as a mock transfer for the woman, potentially allaying any fears she may have. It also provides the physician and laboratory personnel with information they need for possible transfers. As well, a vaginal ultrasound may be performed to familiarize the woman with this technology and to give the physician a baseline monitoring of the woman's pelvis.

During this interview, the physician should repeatedly offer to answer any additional questions and as necessary s/he should reinforce the potential harms. Since the advice of a physician typically overshadows that of other members of the team (at least from a patient or subject point of view), open communication between the physician and team members is crucial so that couples receive accurate and consistent information.

(e) Program Coordinator

The assessment day ends with a visit to the program coordinator. During this meeting the couple is asked whether they want to proceed with an ART. The consent form is read out loud and the couple is encouraged to interject at any point if they have questions or require further clarification. Only those couples who believe they have a reasonably adequate understanding of the relevant facts and who wish to proceed are asked to sign the consent forms.

Notes

1. Summary prepared by Heather Erskine (former Program Coordinator of the Infertility Program at University Hospital in London, Ontario) and edited by Françoise Baylis.

2. D.R. Young, D.T. Hooker, and F.E. Freeberg, "Informed Consent Documents: Increasing Comprehension by Reducing Reading Level," *IRB: A Review of Human Subjects* 12 (May-June 1990), 5.

3. J.A. Erskine, M. Leenders, and L. Mauffette-Leenders, *Teaching with Cases* (Waterloo: Davis and Henderson, 1981), 10.

Part 2. *In Vitro* Fertilization and Embryo Transfer: Informed Choice

Much of the focus on assisted reproductive technologies (ARTs) is on the scientific, economic, political, and ethical aspects of *in vitro* fertilization and embryo transfer (IVF-ET).[1] This is not surprising given that this technology — by means of which conception occurs outside of the body — is integral to many other infertility interventions including oocyte donation, embryo freezing, preimplantation genetic diagnosis, and embryo research.

This paper provides a summary account of some of the more important aspects of disclosure relevant to this technology. The underlying assumption is that such disclosure is essential in order for prospective participants to make an informed choice.

1. A description of the infertile couple's current medical status

IVF-ET was initially developed to circumvent tubal factor infertility, and at least one centre in Canada still limits IVF-ET to

> patients who have disease of the fallopian tubes which might include: (a) failed tubal surgery; (b) surgical repair with less than 10 percent chance of pregnancy; and (c) absent fallopian tubes.[2]

At most Canadian centres, however, IVF-ET is used to treat a variety of other infertility problems, including a low sperm count, endometriosis, untreatable cervical factors, and unexplained or idiopathic infertility.

Couples seeking information about IVF-ET must understand the cause of their infertility so that they can understand why they are eligible for IVF-ET and choose effectively between IVF-ET and other available options.

2. Information about the nature and objective of IVF-ET, as well as similar information about available alternatives and adjunct interventions

Nature of IVF-ET

IVF-ET, as it is currently practised, typically involves five steps. In brief, the first step is the medical induction of ovulation (controlled ovarian hyperstimulation or COH). Ovarian stimulants (fertility drugs) are administered to the woman on a daily basis to promote the maturation of several oocytes per cycle. (Usually only one oocyte is produced in a natural physiological cycle.) The second step is oocyte retrieval. Typically, the oocytes are aspirated with the aid of transvaginal ultrasound, but with some women laparoscopy is required. The third step is semen collection. Once the oocytes have been retrieved, the male partner produces a semen specimen. Alternatively, frozen sperm (husband or donor) may be thawed for the purpose of insemination. The fourth step is *in vitro* fertilization (IVF). Several hours after the oocytes have been retrieved, they are exposed to human sperm. (A delay of one to six hours is usually required for sperm capacitation and for immature oocytes to complete their maturation.) Next, approximately 16 to 20 hours later, the oocytes are checked for fertilization and those that have fertilized are screened for morphological abnormalities (for example, three pronuclei or abnormal cleavage).

The final step is embryo transfer. This is usually done about 48 to 56 hours later when the embryo is at approximately the four-cell stage. A number of embryos are usually returned to the woman's uterus through a very fine teflon catheter passed through the cervix. Then the waiting begins to see whether implantation occurs. If there is no menstrual period by day X (the range is between 12 and 18 days), blood samples are taken to determine whether implantation has occurred. If the blood test is positive, an ultrasound examination is scheduled to confirm the pregnancy and identify the number of gestational sacs.

From this summary description of IVF-ET, one can see how a decision to authorize or refuse this reproductive technology is necessarily informed by a number of prior decisions concerning the various stages of IVF-ET. For example, decisions are required about whether to undergo IVF-ET with or without ovarian hyperstimulation; whether to use transvaginal follicle aspiration or laparoscopy; whether to expose all or some oocytes to human sperm; whether to use partner or donor sperm; and whether to transfer one or more embryos to the uterus.

Decisions about these issues determine the nature of the IVF-ET cycle that the couple chooses to authorize or refuse. To be sure, different facts and different policies at different clinics constrain decision making in different ways. Ideally, however, as much control as possible should remain with the couple, who should be given appropriate information about the various ways IVF-ET can be practised so they can make informed choices about the kind of IVF-ET they want to authorize or refuse.

In addition to a description of IVF-ET (and the various permutations and combinations), couples should be given some account of the practical,

social, and psychological impact an IVF-ET cycle is likely to have on daily living. For example, for the woman, an IVF-ET cycle requires daily visits to the clinic for blood tests to check estrogen levels and for injections of the ovarian stimulant. There is the likelihood of some inconvenience and physical discomfort. Also, as the cycle progresses, ultrasound scans are required to monitor the growth (location, size, and number) of the follicles. A major time and energy commitment is thus required of the woman. In some cases, this may seriously limit her ability to work during a cycle. In fact, some clinics instruct women to stop working once daily monitoring begins.[3]

Also, anecdotal evidence about the psychological impact of IVF-ET suggests that it is a very stressful experience. If the cycle has to be cancelled because of an inadequate response to controlled ovarian hyperstimulation, a significant risk of severe hyperstimulation syndrome, or premature ovulation, there is sometimes panic and blame. If the oocytes retrieved fail to fertilize because of extreme immaturity there may be more disappointment. If the embryos transferred do not implant, the stress and emotional turmoil may intensify. An understanding of these "facts" is as important as an understanding of the proposed technological interventions.

Objective(s) of IVF-ET

It is not uncommon for couples, IVF-ET practitioners, and society at large to construe the objective of IVF-ET narrowly as the establishment of pregnancy and the birth of a healthy child or children. A broader understanding of the objective of IVF-ET is required, however, particularly as pregnancy and take-home-baby rates are (and probably will remain) limited. From the outset couples should be encouraged to view IVF-ET as an opportunity for them to move beyond their present state of infertility into parenthood or into an appropriate way of coming to terms with their situation.

Available Alternatives to IVF-ET and Adjunct Interventions

Depending upon the cause of infertility, technological alternatives to controlled ovarian hyperstimulation IVF-ET include non-stimulated IVF-ET; gamete intra-fallopian transfer (GIFT) (by laparoscopy or ultrasound-guided tubal transfer); zygote intrafallopian transfer (ZIFT); intrauterine insemination (IUI); and ovulation induction and intrauterine insemination (OI-IUI). Other alternatives, irrespective of the cause of infertility, include adoption (which may be pursued instead of, or concomitant with, IVF-ET) and a decision to remain child-free. In addition, the adjunct interventions include gamete and embryo donation, embryo cryopreservation, pre-transfer genetic screening, and preconception agreements.

Space limitations prevent discussion of the nature and objective(s) of alternative and adjunct interventions here. Preconception agreements, oocyte donation for clinical purposes, embryo freezing for subsequent transfer, and preimplantation genetic diagnosis are discussed in detail in subsequent papers.

3. Information about the nature and probability of the known and possible consequences (i.e., the benefits, harms, and inconveniences) of the various options (i.e., the proposed intervention, alternative interventions, and the option of no intervention)

Potential Benefits of IVF-ET

From the perspective of most infertile couples, *the* potential benefit of IVF-ET is the birth of "their own" child. Thus, a critical consideration for couples assessing the benefit-harm ratio of IVF-ET is the likelihood of their having a child as a result of the technology. For this reason, a realistic estimate of the success rates of IVF-ET is particularly relevant.

At present, it is common knowledge that the "success" rates for IVF-ET are low; beyond this, however, confusion reigns for several reasons. First, the percentages cited by different clinics do not all use the same numerators or denominators. There are biochemical pregnancy rates, clinical pregnancy rates and take-home-baby rates. These rates are available per cycle, per oocyte retrieval, and per embryo transfer.[4]

Second, there is confusion because rates vary from clinic to clinic, and clinics do not compile and present uniform statistical information for a standard reporting period. (For example, some clinics present the data on a yearly basis, while others include more than one year in their statistics.[5]) Also, rates at each clinic vary from year to year as team members gain experience and expertise or as team members join or leave the clinic. In addition, rates vary with the cause of infertility and the age of the female partner. Select examples are cited below to illustrate each of these points:

(a) There is no standard reporting period.
At London's University Hospital the overall clinical pregnancy rate per embryo transfer as at June 1990 (for an unspecified period of time) was 24.4 percent.[6] At IVF Canada from May 1988 to December 1990 it was 21.3 percent,[7] and at the University of British Columbia for 1990 it was 19 percent.[8] Because of the way data are recorded and presented the figures are not readily comparable.

(b) The rates vary from year to year.
The clinical pregnancy rate per embryo transfer for all indications at the University of British Columbia was approximately 16.6 percent for 1985 to 1990. Per annum, it was 21 percent for 1985, 15 percent for 1986, 13 percent for 1987, 16 percent for 1988, 16 percent for 1989, and 19 percent for 1990.[9]

(c) The rates vary depending upon the cause of infertility.
The overall clinical pregnancy rate per cycle for 1985-1990 at the University of British Columbia for tubal factor infertility was 18 percent; for endometriosis it was 16 percent; for male factor infertility it was 10 percent; for unexplained infertility it was 23 percent; for tubal and other factor infertility it was 9 percent;

for ovulatory disorders and luteal phase dysfunction it was 15 percent; and for endometriosis and other factor infertility it was 6 percent.[10]

(d) The rates vary depending upon the age of the female partner. At IVF Canada the overall pregnancy rate per embryo transfer, from May 1988 to December 1990, was 21.3 percent. At one end of the spectrum were women under the age of 25, with a pregnancy rate per embryo transfer of 27.8 percent. At the other end the spectrum were women over 40, with a pregnancy rate per embryo transfer of only 2.8 percent.

A third factor that contributes to confusion about the "success" of IVF-ET is the use of broad statistical ranges. For example, the patient consent form used by the Endocrine and Infertility Centre at Dalhousie University states that the "current success rate of documented pregnancies ranges from 15 to 25 percent per cycle of therapy."[11] The difference between 15 percent and 25 percent is significant.

A fourth concern is inconsistency in the references to pregnancy rates for normal fertile couples. For example, the University of British Columbia maintains that the likelihood of pregnancy per transfer for fertile couples is in the range of 25 to 30 percent.[12] The IVF Program at University Hospital in London cites slightly lower figures of 20 to 25 percent.[13] The Endocrine and Infertility Centre at Dalhousie University reduces these percentages further to between 15 and 25 percent.[14]

Finally, there is confusion because clinics typically cite pregnancy rates per embryo transfer, despite the fact that what is most relevant to infertile couples are take-home-baby rates per cycle — "to most couples, success is a baby, not a pregnancy."[15] This common practice of reporting and emphasizing pregnancy rates per embryo transfer is not only confusing, it is also misleading given the high rate of miscarriage and the known incidence of ectopic pregnancy, both of which explain, in part, the lower take-home-baby rate.

IVF Canada, for example, acknowledges that the rate of miscarriage with IVF-ET is about 30 percent[16] and the ectopic pregnancy rate is about 7 percent.[17] Thus, although the overall pregnancy rate from May 1988 to December 1990 was 21.3 percent, the take-home-baby rate was just 13 percent.[18] Similarly, the IVF Program at the University of British Columbia had an overall pregnancy rate for 1990 of 19 percent and a take-home-baby rate of 15 percent.[19] The IVF Program at University Hospital (London), as at June 1990, had an overall pregnancy rate of 24.4 percent and a take-home-baby rate of 8 percent,[20] and so on.

In deciding whether to authorize or refuse IVF-ET, couples typically weigh the potential benefit of having a child against the potential harms of IVF-ET. For their choice to be informed, the take-home-baby rate (which is consistently lower than the pregnancy rate) must be disclosed and emphasized. Unfortunately, this is not current practice.

Potential Harms, Discomforts, and Inconveniences of IVF-ET

The potential harms, discomforts, and inconveniences of IVF-ET are many. Of particular concern are severe hyperstimulation syndrome and multiple gestation.

As described by one pharmaceutical company,

> [s]evere ovarian enlargement, known as hyperstimulation syndrome, is characterized by sudden enlargement of the ovary and an accumulation of fluid in the abdomen. This fluid can also accumulate around the lungs and may cause breathing difficulties. If the ovary ruptures, blood can accumulate in the abdominal cavity as well. The fluid imbalance can also affect blood clotting and, in rare cases, could be life-threatening.[21]

More specifically, severe hyperstimulation syndrome can result in deep vein thrombophlebitis, stroke, pulmonary embolism shock, pulmonary edema, and kidney problems.[22]

These potential consequences of severe hyperstimulation are serious. Their likelihood of occurrence is slight, however, because cycles are usually cancelled if there is thought to be a significant risk of hyperstimulation syndrome. According to the American Fertility Society, approximately 10 percent of women who undergo controlled ovarian hyperstimulation have a mild case of hyperstimulation syndrome and less that 1 percent have a case severe enough to require hospitalization.[23]

The other significant potential harm with IVF-ET is multiple pregnancy. With ovulation induction alone, the risk of multiple pregnancy is approximately 5 percent with clomiphene citrate (CC) and approximately 20 percent with human menopausal gonadotropin (hMG). When these drugs are used as part of an IVF-ET protocol, this risk can be reduced in theory by limiting the number of embryos transferred. In practice, however, the risk of multiple gestation remains significant because of the number of embryos that are routinely transferred per cycle. Recent data from Britain for 1978-1987 show that whereas the rate of multiple pregnancy for natural conceptions is about 1 percent, it is 23 percent for IVF and GIFT (19 percent are twins and 4 percent are triplets and more).[24]

The number of embryos for transfer per cycle is an issue of particular concern because of its relevance to a couple's assessment of the benefit-harm ratio of IVF-ET. At IVF Canada, the recommended maximum number of embryos for transfer on the first attempt is five, but the final decision rests with the couple.[25] At the Chedoke-McMaster IVF Program, couples decide how many oocytes are to be exposed to human sperm. The maximum number is six, and couples know that *all oocytes that fertilize* will be transferred.[26]

By comparison, at the University of British Columbia IVF Program there are three distinct options for couples to choose from. With option #1 as many oocytes as possible are retrieved and inseminated; the best three or four embryos are transferred, and the remaining good embryos are cryopreserved. With option #2 a maximum number of oocytes are retrieved and inseminated, and the best three or four embryos are transferred. The

remaining embryos are either fixed for chromosomal analysis or discarded. Option #3 is for those who object to cryopreservation and selection. A maximum of six oocytes are exposed to human sperm, and all embryos created are transferred. For those who wish to avoid the possibility of having six embryos transferred, the number of oocytes exposed to human sperm can be reduced to four.[27]

The reason for transferring more than one embryo per cycle is to increase the chance of pregnancy. The reason for limiting the number of embryos transferred is to avoid the increased short-term and long-term risks — both for the woman and for the fetus — commonly associated with multiple pregnancies. These risks include premature labour and delivery, obstetric complications, serious post-partum haemorrhage, and perinatal mortality and morbidity (physical and mental), as well as infant mortality.[28]

Recent data indicate that as the number of IVF embryos transferred increases — up to a maximum of three — the pregnancy rate also increases. When more than three embryos are transferred, however, the pregnancy rate does not increase further.[29] In addition, one extensive study on mortality rates after multiple gestations indicates that there is a marked increase in the percentages of perinatal and infant deaths between triplets, on the one hand, and quadruplets and quintuplets, on the other.[30] These findings suggest that a maximum pregnancy rate and an acceptable multiple pregnancy rate could be achieved by transferring only three embryos per cycle.[31]

A recent comparative study of unstimulated IVF-ET and controlled ovarian hyperstimulation IVF-ET supports this conclusion. In this study, there were sixteen cycles with single embryo transfers, eight cycles with two embryos transferred and one cycle with three embryos transferred. The clinical pregnancy rate was 20 percent per embryo transfer and 17 percent per oocyte retrieval. The take-home-baby rate was 16 percent per embryo transfer and 13 percent per oocyte retrieval. These rates are respectable when compared with those of clinics that routinely transfer more than three embryos per cycle.[32]

The purpose of this lengthy discussion about the number of embryos transferred is to highlight an important question about the adequacy of disclosure and understanding about the benefits and harms of transferring four or more embryos per cycle. If couples understood that increasing the number of embryos transferred beyond three increased the potential for harm without increasing the potential for benefit, would they choose to have more than three embryos transferred?

In addition to the major potential harms of severe hyperstimulation syndrome and multiple gestation, there are the many potential side-effects of the various drugs used to mature the oocytes, to suppress ovarian function, and to induce ovulation. These are listed below for the drugs most commonly used in IVF-ET programs. Providing precise information about each drug is important, because women undergoing IVF-ET follow different drug regimens and are therefore exposed to different potential side-effects.

- **Clomiphene Citrate (CC) (See Table 1)**
  Minor potential side-effects include hot flushes (caused by changes in the body's hormone levels), abdominal discomfort and/or pain (due to ovarian enlargement), breast tenderness, mood swings, nervousness, nausea and vomiting, and fatigue (symptoms of ovulation induction).

  Of significant concern are scotomas (flashes of light that appear in front of the eyes) and headaches or dizziness. These side-effects are rare but may reflect potentially serious medical problems. In particular, there is the risk of a hormone-induced migrainous stroke. Migraines may be associated with or may predispose to an increased incidence of vascular spasm strokes — the blood vessels go into spasms, stopping blood flow to the brain (this risk is almost always reversible).[33]

- **Human Menopausal Gonadotropin (hMG) (See Table 2)**
  Minor potential side-effects include abdominal distension and/or abdominal pain (due to ovarian enlargement), allergic sensitivity, pain, rash, some discomfort at the injection site (swelling), mood swings (due to ovulation), and hot flushes.

  Of significant concern is the potential risk of severe ovarian hyperstimulation syndrome requiring hospitalization and possibly intensive care.

- **Gn-RH Analogue**
  Minor potential side-effects include hot flushes, a decrease in libido, some discomfort at the injection site, dyspareunia (painful intercourse), and other hypoestrogenic side-effects such as osteoporosis. (Osteoporosis is a minor concern because the risk is relevant only if the Gn-RH analogue is used over a long period [e.g., six months] without estrogen.)

  Of significant concern is the risk of severe ovarian hyperstimulation syndrome requiring hospitalization and possibly intensive care.

- **Human Chorionic Gonadotropin (hCG) (See Table 3)**
  Minor potential side-effects include abdominal distention and/or pain (due to ovarian enlargement), irritability, restlessness, depression, fatigue, some discomfort at the injection site (redness and tenderness), Mittleschmerz (pain at ovulation), and hot flushes.

- **Progesterone**
  Minor side-effects include fatigue, bloating, weight gain, and breast tenderness.

In addition to these known potential harms, there may be additional unanticipated long-term side-effects of the various drugs and hormones. For example, it has been suggested that there may be increased rates of spontaneous abortion following conceptions induced by CC or hMG. In response, it has been argued that there is no real increase in spontaneous

abortion rates but only the perception of an increase because of earlier diagnosis of pregnancy.

Others have suggested that if a woman undergoes three or four stimulated cycles per annum, she may experience earlier menopause because of the depletion of the germ cell population. In response it has been argued that if this were true, then by analogy women who use oral contraceptives (and do not release any eggs) should have later menopause, yet this has not been documented. It is further argued that although early menopause does occur when follicles are destroyed (e.g., by chemotherapy), it is not evident that early menopause will occur because a number of eggs are being matured each cycle. It is hypothesized that a number of eggs are naturally released each month and that the drugs used for ovarian stimulation only encourage the maturation of those eggs that would normally be released.

Finally, some have suggested that there may be a link between ovarian hyperstimulation and cancer.[34] This possibility remains a concern although no causal relationship has been established. Recently it has been noted that

> [p]roving an association between the two will be difficult because of the likely rarity of the complication and the long time that may elapse between treatment and the clinical appearance of cancer. A retrospective case-control study would therefore answer the question sooner than a long term cohort study.[35]

Step two of IVF-ET is oocyte retrieval. This can be done by transvaginal aspiration or by laparoscopy; with either procedure there are potential harms. With transvaginal aspiration there is a small possibility that nearby organs and tissues may inadvertently be pierced. This may result in minor bladder symptoms (e.g., bloody urine, frequent urge to urinate) and pain. Other more significant potential harms include internal bleeding, visceral damage (e.g., bowel, bladder), damage to major pelvic sidewall vessels (iliac vessels), and infection. Those most at risk of infection are women with previous pelvic inflammatory disease (PID). Generally these women are given prophylactic antibiotics as a precautionary measure.

Laparoscopy, the other means of oocyte retrieval, is no longer commonly used in Canada. When it is used, the potential complications of general anaesthesia are added to the potential harms of transvaginal aspiration. Also, with laparoscopy the risk of damage to the bladder, bowel, or a blood vessel may be greater if the patient has severe scarring inside the abdominal cavity.

With either transvaginal aspiration or laparoscopy, approximately one patient in 1 000 requires a major operation to repair damage from complications of oocyte retrieval, and about one in 10 000 to one in 100 000 may die from the complications.[36]

If a pregnancy is established after oocyte retrieval, fertilization, and embryo transfer, other potential harms may ensue. For example, many

IVF-ET patients are older women who will be exposed to the general risks of pregnancy in this higher risk population. In addition, for all women, there are the risks of ectopic pregnancy and miscarriage.

Information provided to prospective IVF-ET patients about the risk of ectopic pregnancy seems to vary from clinic to clinic. To cite but two examples, at IVF Canada the ectopic pregnancy rate is about 7 percent,[37] whereas at the UBC IVF Program the ectopic pregnancy rate is between 2 and 12 percent.[38]

Similarly, information provided to prospective IVF-ET patients about the risk of miscarriage seems to vary from clinic to clinic. IVF Canada acknowledges that the rate of miscarriage with IVF-ET is about 30 percent[39] (which is similar to the rate of miscarriage with natural conception).[40] The UBC IVF Program suggests, however, that the rate of miscarriage is only 15 to 25 percent.[41]

The remaining potential harms are those generally associated with multiple gestations. The most serious of these harms, from the couple's perspective, is potential harm to the offspring. It is widely recognized that a significant determinant of the health of children born by means of IVF is the frequency of multiple births.

In addition, there is the increased risk of premature delivery, low birthweight infants, stillbirths, perinatal mortality, and neonatal and infant mortality. Some of these risks are discussed briefly below using statistical information from the British registry for conceptions by IVF-ET or GIFT in England, Scotland, or Wales between 1978 and 1987.[42] (Equivalent Canadian data are not available.)

(a) increased incidence of multiple births

With natural conceptions the rate of multiple births is 1 percent of deliveries. With IVF-ET and GIFT this increases to 23 percent (249/1 029) of deliveries (19 percent are twins and 4 percent are triplets or more).

(b) increased incidence of premature delivery

For natural conceptions the incidence of premature delivery (prior to 37 completed weeks of gestation) is 6 percent for all deliveries in England and Wales. For IVF-ET and GIFT the rate is 24 percent (248/1 015) of deliveries (33 percent [431/1 291] of babies). This difference is due primarily to the increased frequency of multiple births.

(c) increased incidence of low birthweight infants

With natural conceptions, the incidence of low birthweight infants is low. For all births in England and Wales, 7 percent have a birthweight of less than 2 500 g and 1 percent have a birthweight of less than 1 500 g. By comparison, 32 percent (406/1 269) of infants conceived by IVF-ET or GIFT have a birthweight of less than 2 500 g and 7 percent (89/1 289) have a birthweight of less than 1 500 g.

The increased incidence of low birthweight infants is linked to the frequency of multiple births, but singleton and twin birthweights are also lower than average. This could be due to older maternal age and early induction. (A consequence of the "premium pregnancy psychology" is that women may be induced while still healthy.)

(d) increased incidence of perinatal morbidity and mortality
Perinatal mortality figures for IVF-ET and GIFT are 27.2 per thousand. By comparison the national average in England and Wales in 1985 was 9.8 per thousand.

(e) increased incidence of neonatal and infant mortality
Neonatal and infant mortality figures for IVF-ET and GIFT are 23.7 per thousand. By comparison the national average in England and Wales in 1985 was 9.4 per thousand.

Another significant concern for most couples considering IVF-ET is the possibility of giving birth to a child with a congenital abnormality.[43] Recent reports suggest, however, that there is no (or very little) difference between the incidence and range of abnormalities for children born of IVF-ET and children conceived during a natural cycle. For example, the 1990 annual report of Britain's Interim Licensing Authority concludes that

> it does not appear ... that there is a significant increase in congenital abnormalities in babies born by IVF.[44]

Similarly, the British MRC Working Party on Children Conceived by In Vitro Fertilisation reports, in a survey of IVF and GIFT births in Britain between 1978 and 1987, that

> ... among the births resulting from assisted conception 2.2% had one or more major malformation diagnosed in the first week of life. This is comparable with the expected values from all three data sets in Britain and with the findings from Australia and New Zealand.[45]

In a Canadian context, the UBC IVF Program claims that

> There have been approximately 8,000 to 10,000 babies born through IVF in the world and very careful study of these babies thus far has not demonstrated any increased incidence of abnormalities and, in fact, the risk of an abnormality appears to be slightly less than that which is seen in the general population.[46]

The problem with the data on which such statements are based is that

> the numbers [are] small, diagnostic criteria varied, and the same children may have been included in more than one study. Formal pooling of the international data is required not only to increase statistical power but also to ensure that standard definitions are used and that each child is included only once in the totals.[47]

This being said, a consistent excess of central nervous system disorders has been noted among IVF births.[48]

Last but not least, there are the potential psychological harms of IVF-ET. Generally speaking these are very personal, and for this reason they are not discussed here in detail. In brief, however, it must be noted that couples' expectations and hopes are high, while take-home-baby rates are limited. The potential for frustration, anger, isolation, and resentment is therefore significant. These emotions may lead to low self-esteem and depression.

4. Information about the qualifications and experience of the various team members

As noted previously the success rates for IVF-ET vary considerably from clinic to clinic. This results in part from the different levels of experience and expertise of team members. Couples who are considering an IVF-ET cycle must be apprised of this fact, particularly if the clinic is new and has a limited success rate as compared with the national average.

5. Information about the costs involved

In all provinces except Ontario, IVF-ET is not an insured service. Thus, all IVF-ET clinics outside Ontario and the one private clinic in Ontario (IVF Canada) must give prospective candidates relevant information about the cost of required physician-related procedures, laboratory work, and hospital stays. In addition, all clinics (including Ontario clinics) must discuss the costs of the required drugs. This is an unusual aspect of consent to medical treatment in a Canadian context, but it is necessary given that government-funded health care programs outside Ontario do not reimburse couples for IVF-ET expenses, and given that not all insurance companies reimburse couples for all of the drug costs.

In Canada the average cost per IVF-ET cycle is approximately $4 000. For example, the UBC IVF Program charges $2 782.50 per cycle for ovulation induction, oocyte retrieval, gamete laboratory work, and embryo replacement. In addition, there is a $452 fee for the two required hospital stays, and drug costs are estimated to be between $800 and $1 000.[49] The total is approximately $4 135.

At the Endocrine and Infertility Centre in Halifax the base cost is $2 804; in addition drug costs are estimated to be approximately $900, for a total of $3 700.[50] At the Institut de Médecine de la Reproduction de Montréal, the base cost is $3 200, and drugs costs range between $500 and $2 000 per cycle.[51]

As a final point of comparison, at IVF Canada, Ontario patients pay approximately $3 700 per cycle, which includes the purchase of Perganol, whereas non-Ontario residents pay approximately $4 900 for services and Perganol.[52] The additional $1 000 is for physician-related procedural fees otherwise billable through the provincial health care plan.

In addition to physician-related procedure fees, laboratory work, required hospital stays, and drug costs, there are the additional incidental costs of IVF-ET. These include time missed from work and possibly travel and accommodation costs if the couple lives at a distance from the clinic.

6. Additional information that may assist a couple considering IVF-ET to make an informed choice

Additional information that a couple may require to make an informed choice typically will be of a personal nature. Not all relevant additional information is specific to the couple, however. Some clinics, for example, have a stopping rule whereby a couple is eligible for only a fixed number of cycles. At the UBC IVF Program, for example, a couple is eligible for a maximum of three cycles. At the Chedoke-McMaster IVF Program a couple is eligible for four stimulated cycles after which they may go back on the waiting list if they are still interested in IVF-ET. (In addition to the stimulated cycles, some couples are eligible for an unstimulated cycle.) At the University of Calgary program, there is no restriction on the number of cycles.

Another example of a policy choice that may influence a couple's decision to authorize or refuse IVF-ET is UBC's team approach to IVF-ET, a direct consequence of which is that care is not provided by a particular physician. For couples who want this type of care, this may be a serious disincentive.

Another relevant consideration for some couples is the availability of prenatal diagnostic services. This may be particularly important for couples at risk for a specific genetic disorder, or couples where the female partner is over the age of 35.

7. A statement that patients or subjects may ask questions now and later

Many of the IVF programs in Canada specifically invite prospective candidates to ask questions. They include the Calgary IVF Programme, the Chedoke-McMaster IVF Program, IVF Canada, the Toronto Hospital General Division In Vitro Fertilization Unit, the Institut de Médecine de la Reproduction de Montréal, the Centre de Fécondation In Vitro CHUL, and the Endocrine and Infertility Centre.[53]

8. A statement that confidentiality will be respected

The UBC IVF Program, the University Hospital IVF Program, the Toronto Hospital General Division In Vitro Fertilization Unit, the Centre de Fécondation In Vitro CHUL, and the Endocrine and Infertility Centre are amongst the IVF centres that promise explicitly to respect confidentiality.[54] Generally, however, they do not qualify this promise, and this is certainly problematic. Prospective participants should be informed of the limits that apply to any promise of confidentiality.

9. A statement that the patient or subject may refuse to participate without jeopardizing access to health care

Only the UBC IVF Program and the University Hospital IVF Program explicitly state in writing that the prospective participant may refuse IVF-ET.[55]

10. A statement that consent and refusal are revocable. In principle, the patient or subject may withdraw his/her consent or overturn his/her previous refusal without jeopardizing access to health care

Many of the Canadian IVF programs specifically recognize the couple's right to withdraw at any time without jeopardizing access to health care — the UBC IVF Program, the Calgary IVF Programme, the University Hospital IVF Program, the Chedoke-McMaster IVF Program, the Toronto Hospital General Division In Vitro Fertilization Unit, and the Centre de Fécondation In Vitro CHUL.[56]

Notes

1. Recent successful attempts at IVF-ET without controlled ovarian hyperstimulation (COH) suggest the need to distinguish between COH-IVF-ET and IVF-ET without COH. However, since it is common to use the acronym IVF-ET for stimulated *in vitro* cycles, this acronym is used throughout this paper to refer to stimulated IVF-ET cycles.

2. Dalhousie University, Department of Obstetrics and Gynaecology, Endocrine and Infertility Centre, *In Vitro Fertilization and Embryo Transfer* (Halifax, n.d.), 2.

3. See, for example, University Hospital IVF Program, *In Vitro Fertilization* (London: University Hospital, 1990), 8.

4. This problem could be resolved with the introduction of a Canadian registry. At present, however, "the fate of the IVF registry is unclear due to funding problems." See Ontario Medical Association Newsletter, *Section on Reproductive Biology*, February 1992. The Canadian Voluntary Regulatory Association (CVRA), with funds from Serono, Abbott, and the individual clinics, hopes to establish a Canadian registry. All centres in Canada, except for the Chedoke-McMaster IVF Program, have agreed to provide funds for the registry. The Chedoke-McMaster IVF Program agrees with the need for a registry but objects to the use of patient-care funds to pay for the registry. Personal communication, Salim Daya, Chedoke-McMaster IVF Program, April 13, 1992.

5. Of interest is a recent survey of IVF directors in the United States that found that 75 percent of directors opposed the idea of mandatory filling of quarterly reports. A.L. Bonnicksen and R.H. Blank, "The Government and In Vitro Fertilization (IVF): Views of IVF Directors," *Fertility and Sterility* 49 (1988): 396-98.

6. University Hospital IVF Program, *In Vitro Fertilization*, insert 1A. This is the published figure in the patient handout as at June 1990. It is not clear what period of time this percentage is for.

7. IVF Canada, *Statistical Report January 1991* (Toronto: IVF Canada, 1991), 1.

8. University of British Columbia, Department of Obstetrics and Gynaecology, *The In Vitro Fertilization Program* (videocassette) (Vancouver, 1991). Surprisingly, the patient information handout (*In Vitro Fertilization Program* (Vancouver, 1991), 3) states that the overall pregnancy rate is approximately 15 percent. On the basis of the information provided it is not possible to explain the discrepancy.

9. University of British Columbia, *In Vitro Fertilization Program* (videocassette). The reason for the sharp decline between 1985 and 1986 is that patient selection criteria were broadened.

10. Ibid.

11. Dalhousie University, Department of Obstetrics and Gynaecology, Division of Endocrinology, *Consent for In Vitro Fertilization* (Halifax: Endocrine and Infertility Centre, n.d.).

12. University of British Columbia, *In Vitro Fertilization Program*, 3.

13. University Hospital IVF Program, *In Vitro Fertilization*, 1.

14. Dalhousie University, *In Vitro Fertilization and Embryo Transfer*, 2.

15. American Fertility Society, *IVF & GIFT: A Patient's Guide to Assisted Reproductive Technology* (Birmingham: American Fertility Society, 1989), 13.

16. IVF Canada, *Patient Information Booklet 1* (Toronto: IVF Canada, 1989), 8.

17. Ibid., 9.

18. Ibid., 1.

19. University of British Columbia, *In Vitro Fertilization Program* (videocassette). By comparison, according to the patient handout, the overall pregnancy rate is approximately 15 percent and the overall take-home-baby rate is approximately 11 percent. On the basis of the information provided this discrepancy cannot be explained.

20. University Hospital IVF Program, *In Vitro Fertilization*, insert 1A.

21. Serono Laboratories, *Information on Pergonal/Profasi HP Therapy* (Norwell: Serono Laboratories, 1987), 3-4.

22. Personal communication, Dr. Jeff Nisker, University Hospital IVF Program, London.

23. American Fertility Society, *IVF & GIFT: A Patient's Guide*, 10.

24. MRC Working Party on Children Conceived by In Vitro Fertilisation, "Births in Great Britain Resulting from Assisted Conception, 1978-87," *British Medical Journal* (12 May 1990): 1229-33. These data from Britain cannot be extrapolated directly to the Canadian experience.

25. IVF Canada, *Patient Information Booklet 1*, 10.

26. It is rare for six embryos to be transferred, but this does happen. Personal communication, Dr. M. Sagle, Chedoke-McMaster IVF Program (Information Night, 17 April 1991).

27. University of British Columbia, Department of Obstetrics and Gynaecology, *In Vitro Fertilization Program: Consent Form* (Vancouver, 1991), 1-2.

28. A.A. Yuzpe et al., "Rates and Outcome of Pregnancies Achieved in the First 4 Years of an In-Vitro Fertilization Program," *Canadian Medical Association Journal* 140 (1989), 171; and J.C. Hobbins, "Selective Reduction — A Perinatal Necessity?" *New England Journal of Medicine* 318 (1988), 1062.

29. Yuzpe et al., "Rates and Outcome of Pregnancies Achieved," 171.

30. Hobbins, "Selective Reduction — A Perinatal Necessity?" 1062.

31. F. Baylis, "The Ethics of *Ex Utero* Research on Spare 'IVF' Human Embryos," Ph.D. dissertation, University of Western Ontario, 1989, 104.

32. R.J. Paulson et al., "In Vitro Fertilization in Unstimulated Cycles: A Clinical Trial Using hCG for Timing of Follicle Aspiration," *Obstetrics and Gynecology* 76 (1990): 788-91.

33. Personal communication, Dr. Jeff Nisker, University Hospital IVF Program, London.

34. See, for example, M.E. Carter and D.N. Joyce, "Ovarian Carcinoma in a Patient Hyperstimulated by Gonadotropin Therapy for In Vitro Fertilization: A Case Report," *Journal of In Vitro Fertilization and Embryo Transfer* 4 (1987): 126-28; and H. Ben-Hur et al., "Ovarian Carcinoma Masquerading as Ovarian Hyperstimulation Syndrome," *Acta Obstetricia Gynecologica Scandinavica* 65 (1986): 813-14.

35. B.H. Smith and I.D. Cooke, "Ovarian Hyperstimulation: Actual and Theoretical Risks," *British Medical Journal* (19 January 1991), 127.

36. American Fertility Society, *IVF & GIFT: A Patient's Guide*, 11.

37. IVF Canada, *Patient Information Booklet 1*, 9.

38. University of British Columbia, *In Vitro Fertilization Program*, 4.

39. IVF Canada, *Patient Information Booklet 1*, 8.

40. A.J. Wilcox et al., "Incidence of Early Loss of Pregnancy," *New England Journal of Medicine* 319 (1988), 189.

41. University of British Columbia, *In Vitro Fertilization Program*, 4. "The miscarriage rate after in vitro fertilization appears to be the same as in nature which is approximately 15-25%."

42. MRC Working Party, "Births in Great Britain Resulting from Assisted Conception." It is important to remember that couples who conceive through IVF-ET and GIFT are not the same as couples who conceive naturally (e.g., increasing maternal age, inability to conceive, history of adverse pregnancy outcomes).

43. R. Klein and R. Rowland, "Women as Test-Sites for Fertility Drugs: Clomiphene Citrate and Hormonal Cocktails," *Reproductive and Genetic Engineering* 1 (1988), 251. Klein and Rowland note that there are significant structural similarities between Clomid® (clomiphene citrate) and DES (diethylstilbestrol) and maintain that there is already evidence to suggest a correlation between the use of clomiphene and abnormalities in children (pp. 258-61). Others dispute this claim. They state that the incidence and range of abnormalities with COH-IVF-ET is similar to that with natural conceptions (approximately 3 percent), there being some increased risk to the fetus with IVF-ET pregnancies because of the incidence of prematurity.

44. Interim Licensing Authority, *The Fifth Report of the Interim Licensing Authority of Human In Vitro Fertilisation and Embryology 1990* (London (U.K.): ILA Secretariat, 1990), 19.

45. MRC Working Party, "Births in Great Britain Resulting from Assisted Conception," 1233.

46. University of British Columbia, *In Vitro Fertilization Program*, 3.

47. MRC Working Party, "Births in Great Britain Resulting from Assisted Conception," 1233.

48. Australian In-Vitro Fertilization Collaborative Study, "In-Vitro Fertilization Pregnancies in Australia and New Zealand, 1979-1985," *Medical Journal of Australia* 148 (1987): 429-36; Medical Research International, Society of Assisted Reproductive Technology and American Fertility Society, "In Vitro Fertilization/Embryo Transfer in the United States: 1987 Results from the National IVF-ET Registry," *Fertility and Sterility* 51 (1989): 13-19; and MRC Working Party, "Birth in Great Britain Resulting from Assisted Conception."

49. University of British Columbia, *In Vitro Fertilization and Embryo Transfer.*

50. Dalhousie University, *In Vitro Fertilization and Embryo Transfer.*

51. Institut de Médecine de la Reproduction de Montréal, *Notice explicative destinée aux couples candidats à la fécondation in vitro* (Mount Royal: Clinique René Laennec, 1990), 7.

52. IVF Canada, *Application Form* (Toronto: IVF Canada, 1991).

53. This listing is not based on complete information about all of the IVF programs in Canada. It is based on information available at the time of submission. At the time of writing, information about the GOAL Program, the LIFE Program, the Toronto Fertility and Sterility Program, the Clinique de Fertilité, the Centre FIV St-Luc, and the Montreal General IVF Program was not available.

54. Ibid.

55. Ibid.

56. Ibid.

The following tables are based on information in the patient handouts and the consent forms used by some Canadian IVF programs. This narrow focus on written material is appropriate given that (1) all relevant information should always be provided in writing; other means of communication should be used to enhance the written information; (2) not all IVF programs use slides and videos, and not all of the programs that do use such material were able to provide copies; (3) I was unable to attend patient information evenings at each of the clinics that have such meetings; and (4) I was unable to attend private counselling sessions at which presumably more information would be provided to prospective candidates.

Table 1.

Clomiphene citrate	Hot flushes	Abdominal discomfort and/or pain	Breast tenderness	Mood swings	Nervousness	Nausea/ vomiting	Fatigue	Headaches	Dizziness	Visual disturbances
Serono Laboratories	●	●	●		●	●	●	●	●	●
In Vitro Fertilization Program, U.B.C.	●	●				●				
Calgary IVF Programme										
University Hospital IVF Program *Booklet*	●	●	●	●				●	●	●
University Hospital IVF Program *Handout*	●	●	●					●		
Chedoke-McMaster Hospitals										
IVF Canada*	●	●				●			●	●
Toronto Hospital General Division In Vitro Fertilization Unit*										
Institut de Médecine de la Reproduction de Montréal Inc.										
Centre de Fécondation In Vitro CHUL**										
Endocrine and Infertility Centre Dalhousie University										

No mention of this drug ● Side-effect mentioned

* These clinics provide prospective participants with copies of pamphlets prepared by the pharmaceutical company.

** No written information provided to participants.

Note: The data in this table are based on information available as at January 1991.

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Table 2.

Human menopausal gonadotropin (hMG)	Abdominal distension and/or pain	Allergic sensitivity	Pain	Rash	Discomfort at injection site	Mood swings	Hot flushes	Breast tenderness	Hyperstimulation syndrome	Sleep disturbances and headaches	Weight gain
Serono Laboratories	●	●	●	●	●				●		
In Vitro Fertilization Program, U.B.C.	●						●		●		
Calgary IVF Programme	●					●			●		
University Hospital IVF Program *Booklet*					●	●	●		●		
University Hospital IVF Program *Handout*	●				●		●	●			
Chedoke-McMaster Hospitals	●		●			●			●	●	●
IVF Canada*									●		
Toronto Hospital General Division In Vitro Fertilization Unit*											
Institut de Médecine de la Reproduction de Montréal Inc.											
Centre de Fécondation In Vitro CHUL**											
Endocrine and Infertility Centre Dalhousie University	●								●		

▒ No mention of this drug ● Side-effect mentioned

* These clinics provide prospective participants with copies of pamphlets prepared by the pharmaceutical company.

** No written information provided to participants.

Note: The data in this table are based on information available as at January 1991.

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Table 3.

Human chorionic gonadotropin (hCG)	Headaches	Irritability	Restlessness	Depression	Fatigue	Lower abdominal tenderness	Redness & tenderness at injection site	Hot flushes
Serono Laboratories	●	●	●	●	●	●	●	●
In Vitro Fertilization Program, U.B.C.	▒	▒	▒	▒	▒	▒	▒	▒
Calgary IVF Programme								
University Hospital IVF Program *Booklet*				●	●	●	●	
University Hospital IVF Program *Handout*								
Chedoke-McMaster Hospitals								
IVF Canada*								
Toronto Hospital General Division In Vitro Fertilization Unit*								
Institut de Médecine de la Reproduction de Montréal Inc.								
Centre de Fécondation In Vitro CHUL**								
Endocrine and Infertility Centre Dalhousie University								

▒ No mention of this drug ● Side-effect mentioned

* These clinics provide prospective participants with copies of pamphlets prepared by the pharmaceutical company.

** No written information provided to participants.

Note: The data in this table are based on information available as at January 1991.

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Part 3. Preconception Agreements: Informed Choice

A number of factors are relevant in considering the moral acceptability of preconception agreements[1] to transfer custody of a child to be conceived from the woman who will give birth to the child[2] to another couple.[3] Among these factors is the informed choice of (1) the gestational woman[4] (i.e., the woman who will make a gestational, and often a genetic, contribution to the child); (2) her male partner[5] (when applicable); (3) the couple who expect to have custody of the child thus conceived; and (4) the gamete donor(s), if other than those named above.

The relevant aspects of informed choice for the gestational woman and the commissioning couple are described briefly in this paper. Considerations relevant to the informed choice of the gestational woman's male partner and possible gamete donors are beyond the scope of this paper.

1. A description of the participants' current medical status

As with other assisted reproductive technologies (ARTs), the medical status of the prospective participants (i.e., of the commissioning couple and of the gestational woman) has a bearing on their ability to make an informed choice. Specific to preconception agreements, however, is the need for both the commissioning couple and the gestational woman to have information about the other party's medical status in addition to information about their own medical status.

The Gestational Woman

The gestational woman needs to know that she is healthy and capable of undertaking the physical and emotional risks of pregnancy. In addition she needs information about the medical status of the commissioning couple.

For example, the gestational woman who will be inseminated needs to know whether the male partner has any infectious diseases that might present a risk to her or the offspring. Of particular concern in this regard is the male partner's HIV (human immunodeficiency virus) status. With embryo transfer, on the other hand, the gestational woman will need such information about both gamete donors. (These may or may not be the same persons as those who enter into the preconception agreement.) In addition to information about possible infectious diseases, of legitimate interest to the gestational woman is information about any history of genetic disease.

The gestational woman also needs to know whether the female partner is capable of providing either the genetic and/or gestational components of reproduction. An important motivating factor for some prospective gestational women is the belief that they are assisting an infertile couple to have a child they could not otherwise have. It is of critical importance, therefore, that the gestational woman know whether the couple's decision to enter into a preconception agreement is motivated by a desire to overcome infertility or by some other medical or social consideration. If

motivated by a desire to overcome infertility, information about the nature of the infertility is important because this may determine whether only the gestational, or both the genetic and gestational, components of reproduction are to be provided.

The Commissioning Couple

Couples who are considering entering into a preconception agreement should know whether one or both partners are fertile or carriers for a specific genetic disorder. These facts may ultimately influence the nature of the preconception agreement.

For example, if the male partner is fertile, he will usually provide the sperm. If he is infertile, however, donor sperm will be required. On the other hand, if the female partner is fertile, the reason(s) for seeking a preconception agreement should be clearly understood. Alternatively, if she is infertile, the couple should fully understand the cause of the infertility. Information about the woman's medical condition is critical because it may determine whether another woman is to provide both the genetic and gestational components of reproduction, or only one of these components.

For example, a woman whose ovaries and uterus have been removed can provide neither the genetic nor the gestational component of reproduction. On the other hand, a woman who has had a hysterectomy but who still has her ovaries could make a genetic, but not a gestational, contribution to childbearing. This is also true for a woman suffering from severe diabetes, severe hypertension, or a uterine malformation.[6] Conversely, a woman with premature menopause or a woman at risk for passing on a genetic defect to her offspring could provide the gestational but not the genetic component of reproduction.

The commissioning couple needs to understand the medical situation fully in order to appreciate all the available options. For some couples, ova or embryo donation may be an alternative to a preconception agreement. Other couples may not be able to choose between a preconception agreement and some other ART. An available option, however, may be for the commissioning couple to provide the genetic component of reproduction (i.e., the embryo) instead of including this contribution to childbearing in the preconception agreement.

In addition to information about their own medical status, the commissioning couple also requires information about the physical and genetic health of the gestational woman. This includes information about (1) any infectious diseases that could create a risk for the child (including HIV infection);[7] (2) any use of alcohol, tobacco, narcotics, or prescription or non-prescription drugs; and (3) any family history of genetic disease. Also of interest is information about the mental and emotional fitness of the gestational woman to enter into and carry out the terms of the preconception agreement.

2. Information about the nature and objective(s) of the proposed intervention, along with similar information about available alternatives and adjunct interventions

Nature of Preconception Agreements

At present, preconception agreements typically involve the insemination of a gestational woman with sperm from the male partner of the commissioning couple. Thus, the gestational woman makes both a genetic and a gestational contribution to childbearing (i.e., she is genetically related to the child). In some cases, however, both the sperm and the ova are provided by the commissioning couple, and the gestational woman provides only the gestational component of reproduction (i.e., she is not genetically related to the child).

Current practice aside, in principle it is possible for gamete donors other than the gestational woman or the commissioning couple to be involved in a preconception agreement. In fact, there can be as many as five intimate participants in a preconception agreement: (1) a woman who will carry the pregnancy; (2) a woman who will provide the egg; (3) a woman who expects to parent the child; (4) a male who provides the sperm; and (5) a male who expects to parent the child.

This being said, it is important to note that preconception agreements (whether for a genetic and a gestational contribution or a gestational contribution alone) cannot, at this time, rightfully be described as therapy. Arguably, the objective of a preconception agreement is therapeutic, and the intervention seems efficacious as compared with some other forms of assisted reproduction. However, safety is unknown, and professional consensus as regards the long-term therapeutic merits of the intervention for all concerned parties is lacking. The frequency with which preconception agreements are entered into is low;[8] consequently many important questions regarding this practice remain unanswered.

Preconception agreements are best described as non-validated practice and, as with all non-validated practices, they

> *should* be conducted in the context of a research project designed to test their safety or efficacy or both; however, the research should not interfere with the basic therapeutic (or diagnostic or prophylactic) objectives.[9]

This claim is consistent with the recommendations of the Ethics Committee of the American Fertility Society that preconception agreements be pursued as a clinical experiment so as to study:

> (a) the psychological effects of the procedure on the surrogates [or surrogate gestational mothers], the couples, and the resulting children;
>
> (b) the effects, if any, of bonding between the surrogate [or surrogate gestational mother] and the fetus *in utero*;

(c) the appropriate screening of the surrogate [or surrogate gestational mother] and the man who provides the sperm;

(d) the likelihood that the surrogate [or surrogate gestational mother] will exercise appropriate care during the pregnancy;

(e) the effects of having the couple and the surrogate [surrogate gestational mother] meet or not meet;

(f) the effects on the surrogate's [or surrogate gestational mother's] own family of her participation in the process;

(g) the effects of disclosing or not disclosing the use of a surrogate mother [or surrogate gestational mother] or her identity to the child; and

(h) other issues that shed light on the effects of surrogacy [or surrogate gestational motherhood] on the welfare of the various persons involved and on society.[10]

Objective(s) of Preconception Agreements

From one perspective, the objective of a preconception agreement is simple and straightforward — to alleviate childlessness. To this end, a woman agrees to conceive or bear a child on the understanding that she will surrender the child to the commissioning couple immediately following the birth.

If one considers the option of a preconception agreement from the perspective of either contracting party, however, then additional possible objectives surface. For example, in addition to helping an infertile couple have a child, a gestational woman may enter into a preconception agreement to earn money or to relive the experience of pregnancy in a psychologically positive way so as to deal with a previous birth-related trauma.[11]

As for the commissioning couple, the objective may not be simply to relieve childlessness, but to do so in a way that will allow one or both partners to have a genetic link with the offspring. Other important objectives for the female partner of the commissioning couple, if she is not infertile, may be a desire to avoid the potentially harmful and possibly lethal risks of pregnancy, as when the woman has severe diabetes or hypertension, or a desire to avoid passing on a genetic defect to an offspring. Alternatively, the female partner of the commissioning couple may have other motivations — for example, a desire to avoid pregnancy for personal, professional, aesthetic, or other reasons of convenience.

These potentially different objectives explain how preconception agreements may differ. Three important distinguishing features are (1) whether the agreement entails an exchange of money (altruistic or commercial preconception agreements); (2) whether the gestational woman is known to the commissioning couple (anonymous or non-anonymous preconception agreements); and (3) whether the agreement is for both a

genetic and gestational contribution to childbearing or only a gestational contribution.

Available Alternatives to Preconception Agreements and Adjunct Interventions

Alternatives to a preconception agreement include adoption, child-free living, and nurturing children in ways other than as parents. Another alternative for some couples is to receive an ova or embryo donation. This may be an option when the female partner is capable of carrying a pregnancy. When this is not possible or could be harmful, however, a preconception agreement may be the only way the couple can have a child with whom one or both partners can have a genetic link. The options in this case would be a preconception agreement that involves insemination or a preconception agreement that involves *in vitro* fertilization and embryo transfer (IVF-ET).

3. Information about the nature and the probability of the known and possible consequences (i.e., benefits, harms, and inconveniences) of the various options (i.e., the proposed intervention, alternative interventions, and the option of no intervention)

The benefits, harms, and inconveniences of preconception agreements are many. Of particular concern, however, is not their number, but rather the fact that the benefits, harms, and inconveniences seem to accrue in a disproportionate way to the two contracting parties. If all goes well, most of the benefits seem to go to the commissioning couple, who have a child as a direct benefit of the preconception agreement. Most of the harms and inconveniences, however, seem to go to the gestational woman, who is exposed to the physical and psychological risks of pregnancy and childbirth, and who must deal with the social and psychological effects (for herself and her family) of giving up the child.

Because the benefits, harms, and inconveniences seem to accrue in a disproportionate way to the different parties to the contract, disclosure of the known and potential benefits, harms, and inconveniences of preconception agreements is essential. These are listed below in summary fashion.

The Gestational Woman

The potential benefits of preconception agreements for the gestational woman are psychological and financial. If everything goes as planned, the emotional rewards for the gestational woman may be significant. If the female partner of the commissioning couple is infertile, or a carrier for a serious genetic disorder, the gestational woman may have helped the couple to have a child they might otherwise not have had. This psychological benefit is likely to be particularly important when the infertile woman is a family member or a close friend of the gestational woman and no fee is paid.

The second potential benefit of preconception agreements for gestational women is financial. With commercial preconception agreements the gestational woman typically receives about $10 000 U.S.

For these potential psychological and financial benefits, the gestational woman exposes herself and her family to a number of potential harms and inconveniences. First, there is the risk of HIV infection if the gestational woman is inseminated with fresh sperm. To minimize this potential harm, the gestational woman who provides both the genetic and gestational components of reproduction should be inseminated only with frozen sperm after there has been appropriate post-collection HIV testing. For this same reason, the gestational woman who provides only the gestational component of reproduction should have transferred to her uterus only embryos that have been created using appropriately screened gametes.[12]

Second, there are the potential physical harms of pregnancy and birth. Specifically, these are

> [the] complications which may harm or rarely kill, the discomfort — on average a pregnant woman suffers six to nine symptoms — the reduced physical and social activity and the emotional stress ... the pain of birth ... possible changes in the body — weight change, varicosities, and breast distortion.[13]

To these harms may be added the physical and emotional harms associated with the termination of pregnancy if a therapeutic abortion is sought for reasons of fetal indication at the initiative of either the commissioning couple or the gestational woman.

Third, there may be disappointed hopes about ongoing friendship with the couple who will have custody of the child. An important motivating factor for some gestational women "seems to be the desire for friendship with the parents-to-be."[14] In most instances, this anticipated benefit results in serious disappointment because the commissioning couple typically wants no (or little) interaction with the gestational women after they have custody of the child. Some suggest that this is less likely when the gestational woman is acting on behalf of a family member or close friend, but even then there is the possibility of disappointment.

Fourth, there is the psychological trauma that may result from surrendering the child to the commissioning couple. At present the long-term psychological effects of giving up custody are unknown. Some research reveals, however, that gestational women "go through a period of grief and mourning after giving up the child," and some experience long-term regret.[15]

Fifth, there is the possibility that the commissioning couple may reject the child should s/he be born with a physical or mental disability. If this happens, because of the present state of legal uncertainty, the gestational woman may have to keep (or place for adoption) a child that she would not otherwise have conceived. In Canada there is no legislation specific to preconception agreements. In 1985, the Ontario Law Reform Commission

recommended that preconception agreements be legalized,[16] but this recommendation was not acted upon. For comparative purposes: in Victoria, Australia, and in Great Britain, where the social, ethical, and legal aspects of ARTs have been addressed by the Waller and Warnock committees respectively, commercial preconception agreements have been prohibited.[17] In the United States commercial preconception contracts are legal in some states and illegal in others.[18]

Sixth, there is the possibility that the decision to enter into a preconception agreement will undermine, if not destroy, the gestational woman's relationship with her male partner. The partner may initially agree with, and be supportive of, the woman's choice, but this attitude may change over time. One woman reports, "He calls me a whore, prostitute and rent-a-womb." Another says "His attitude has turned against me. We're hardly having any sex at all now."[19]

Seventh, an indirect but very relevant potential harm for the gestational woman to consider is the potential harm to any children she might have. If the children at home are aware of the situation, they may be upset by their mother's decision to "give away" one of her children, and they may fear that they too will be given away.

The Commissioning Couple

The anticipated benefit of a preconception agreement for the commissioning couple is the birth of a healthy child. If all goes as planned, this benefit may be secured with little or no harm to the commissioning couple. If there are problems, however, with the terms of the agreement or with the transfer of custody, this benefit may not be achieved, or may be achieved only at some cost — both emotional and financial.

The most significant potential harm for the commissioning couple is the possibility that the gestational woman will change her mind and not want to give up the child after birth. It has been suggested that there is a one in 200 chance of this happening.[20] This potential harm is a stress that the couple may experience during the pregnancy, and even the infancy and childhood of the child.

The Gestational Woman and the Commissioning Couple

Finally, it is important for both the gestational woman and the commissioning couple to understand from the outset that they and their families may be subject to criticism from other family members, friends, colleagues, and society at large. Many explicitly condemn preconception agreements[21] (particularly commercial agreements) because, in their view, they commercialize human reproduction and treat women and children as commodities; exploit women (especially those who are socially and economically disadvantaged); undermine the nuclear family by eliminating the biological link between parents and child when a third party is introduced; and harm other family members (especially other children of the gestational woman).[22]

Also to be appreciated by both the gestational woman and the commissioning couple are the potential psychological harms to any offspring in the event that there are problems with the transfer of custody or there are altered familial relations (as when the gestational woman is a relative). The long-term potential harms are unknown, but the prognosis in certain cases is grim. Consider, for example, the case of Baby M where the commissioning couple and the gestational woman have joint custody and the child has a dual family life.

4. Information about the qualifications and experience of the various team members

Preconception agreements that use artificial insemination do not require any medical expertise specific to this arrangement. If anonymity is not an issue, it is relatively easy for the male partner to provide a semen sample and for the gestational woman to then inseminate herself. Preconception agreements that involve IVF-ET or GIFT, however, do require expertise. In these cases, the qualifications and experience of health care team members may be of critical importance given that the expertise of team members affects the success rates for IVF-ET and GIFT.

In addition to information about the qualifications and experience of the medical team, there is a clear need for similar information about those responsible for drafting the terms of the legal agreement. This is important for both parties to the agreement. The commissioning couple has an interest in making sure the terms of any contract are respected, regarding conduct during pregnancy so as to reduce risk to the offspring; transfer of the child after birth; and conduct after the transfer with respect to efforts to contact the offspring. On the other hand, the gestational woman usually has an interest in ensuring that her freedom is not unduly constrained by the terms of the contract and that the commissioning couple will accept transfer of custody. As such, both the gestational woman and the commissioning couple need information about the qualifications and experience of those drafting the relevant documents and those providing legal counsel.

A separate but related concern is the conflict of interest that arises when the person acting as legal counsel for one party is also acting in this capacity for the other party. This issue is of particular concern when a lawyer is in the business of advertising for both the gestational women and the commissioning couples.

5. Information about the costs involved

Information about the financial costs involved in preconception agreements is predominantly an issue of concern for the commissioning couple who is considering entering into a commercial (as contrasted with an altruistic) preconception agreement.

As reported to the Office of Technology Assessment (OTA) in a 1988 survey,[23] a gestational woman is usually paid about $10 000 U.S. In principle, however, the fee is negotiable, as is the schedule of payments

(e.g., a lump sum at the time of birth or monthly instalments). As well, there may be a reduced fee in the event of a miscarriage, a therapeutic abortion for fetal indication, or a stillbirth.

In addition to the fee for the gestational woman, there are fees for the broker ($3 000 to $7 000), the lawyer (up to $5 000), the physician ($2 000 to $3 000), and the psychiatrist ($60 to $150/hour). Also, there may be medical and travel expenses as well as expenses for food, shelter, maternity clothes, and other incidentals for the nine months of pregnancy.[24] Some preconception agreements include compensation for lost wages and a life insurance policy for the gestational woman (the beneficiary to be identified by her).[25] The total cost is usually between $25 000 and $50 000, depending upon the terms of the agreement. (These figures are all in U.S. dollars.)

Further legal costs may be added if there are problems obtaining custody of the child. The gestational woman may have a change of heart, as was the case with Baby M, or the state may intervene and prevent the commissioning couple from having custody of the child, as with Baby Cotton.[26]

6. Additional information that may assist the prospective participants to make an informed choice

Preconception agreements typically detail expectations of the gestational woman both during and after pregnancy. Relevant to conduct during pregnancy are issues pertaining to the use of alcohol, tobacco, narcotics, and prescription and non-prescription drugs; access to prenatal care; and the option to terminate the pregnancy. Many agreements forbid the termination of pregnancy without the consent of the commissioning couple, but require termination of pregnancy if prenatal testing reveals a fetal abnormality. Relevant to conduct after the birth of the child are disclosure to the media; efforts by the gestational woman to form a parent-child relationship with the offspring; and efforts at some later stage to disclose to the child the nature of his/her relationship to the commissioning couple. Details regarding these issues must be clearly explained to the gestational woman for her to consider as a basis for her consent or refusal.

Relevant to the commissioning couple is information about adoption. If the gestational woman is providing both the genetic and gestational components of reproduction, the female partner of the commissioning couple will presumably need to adopt the child. If the gestational woman is providing only the gestational component, both parties may adopt the child given current assumptions about parenthood at the time of birth. The commissioning couple needs accurate information about adoption laws and the short- and long-term implications of adoption.

In addition, both parties should be aware of the potential for subtle coercion arising from financial incentives or personal relationships. It is important for this to be discussed openly as it may affect the participation of either or both parties to the agreement.

7. A statement that participants may ask questions now and later

An offer to answer questions as they arise should be made by the medical and legal professionals involved in preconception agreements. Clearly, this offer should be made to both the gestational woman and the commissioning couple.

8. A statement that confidentiality will be respected

There are at least three areas of concern about confidentiality: disclosure to the gestational woman or the commissioning couple; disclosure to the general public; and disclosure to the offspring.

Some preconceptions agreements are between family members or close friends. Others, however, are between strangers, and the agreement may state explicitly that the identity of the commissioning couple is not to be revealed to the gestational woman. Similarly, the gestational woman may stipulate that her identity not be disclosed to the commissioning couple. Moreover, as regards disclosure to the public, just as the commissioning couple may not want to be identified publicly as infertile, so too the gestational woman may not want to be publicly identified.

In addition to concerns about the potential disclosure of identity, there may be concerns about the potential disclosure of other personal information. Only with the gestational woman's permission could one disclose to the commissioning couple information about her physical, genetic, and psychological health. Similarly, only with permission from the commissioning couple might it be appropriate to disclose to the gestational woman the reason(s) the couple has chosen this means of reproduction. The point is that each party would have to understand fully and agree to the disclosure of personal information before this could occur.

Disclosure to the offspring is an altogether different matter, given existing provincial laws concerning the disclosure of adoption information to adoptees. Preconception agreements are typically followed by adoption hearings, and in many jurisdictions adoptees can have access to adoption information. In Ontario, for example, adopted children over the age of 18 who were adopted in Ontario may register with the Adoption Disclosure Registry to obtain information about their birth parents and birth relatives. Similarly, birth parents and birth relatives may apply to the Registrar to be named in the register. As such, if the gestational woman and the child(ren) she conceived are registered with the Adoption Disclosure Registry, information about the preconception agreement could become known to the adoptee.[27] This is not something the commissioning couple could prevent, unless they were to withhold from the child information about the adoption.

Both the gestational woman and the commissioning couple need accurate information about the kind of records that will be kept, to whom these records may become available, at what time, and under what circumstances.

9. A statement that one may refuse to participate without jeopardizing access to health care

This requirement applies to all prospective participants but is perhaps particularly relevant to the gestational woman who requires technical medical assistance. This statement is self-explanatory.

10. A statement that consent and refusal are revocable. In principle, either participant may withdraw his/her consent or overturn his/her previous refusal without jeopardizing access to health care

This statement is true as regards consent to, or refusal of, the medical interventions associated with preconception agreements. For example, a prospective gestational woman can revoke her consent to artificial insemination or IVF-ET.

The statement is perhaps less true, however, with respect to consent to the non-medical aspects of preconception agreements. For example, a gestational woman may not be free to revoke her consent to surrender the custody of the child after birth. Similarly, the commissioning couple may not be free to refuse to assume custody of the child born to the gestational woman.

Currently, the legal status of preconception agreements in Canada is unclear. If presented with a contested preconception agreement, the courts might turn to adoption law, contract law, or custody law for guidance. Alternatively, the courts might look outside the established legal system. Depending on where the courts turned for guidance and what, if any, situations were deemed analogous, consent might or might not be deemed revocable.

If the courts looked to adoption law, they might conclude that consent to surrender custody of a child (as per the terms of a preconception agreement) is revocable. In many Canadian jurisdictions there is a specific post-birth period before which consent to adoption may not be given and a grace period within which the birth mother can withdraw her consent. The Adoption Act of Prince Edward Island, for example, requires that the child be 14 days old at the time that consent to adoption is given.[28] In Ontario the Child and Family Services Act, 1984 states that written consent to adoption cannot be given until the child is 7 days old and may be withdrawn within 21 days of the day it was given. Moreover, the consent may be withdrawn after the 21-day period if this is in the child's best interest.[29] By comparison, The Family Services Act of Saskatchewan allows 30 days for the withdrawal of consent to adoption,[30] whereas the Child Welfare Act of Alberta only allows 10 days.[31]

If the courts looked to contract law for guidance, they might or might not conclude that consent is revocable. If the courts assumed that the contract was legally enforceable, they would have to determine an appropriate remedy for breach. If the courts deemed that the contract was for a unique good (i.e., the child), they would likely award specific performance. (Deeming the contract to be for a unique good raises the

issue of slavery and commodification.) If, on the other hand, the courts deemed the contract to have been for personal service (i.e., gestation), they would likely award damages rather than specific performance. The remedy of specific performance implies that consent is not revocable. The remedy of damages implies that it is.

If the courts found that the contract was not enforceable, they might turn to custody law and thereafter focus on the best interests of the child. Revocation of consent would then be permitted only if doing so would be in the child's best interests.

Finally, if the courts entered uncharted legal territory and rendered decisions based on other considerations, there is no way to anticipate their conclusions regarding the revocation of consent. In summary, the legal status of preconception agreements is unclear.

At present both the gestational woman and the commissioning couple involved in such arrangements must be fully informed of this uncertainty regarding the revocation of consent.

Notes

1. "Surrogate motherhood arrangement" and "surrogacy contract" are terms commonly used to describe a preconception agreement between a woman who will make a gestational (and perhaps a genetic) contribution to a child not yet conceived, and a couple who expects/intends to have custody of the child. These terms are both inaccurate and ambiguous. Therefore, the term "preconception agreement" is used throughout this paper — short for "preconception agreement concerning the transfer of custody of a child to be conceived from the woman who will bear the child, to some other person(s)."

2. The singular term "child" is used throughout the document. It is possible, however, that the gestational woman would bear more than one child, particularly if only the gestational component of reproduction is being provided by the gestational woman, in which case a number of embryos might be transferred after *in vitro* fertilization.

3. As with all the papers in this series, issues specific to informed choice with non-traditional families (e.g., homosexual couples, single persons) are not discussed. To be precise, this paper on informed choice and preconception agreements refers only to "the commissioning couple," and it is assumed that the couple is both heterosexual and married or living common-law. As stated previously, this limitation in no way reflects a belief that homosexual couples or single persons should be denied access to ARTs.

4. The term "gestational woman" may seem a strange alternative to the terms "surrogate" or "surrogate mother," particularly as this term does not allow one to distinguish between women who make both a genetic and gestational contribution to childbearing and women who make only a gestational contribution. In the literature, there are references to: "surrogate mothers" and "surrogate gestational mothers"; "partial surrogacy" and "full surrogacy." Common to both types of

"surrogacy," however, is the gestational contribution to the reproductive process. Hence, it seems more appropriate to use the term "gestational woman" to refer to all women who make a gestational contribution to childbearing under the terms of a preconception agreement. Then, as appropriate, this term may be further qualified.

5. The informed choice of the gestational woman's male partner is relevant insofar as (1) he must agree to abstain from sexual relations with his partner during the time of insemination or embryo transfer (depending upon the nature of the preconception agreement), and perhaps for the first three months of pregnancy; and (2) he may have legal obligations to the offspring conceived if the preconception agreement does not take effect as planned. As regards this last point, it has been suggested that the male partner of the commissioning couple in a preconception agreement involving artificial insemination is a sperm donor. A sperm donor typically has no legal relationship with, nor obligation to, the resulting offspring. Rather, the male partner of the woman who gives birth to the child is generally presumed to be the legal father of the child. (This may or may not be a relevant issue given the availability of human leukocyte antigen or DNA testing.)

From another perspective, the consent of the male partner is important given that women who have entered into preconception agreements maintain that the emotional support of the male partner is critical. One may assume that the male partner is more likely to provide the requisite emotional support if he has been consulted.

This being said, given the scope of this paper, this discussion of informed choice does not address the concerns relevant to the gestational woman's male partner.

6. A more complete list of the medical indications for preconception agreements limited to a gestational contribution to childbearing is provided by J.G. Schenker and D.A. Frenkel, "Medico-Legal Aspects of *In Vitro* Fertilization and Embryo Transfer Practice," *Obstetrical & Gynecological Survey* 42 (1987): 405-13. This list includes medical conditions that make pregnancy and delivery dangerous, e.g., severe cardiovascular disease, kidney disease, severe high blood pressure, or advanced collagen disease; congenital absence of uterus or severe malformations of Muller's duct; severe Asherman syndrome; tuberculous endometritis; after hysterectomy in women in the reproductive age; and uterine leiomyoma.

7. W.R. Frederick et al., "HIV Testing of Surrogate Mothers," *New England Journal of Medicine* 317 (1987), 1352.

8. M. Eichler and P. Poole, "The Incidence of Preconception Contracts for the Production of Children Among Canadians," report prepared for the Law Reform Commission of Canada (Toronto: Ontario Institute for Studies in Education, 1988).

9. R.J. Levine, *Ethics and Regulation of Clinical Research*, 2d ed. (Baltimore: Urban & Schwarzenberg, 1986), 4. This statement is an endorsement of the conclusion reached by the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

10. "Surrogate Mothers," *Fertility and Sterility* 53 (Suppl. 2)(1990), 73S. Also, on page 67S ("Surrogate Gestational Mothers: Women Who Gestate a Genetically Unrelated Embryo"), a similar listing with almost identical wording is provided for preconception agreements that entail only a gestational contribution to the reproductive process ("surrogate gestational mothers" in the language of the

Committee's report). This explains the use of square brackets throughout the citation.

11. Payment, a desire to be pregnant, and the urge to reconcile a birth-related trauma (such as an abortion, giving up a child for adoption, or having been placed for adoption) are among the motives of gestational women. See P.J. Parker, "Motivation of Surrogate Mothers: Initial Findings," *American Journal of Psychiatry* 140 (1983): 117-18; and P.J. Parker, "Surrogate Motherhood, Psychiatric Screening and Informed Consent, Baby Selling, and Public Policy," *Bulletin of the American Academy of Psychiatry and the Law* 12 (1984): 21-39.

12. The risk of HIV transmission from donor ova is unknown. Some speculate that there may be a small risk of transmission; others disagree. This being said, to minimize the risk of HIV transmission, ova should be screened as well as sperm. The problem is that the freezing of ova (first reported by C. Chen, "Pregnancy After Human Oocyte Cryopreservation," *Lancet* (19 April 1986): 884-86) is controversial because of potential damage to the spindle during the freezing process.

13. C. Wood and P. Singer, "Whither Surrogacy," *Australia Medical Journal*, as cited in S. Downie, *Babymaking: The Technology and Ethics* (London (U.K.): The Bodley Head, 1988), 144.

14. J. Glover et al., *Ethics of New Reproductive Technologies: The Glover Report to the European Commission* (De Kalb: Northern Illinois University Press, 1989), 76.

15. P. Parker, "Effects of Surrogate Motherhood: Other Childbearing Options Need Closer Study, Says Researcher," *Psychiatric News* (18 May 1984), 10.

16. Ontario Law Reform Commission, *Report on Human Artificial Reproduction and Related Matters*, Vol. II (Toronto: Ministry of the Attorney General, 1985).

17. Infertility (Medical Procedure) Act 1984, Act No. 10163 (Melbourne: Victorian Government Printing Office, 1984). This act outlaws commercial preconception agreements and renders all such agreements void. United Kingdom, Surrogacy Arrangements Act 1985, c. 49, ss. 1-5. This act renders commercial preconception agreements a criminal offence.

18. R.A. Charo, "Legislative Approaches to Surrogate Motherhood," *Law, Medicine & Health Care* 16 (1988): 96-112.

19. S. Downie, *Babymaking: The Technology and Ethics* (London (U.K.): The Bodley Head, 1988), 124.

20. Ibid., 159.

21. See, for example, Queensland, Australia, *Report of the Special Committee Appointed by the Queensland Government to Enquire into the Laws Relating to Artificial Insemination, In Vitro Fertilization, and Other Related Matters* (Brisbane, 1984); Sweden, *Barn Genon Befruktning Uthanfor Kroppenun (Swedish Governmental Committee: In Vitro Fertilization)* (Stockholm, 1985); United Kingdom, *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, Cmnd 9314 (London (U.K.), 1984); Victoria, Australia, Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on the Disposition of Embryos Produced by In Vitro Fertilization* (Melbourne, 1982-1984); and Congregation for the Doctrine of the Faith, *Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day* (Vatican City, 1987).

22. See, for example, B.K. Rothman, "Reproductive Technology and the Commodification of Life," *Women and Health* 13 (1987): 95-100; S. Callahan, "No Child Wants to Live in a Womb for Hire," *National Catholic Reporter* (11 October 1985), 20; and Glover et al., *Ethics of New Reproductive Technologies.*

23. E. Thorne and G. Langner, "Expenditures on Infertility Treatment," in U.S. Congress, Office of Technology Assessment, *Infertility: Medical and Social Choices*, vol. III, *Economics of Infertility* (Washington, DC: OTA, 1988).

24. Charo, "Legislative Approaches to Surrogate Motherhood," 97.

25. Denise Mounce, who died of a heart condition known as myocardial hypertrophy, is believed to be the first gestational women to die during a commissioned pregnancy. C. Gordon, "Secret Surrogate: Coroner Sees Negligence After Heart Attack Kills Contract Mom," *Houston Chronicle* (11 November 1987).

26. The infertile couple paid the agency £13 000, half of which was paid to Kim Cotton (the gestational woman). At the time of birth, the Barnet Council authorities intervened, and the child was made a ward of the court. The putative reason for the intervention was to make sure that the commissioning couple were suitable parents. The couple ended up paying an additional £11 000 in legal fees to get custody of the child. See Downie, *Babymaking*, 133-35.

27. Child and Family Services Act, 1984, S.O. 1984, c. 55, s. 158(4), am. S.O. 1988, c. 4. By comparison, in Nova Scotia adoption records are sealed and are not "open to inspection except upon leave of the county court or upon an order in writing of the Minister." Children's Services Act, S.N.S. 1976, c. 8, s. 28(2), R.S.N.S. 1989, c. 68.

28. Adoption Act, R.S.P.E.I. 1988, c. A-4, s. 6.

29. Child and Family Services Act, 1984, ss. 131(3), 131(8), 133.

30. The Family Services Act, S.S. 1978, c. F-7, s. 52(4).

31. Child Welfare Act, S.A. 1989, c. C-8.1, s. 57(1).

Part 4. Oocyte Donation for Clinical Purposes: Informed Choice

Unlike oocyte donation for research purposes, oocyte donation to help another woman establish a pregnancy involves a donor and a recipient.[1] The informed choice of both of these participants is of the utmost importance as regards the moral acceptability of this intervention.

Current practice in Canada with oocyte donation is to obtain written consent from both the donor and the recipient. The specifics of this practice, however, vary from clinic to clinic. Although all clinics uniformly identify the recipient as the infertile couple, some clinics identify the donor as the woman who will actually donate the oocytes, while others consider the woman and her male partner the donor.[2]

In this paper the discussion of informed choice is limited to considerations relevant to the couple as recipient and the woman as donor.[3]

The informed choice of both the male and female partner of the recipient couple is important, insofar as the woman and her partner should be in agreement concerning the nature and objectives of the proposed intervention, since both will bear the consequences of any decision made. However, the consent to or refusal of the potential physical harms and inconveniences of oocyte transfer is the sole prerogative of the female partner of the recipient couple.

Conversely, there is no reason to involve the oocyte donor's male partner in the decision-making process. The male has no property rights to, or rights of disposal over, his partner's reproductive cells. Thus, his consent or refusal is not only unnecessary but completely irrelevant.

1. A description of the participants' current medical status

The Female Recipient

There are several medical indications for assisted reproduction through oocyte donation. These include[4] (1) primary ovarian failure where there is no evidence of previous ovarian function; (2) premature ovarian failure, which occurs in 1 percent of women under the age of 40;[5] (3) iatrogenic ovarian failure as a result of ionizing radiation therapy or chemotherapy radiation therapy; (4) gonadal dysgenesis; (5) surgical castration; (6) extending reproductive potential to women over 40;[6] and (7) ovarian inaccessibility where "contemporary methods of egg harvest are inadequate to retrieve eggs from ovaries that otherwise seem to function with reasonable normality."[7]

Other women for whom oocyte donation may be an option are women who wish to avoid the transmission of autosomal dominant or sex-linked genetic disorders to their offspring and for whom prenatal diagnosis is not an option. An example of the former is Huntington's chorea; an example of the latter is Duchenne's muscular dystrophy. Also, it is possible that a woman who is a carrier for an autosomal recessive disorder such as Tay-Sachs disease and whose partner is also a carrier for the same autosomal recessive disorder may choose oocyte donation instead of sperm donation.

Women presented with the option of oocyte donation must clearly understand why the proposed intervention is an option. This is important because in some cases (for example, premature ovarian failure), the woman cannot experience pregnancy and childbirth using her own ovum. In the other cases (for example, the risk of a sex-linked or other genetic disorder) the use of one's own ovum remains possible with other strategies, such as preimplantation diagnosis, as options. A clear understanding of one's medical diagnosis, therefore, informs one's understanding of the available alternatives.

The Donor

Oocyte donors are usually women undergoing *in vitro* fertilization and embryo transfer (IVF-ET) who are willing to donate excess oocytes; women undergoing elective sterilization or other abdominal surgery that provides

easy access to the ovaries; or healthy volunteers — usually family members or friends of the female recipients.

Of particular concern with respect to the potential donor's medical status is the absence of inheritable genetic disorders, sexually transmissible diseases (including human immunodeficiency virus (HIV) infection), and psychological disorders. For this reason, potential oocyte donors are usually screened to ensure that they are under the age of 35, and have no family history of genetic disease, no sexually transmissible diseases, no risk factors for HIV infection (or are not HIV positive), and no apparent psychological disorders.

2. Information about the nature and objective(s) of the proposed intervention, along with similar information about available alternatives and adjunct interventions

Nature of Oocyte Donation

There are at least two well-documented technical approaches to oocyte donation when the objective is to help a woman, unable to produce her own healthy oocytes, to achieve a pregnancy. The first typically involves superovulation, artificial insemination, uterine lavage, and embryo transfer.[8] The potential harms to the donor with oocyte donation by uterine lavage are so great, however, that few promote this method of oocyte donation.[9]

This discussion is therefore limited to the second of the two technical approaches. This usually involves superovulation, oocyte retrieval by transvaginal ultrasound or laparoscopy, and IVF-ET, gamete intrafallopian transfer (GIFT), zygote intrafallopian transfer (ZIFT), pronuclear stage transfer (PROST), or tubal embryo stage transfer (TEST).[10] With either approach, the recipient has to be maintained on a synchronized hormonal regimen[11] or, alternatively, has to choose between oocyte freezing and embryo freezing.

It is important for both the recipient and the donor to have a general understanding of the various steps involved in oocyte donation and a specific understanding of the medical interventions each will be involved in. The recipient and donor should also be aware that oocyte donation can be anonymous or non-anonymous. For example, at Toronto East General, the recipient couple must provide their own donor. At Toronto Hospital General Division, the donors are women in the IVF-ET program who agree to donate excess oocytes. A recipient couple in the Toronto East General program should be aware of the option of anonymous donation; similarly, a recipient couple at Toronto Hospital General Division should be aware of the option of non-anonymous donation.

Such information is of obvious importance to the recipient, who may have a preference between anonymous and non-anonymous donation. This may also be of particular importance to the potential non-anonymous donor

who may feel obliged to consent to oocyte donation, unaware that the option of anonymous donation is available to the recipient couple.

Finally, the recipient in particular must understand clearly that oocyte donation is not sufficiently well established or understood to be offered as a *therapy* for women unable to produce oocytes or to women with a presumed or proven genetic defect in their oocytes. At best oocyte donation qualifies as a non-validated practice, in which case it "*should* be conducted in the context of a research project designed to test [its] safety or efficacy or both."[12]

Specifically, research is needed to improve understanding of "the size of the window of endometrial receptivity,[13] the optimal stage for transfer of the conceptus, and the appropriate hormonal balance."[14] Research is also required into the risk of HIV transmission and the long-term risks of intra-familial donation. Finally, specific research is needed to understand the social conditions conducive to oocyte donation and the circumstances under which oocyte donation (particularly non-anonymous donation) is contraindicated.[15]

Alternatives to Oocyte Donation: The Recipient Couple

In addition to adoption and child-free living, alternatives to oocyte donation (whether anonymous or non-anonymous, synchronized or cryo-preserved) include a variety of medical interventions, the appropriateness of which depends on the medical status of the couple (particularly the female partner), among other factors.

If, for example, the female partner has premature ovarian failure, a preconception agreement may be an option,[16] albeit one that poses additional ethical and social dilemmas. If the recipient couple is considering oocyte donation to avoid the transmission of a sex-linked or other genetic disorder, the available options include reproducing and accepting the birth of a child who may be handicapped; reproducing, seeking prenatal testing, and terminating the pregnancy if the fetus is affected; and reproducing by means of IVF-ET and participating in research on preimplantation genetic diagnosis (assuming, of course, that the couple qualifies as a research subject).[17]

Alternatives to Oocyte Donation: The Donor

Alternatives to oocyte donation for purposes of artificial conception include oocyte donation for research purposes and no donation. Some women have qualms about donating their oocytes to create children they will have no knowledge of, but they are willing to donate them for research purposes. Other women prefer not to donate their oocytes for either research or clinical purposes, but rather to keep them for their own possible pregnancies. This is particularly true of women in IVF-ET programs who can choose to have their excess oocytes fertilized and frozen for use in a subsequent unstimulated cycle.

3. Information about the nature and the probability of the known and possible consequences (i.e., benefits, harms, and inconveniences) of the various options (i.e., the proposed intervention, alternative interventions, and the option of no intervention)

The Recipient Couple

Oocyte donation, whether anonymous or non-anonymous, provides the female partner of the recipient couple with a fertility alternative that includes a chance of pregnancy and childbirth. The ultimate hoped-for benefit for the couple is a healthy child. The likelihood of this benefit is limited, however.

According to most recent published data from the United States Registry, the take-home-baby rate with oocyte donation is just over 20 percent per transfer:

> In 1989, 48 clinics reported performing IVF-ET with donated oocytes. There were 328 patients who underwent 377 donor transfers. One hundred nine (29%) of the donor transfers produced a clinical pregnancy. Eighty-one (21%) live deliveries resulted, including 25 sets of twins and 3 sets of triplets.[18]

By comparison, the statistics in Canada are not documented. At least five IVF programs offer oocyte donation as an adjunct intervention — the Chedoke-McMaster IVF Program, the LIFE program (Toronto East General Hospital), the Toronto Hospital IVF Program, the Toronto Fertility and Sterility Institute, and the Institut de Médecine de la Reproduction de Montréal Inc. Only the Chedoke-McMaster IVF Program provided information about the success of their oocyte program; as of May 1991, there had been eight cycles with oocyte donation and no pregnancies.[19]

In addition to the hoped-for benefits of childbearing and childbirth, there are different potential benefits with anonymous and non-anonymous donation. With anonymous donation, privacy and confidentiality are maintained more easily, and potential problems with parenting between the donor and recipient can thus be avoided. With non-anonymous donation on the other hand, there is "firsthand knowledge of the donor's phenotype, personality, family, and social history."[20] To quote one recipient, "With my sister's eggs we are continuing the family's bloodline — at least there is still that connection with my parents and grandparents."[21]

Not surprisingly the benefits of non-anonymous donation are by and large the harms of anonymous donation and vice versa. For example, with anonymous donation the oocytes do not come from "within the family," and this may be a significant harm for those who place a high value on genetic inheritance and the "family gene pool." Also there is the risk of genetic disorders despite a negative history, as well as the possibility of a genetic mismatch (while every effort is usually made to match the donor and the recipient on the basis of phenotypic and ethnic similarities, choice is limited and errors are possible).

On the other hand, with non-anonymous donation, the relationship between the donor and the child is of concern. There is the risk that the donor may want a special role in the upbringing of the child; in some cases this might even lead to a custody battle. The impact on a child's own identity formation is not known, nor is the impact on family relationships following such arrangements. Alternatively, a donor who might otherwise have provided care may withdraw.

Two other potential harms for the recipient couple are a function of the method of oocyte donation chosen. With a synchronized cycle, the donor and the recipient must start the cycle at the same time; if the donor's cycle must be cancelled (or if the donor is a woman in an IVF-ET program and too few oocytes are collected), the recipient's cycle must also be cancelled. On the other hand, with the transfer of frozen and thawed donor oocytes (or, as is more common, the transfer of frozen and thawed embryos created from donor oocytes),[22] success rates are lower. For example, a recent study of forty cycles of donation showed that of

> the [71] fresh embryos that were transferred to the recipients, 24 percent were successfully implanted, as compared with only 7.7 percent of the [91] frozen and thawed embryos ($P<0.01$). A pregnancy success rate of 37 percent per recipient cycle was observed in the recipients of fresh embryos, as compared with a rate of only 16 percent in those receiving frozen and thawed embryos ($P<0.05$).[23]

Finally, the potential medical harms for the female recipient include the harms commonly associated with the ART chosen for transfer purposes (for example, IVF-ET, GIFT, ZIFT); the harms (i.e., medical complications) typically associated with pregnancy (which increase with maternal age); and the risk of HIV transmission from an unrecognized infected donor.

Currently, the risk of HIV infection is unknown. To minimize this potential harm, the Interim Licensing Authority in Britain has advised IVF centres

> to test for HIV antibodies during the initial screening process and again during the cycle in which the oocytes are collected, the two tests being three months apart, in order to minimise the risk to patients.[24]

To this same end, the Canadian Fertility and Andrology Society and the Society of Obstetricians and Gynaecologists of Canada have recommended

> insemination of the egg with freezing of the embryo for a period of quarantine (while the egg donor is tested for the appearance of HIV antibodies) or the immediate testing of donor blood for the AIDS virus employing polymerase chain reaction (PCR) technology.[25]

The Donor

For the three broad categories of potential oocyte donors — women undergoing IVF-ET, women undergoing other medical procedures, and healthy volunteers — the most significant potential benefit of oocyte

donation is probably the psychological benefit that comes from helping another woman establish a pregnancy. In addition, for some donors there may also be direct financial benefit.[26]

These potential benefits must be weighed against a number of potential harms. First, there are the harms associated with the screening process. For example, with genetic screening there is the possibility that the donor may learn of a genetic risk factor she was previously unaware of. This possibility must be discussed with the prospective donor, and a decision should be made at the outset about what information the donor wishes to be given following the screening.

There are also the potential harms associated with serological testing for hepatitis B, syphilis, and HIV and with cervical cultures for gonorrhoea, chlamydial infection, and herpes. One of the more serious of these harms is disclosure to public health authorities if the prospective donor has a sexually transmissible disease.

In addition, for some women there may be serious harms associated with the psychological screening that is done to assess the prospective donor's emotional and psychological well-being. Questions about any history of sexual abuse or psychiatric disorders may constitute a grave harm for some women.

Another category of harms consists of the potential medical harms and side-effects associated with superovulation. Most significant is the risk of severe hyperstimulation syndrome. There are also several potential minor side-effects: hot flushes, abdominal discomfort, weight gain, and restlessness.[27]

If the donor is undergoing IVF-ET, then the harms and discomforts associated with superovulation are being incurred irrespective of any decision to donate oocytes. As such, oocyte donation does not contribute any additional potential harms. If the prospective donor is not undergoing IVF-ET, however, the potential harms of ovulation enhancement are *de novo* and must be explained as such.

Third, for donors other than women in an IVF-ET program, there is the potential harm of inadvertent pregnancy. This may occur if one or more of the oocytes is not retrieved successfully and the donor is sexually active and barrier methods of contraception fail. For some women this risk may entail the harms associated with termination of pregnancy.

Fourth, there is the inconvenience of monitoring and the potential harms of oocyte retrieval (whether by laparoscopy or transvaginal ultrasound-guided follicle aspiration).[28] Most commonly,

> [w]omen undergoing ultrasound-directed egg recovery may notice a small amount of blood in their urine or from their vagina for a day afterwards. This is quite common and should not cause concern.
>
> Laparoscopy carries the usual minor risks and side-effects of any procedure requiring a general anaesthetic. Most women have very little discomfort and no pain after laparoscopy. Some women experience

> soreness in the stomach, chest or shoulders, or vaginal bleeding for a few days after the operation.[29]

If the prospective donor is an IVF-ET participant, no additional physical harms are incurred in choosing to become a donor. If the prospective donor is a woman seeking elective sterilization, however, or a woman undergoing other surgery that provides easy access to the ovaries (and the oocyte retrieval is done at the same time as the surgery), there may be increased minimal risks during the egg retrieval procedure (e.g., lengthening of the surgical procedure). If the potential donor is neither an IVF-ET participant nor a woman undergoing some other medical procedure, then the potential harms are *de novo* and must be explained as such.

A fifth potential harm, one that is specific to women who are undergoing IVF-ET, is the possibility that the recipient may conceive while the donor may not:

> While all donors may enjoy the psychological benefits of knowing they have helped another infertile couple by donating eggs, the psychological effects of successful egg donation by an infertile woman who fails in her own attempt at IVF are less well established.[30]

To minimize the psychological harm that may come of knowing one has helped to create a child while remaining childless, many clinics do not disclose the results of donations to the donors. Donors must be apprised of this fact prior to donation.

A sixth potential harm is that the donor may later regret her decision to donate and have a number of concerns about the possibility of there being a child genetically related to her which she has no knowledge of or responsibility for.

Finally, it is important for both the donor and the recipient to appreciate that, in the abstract, the benefits and harms of oocyte donation accrue to different people. Most of the potential benefits are to the recipient, while most of the potential harms are to the donor.

4. Information about the qualifications and experience of the various team members

Oocyte donation is a relatively new ART. It was only in 1984 that Lutjen et al. reported the first human pregnancy from an IVF donor,[31] and the first baby conceived in Canada with a donated oocyte was born in July 1990 (LIFE program at Toronto East General Hospital).[32] Canadian experience with oocyte donation is limited, and such data as are available on success rates do not compare favourably with international data.

Prospective oocyte donors and recipient couples must be apprised of this fact and given accurate information about the qualifications and experience of all of the team members, as this has a direct effect on success rates.

5. Information about the costs involved

Insofar as the recipient couple is concerned there is no cost for oocyte donation *per se*. The costs involved are those for the ART chosen for the transfer of gametes or embryos.[33] In part, there is no additional cost because oocyte donors generally are not reimbursed in Canada (which is presumably a cost the recipient would ultimately pay).[34] In the United States, by contrast, oocyte donors are paid as much as $1 500 per donation.[35]

Information about reimbursement, or rather lack thereof, must be disclosed to prospective oocyte donors, particularly as some donors might reasonably expect to be reimbursed "for expenses, time, risk, and inconvenience associated with the donation."[36] In Ontario, for example, sperm donors are usually paid $25 to $50 per donation. Oocyte donation is more difficult and riskier than sperm donation; it would not be unreasonable, therefore, for female donors to expect compensation greater than that typically offered male donors. It seems, however, that women are expected to be altruistic — to participate "in the spirit of sharing" and to "help those less fortunate." Women must be informed of this discrepancy since this may influence their decision to participate in oocyte donation.

6. Additional information that may assist the prospective participants to make an informed choice

The Recipient Couple

Canadian experience with oocyte donation is very limited. For this reason, it is particularly important that recipient couples be given as much additional information as possible about the various factors that may affect the pregnancy rate with oocyte donation. For example, recent evidence suggests that whereas the age of the female recipient does not appear to influence the success rates of oocyte donation,[37] younger donors are associated with higher pregnancy rates in their recipients.[38] This information must be disclosed to potential recipients, enabling them to choose a younger donor if one is available. Another relevant consideration is that when the donor is a woman in an IVF-ET program, the donated oocytes "tend to be the least desirable morphologically, as the oocytes with the best morphology are saved for the IVF patient."[39] This information may influence a woman's choice of donor.

In addition to further information about the likelihood of "success," it is important to share information about the many questions that remain unanswered with oocyte donation:

> Does biological relatedness influence one's ability to love a child ... to accept a child's limitations? What should potential parents know about an anonymous donor? Is it acceptable to use a known donor? A relative? Who should be told about the donor? Will the child's means of conception be a stigma? What will the child want to know about the donor? If the child knows (about) the donor, will the knowledge be enlightening or confusing? Will the child be accepted by his

grandparents, aunts, and uncles? Will the nonbiological parent accept the child?[40]

Recipient couples must be encouraged to consider such questions about the long-term implications of oocyte donation in coming to a decision about whether to proceed with this procedure.

The Donor

Information about the legal relationship between the donor and any potential offspring is relevant to all prospective donors irrespective of whether they are women undergoing IVF-ET, women undergoing some other medical procedure, or women undergoing no medical procedure. In Ontario, for example, the woman who gives birth is the legal mother. Thus, it must be clear to the oocyte donor, at the time of donation, that she will have no legal rights or duties in respect of the child that may be born as a result of a donation.

Other information that may be of interest and should be disclosed to prospective donors is the clinic's policy regarding the distribution of donated gametes. For example, an anonymous donor may want to know how many women will be recipients of her oocytes; a non-anonymous donor may want to know that her donated oocytes will be transferred only to the designated recipient. Anonymous and non-anonymous donors alike may want to know whether their donated oocytes will be used exclusively for clinical purposes or whether they may be used for research purposes.[41]

7. A statement that participants may ask questions now and later

An offer to answer questions as they arise should be made by members of the health care team to both the recipient couple and the donor.

8. A statement that confidentiality will be respected

Promises to respect the confidentiality of the participants, as well as the limits on this promise, must be clear and explicit. First, there is the promise not to share personal medical information with the general public. Second, with anonymous donation, there is the promise not to share information about the identity of one participant (recipient or donor) with the other. Third, there is the anonymous donor's wish for continued anonymity to avoid future expectations from donor children and the recipient's wish that information about genetic origin not be shared with any child conceived of oocyte donation.

The first promise is limited by the obligation to share information with the scientific community so as to contribute to a better understanding of the reproductive process and better success rates for oocyte donation. Both the recipient and the donor must be assured, however, that no identifying information will be published.

The limits on the second promise are mostly practical. With anonymous, synchronized oocyte donation, chance contact between the donor and the recipient is possible, particularly if the donor is in the IVF

program, because of the physical set-up at a clinic or hospital facility. To minimize any breach of confidentiality, some clinics rely on creative scheduling, while others do not offer synchronized cycles.

Finally, as concerns disclosure to any potential offspring, recipient couples and prospective donors must understand what kinds of records will be kept to protect the confidentiality of both the donor and the recipient; to whom these records are available; and the circumstances under which the information may be disclosed.

Moreover, in discussing this issue with the recipient couple it is worth sharing information about the "growing body of research documenting the negative effects of family secrets and their unique power in the family."[42]

> Keeping a secret requires a great deal of emotional energy and innumerable lies to maintain over a long period of time. Sharing the information is a delicate, somewhat awkward process that occurs many times over a child's lifetime and the responses to which require skill, patience, and love. Couples should keep in mind that both of these choices are difficult, and both have effects on the couple and on the child. Whatever the choice, a mutually workable decision about whether or not to tell the child as well as the ways they will discuss that choice over their lifetime should be discussed prior to the procedure.[43]

9. A statement that participants may refuse to participate without jeopardizing access to health care

A statement to this effect must be made to both the recipient couple and the prospective donor. In particular, the female partner of the recipient couple must feel free to refuse the option of oocyte donation. Similarly, the potential oocyte donor must understand that she can refuse to participate. If the prospective donor is a woman undergoing IVF-ET or another medical procedure, she may feel obliged to acquiesce to her physician's request that she donate oocytes for fear that otherwise her care may be compromised. A clear statement that one may refuse to participate without jeopardizing access to health care may help to counter any undue pressure. On the other hand, if the prospective donor is a family member or a friend, there may be pressure to consent because of familial or social relationships. Members of the health care team may help limit any undue overt or covert pressure by informing the prospective donor that she is free to refuse to participate.

10. A statement that consent and refusal are revocable. In principle, the recipient couple and the donor may withdraw their consent or overturn their previous refusal without jeopardizing access to health care

An explicit reference to this disclosure requirement can be found in the *Guidelines for both Clinical and Research Applications of Human In Vitro Fertilisation*, published by the Interim Licensing Authority in Britain:

> The donor must know that she is free to withdraw consent to the egg donation at any time without threat of financial penalty and, where

> appropriate, without impairment of her interest in the successful conduct of the primary operation.
>
> The centre must be prepared to accept, in the event of withdrawal after preparation for egg recovery has begun, the financial loss incurred.[44]

These guidelines give particular attention to financial considerations, because in Britain free sterilizations are offered to women in exchange for the donation of their oocytes. This is not relevant in a Canadian context, but the point remains that the donor must be free to withdraw her consent, without prejudice, at any time prior to the use of the donated gametes.

Similarly, the recipient couple must also be free to withdraw consent, without prejudice, at any time prior to the transfer of the donated genetic material.

Notes

1. A discussion of oocyte donation for research purposes is beyond the scope of this paper.

2. For example, the consent form from the Toronto Hospital IVF Program requires the signature of the male and female partner. The consent form from the Toronto Fertility and Sterility Institute requires the signature of the wife and husband. The Institut de Médecine de la Reproduction de Montréal Inc. has separate consent forms for the donor and her male partner.

3. As with all the papers in this series, issues specific to informed choice with non-traditional families (e.g., homosexual couples, single persons) are not discussed. This paper makes no assumptions about the sexual orientation or marital status of the donor, but it is assumed that the recipient couple is heterosexual and married or common-law. This limitation on the discussion, necessitated by the limited scope of this paper, in no way reflects a belief that lesbian couples or single women should not be oocyte recipients.

4. For a complete list of the medical indications for oocyte donation see Z. Rosenwaks et al., "Oocyte Donation: The Norfolk Program," in *In Vitro Fertilization and Other Assisted Reproduction*, ed. H.W. Jones and C. Schrader, *Annals of the New York Academy of Sciences* 541 (1988), 729.

5. H.I. Abdalla et al., "Pregnancy in Women with Premature Ovarian Failure Using Tubal and Intrauterine Transfer of Cryopreserved Zygotes," *British Journal of Obstetrics and Gynaecology* 96 (1989), 1074.

6. M.V. Sauer, R.J. Paulson, and R.A. Lobo, "A Preliminary Report on Oocyte Donation Extending Reproductive Potential to Women Over 40," *New England Journal of Medicine* 323 (1990): 1157-60.

7. American Fertility Society, Ethics Committee, "Donor Eggs in In Vitro Fertilization," *Fertility and Sterility* 53 (Suppl. 2)(1990), 48S.

8. See, for example, J.E. Buster et al., "Non-Surgical Transfer of In Vivo Fertilised Donated Ova to Five Infertile Women: Report of Two Pregnancies," *Lancet* (23 July 1983): 223-24; L. Formigli, G. Formigli, and C. Roccio, "Donation of Fertilized

Uterine Ova to Infertile Women," *Fertility and Sterility* 47 (1987): 162-65; and M.V. Sauer, R.E. Anderson, and R.J. Paulson, "A Trial of Superovulation in Ovum Donors Undergoing Uterine Lavage," *Fertility and Sterility* 51 (1989): 131-34. A good non-technical summary of what oocyte donation involves can be found in Interim Licensing Authority, *Egg Donation: Your Questions Answered* (London (U.K.): ILA Secretariat, n.d.).

9. See, for example, Canadian Fertility and Andrology Society and Society of Obstetricians and Gynaecologists of Canada, Combined Ethics Committee, *Ethical Considerations of the New Reproductive Technologies* (Toronto: Ribosome Communications, 1990).

10. See, for example, P. Lutjen et al., "The Establishment and Maintenance of Pregnancy Using *In Vitro* Fertilization and Embryo Donation in a Patient with Primary Ovarian Failure," *Nature* 307 (1984): 174-75; and D. Navot et al., "Artificially Induced Endometrial Cycles and Establishment of Pregnancies in the Absence of Ovaries," *New England Journal of Medicine* 314 (1986): 806-11.

11. The synchronization regimen is reported in A. Trounson et al., "Pregnancy Established in an Infertile Patient After Transfer of a Donated Embryo Fertilised In Vitro," *British Medical Journal* (12 March 1983): 835-38.

12. R.J. Levine, *Ethics and Regulation of Clinical Research*, 2d ed. (Baltimore: Urban & Schwarzenberg, 1986), 4.

13. At present, "the window of receptivity for a 2-day embryo has been defined as day 17 to day 19 of an idealized 28-day cycle, or the third to fifth day of progesterone exposure to the endometrium." D. Meldrum et al., "Artificial Agonadism and Hormone Replacement for Oocyte Donation," *Fertility and Sterility* 52 (1989), 509.

14. J. Robertson, "Ethical and Legal Issues in Human Egg Donation," *Fertility and Sterility* 52 (1989), 353.

15. F. Price, "Establishing Guidelines: Regulation and the Clinical Management of Infertility," in *Birthrights: Law and Ethics at the Beginnings of Life*, ed. R. Lee and D. Morgan (London (U.K.): Routledge, 1989), 48.

16. It is difficult to counsel properly women with premature ovarian failure as to the available options given the present lack of information about the incidence of spontaneous ovarian function. See N. Santoro and C.L. Schmidt, "Pregnancy After an Unsuccessful Oocyte Donation Cycle," *Fertility and Sterility* 53 (1990): 174-76.

17. Research in Canada on preimplantation genetic diagnosis was recently approved at University Hospital, London, Ontario (summer 1991).

18. Medical Research International, Society for Assisted Reproductive Technology, and American Fertility Society, "In Vitro Fertilization-Embryo Transfer (IVF-ET) in the United States: 1989 Results from the IVF-ET Registry," *Fertility and Sterility* 55 (1991), 20.

19. Personal communication, Salim Daya, Department of Obstetrics and Gynaecology, Chedoke-McMaster IVF Program, May 1991.

20. M. Sauer et al., "Oocyte and Pre-Embryo Donation to Women with Ovarian Failure: An Extended Clinical Trial," *Fertility and Sterility* 55 (1991), 42.

21. C. Steven, "Test-Tube Sisters," *Independent*, 29 September 1987, 13, as cited in Price, "Establishing Guidelines: Regulation and the Clinical Management of Infertility," 46.

22. Because of concerns regarding potential damage to the spindle during the freezing process, it is more common to freeze embryos than oocytes.

23. D. Levran et al., "Pregnancy Potential of Human Oocytes — The Effect of Cryopreservation," *New England Journal of Medicine* 323 (1990), 1153.

24. Interim Licensing Authority, *The Sixth Report of the Interim Licensing Authority for Human In Vitro Fertilisation and Embryology 1991* (London (U.K.): ILA Secretariat, 1991), 13.

25. Canadian Fertility and Andrology Society et al., *Ethical Considerations of the New Reproductive Technologies*, 9.

26. J. Riegler and A. Weikert, "Product Egg: Egg Selling in an Austrian IVF Clinic," *Reproductive and Genetic Engineering* 1 (1988): 221-23. This article is an interview with an oocyte donor who was paid $800 U.S. for donations and $80 U.S. for vaginal examinations to measure the mucus secretions of the vagina and blood supply to the uterus. At the time of printing the donor had already made five donations and was scheduled for a sixth.

27. For a detailed discussion of the many potential side-effects of the medications commonly used to stimulate the ovaries see F. Baylis, "*In Vitro* Fertilization and Embryo Transfer: Informed Choice," in this series of papers.

28. Ibid.

29. Interim Licensing Authority, *Egg Donation*, 4.

30. Canadian Fertility and Andrology Society et al., *Ethical Considerations of the New Reproductive Technologies*, 9.

31. Lutjen et al., "The Establishment and Maintenance of Pregnancy Using *In Vitro* Fertilization and Embryo Donation."

32. Canadian Press, "First Baby Born in Canada to Mother with Donor Eggs," *Globe and Mail* (19 July 1990), A6; and "Baby from Donated Ova Called Nation's First," *Toronto Star* (19 July 1990), A7.

33. As noted previously, in Ontario ARTs are paid for by the government-funded health insurance system and there is no cost to the infertile couple.

34. No documents specific to payment of oocyte donors were made available to me by the clinics that acknowledged having an oocyte donor program. This being said, Appendix 2, "Recipient of egg(s)," from the Toronto Fertility and Sterility Institute states that "the donor signs a consent that she will not ... request any financial reward except a predetermined amount which is costs only." Meanwhile, the donor consent form reads, "We do not expect, nor will we seek, any financial or other material reward for this donation." No reference is made to payment of any predetermined amount. By comparison, the donor consent form for the Toronto Hospital General Division states, "I understand that in accordance with the Provincial Human Tissue Gift Act that this donation involves no remuneration."

35. Sauer et al., "A Preliminary Report on Oocyte Donation Extending Reproductive Potential to Women Over 40."

36. This wording is from the Ethics Committee of the American Fertility Society, which recommends no compensation to the donor for the egg but explicitly states that "this does not exclude the reimbursement for expenses, time, risk and inconvenience associated with donation." American Fertility Society, "Donor Eggs in In Vitro Fertilization," 49S.

37. Sauer et al., "Oocyte and Pre-Embryo Donation to Women with Ovarian Failure," 42.

38. D.A. Rotsztejn et al., "Variables That Influence the Selection of an Egg Donor," Abstract No. P-022, 39th Annual Meeting of the Pacific Coast Fertility Society held in Scottsdale, Arizona, 10-14 April 1989 (Birmingham: American Fertility Society, 1989), A13.

39. Rosenwaks et al., "Oocyte Donation: The Norfolk Program," 747.

40. P.P. Mahlstedt and D.A. Greenfeld, "Assisted Reproductive Technology with Donor Gametes: The Need for Patient Preparation," *Fertility and Sterility* 52 (1989), 908-909.

41. At least two clinics expect prospective donors to consent to the unrestricted use of their oocytes (Toronto Hospital and Toronto East General Hospital). This is morally objectionable. Oocyte donors must be allowed explicitly to restrict the use of their donated genetic material. A woman willing to consent to oocyte donation to help an infertile couple establish a pregnancy may not be willing to consent to research using her gametes.

42. Mahlstedt and Greenfeld, "Assisted Reproductive Technology with Donor Gametes," 910.

43. Ibid., 911.

44. Interim Licensing Authority, *The Sixth Report of the Interim Licensing Authority for Human In Vitro Fertilisation and Embryology*, 67.

Part 5. Embryo Freezing for Subsequent Transfer: Informed Choice

Embryo freezing (cryopreservation) for subsequent transfer during an unstimulated (natural) menstrual cycle[1] is an assisted reproductive technology (ART) that requires informed choice for the freezing and storage of embryos; the thawing and transfer of frozen embryos; and the use or disposal of untransferred frozen embryos.

Typically these decisions are made by the gamete donors on the assumption that the embryo "'belongs' to its [genetic] parents, as a sort of chattel, and is their sole property."[2] As once stipulated by the American Fertility Society,

> it is understood that the gametes and concepti are the property of the donors. The donors therefore have the right to decide at their sole discretion the disposition of these items ...[3]

The property model is problematic, however, because in common law, there are no ownership rights over the body or body parts.[4]

An alternative to the property model is the guardianship model. This model supposes that upon fertilization, the gamete donors' limited rights of use and disposal are exhausted and the resulting embryo properly becomes the subject of guardianship. On this point, Australia's Waller Committee writes:

> The Committee does not regard the couple whose embryo is stored as owning or having dominion over that embryo. It considers that those concepts should not be imported into and have no place in a consideration of issues which focus on an individual and genetically unique human entity ... The Committee nevertheless does consider that the couple whose gametes are used to form the embryo in the context of an IVF programme should be recognized as having rights which are in some ways analogous to those recognized in parents of a child after its birth. The Committee does not consider that those rights are absolute, just as the rights of parents are limited by the rights and interests of the child, and by the larger concerns of the community in which they all live.[5]

Given the widely accepted principle that human beings (and human body parts) are not property, the guardianship model better captures certain intuitive notions about how one should treat early human embryos. The assumption underlying this model is that because parents are usually responsible for making decisions on behalf of their children, responsibility for determining the fate of embryos should rest with the prospective parents. In this view, embryo recipients (who may or may not be the same persons as the gamete donors) are the legitimate decision makers.

The guardianship model, like the property model, is problematic, however. The relationship between parents (or legal guardians) and children is, in significant respects, disanalogous to the relationship between gamete donors and embryos. The Waller Committee notes correctly that "the rights of parents [or legal guardians] are limited by the rights and interests of the child."[6] However, the best interests test, which limits the rights of parents (or legal guardians) over children, does not obviously apply to decisions about embryos. For example, decisions about freezing, storage, thawing, transfer, use, or disposal of embryos are not governed by consideration of the embryos' best interests.

In this paper, a trusteeship model, which confers no ownership rights upon gamete donors and makes no status claims on behalf of embryos, is considered a helpful alternative to the property and guardianship models. With a trusteeship model, the persons responsible for decisions regarding the use or disposal of embryos are those who provide the genetic material from which the embryos are created and who thereby have a unique moral interest in the use of the genetic material.[7]

On this reasoning, it is argued that informed choice for the freezing and storage of embryos, as well as for the use or disposal of frozen

embryos, must come from the gamete donors. Informed choice for the thawing and transfer of frozen embryos, however, is required of the embryo recipients (who may or may not be the same persons as the gamete donors). Decision-making authority regarding the transfer of frozen-thawed embryos is the responsibility of the recipients, who have the right to decide whether to become biological (and legal) parents. A necessary prerequisite to this view is that, in instances where the recipients are not the same persons as the gamete donors, the donors have already consented to embryo freezing and donation, as well as to the use or disposal of frozen embryos in the event that they are not used for donation.

This being said, for purposes of this discussion, the recipient couple and the gamete donors are the same people.

1. A description of the participants' current medical status

When embryo freezing is offered to "infertile" couples[8] in an *in vitro* fertilization and embryo transfer (IVF-ET) program as a "routine" adjunct intervention (e.g., "our policy is to freeze all spare embryos"), there is little if any information about medical status that is of specific relevance to decisions about embryo freezing. However, when embryo freezing is offered for any reason other than to increase the chances of pregnancy and reduce the loss of human embryos (the general objectives of embryo freezing), accurate information about the woman's medical status is imperative.

For example, if embryo freezing is offered as a way of managing incipient severe ovarian hyperstimulation syndrome,[9] the potential harms of severe hyperstimulation syndrome must be carefully explained. Also, it must be understood that even when the medical induction of ovulation is followed by embryo freezing the possibility of significant side-effects (e.g., nausea, lower abdominal pain, hyperstimulation, and abdominal distention) remains, but may be reduced in subsequent natural cycles.

Alternatively, if embryo freezing is offered as insurance against future infertility because the female partner has a disease that affects the functioning of the ovaries (such as cancer, endometriosis, recurrent cysts, and infection), then for there to be an informed choice about embryo freezing, the likelihood of infertility as a result of chemotherapy, radiation therapy, or surgical removal of the ovaries must be discussed. In sum, as the situation warrants, relevant information about the woman's medical status must be disclosed.

2. Information about the nature and objective(s) of the proposed intervention, along with similar information about available alternatives and adjunct interventions

Nature of Embryo Freezing

Couples considering embryo freezing should have a basic understanding of the steps involved. At the very least, they should have general information about how embryos are frozen and stored, as well as

general information about how frozen embryos are thawed and transferred. Below is an excerpt from a patient information handout:

> Embryo freezing (cryopreservation) is a technical procedure by means of which embryos are stored for long periods of time at a low temperature (–196°C). Water in the embryos is replaced with a chemical solution (cryoprotectant) that functions like an antifreeze. If a cryoprotectant is not used, as the temperature decreases, water in the embryos freezes and forms ice crystals. These crystals destroy embryos. When embryos are thawed, the cryoprotectant is removed and replaced with water.
>
> Frozen embryos usually are returned during a natural menstrual cycle (no medications). During this cycle certain hormone levels are measured daily and ultrasound examination is performed. At the appropriate time, the frozen embryos are thawed ... The embryos are then cultured for a short time to determine whether they have survived the procedure. A few hours after thawing (or perhaps a day later), the surviving embryos are transferred using the same method as that used to transfer embryos during a stimulated IVF cycle.[10]

In addition to understanding the "mechanics" of embryo freezing, couples must also be given some understanding of the experimental nature of this ART. Like many other ARTs, embryo freezing requires carefully designed research to ascertain both safety and efficacy. On this point, the Ethics Committee of the American Fertility Society is most explicit:

> From a medical viewpoint, the Committee believes that cryopreservation techniques in human pre-embryos show promise and should be further investigated. Because neither the long-term risks nor the benefits of the procedure can be fully assessed at present, it is difficult to render a definitive ethical judgment on all aspects of the use of cryopreservation ... The Committee believes that research using cryopreservation techniques should be pursued, with careful oversight, in those centers that perform this type of research.[11]

In Canada, although it is widely recognized that freezing technology is "new and requires considerable development,"[12] care is taken not to describe embryo freezing as research. The closest to an acknowledgment of the experimental nature of embryo freezing is found in the consent form of the LIFE Program, according to which:

> ... the procedure(s) or *treatments* contemplated, while not *necessarily experimental*, are in some respects new to the medical practitioners or medical technical staff who are involved in the procedures or treatments.[13] (emphasis added)

Objectives of Embryo Freezing

Couples must be made aware of the relevant objectives of embryo freezing. These objectives vary depending upon the nature of the primary intervention to which the option of embryo freezing is added. For example, with embryo freezing for subsequent transfer during an unstimulated cycle the objectives are (in random order): to reduce the number of embryos

routinely discarded; to reduce the need for ovulation induction; to increase the chances of pregnancy; and to reduce the inconvenience, discomfort, and costs of IVF-ET. By comparison, the objectives of embryo freezing for the purpose of embryo donation are to eliminate the need to synchronize the donor's and recipient's cycle and, in some instances, to protect the anonymity of the donor.

Alternatives to Embryo Freezing

The alternatives to embryo freezing must be discussed with the prospective participants. This discussion must take into consideration the objectives/benefits sought by the couple. For example, if the objective is to limit the number of embryos routinely discarded, one option is to create fewer embryos. On the other hand, if the objective is to avoid multiple births, an option is to transfer fewer embryos per cycle. Also, in examining the alternatives to embryo freezing, there may be some value in exploring options that do not coincide with the couple's present objectives (such as adoption or child-free living), so that the couple can have a broader understanding of the alternatives available to them.

3. Information about the nature and the probability of the known and possible consequences (i.e., benefits, harms, and inconveniences) of the various options (i.e., the proposed intervention, alternative interventions, and the option of no intervention)

Potential Benefits of Embryo Freezing

One benefit of embryo freezing often cited is that it eliminates the problem of "spare" embryos by providing an alternative to transferring or discarding excess embryos. Embryo freezing, however, does not eliminate the problem of spare embryos. At best, it may reduce the tendency to transfer an excessive number of embryos per cycle, and it may reduce the number of embryos routinely discarded. Some practitioners will continue to transfer an excessive number of embryos, however, and some spare embryos will be discarded because they are unsuitable for freezing or, if frozen and thawed, because they are unsuitable for transfer or research purposes. Thus, a first benefit of embryo freezing is not that it eliminates the problem of spare embryos, but rather that it may reduce the number of embryos transferred per cycle or routinely discarded.

A second potential benefit of embryo freezing is that it reduces the need for ovulation induction (the potential harmful consequences of which include severe hyperstimulation syndrome, cysts, etc.), because frozen and thawed embryos usually can be transferred during a unstimulated (natural) menstrual cycle.

A third potential benefit of embryo freezing is that it may reduce the multiple pregnancy rate. With embryo freezing as an alternative to discarding embryos, the imperative to transfer all embryos may be removed. This can benefit the couple by reducing the chances of multiple pregnancy.

A fourth potential benefit of embryo freezing is that it may increase the pregnancy and take-home-baby rates. The drugs used to stimulate the ovaries during a typical IVF-ET cycle temporarily raise the level of ovarian hormones in the body. This alters the lining of the uterus and reduces the chances of implantation. With embryo freezing, the frozen-thawed embryos can be transferred during a non-stimulated cycle, potentially increasing the chances of pregnancy.[14]

There is much controversy about this potential benefit. Recently it has been estimated that with embryo freezing the "pregnancy rates per patient may increase by 8% to 12%."[15] However, a study by Levran and colleagues shows a much lower pregnancy rate with frozen-thawed embryos as compared with fresh embryos:

> Of the [71] fresh embryos that were transferred to the recipients, 24 percent were successfully implanted, as compared with only 7.7 percent of the [91] frozen and thawed embryos ($P<0.01$). A pregnancy success rate of 37 percent per recipient cycle was observed in the recipients of fresh embryos, as compared with a rate of only 16 percent in those receiving frozen and thawed embryos ($P<0.05$).[16]

According to data from the U.S. IVF-ET Registry for 1989, the clinical pregnancy rate for frozen embryo transfer cycles was 11 percent and the delivery rate was 8 percent whereas

> [t]he overall live delivery rates were 14% for IVF (based on 15,392 retrievals), 23% for gamete intrafallopian transfer (GIFT) (based on 3,652 retrievals), 26% for IVF and GIFT in combination (based on 452 retrievals), and 17% for zygote intrafallopian transfer (ZIFT) and related practices (based on 908 retrievals).[17]

In Canada, the IVF Program at the University of British Columbia cites a pregnancy rate of between 6 percent and 10 percent per embryo that survives the freeze-thaw process. The LIFE Program and IVF Canada claim a 10 percent pregnancy rate per frozen-thawed embryo, and the Centre de Fécondation in Vitro du CHUL claims only a 3 to 4 percent pregnancy rate per frozen-thawed embryo. The IVF Program at the University of British Columbia cites international data.[18]

A final benefit of embryo freezing for subsequent transfer is that it may reduce the inconvenience, discomfort, and costs of IVF-ET. With the use of frozen and thawed embryos there is no need for ovulation induction, anaesthesia, or surgery, interventions that are potentially harmful, inconvenient, and costly.[19]

Potential Harms of Embryo Freezing

Against these potential benefits of embryo freezing several potential harms must be weighed. First, there is the possibility that the embryos may be irrevocably damaged by the freeze-thaw process, and therefore may not be suitable for transfer. Available data suggest that only 50 to 60 percent of embryos survive the freeze-thaw process.[20] At present it is not clear whether this results from the freezing technology or the poor

quality of embryos available for freezing. Another potential harm worth noting is the inadvertent destruction of frozen embryos because of equipment failure — despite back-up freezer systems.

Second, on occasion, an unstimulated cycle may have to be cancelled because all the embryos thawed are unsuitable for transfer. This would result in a delay in a woman's fertility treatment which for some women could be a significant harm.

Third, there is the possibility that although frozen embryos have been thawed and transferred successfully, a pregnancy may not be established because of failure of implantation. The pregnancy rate for embryos that survive the freeze-thaw process is only 11 percent.[21]

Fourth, there may be an increased risk of malformations occurring in the children born of IVF-ET and embryo freezing.[22] Recent experience with animal models suggests that this is not a serious risk; it is difficult to extrapolate from animal models to the human model, however, because of differences in freezing technology, and because it is not possible to assess the potential impact of freezing on future intellectual abilities. To date,

> there have been a limited number of viable births resulting from human preembryo freezing and storage; ... these births have been normal; [however] the risk of physical [or mental] defects which might be delayed in their manifestation after freezing and storage is still unknown.[23]

Fifth, there are the potential emotional and psychological harms of embryo freezing. As Bonnicksen writes:

> Freezing ... increases the patient's dependence on IVF as the answer to infertility in a way that can be emotionally unhealthy .... Freezing interferes with closure on infertility for women who want to adopt or move on to other life goals but who find they cannot terminate the effort because of stored embryos.[24]

The potential emotional and psychological harms of embryo freezing are clearly identified in the patient information handout for couples considering London's University Hospital IVF Program:

> **Although embryo freezing offers couples added opportunities to conceive, each new opportunity for success is also another possible source of disappointment.** Because the success of freezing and thawing is low, the potential for added sadness and feelings of loss is quite real.
>
> **The existence of frozen embryos can create pressure to continue treatment.** Although couples often have a strong desire to try every available treatment option to achieve a pregnancy, such feelings can change. Couples may begin to feel they have done enough. However, if there are remaining stored embryos, there may be feelings of guilt about ending treatment and moving on to other life goals.
>
> **Initially partners might be in complete agreement about embryo freezing but if problems in the relationship arise, the ownership and disposition of embryos might become problematic.**[25]

Additional Considerations

Finally, if a centre offers embryo freezing, the provision of accurate and comprehensive information about the relevant potential benefits and harms should not be delayed until after fertilization when it has become obvious that there are more embryos available for transfer than can reasonably be transferred. Embryo freezing is an adjunct intervention that requires not only a decision about freezing and storage, but also decisions about thawing and transfer and about the eventual disposal of untransferred frozen embryos. Couples need time to consider the various aspects of embryo freezing for which informed choice is required. It is therefore essential that this option be considered early in the decision-making process.[26]

Also, for women considering embryo freezing as a potential means of preserving their reproductive potential, it is inappropriate to discuss the potential benefits and harms of embryo freezing without also discussing the potential benefits and harms of IVF-ET. Information about IVF-ET is clearly relevant to any decision about whether to freeze and store embryos for subsequent transfer, because freezing and storage without IVF-ET do not constitute an alternative means of reproduction. As such, the potential benefits and harms of embryo freezing, as well as the potential benefits and harms of IVF-ET, must be considered jointly.

4. Information about the qualifications and experience of the cryobiologist

Successful embryo freezing requires special skills and equipment. Of particular importance is the need for an embryologist experienced in animal or human cryopreservation. Couples considering embryo freezing should know whether the clinic offering embryo freezing has a qualified cryobiologist or whether they are relying on other lab technicians to learn embryo freezing on the job.

5. Information about the costs involved

Full information on the costs of embryo freezing should include information about

> whether the storage fee is for each embryo or for all embryos, indefinite or subject to periodic renewals, constant or subject to cost-of-living adjustments, and inclusive of thawing and transfer fees.[27]

Not surprisingly, these details vary from clinic to clinic. For example, at the IVF Program at the University of British Columbia, the fee for freezing and storage is $421[28] and the fee for transfer of frozen embryos is $748.

By comparison, the LIFE Program's fee for freezing and storage for the first year is $200 plus $14 Goods and Services Tax (GST); for each additional six months' storage the fee is $50 plus $3.50 GST. There is no fee for the transfer of frozen embryos; this "is considered a continuation of the previous IVF cycle" and is paid for by government-funded health insurance.[29]

The IVF Programme at the University of Calgary has chosen to absorb the cost of embryo freezing because of its experimental (as contrasted with therapeutic) nature. The patient information handout reads:

> The cost of embryo freezing and storage for the first year will be borne by the Programme during the initial phase ... When the procedure has demonstrated acceptable effectiveness and safety in this Programme, all costs will be borne by the patients.[30]

In addition to providing accurate information about the costs of freezing, it is important to help couples put this information in perspective. Embryo freezing is supposed to reduce the costs of IVF-ET because fewer stimulated cycles are required. For example, will embryo freezing really be less expensive for couples in Ontario, where IVF-ET is paid for by government-funded health insurance but embryo freezing is not? Also, what if long-term storage is required? At some IVF centres the maximum allowable storage period is 10 years. Couples must be encouraged to consider these kinds of issues and must be informed of the consequences of non-payment. (Typically, authority over the embryos reverts to the storage facility if fees are not paid.)

6. Additional information that may assist the prospective participants to make an informed choice

With embryo freezing a lot of additional information must be disclosed. This includes information about (1) the quality of embryos available for freezing; (2) the quality and number of frozen-thawed embryos available for transfer; (3) the maximum allowable storage period; (4) the factors that affect the success rates of embryo freezing and IVF-ET; (5) the options available for the use or disposal of untransferred frozen embryos; and (6) any additional program-specific rules governing the practice of embryo freezing.

Quality of Embryos Available for Freezing

An ongoing question within the scientific and medical community is

> whether technicians should transfer the strongest embryos while they are fresh and freeze the weaker ones (this makes sense if the strong embryos do not survive the freeze-thaw process), or transfer the weak embryos and freeze the strong ones (which makes sense if the strong embryos will survive and can be transferred to the woman at a later, presumably more receptive cycle when she has not been hormonally stimulated).[31]

With the present limited success of embryo freezing, it is common practice to transfer the better-quality embryos (up to a maximum of three, four, five, or six, depending upon the clinic) and to freeze the remainder. Couples should understand that this practice speaks to the efficacy of embryo freezing. If embryo freezing were truly effective, then the better-quality embryos (if not all the embryos) would be frozen for subsequent transfer in a non-stimulated (presumably more receptive) cycle.

Quality and Number of Frozen-Thawed Embryos Available for Transfer

Many embryos are damaged during the freeze-thaw process and as a result are considered unsuitable for transfer. At the outset, couples must understand that the number of embryos frozen may not equal the number of frozen-thawed embryos available for transfer. Typically, frozen-thawed embryos are examined carefully after thawing to determine their suitability for transfer. Usually a minimum number of cells must survive the freeze-thaw process for the embryo to be considered eligible for transfer. One group of researchers has suggested, however, that "all the embryos with at least one cell after thawing should be transferred into the uterus."[32]

As regards the number of frozen-thawed embryos used for transfer during an unstimulated cycle, there is much variability between clinics. To increase the chances of pregnancy and to minimize the risk of multiple pregnancy, it has been suggested that embryos be frozen in individual straws, then thawed and transferred one per cycle.[33] To avoid the risk of cancellation because the one embryo thawed may not survive, many clinics prefer to thaw more than one embryo per cycle.

Maximum Allowable Storage Period

Concerns have been expressed about the length of time that human embryos can be stored in liquid nitrogen at −196°C and still remain viable. The answer seems to be a very long time. "The reason is that direct ionizations from background radiation are the only source of damage at such temperatures. Ordinary chemical reactions cannot occur."[34]

This being said, there are many pragmatic reasons for not storing frozen embryos indefinitely, and most IVF-ET clinics have policies concerning the maximum allowable storage period. At IVF Canada and the LIFE Program, the maximum storage period is 10 years from the date of cryopreservation or until one of the partners reaches the age of 40.[35] At the other extreme, the Toronto Fertility and Sterility Institute requires embryos to be used within four months; otherwise the Institute is "authorized to donate these to other infertile couples."[36]

Between these two extremes, there are the Department of Obstetrics and Gynaecology at the University of British Columbia, and the University Hospital IVF Program in London, which have a maximum storage period of five years, the IVF Programme at the University of Calgary, which has a three-year renewable consent for freezing and storage, and the Institut de Médecine de la Reproduction de Montréal Inc., which has a two-year renewable consent for freezing and storage.

Those who are offered embryo freezing must be informed of the usual maximum allowable storage period and any clinic-specific rules regarding renewals of consent for freezing and storage.

Factors Affecting the Success Rates of Embryo Freezing and IVF-ET

A number of factors affect embryo survival after freezing. These include the following:

> (1) the developmental stage of frozen embryos; (2) the appearance of the embryo at the time of freezing; and (3) the mode of ovarian stimulation in the IVF cycle.[37]

The pregnancy rate with frozen-thawed embryos seems to be greater with four-cell embryos than with embryos at any other developmental stage. Also, the morphological features of the blastomeres at the time of freezing seem to influence embryo survival after freezing and thawing. Finally there seem to be better survival rates with women who produce fewer oocytes (e.g., one to five oocytes) during their stimulated cycle. Often multiple oocytes are "the product of a cycle with high levels of estradiol and progesterone."[38] These and other factors that may affect the success rates of embryo freezing should be disclosed to prospective participants.

Options Available for the Use or Disposal of Untransferred Frozen Embryos

It is important for clinics that offer a range of ARTs (including donation and research) to ask couples who consent to embryo freezing to give the storage facility precise advance directives for the use or disposal of untransferred embryos in the event of (1) a subsequent disagreement between the partners; (2) a dissolution of the partnership by divorce, separation, or the death of one or both partners; (3) a decision to withdraw from (or not proceed with) IVF-ET; or (4) the termination of the freezing component of the IVF-ET program (or closure of the program).

For example, in the IVF Program at the University of British Columbia, at the couple's discretion, untransferred frozen embryos can be donated to another infertile couple, used for research purposes, or "destroyed either by fixing the embryos on a glass slide or by allowing the embryos to degenerate."[39] At the Institut de Médecine de la Reproduction de Montréal Inc., the available options are limited to donation or destruction,[40] whereas in the IVF Program at University Hospital in London the available options are limited to research or destruction.[41] The IVF Programme at the University of Calgary, the LIFE Program, and IVF Canada stipulate that untransferred embryos are to be discarded by the storage facility.[42]

Couples considering embryo freezing should know that different clinics have different policies concerning the use or disposal of untransferred frozen embryos. Also, they should be aware of the operative policy of the clinic of their choice. For some couples this may be an important factor in deciding whether to proceed with embryo freezing at a particular clinic.

Program-Specific Rules Governing Embryo Freezing

In addition to the generic information all programs should provide, couples require additional information about program-specific rules. For example, there may be rules about the number of frozen embryos to be thawed per transfer cycle, the need for periodic renewals of consent,[43] the requirement that all frozen embryos be transferred prior to the creation of new embryos, and the need for genetic screening if untransferred frozen embryos are to be donated to other infertile couples.

7. A statement that participants may ask questions now and later

The importance of offering to answer questions as they arise has been noted in all previous papers in this series. This disclosure requirement is particularly important with embryo freezing because of the considerable amount of additional information that must be disclosed to prospective participants. Questions should always be welcome. When they cannot be answered because of the many uncertainties associated with embryo freezing, this should be acknowledged honestly.

8. A statement that confidentiality will be respected

With embryo freezing, the promise of confidentiality is perhaps most relevant with respect to decisions concerning the use or disposal of frozen embryos. In theory, couples may choose to have their frozen embryos donated to another couple, donated for research purposes, or destroyed. For many couples it will be important for them to know that their choice will remain private. Moreover, if donation is the preferred option, there may be a special desire for anonymity.

9. A statement that the couple may refuse to participate without jeopardizing access to health care

Some IVF-ET clinics present embryo freezing not as an option for couples to consider (and either accept or reject), but rather as a routine part of IVF-ET. Embryo freezing should not be presented in this manner. Couples must understand that they are free to refuse embryo freezing without jeopardizing access to IVF-ET or other ARTs.

10. A statement that consent and refusal are revocable. In principle, the couple may withdraw their consent or overturn their previous refusal without jeopardizing access to health care

If a couple, or one of the partners, withdraws consent to embryo freezing prior to the freezing of embryos, there are no pragmatic problems — no embryos are frozen. Alternatively, if the couple or one partner withdraws consent after embryos have been frozen, their prior directives regarding the use or disposal of untransferred frozen embryos in the event of a subsequent disagreement come into effect. Because of this practical limit on the choice to withdraw from embryo freezing, it is particularly important that couples' choices regarding the use or disposal of untransferred frozen embryos be well informed.

Notes

1. With some IVF-ET programs, embryo freezing is available only for subsequent transfer during an unstimulated cycle, and all untransferred frozen embryos are ultimately discarded. Typically, these clinics do not offer embryo donation and do not engage in research involving human embryos. Other clinics restrict embryo freezing so that it is available only for subsequent transfer during an unstimulated

cycle; however, untransferred frozen embryos may be used for donation or research purposes. Even fewer clinics offer embryo freezing explicitly for the purpose of donation or research, as well as subsequent transfer (see, for example, the LIFE Program and IVF Canada). This being said, given the limited time and space available, this paper focusses narrowly on embryo freezing for subsequent transfer during an unstimulated cycle. It is further assumed that the transfer will not be to a gestational woman.

2. R.G. Edwards and M. Puxon, "Parental Consent Over Embryos," *Nature* 310 (July 1984), 179.

3. American Fertility Society, Ad Hoc Committee, "Ethical Statement on In Vitro Fertilization," *Fertility and Sterility* 41 (1984): 12.

4. See, for example, R. Scott, *The Body as Property* (London (U.K.): Allen Lane, 1981).

5. Victoria, Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on the Disposition of Embryos Produced by In Vitro Fertilization* (Melbourne, 1984), 27.

6. Ibid.

7. This discussion borrows heavily from F. Baylis, "The Ethics of *Ex Utero* Research on Spare 'IVF' Human Embryos," Ph.D. dissertation, University of Western Ontario, 1989, 142-43.

8. This paper on embryo freezing, as with all previous papers in this series, focusses narrowly on the heterosexual couple. Again, this is not to suggest that homosexual couples or single persons should be denied access to ARTs.

9. N.N. Amso et al., "The Management of Predicted Ovarian Hyperstimulation Involving Gonadotropin-Releasing Hormone Analog with Elective Cryopreservation of All Pre-Embryos," *Fertility and Sterility* 53 (1990): 1087-90.

10. F. Baylis et al., *Information on Embryo Freezing* (London: University Hospital, 1991), 1, 3.

11. American Fertility Society, Ethics Committee, "Ethical Considerations of the New Reproductive Technologies," *Fertility and Sterility* 53 (Suppl. 2)(1990): 60S-61S.

12. Baylis et al., *Information on Embryo Freezing*, 3.

13. LIFE Program, *Consent Form* (Toronto: Toronto East General Hospital, 1990), 3.

14. Testart and colleagues estimate that with the immediate transfer of up to three embryos (with all excess embryos being discarded), the pregnancy rate per cycle is 14.8 percent with one embryo, 19.9 percent with two embryos, and 26.3 percent with three embryos. By comparison, if only one fresh embryo is transferred and all remaining embryos are frozen at the four-cell stage in individual straws (for individual transfer), the pregnancy rate with two embryos per cycle is 26.4 percent and this increases to 54 percent with three embryos, 73.6 percent with four embryos, 93.2 percent with five embryos, and 112.8 percent with six embryos. J. Testart et al., "Human Embryo Freezing," in *In Vitro Fertilization and Other Assisted Reproduction*, ed. H.W. Jones and C. Schrader, *Annals of the New York Academy of Sciences* 541 (1988), 539.

15. P.E. Patton, L.R. Hickok, and D.P. Wolf, "Successful Hysteroscopic Cannulation and Tubal Transfer of Cryopreserved Embryos," *Fertility and Sterility* 55 (1991), 640. In this article no estimates are provided for the birth rates (as contrasted with the pregnancy rates) of fresh as compared with frozen embryo transfers.

16. D. Levran et al., "Pregnancy Potential of Human Oocytes — The Effect of Cryopreservation," *New England Journal of Medicine* 323 (1990), 1153.

17. Medical Research International, Society for Assisted Reproductive Technology and American Fertility Society, "In Vitro Fertilization-Embryo Transfer (IVF-ET) in the United States: 1989 Results from the IVF-ET Registry," *Fertility and Sterility* 55 (1991), 14.

18. For centres with established freezing programs, the centre's own data should be shared with the couple. For centres initiating freezing programs, international data may be used, but it should be emphasized that similar success rates probably will not be obtained during the first years.

19. See F. Baylis, "*In Vitro* Fertilization and Embryo Transfer: Informed Choice," in this series of papers.

20. See, for example, L.R. Mohr, A. Trounson, and L. Freemann, "Deep-Freezing and Transfer of Human Embryos," *Journal of In Vitro Fertilization and Embryo Transfer* 2 (1985): 1-10; and J. Cohen et al., "Pregnancies Following the Frozen Storage of Expanding Human Blastocysts," *Journal of In Vitro Fertilization and Embryo Transfer* 2 (1985): 59-64.

21. Medical Research International et al., "In Vitro Fertilization-Embryo Transfer (IVF-ET) in the United States," 20.

22. See, for example, B. Rizk et al., "Edwards' Syndrome After the Replacement of Cryopreserved-Thawed Embryos," *Fertility and Sterility* 55 (1991): 208-10.

23. American Fertility Society, "Ethical Considerations of the New Reproductive Technologies," 59S.

24. A.L. Bonnicksen, "Embryo Freezing: Ethical Issues in the Clinical Setting," *Hastings Center Report* 18 (6)(1988), 27.

25. Baylis et al., *Information on Embryo Freezing*, 2.

26. An empirical study is being designed at University Hospital (London, Ontario) to examine the effectiveness of disclosure regarding the possibility of embryo freezing at different stages during the IVF cycle (prior to the beginning of the cycle for all couples, or after egg recovery and prior to transfer for only those couples for whom freezing is an option).

27. Bonnicksen, "Embryo Freezing," 28.

28. No time frame is specified.

29. LIFE Program, *Information Booklet II* (Toronto: Toronto East General Hospital, 1990), 2, 3.

30. Endocrine/Infertility Clinic and IVF Programme, *Patient Information: Cryopreservation and Subsequent Replacement of Human Embryos* (Calgary: IVF Programme, n.d.), 2.

31. Bonnicksen, "Embryo Freezing," 29.

32. Testart et al., "Human Embryo Freezing," 539.

33. Ibid.

34. P. Mazur, "Stopping Biological Time: The Freezing of Living Cells," in *In Vitro Fertilization and Other Assisted Reproduction*, ed. H.W. Jones and C. Schrader, *Annals of the New York Academy of Sciences* 541 (1988), 514.

35. Because the chances of pregnancy decrease with maternal age, with most of the reproductive technologies there is some concern about the age of the female partner. The consent forms used by IVF Canada and the LIFE Program, however, do not specifically limit the storage period until the *woman* reaches the age of 40. This may or may not be intentional.

36. Toronto Fertility and Sterility Institute, *Consent Form* (Toronto: Toronto Fertility and Sterility Institute, n.d.), 1.

37. J. Testart et al., "Factors Influencing the Success Rate of Human Embryo Freezing in an In Vitro Fertilization and Embryo Transfer Program," *Fertility and Sterility* 48 (1987), 107.

38. Levran et al., "Pregnancy Potential of Human Oocytes," 1156.

39. University of British Columbia, Department of Obstetrics and Gynaecology, *Consent to Cryopreservation and Disposition of Human Embryos* (Vancouver, 1990), 5.

40. Institut de Médecine de la Reproduction de Montréal, *Consentement pour congélation et conservation d'embryons* (Montreal: Institut de Médecine de la Reproduction de Montréal, 1990).

41. Baylis et al., *Information on Embryo Freezing*, 4-5.

42. See Endocrine/Infertility Clinic and IVF Programme, *Patient Information: Cryopreservation and Subsequent Replacement of Human Embryos*, 1; LIFE Program, *Information Booklet II* and *Consent Form*, 2; and IVF Canada, *Consent Form — Frozen Embryo* (Toronto: IVF Canada, n.d.), 1.

43. A number of clinics require periodic renewals of the consent to embryo freezing and storage (for example, 12 months with the IVF Program at the University of British Columbia and 6 months with the LIFE Program and IVF Canada.) A number of clinics also require renewal of consent by both partners at the time of thawing and transfer to avoid a situation in which the male partner unknowingly becomes a parent subsequent to the dissolution of the partnership.

Part 6. Preimplantation Genetic Diagnosis: Informed Choice

Prenatal genetic diagnosis is available to couples at risk of transmitting genetic diseases, including autosomal dominant disorders (e.g., Huntington's chorea), autosomal recessive disorders (e.g., Tay-Sachs disease), and X-linked recessive disorders (e.g., haemophilia and Duchenne's muscular dystrophy). Currently, this is possible using amniocentesis at approximately 16 weeks after conception or, for some couples, by chorionic villus sampling (CVS) at approximately 11 weeks, with

cytogenetic, biochemical, or deoxyribonucleic acid (DNA) analysis of fetal material. If the fetus is affected by the disorder (or if the fetus is male, in the case of an X-linked disorder), the birth of an affected child can be avoided by terminating the pregnancy.

Although prenatal diagnosis followed by termination of pregnancy is acceptable to some couples carrying genetic disease, for others it is morally unacceptable. For others still, termination is morally acceptable but it is physically and emotionally traumatic. Therefore, some couples at risk of having a child with a genetic disorder choose not to conceive. Others choose to conceive and take their chances. (For example, with an X-linked disorder, there is a 25 percent chance of an affected male, a 25 percent chance of a carrier female, and a 50 percent chance of a healthy child.) Still others choose to conceive, have prenatal testing (e.g., CVS or amniocentesis), and abort all potentially affected fetuses, carrying to term those likely to be healthy.

An alternative means of prenatal diagnosis of genetic disease that does not require the establishment of pregnancy is preimplantation genetic diagnosis, which is currently in a research phase. This technique involves *in vitro* fertilization (IVF) or embryo recovery by uterine lavage,[1] followed by the testing of preimplantation embryos and transfer to the uterus of only those embryos likely to be healthy. Research of this kind is currently under way on several genetic diseases, including cystic fibrosis and Duchenne's muscular dystrophy,[2] beta-thalassaemia, haemophilia, and sickle cell disease,[3] as well as X-linked recessive diseases.[4] Research on X-linked disorders is currently focussed on the preimplantation identification of the Y-chromosome, rather than the preimplantation diagnosis of the specific defect.

Preimplantation genetic diagnosis by sexing the embryo was first suggested for sex-linked recessive disorders by Edwards in 1965.[5] Shortly thereafter, in 1968, Gardner and Edwards reported on the sexing of rabbit embryos by examining sex chromatin in trophoblast cells.[6]

Since then, a number of biopsy and genetic analysis techniques have been developed for the preimplantation diagnosis of genetic disease. Biopsy methods include (1) separating cells at the two-cell stage;[7] (2) removing one or two cells at the four- to eight-cell stage;[8] and (3) removing part of the trophectoderm from the blastocyst.[9] Genetic analysis techniques include (1) chromosome analysis;[10] (2) Y chromosome-specific DNA probes;[11] (3) measuring dosage difference in metabolic activity of gene products of the X chromosome prior to its inactivation;[12] (4) DNA amplification of a Y-specific sequence using the polymerase chain reaction;[13] and (5) fluorescent *in situ* hybridization using Y-specific probes.[14]

These biopsy and genetic analysis techniques have different advantages and disadvantages. For example, with trophectoderm biopsy, as contrasted with embryo biopsy, the cells removed are strictly extra-embryonic, and there is more genetic material available for analysis.

Trophectoderm biopsy, however, may damage remaining trophectoderm cells, which may in turn affect implantation success.[15]

Similarly, comparisons can be made between the different methods of genetic analysis. For example, Y-specific DNA amplification using the polymerase chain reaction is quick and effective,[16] but there is the risk of misdiagnosis by contamination or the inadvertent sampling of a nuclear cytoplasmic fragment. An alternative but much lengthier method of sexing human embryos is *in situ* hybridization using Y-specific probes.[17]

In April 1990 Handyside et al. at Hammersmith Hospital reported the first established pregnancies from biopsied human preimplantation embryos sexed by Y-specific DNA amplification. The genetic risks involved were adrenoleukodystrophy and X-linked mental retardation syndrome:

> Two female embryos were transferred after *in vitro* fertilization (IVF), biopsy of a single cell at the six- to eight-cell stage, and sexing by DNA amplification of a Y chromosome-specific repeat sequence.[18]

More recently, in June 1991, Soussis and colleagues at Hammersmith Hospital reported that a total of "five treatment cycles [had] resulted in three singleton and two twin viable pregnancies. Three of these pregnancies resulted in the delivery of baby girls, the fourth is ongoing and the fifth was terminated because of misdiagnosis."[19]

Similar research on preimplantation genetic diagnosis of X-linked recessive disorders is under way in Canada. In June 1991 the University of Western Ontario Review Board for Health Sciences Research Involving Human Subjects approved, without modification, a two-part research project on the cell sampling of human embryos.[20]

The first part of this research, on the "Technical Evaluation of Minor Modifications to *In Vitro* Methodology and Routine Quality Control," involves the research use of non-viable embryos currently being discarded at the University Hospital IVF Program. This research is designed primarily (1) to ensure that the glass micro-instruments used for holding, zona drilling, and cell sampling are appropriately scaled in size for the eight-cell human embryo; and (2) to determine whether the proposed minor modifications to the micro-manipulators and the glass micro-instruments as originally described by Handyside et al.[21] (a) are compatible with efficient cell sampling; and (b) improve upon current cell sampling methodology. This research phase is complete.

The second part of the research, to begin in the spring/summer of 1992, is the "Pilot Programme for Early Preimplantation Cell Screening." This research phase is designed primarily to develop an alternative method of genetic screening for couples carrying genes for severe X-linked recessive disorders. Participants in the research project (50 couples at risk of having a child with a severe X-linked mental retardation syndrome) will have their embryos created *in vitro*. At the eight-cell stage, two blastomeres will be removed for preimplantation genetic diagnosis. Only embryos not at risk of developing a severe X-linked mental retardation syndrome (i.e., only

female embryos) will be transferred to the uterus. To cite the research proposal:

> Participating couples will initially provide blood samples by venipuncture which will be used to prepare DNA or single nucleated cells for testing in the DNA amplification reaction. This step ensures that the Y chromosome specific DNA sequence from the male (which may be variable in size) is detectable and that the female DNA does not unexpectedly contain similar sequences. Couples will then be scheduled for a normal IVF cycle consisting of hormonal stimulation and multiple oocyte recovery with subsequent in vitro fertilization by the husband's sperm. Normally fertilized oocytes (as indicated by two pronuclei) will be cultured to the 8-cell stage, while abnormally fertilized oocytes (1 or > 2 pronuclei) will be either discarded or donated (by informed consent) for quality control procedures ... After approximately 2 - 3 days in culture morphologically normal 8-cell embryos (actual number may vary from 6 - 8 cells) will have early preimplantation cell screening (EPICS) procedures performed, which includes removal of two cells by micromanipulation and DNA amplification and analysis on each of the two sampled cells ... After the cell sampling procedures pre-embryos will be maintained in culture until genetic results are known, normally in less than 8 hours. On the basis of the DNA tests, pre-embryos that are diagnosed as female will be determined and two selected for transfer to the uterus on the basis of the reliability of the diagnostic result and the best morphological appearance. Post transfer pregnancy testing and care will be the same as for IVF patients, with the addition of prenatal testing (i.e. standard karyotyping) by CVS for singletons or amniocentesis for twin gestations. This will confirm the preimplantation diagnosis of sex, which determines whether a fetus is free of the potential of developing the severe mental retardation syndromes.[22]

A further objective of the second research phase is to compare the pregnancy rate in fertile couples who participate in the research with the pregnancy rate in infertile couples in the current IVF Program at University Hospital and the pregnancy rate in couples participating in the pre-implantation genetic diagnosis program at Hammersmith Hospital, London, England (at the time of writing, the only centre with published data on pregnancy and birth rates following human embryo biopsy and DNA amplification).[23]

Drafting of the research protocol for this project involved debate of several issues concerning disclosure to potential research subjects; these deliberations shaped certain aspects of the final research proposal. This paper summarizes some of the written information provided to prospective research participants for the second part of the proposed research.[24] The following comments are mostly descriptive.[25]

1. A description of the research participants' medical status insofar as this is relevant to the eligibility criteria for the study

Prospective research participants should know why they qualify to participate in the proposed research. Specifically, they should be aware of

the inclusion criteria for the study and, when necessary, they should also be informed of the exclusion criteria.

As regards the inclusion criteria for the research proposed at University Hospital, it is appropriate first to note that the World Medical Association recommends

> that physicians refrain from intervening in the reproduction process for the purpose of making a choice as to the foetus' sex, unless it is to avoid the transmission of a *serious* sex-linked disease.[26] (emphasis added)

Consistent with this recommendation, the preimplantation genetic diagnosis research at University Hospital is designed to avoid the transmission of serious sex-linked disorders; furthermore, for purposes of the proposed research, "serious" has been interpreted narrowly to apply only to severe, X-linked mental retardation syndromes. The scope of the proposed research thus seems narrower than that now under way at the Hammersmith Hospital, at the Strom Reproductive Genetics Institute in Chicago, at the Royal North Shore Hospital in Sydney, Australia, and perhaps elsewhere.

The decision to limit the research in this way was motivated by a number of considerations, including a desire to avoid both the appearance and the risk of drifting toward the practice of sex selection for frivolous reasons. Already a number of authors have suggested that the sexing of embryos to avoid the transmission of sex-linked disorders will lead inevitably to the selection of embryos solely on the basis of sex.[27]

The preimplantation genetic diagnosis research at University Hospital is limited to X-linked disorders

> in which severe mental retardation is either the primary defect (e.g. non-specific X-linked mental retardation syndromes) or the result of an inborn error of metabolism (e.g. HGPRT enzyme-deficiency in Lesch Nyhan syndrome) ... Mental retardation syndromes ... specifically excluded in the pilot programme are those in which mental retardation is itself not necessarily severe and is accessory to another prevailing disorder (e.g. Duchenne muscular dystrophy), or [that] do not have the specific gene for the disorder identified on X-chromosome.[28]

Thus, although the proposed screening technique could be used to screen any X-linked recessive disease, not all couples at risk of having a child with an X-linked recessive disorder are eligible research candidates. To qualify for the research program, one (and only one) parent must carry the gene for a severe recessive X-linked mental retardation syndrome (e.g., Lesch-Nyhan disease, Hunter syndrome, or non-specific X-linked mental retardation syndromes).

There are also a number of exclusion criteria. They include psychological contraindications,

> the presence of other genetic disease, women over age 40, women with medical problems making the IVF procedure dangerous, diagnosis of an infertility problem making the couple unsuitable for IVF, and on

pre-EPICS screening the inability to detect Y-chromosome specific sequence in single nucleated blood cells (or equivalent amount of DNA from the male partner) or detection of this sequence in single cells or DNA from the female partner.[29]

2. *Information about the nature and objective(s) of the proposed research, along with similar information about the alternatives*

Nature of Preimplantation Genetic Diagnosis

Preimplantation genetic diagnosis is described to prospective research participants as an alternative to CVS and amniocentesis that

> ... involves the genetic screening of preembryos prior to their transfer to the uterus. Fertilization occurs using in vitro fertilization (IVF) technology, which means that preembryos are created outside of the body. When these preembryos have reached the eight cell stage (two to three days after fertilization), two of the blastomeres (cells) are removed from each embryo and used for sex-determination. This is done with a new technique called polymerase chain reaction (PCR). PCR rapidly multiplies the genetic material from the cell, so that the genetic screening tests can be carried out ... At present preembryos cannot be screened for specific disorders, but only by gender. With X-linked recessive diseases half of all male preembryos will develop the genetic disease. For this reason only female preembryos are transferred back to the woman.[30]

This descriptive account of preimplantation genetic diagnosis is summarized in the consent form as a five-step process:

1. venipuncture for parental DNA
2. genetic counselling
3. IVF (controlled ovarian hyperstimulation, vaginal ultrasound monitoring, oocyte retrieval, IVF, and embryo transfer [ET])
4. preimplantation cell screening
5. polymerase chain reaction amplification of cell DNA.[31]

Objectives of Preimplantation Genetic Diagnosis

Two separate research objectives are clearly identified for prospective research participants — one of direct interest to research candidates, the other primarily (if not exclusively) of interest to the scientific community. The first research objective is to determine whether preimplantation cell screening is an effective method of genetic diagnosis for couples carrying genes for severe X-linked recessive mental retardation syndromes. The second research objective is to determine the implantation rate of fertile couples choosing to have IVF-ET followed by cell screening, and to use these data for comparative purposes.

Alternatives to Preimplantation Genetic Diagnosis

A number of alternatives to preimplantation genetic diagnosis are listed in summary fashion in the written information provided to research candidates; with each alternative are listed the anticipated benefits and harms. The alternatives identified for prospective research participants who wish to avoid the birth of a handicapped child include

1. not to reproduce and to have no children;
2. not to reproduce and to adopt children when possible;
3. to reproduce and accept the one in four chance that their child may be seriously handicapped and the one in four chance that their child will be a carrier;
4. to reproduce and after standard prenatal diagnosis (CVS or amniocentesis), abort all potentially affected fetuses; and
5. to reproduce using gamete donation (donor sperm or donor eggs).[32]

3. Information about the nature and probability of the known and possible consequences (i.e., benefits, harms, and inconveniences) of the various options (i.e., the proposed research, alternative research, non-research interventions, and the option of no intervention)

The written documentation about the potential benefits and harms of participating in the proposed research begins with a statement that acknowledges the difficulties in trying to anticipate all potential benefits and harms. This being said, various potential benefits and harms are identified.

Potential Benefits

Preimplantation genetic diagnosis offers couples at risk of having a child with a severe X-linked mental retardation syndrome a chance for a healthy child of their own without having to initiate a pregnancy and then consider the option of terminating the pregnancy in the event that prenatal diagnosis reveals that the fetus is male. This is an important potential benefit for couples who wish to avoid the birth of a handicapped child and who choose either not to reproduce because of moral or other objections to termination of pregnancy or to reproduce and use available means of prenatal diagnosis followed by termination of pregnancy if the fetus is male.

In brief, with IVF-ET followed by cell screening, if the embryo transfer is successful and a pregnancy is established, the couple can look forward to the delivery of a healthy child; they avoid the stress of worrying about whether the child is affected, and they are "spared the trauma of undergoing, or at least having to consider, a therapeutic abortion."[33]

Potential Harms

The potential harms of the preimplantation genetic diagnosis include most of the potential harms of IVF-ET. A notable exception is the risk of multiple pregnancy. This potential harm is greatly reduced with cell screening because a maximum of two embryos are transferred per cycle. As noted elsewhere, the potential harms associated with IVF-ET are not insignificant.[34]

In addition, there are a number of additional potential harms specific to preimplantation cell screening. First, there is the possibility of misdiagnosis. There may be a false negative, the consequence of which would be to not transfer a female embryo; alternatively, there may be a false positive, the consequence of which would be to transfer a potentially affected male embryo.

Assuming that the incorrect diagnosis was discovered by CVS or amniocentesis, this would mean either termination of the pregnancy or acceptance of a 50 percent chance that a handicapped child will be born. If a twin pregnancy occurred and CVS or amniocentesis revealed that one embryo was male, the couple would have to decide whether to attempt fetal reduction (with the 20 to 30 percent chance that both fetuses will be lost), or whether to accept the 50 percent chance that one of the fetuses may be affected. As at June 1991, researchers at Hammersmith Hospital had completed 20 cycles[35] and had had five pregnancies, one of which was a false positive.[36]

Second, participation in the research program may result in a delay in achieving pregnancy if the cell screening or the IVF-ET procedure is unsuccessful. To be precise, there is the possibility that the embryos may not survive the cell sampling, as well as the possibility of a failed polymerase chain reaction assay. In addition, there are the limited take-home-baby rates with IVF-ET. These may be even more limited with preimplantation cell screening "since micromanipulation may reduce the chances of continued embryonic development and implantation."[37] Alternatively, take-home-baby rates may be equal to, or slightly better than, the rates with IVF-ET, because couples in the preimplantation genetic diagnosis research program, unlike couples undergoing IVF-ET, are fertile.

Third, there is the possibility that a healthy male embryo will be discarded or that a female carrier will be born. These potential harms are a direct consequence of the current limits of the technology. Only when the technology has developed further, so that it is possible to screen embryos for specific disorders instead of screening on the basis of sex, will it be possible for couples carrying genes for X-linked diseases to have healthy male children and non-carrier female children.

A fourth potential harm of preimplantation genetic diagnosis concerns the risk of pregnancy loss. The risk of pregnancy loss with amniocentesis and CVS is 0.5 percent and 2 percent respectively. The risk of pregnancy loss with preimplantation genetic diagnosis is unknown and is not

addressed in the written information provided to prospective research participants.

4. Information about the qualifications and experience of the members of the research team

The written information on preimplantation cell screening that is given to prospective research participants includes the names, degrees, titles, and affiliations of the various members of the research team. To be sure, this information is probably of limited value to prospective research participants. However, it is noteworthy that this information precedes a descriptive paragraph that very briefly describes the experience of the various investigators in their respective areas of study and explicitly acknowledges that this is the first time the researchers will be attempting human preimplantation cell screening. Also, prospective research participants are invited "to request the full curriculum vitae (biography) of any or all of the investigators."

5. Information about the costs involved

There are no costs to the research subject for the embryo cell sampling. Private funding is available for this research. The funds available, however, do not pay for the IVF-ET component of the protocol.

In Ontario, the government-funded health care program pays for IVF-ET. This means that for Ontario residents there are no costs for the required physician-related procedures (e.g., ovulation induction, oocyte retrieval, and embryo transfer), the gamete laboratory work, and the hospital stays for IVF-ET. Couples from outside the province do not qualify for this funding, however. They may or may not choose to request funding from their province's health care system.

For Ontario residents and out-of-province residents alike, there is no government funding for the medications. These costs are not borne by the hospital or the research program, and they may or may not be covered from private drug insurance. At University Hospital in London, Ontario, drug costs per cycle vary from approximately $900 to nearly $2 000.[38]

6. Additional information that may assist prospective research participants to make an informed choice

Research candidates are provided with the following additional information: (1) the rules for stopping the study and withdrawing the subjects; (2) the disclosure of information regarding new findings; and (3) the reasons why a physician may choose to discontinue the participant's involvement in the research. As well, prospective research subjects are given a one-page summary of the differences between the standard IVF program at University Hospital and the IVF-preimplantation diagnosis program. This information is intended to help couples fully appreciate some of the research aspects of the proposed research program.

First, whereas couples in the standard IVF program are infertile, couples in the research program are most likely fertile but are carriers for

a severe X-linked mental retardation syndrome. Second, with standard IVF-ET embryos are usually transferred to the uterus at the 2- to 4-cell stage (approximately 48 hours after fertilization); with preimplantation cell screening embryos are allowed to develop to the 8- to 12-cell stage for cell sampling. Third, with standard IVF-ET the embryos are not manipulated, but with cell screening the embryos are sampled and screened, and only female embryos are transferred to the uterus. Fourth, whereas with standard IVF-ET as many as five embryos are transferred per cycle, with cell screening a maximum of two embryos are transferred. Fifth, with standard IVF-ET excess embryos may be frozen; excess embryos from the research program will not be frozen. Finally, whereas with standard IVF-ET couples may or may not have genetic testing, with cell screening CVS and amniocentesis are foreseen as routine back-up for the preimplantation genetic diagnosis.

7. A statement that research participants may ask questions now and later

The written information provided to research candidates includes the following statement: "Please feel free to ask questions as they arise, before, during or after your participation. If you have any question [*sic*] call [name of principal investigator] at [telephone number]."

8. A statement that confidentiality will be respected

There is no statement about respecting confidentiality in either the written information provided to couples or the consent form that couples are asked to sign.

9. A statement that research participants may refuse to participate without jeopardizing access to health care

The written information provided to research candidates includes the following statement: "Your participation is entirely voluntary and you may refuse to participate without jeopardizing your access to health care."

10. A statement that consent and refusal are revocable. In principle, the research participants may withdraw their consent or overturn their previous refusal without jeopardizing access to health care

The written information provided to research candidates includes the following statement: "Consent to participate can be withdrawn at any time without jeopardizing access to health care."

Notes

1. L. Formigli et al., "Non-Surgical Flushing of the Uterus for Pre-Embryo Recovery: Possible Clinical Applications," *Human Reproduction* 5 (1990): 329-35; and B. Brambati and L. Tului, "Preimplantation Genetic Diagnosis: A New Simple Uterine Washing System," *Human Reproduction* 5 (1990): 448-50.

2. C. Coutelle et al., "Genetic Analysis of DNA from Single Human Oocytes — A Model for Preimplantation Diagnosis of Cystic Fibrosis," *British Medical Journal* (1 July 1989): 22-24.

3. M. Monk and C. Holding, "Amplification of a β-Haemoglobin Sequence in Individual Human Oocytes and Polar Bodies," *Lancet* (28 April 1990): 985-88.

4. A.H. Handyside et al., "Pregnancies from Biopsied Human Preimplantation Embryos Sexed by Y-Specific DNA Amplification," *Nature* 344 (1990): 768-70.

5. R.G. Edwards, "Maturation In Vitro of Human Ovarian Oöcytes," *Lancet* (6 November 1965): 926-29.

6. R.L. Gardner and R.G. Edwards, "Control of the Sex Ratio at Full Term in the Rabbit by Transferring Sexed Blastocysts," *Nature* 218 (1968): 346-48.

7. M. Nijs, M. Camus, and A.C. Van Steirteghem, "Evaluation of Different Biopsy Methods of Blastomeres from 2-Cell Mouse Embryos," *Human Reproduction* 3 (1988): 999-1003.

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13. A.H. Handyside et al., "Biopsy of Human Preimplantation Embryos and Sexing by DNA Amplification," *Lancet* (18 February 1989): 347-49.

14. D.K. Griffin et al., "Fluorescent In-Situ Hybridization to Interphase Nuclei of Human Preimplantation Embryos with X and Y Chromosome Specific Probes," *Human Reproduction* 6 (1991): 101-105.

15. A. Dokras et al., "Trophectoderm Biopsy in Human Blastocysts," *Human Reproduction* 5 (1990): 821-25.

16. R.K. Saiki et al., "Enzymatic Amplification of β-Globin Genomic Sequences and Restriction Site Analysis for Diagnosis of Sickle Cell Anemia," *Science* 230 (1985): 1350-54.

17. Griffin et al., "Fluorescent In-Situ Hybridization."

18. Handyside et al., "Pregnancies from Biopsied Human Preimplantation Embryos," 768.

19. I. Soussis et al., "Ultrasonic and Biochemical Parameters of Early Pregnancies Following Transfer of Biopsied Human Embryos for X-Linked Genetic Disorders," Abstracts of the 7th Annual Meeting of the European Society of Human

Reproduction and Embryology, Paris, 28 June - 30 June 1991 and the 7th World Congress on In Vitro Fertilization and Assisted Procreation, Paris, 30 June - 3 July 1991, published in *Human Reproduction* 6 (Suppl. 1) (1991), 138.

20. In the submission to the University of Western Ontario Review Board for Health Sciences Research Involving Human Subjects the term pre-embryo is used. As I have argued elsewhere, the use of this term is problematic. It suggests an attempt to finesse some of the more difficult moral questions concerning the use of human embryos for research purposes, particularly as the proposed biological demarcation line between pre-embryo and embryo has been simultaneously proposed as a moral demarcation line. Therefore, throughout this paper the term embryo is used and, as appropriate, the developmental stage is specified. For an alternative viewpoint, see Medical Research Council, "Human Fertilisation and Embryology Bill: A Response to the Second Reading Debate in the House of Lords" (United Kingdom, House of Lords, *Debates*, Vol. 513, no. 11 (7 December 1989), Columns 1002-1014), reprinted in pamphlet form by the Medical Research Council (London (U.K.): 1990), 11-12; and H. Jones Jr. and C. Schrader, "And Just What Is a Pre-Embryo?" *Fertility and Sterility* 52 (1989): 189-91.

21. Handyside et al., "Biopsy of Human Preimplantation Embryos"; and Handyside et al., "Pregnancies from Biopsied Human Preimplantation Embryos."

22. J. Nisker et al., *EPICS Programme*, Submission to the University of Western Ontario Review Board for Health Sciences Research Involving Human Subjects (London, June 1991), 28-29.

23. Handyside et al., "Pregnancies from Biopsied Human Preimplantation Embryos"; A.H. Handyside, "Biopsy of Human Cleavage Stage Embryos," First International Symposium on Preimplantation Genetics, Chicago, 1990, Abstract No. 51, published in *Journal of In Vitro Fertilization and Embryo Transfer* 7 (1990): 209; and Soussis et al., "Ultrasonic and Biochemical Parameters of Early Pregnancies Following Transfer of Biopsied Human Embryos." In addition to the research at Hammersmith, there has been a report from the Strom Reproductive Genetics Institute in Chicago of successful preimplantation genetic diagnosis. However, the pregnancy miscarried at about 7 weeks' gestational age. See S. Milayeva et al., "Successful Preimplantation Diagnosis for Gender Determination," First International Symposium on Preimplantation Genetics, Chicago, 1990, Abstract No. 27, published in *Journal of In Vitro Fertilization and Embryo Transfer* 7 (1990): 197.

24. Ethical issues relevant to disclosure for the first part of the research are not discussed in this paper.

25. The Royal Commission on New Reproductive Technologies was not willing to sponsor site visits to the few other centres worldwide that are currently doing human preimplantation genetic diagnosis. Information from these centres would have allowed me to provide a critical informed perspective on the issues by drawing upon the experience of more practised research teams. Consequently, this is primarily a descriptive paper.

26. World Medical Association, *World Medical Association Statement on In-Vitro Fertilization and Embryo Transplantation*, adopted by the 39th World Medical Assembly, Madrid, Spain, October 1987.

27. C. Ewing, "Australian Perspectives on Embryo Experimentation: An Update," *Issues in Reproductive and Genetic Engineering* 3 (1990): 119-23.

28. Nisker et al., *EPICS Programme*, 69-70.

29. Ibid., 74-75.

30. "Consent to Early Preimplantation Cell Screening (EPICS)," in *Information on EPICS Programme (Early Preimplantation Cell Screening)* (London: University Hospital, 1991), 1.

31. Ibid., 8.

32. Ibid., 4.

33. M. Michael and S. Buckle, "Screening for Genetic Disorders: Therapeutic Abortion and IVF," *Journal of Medical Ethics* 16 (1990), 43.

34. See F. Baylis, "*In Vitro* Fertilization and Embryo Transfer: Informed Choice," in this series of papers.

35. Personal communication from A.H. Handyside to R. Gore-Langton.

36. Soussis et al., "Ultrasonic and Biochemical Parameters of Early Pregnancies Following Transfer of Biopsied Human Embryos."

37. Y. Verlinsky, E. Pergament, and C. Strom, "The Preimplantation Genetic Diagnosis of Genetic Diseases," *Journal of In Vitro Fertilization and Embryo Transfer* 7 (1990), 4.

38. University Hospital IVF Program, *In Vitro Fertilization* (London: University Hospital, 1990).

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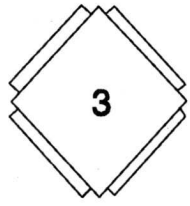

Medicalization and the New Reproductive Technologies

Michael Burgess, Arthur Frank,
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Executive Summary

Medicalization is a term used to describe a social process in which behaviour or a physical condition previously thought outside the arena of health care intervention becomes, in time, regulated by the health care institutions and professionals, or by an authoritative definition of health and technological solutions. Use of the term often implies the negative phenomenon of interpreting complex political, personal, and social issues as medical problems.

Despite the negative implication, there are also benefits of medicalization that include issues related to recognition of, rehabilitation from, and prevention of disease. However, among its negative effects are its potential to reduce individual responsibility and depoliticize behaviour. Stemming from these are other issues, including the trend toward commodification of social life and increased surveillance of the individual.

Feminist critiques of the medicalization of new reproductive technologies (NRTs) take into account the history of society's handling of reproduction and the current trend toward medicalization of women's reproductive lives. This trend includes routine prenatal screening and

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contraception as medicalizations of reproduction, which provide a precedent for evaluating the evolution of NRTs.

While evaluating the evolution of the technologies themselves, it is important to take into account their technical and social costs. Costs of NRTs also affect the medicalization of reproductive issues. Funding NRTs through the health care system could bring social benefits for those who use them, but might also eclipse the alternatives, by loading NRTs with an advantage that makes them more desirable.

Consequently, there are goals to which society should aspire in order to promote access to NRTs without reducing individual choices. These include evaluation of each NRT with respect to social benefits, regulation, funding, and informed consent, as well as support and access for alternative responses.

Introduction

This submission was written as a background paper for the Commissioners. It represents the collaboration of a sociologist who specializes in experiences of illness, a feminist philosopher who has considerable research experience with new reproductive technologies (NRTs), and a philosopher who specializes in bioethics. Although each section was written individually, considerable discussion and redrafting moved us closer together on central themes in medicalization as it applies to NRTs. More specifically, medicalization in general, and medicalization of NRTs in particular, has positive and negative effects. The positive effects include social legitimization of problems, certain social benefits, and better access to services deemed medical. They can be summarized as improved access. The negative effects include individuals' loss of control over the medicalized aspects of life, a relative devaluing of non-medical alternatives, society-wide concerns about use of public funds, and possibly an obligation to use some of the medicalized services. The negative effects of medicalization can be summarized as loss of choice. The practical and ethical concerns of medicalization then focus on how to balance increased access with loss of choice. This paper explores how the negative and positive effects of medicalization occur, particularly regarding the NRTs and public funding.

The first part of the paper establishes a particular notion of medicalization. The second section uses the considerable feminist literature to evaluate the positive and negative effects of medicalization on NRTs. The last section considers the moral basis for a duty to fund any of the NRTs and how the mechanisms of public funding enhance some of the effects of medicalization. We conclude with five objectives that might guide further analysis of the issues of funding and regulation of NRTs.

The Concept of Medicalization

The term "medicalization" was introduced into the sociological literature in the early 1970s (Freidson 1970; Zola 1972; Fox 1977) to describe a social process, occurring over time, in which behaviour that was previously not considered relevant to medical concerns is redefined to fall within those concerns. Numerous case studies of medicalization have appeared, with topics such as old age, premenstrual syndrome, menopause, transsexualism, anorexia nervosa, hyperkinesis, hyperactivity, work site health, alcoholism and addictions, cosmetic surgery, battered wife syndrome, Alzheimer's disease, child abuse, obesity, religious "brainwashing and deprogramming," compulsive gambling, attention deficit disorder and learning disabilities, male sexuality, childbirth, and disability (Conrad 1992).[1] Advances in theoretical understanding have been enhanced, especially by the work of the French philosopher Michel Foucault (Foucault 1973, 1978, 1979; Arney and Bergen 1984; Turner 1987; Eribon 1991; Sawicki 1991).

Although a general description of medicalization cannot account for all of the details of the examples, it is best to start with a general idea. Studies of medicalization have tended to be historical. They typically describe a trajectory, beginning at a time when some physical condition or behaviour has no special status or label attached to it; at most, the condition or behaviour may be recognized as an individual misfortune or a community nuisance. The next stage is its delimitation under some label, the basis of the label being collective morality. This morality may be formalized under either a religious belief (e.g., "sin") or a legal statute. The crucial moment occurs when medicine has developed to a stage at which the moral delimitation becomes medical. With medical intervention, the condition or behaviour acquires a diagnosis, an etiology, and recommended treatment procedures, with these evolving over time, in response to changing social conditions. Progressively, the "unfortunate" become the "diseased" and the "offenders" become the "afflicted." "Punishment" gives way to "treatment." The authority to label and respond to social deviance passes from religious and legal authorities to medical professionals.

These studies have not claimed that the troubles identified as "diseases" only came to exist after medical interest was expressed in them, nor have they disputed that medical intervention may have improved the lives that are affected. The troubles usually have been painfully real, and medical intervention has helped, in some sense.

The point of medicalization studies is that medical intervention is always a social process. What is involved in the applied practice of medicine are social relations, and any social relations reflect and perpetuate distributions of power in society. The study of medicalization is the study of how various social groups, including physicians but hardly

limited to them, operate through medicine to affect the distribution of power in society.

Sawicki both described medicalization and suggested the current emphasis of most studies when she wrote, "The term 'medicalization' usually implies the negative phenomenon of reducing political, personal and social issues to medical problems thereby giving scientific experts the power to 'solve' them within the constraints of medical practice" (Sawicki 1991, 119). In her specific argument on NRTs, Sawicki considered "pregnancy, childbirth, and fertility" as legitimate "healthcare issues."

Sawicki made an important distinction between technology and the power relations that shape the context of its application. Few critics of medicalization want medicine to remove itself from the scene entirely; instead, most want a different distribution of decision making and authority. She did not question whether medicine ought to be involved in NRTs; instead, she questioned how medical power is exercised: "I do not think that medical professionals should monopolize authority over all issues raised in this [medical] context" (Sawicki 1991, 119). Her next point is that "medical power" must be understood as other forms of power operating through medicine (e.g., political and state power, economic power, specific group interests, and the power of technological elites).

NRTs must be situated within a much broader societal movement toward medicalization. The increase of medicalization is beyond dispute; medical judgment is now considered relevant in many venues where it would not have been involved previously. A principal concern is whether social issues are being redefined to make them amenable to technical medical solution, and whether "treatment success" then obscures the remaining social problems.

Some further qualification of the term "medicalization" is made necessary by the sheer volume of the literature on medicalization and the inconsistency in uses of the term.

First, medicalization is always a contested process. This contest was exemplified in the 1960s and 1970s by the anti-psychiatry movement, which changed not only psychiatric practice but also the public perception of mental illness. On the other side are those who argued for the organic basis of mental illnesses and the appropriateness of their medicalization (Vonnegut 1975). The FINRRAGE (Feminist International Network on Resistance to Reproductive and Genetic Engineering) response to NRTs is one side of a current contest over medicalization of reproductive matters. On the other side is the testimony before the Royal Commission on New Reproductive Technologies demanding recognition of "infertility" as a disease and entitlement to treatment of that disease.

In rare instances the extension of medical control has been almost universally accepted as a public good; monitoring for contamination of water supplies is possibly as uncontested a case of medicalization as could be found. Somewhere in the middle of the spectrum are registries of sexually transmitted diseases (STDs), which elicit protest when they are

perceived to be performing a policing function in addition to their public health role. Genetic testing as part of employment or insurance screening is an example of medicalization that will probably be increasingly contested as it is increasingly implemented.

Second, although physicians are usually the ones who implement medicalization procedures, the push for medicalization does not necessarily represent physicians' initiatives. It is fair to observe that medical professional associations have rarely resisted medicalization, and individual physicians have certainly profited, even though they may have objected to what some third party was demanding of them. The "gatekeeping" work physicians do, giving medical approval for activities ranging from immigration to summer camps, exemplifies these demands. In gatekeeping, physicians perform, however grudgingly, a verification function for the third party (e.g., certifying a job-related injury). The involvement of physicians in surrogacy contracts (performing insemination or monitoring the pregnancy) can be a medical involvement that is third-party elicited.

Third, medicalization is not a one-way process. There are also examples of de-medicalization, albeit few. Wikler and Wikler have suggested that the non-physician use of artificial insemination exemplifies de-medicalization (Wikler and Wikler 1991). The Independent Living Movement among people with disabilities is another example. The most politically charged recent case of de-medicalization was the removal of homosexuality as a psychiatric diagnosis from the third edition of the American Psychiatric Association's *Diagnostic and Statistical Manual.*

Who Pushes for Medicalization and How?

Initiatives for medicalization begin in multiple sites, and then overlap. Initiating actors include the following:

- physicians and medical professional organizations, claiming new relevances for medical expertise and thus the need for expanded service delivery;
- medical technology institutions, whether private or governmental, including pharmaceuticals, monitoring and scanning technologies, and research institutes (this technological push can either be for profit or it can represent the natural expansion tendencies of organizations);
- patients who perceive some personal gain (in treatment or in redistribution of responsibility for the "disease"), and their families, who may gain some relief in caregiving (or their own relief from responsibility);
- politicians and bureaucrats, who can use medical definitions of social issues (e.g., drugs, acquired immunodeficiency syndrome [AIDS]) as a way of containing those issues and defining the

public agenda in response to those issues, and who use health care as a political entitlement inducement to voters; and

- third parties for whom medicine acts as an agent. The use of physicians for drug testing or adjudicating qualification for benefits (e.g., workers' compensation) represents third-party initiations of medicalization. When employees use company medical benefits to obtain medical interventions they would not have obtained otherwise, that is also medicalization. How both employer-attempted exclusions and employee-attempted inclusions are evaluated will, again, be contested. In all cases, the scope of medical involvement in people's lives is expanding.

How these groups push for medicalization is part of several broader social trends. For instance, in the last two centuries, there has been a shift from interpreting deviant behaviour in *moral* terms to understanding it as *disease*. The redefinition of alcoholism as a disease instead of a simple moral failing is the paramount example. Many psychiatric diagnoses of what were previously criminal activities represent a shift from "badness to madness" (Conrad and Schneider 1980). This redefinition may represent more humane treatment of those who cannot exercise personal responsibility. Also, it may lessen public standards for responsible action; this is another contested domain. At present, the point is to understand medicalization as part of a more extensive post-Enlightenment shift toward social evaluations based on "scientific" standards.

A second social trend is an increase in scientific knowledge. Public health medicalization results from having more knowledge about disease origins. The discovery of germ and viral theories of disease has produced innumerable individual cures, but defining health in terms suggested by these "discoveries" has also deflected attention away from the social context of health, such as the environment (as more than just a source of infection), the workplace, and forms of induced stress. We may just now be regaining the balance that was lost when scientific discoveries suggested one sort of solution to health problems and thereby excluded other possible inquiries and interventions.

Physicians have been used increasingly as agents of social control, serving third-party interests. This use of the medical profession for state surveillance goes back at least to the eighteenth century (Foucault 1978; Donzelot 1979). More recently, physicians have been commonly used by employers to control employees. The legitimization of "medical excuses" is a simple example. Determining whether applicants for refugee status have been tortured is more complex, both medically and politically. Physicians certify people for everything from disability pensions to release from leases and other contracts, and in this social certification function we see clearly how medicine is used as a tactic in various power relations.

The use of medical language or a medical-sounding language to make social claims and to describe social behaviours has been expanded;

however, this use does not necessarily include actual medical involvement. The recent popularization of co-dependency jargon shows how a quasi-psychiatric language can be used to describe behaviours that previously would not have been labelled or would have been understood in other terms (Goldman and Montagne 1986; Coward 1989). The white laboratory coat has for years been a powerful symbol of legitimization in advertising. The use of medical logos in advertising medicalizes not only the specific product, but also the entire sphere of consumption that product represents (e.g., recently one of the cancer societies allowed its logo, easily confused with a medical caduceus, to be used on a commercial breakfast cereal, thus demarcating breakfast as a "medical" activity).

Medical promises, whether by physicians, their professional organizations, pharmaceutical companies and other corporations marketing through medicine, or governments, have been inflated. Physicians and politicians are fully justified in complaining that public expectations for medical intervention are unrealistic; the issue is where these expectations originated. Few public health advertisements list circumstances when a person should not "see a doctor." Even at a time of real government and corporate concern over the costs of health care, no significant public education on "symptoms that medicine can't do much about" seems forthcoming; instead, advertising from all sources continues to imply an ever-expanding scope of problems for which doctors should be consulted.

This list of different social trends in which medicalization is involved is hardly complete, but it does suggest how deeply medicalization is woven into the contemporary social fabric.

These trends are not intrinsically good or bad. Each has its good and bad sides, and which one is more important will always be contested. As the "technologies" relevant to reproduction change and expand, contests over their use will occur in the context of those that have taken place over many other medicalizations, from fluoridation to drug testing. That each contest is part of a larger trend is not meant to trivialize the specific issues involved. Rather, the proliferation of such contests suggests that what society needs are procedures for orderly processes of public debate and adjudication of various claims for and against specific medicalizations (Dougherty 1991; Hadorn 1991).

Benefits and Problems of Medicalization

The benefits of medicalization seem straightforward:

1. comparative freedom from disease (e.g., control of infectious diseases through public health regulation);
2. appropriate recognition of disease as the underlying cause of some behaviour or disorder, leading to preventive measures;

3. an end to false invocations of religious or legal sanctions, with a shift to medical rehabilitation; and
4. greater enhancement of personal potential, notably staying alive through disease conditions that would have been fatal, or decreasing disease incidence through preventive measures.

However, few social benefits are entirely straightforward. Behavioural disorders can be wrongly attributed to diseases, "health promotion" can institute new myths of personal responsibility for prevention, and the search for enhanced potential can bring iatrogenic problems (e.g., the current controversy over whether some breast implants are carcinogenic).

Few critics have suggested that society either could or would want to turn the clock back on medicalization, but it would be equally naive not to recognize that medicalization has brought certain problems. They include the following:

1. Medicalization obscures the ambiguous connections of medicine to other bases of social power. We tend to experience medical intervention as effecting a change in an *individual* body. The knowledge on which this effect is based is "scientific," implying professional neutrality with respect to power. This individualized, neutral practice is still imagined to be carried out by a physician who is *independent* of other societal and institutional pressures. However, Cassell's (1991) conceptualization of medical practice as less a science than a social relation is taken further by Waitzkin (1991), who argues that as a social relation, medicine reflects and perpetuates the ideologies that support current distributions of power in society. Physicians themselves speak out increasingly strongly against the use of their work to serve other corporate interests than "healing" as classically idealized (see Kleinman 1987, 209-26). Physicians' disillusionment with their vocation was expressed by a prominent local surgeon, recently retired, when he spoke in a seminar conducted by one of the authors. Asked how medical practice had changed during his lifetime he flatly asserted, "the humanity has gone out of medicine," and went on to describe the ascendancy of administrative, third-party control.
2. Medicalization involves some reduction of individual responsibility. The responsibility to get well is little more than a responsibility of lay people to submit to medical attention and follow doctors' orders, and more generally to be subject to public health directives. To be a medical patient is to have one's responsibilities reduced not only in being released from having to perform certain tasks (e.g., work), but also in not being allowed to take some actions or make some decisions (Parsons 1951, 1978; Turner 1987; Frank 1991a). Thus, medicalization is part

(and only part) of a disturbing social trend toward increasing abdication of decision making to those presumed to be "experts" (Habermas 1987). One who is medicalized first loses responsibility for acting in response to her or his own body and eventually loses security in the feelings on which that action would be based. Writing on fetal monitoring techniques, several authors have claimed that the technologies devalue women's lived experiences of pregnancy and favour objective data (Stanworth 1987; Lasch 1977; Rothman 1987, 1989).

3. Medicalization both de-politicizes behaviour and individualizes it. Because the individual patient is the medical unit of analysis, problems are reduced to their locus in the individual (Waitzkin 1991). People are encouraged to think in terms of individual cures rather than concerning themselves with social reform through political channels; thus, the fullest concept of citizenship suffers. When problems are medicalized, the social actor becomes a patient, and when care is provided by the government, the citizen ceases to think of his or her responsibility for the polity and thinks instead of benefits to be obtained from the policy. This concern for entitlement is personal in its perspective, to the exclusion of a more civic orientation. When medical care is expanded in its scope and turned into an entitlement, the citizen of the state becomes the state's client (Habermas 1987). To recognize these dangers in a state-managed medical system is not to argue for privatized medicine, which seems worse in its individualizing and de-politicizing effects, but only to recognize the problems inherent in further medicalization.

4. People are encouraged to think in terms of technological solutions rather than social resolutions. The technical resolution is exemplified by a vaccine; in some cases, like polio, this solution can be effective. But the more complex the contest of social interests involved in the definition of a problem, the less likely it is that any technology will solve it (Sawicki 1991, 84). In the popular image of a "solution," the problem simply disappears, as polio virtually disappeared. A "resolution" is a far more modest end, and thus less popular to propose. A problem can be resolved without going away; instead, people find acceptable ways of living through and with the problem.

   In the case of NRTs, infertility is defined as a "problem" within a complex of expectations. Such expectations include the role of women in society, sources of self-esteem and creative satisfaction available to men and to women, the definition of what constitutes a "family," material and other resources available for people to be adequate parents, the division of labour in conception and parenthood, and even care for the aged (i.e.,

whether the elderly need adult children to care for them and whether care of elderly parents interferes with the care of children). No technological intervention will ever resolve the multiple contradictions embedded in these issues, but we still talk as if "the solution" depended on the perfection of some technology and the possibility of access to it. Whatever real advances medical technology makes, we should not look to it for solutions to social problems.

The possibility of reducing the social to the technical, thus obscuring deeper dimensions of a problem and the interests involved in how that problem is addressed, is the seduction of medicalization. The response to this seduction is not to do away with medicalization (or the larger category of the technological), even if this were possible. Rather, it is the power relations within which medicine is practised that need reform. Sawicki summarized: "The question is not whether these women [who want to use NRTs] are victims of false consciousness insofar as they desire to be biological mothers, as much as it is one of devising feminist strategies in struggles over who defines women's needs and how they are satisfied" (Sawicki 1991, 84).

The technological seduction is a problem insofar as it distracts attention from the a priori questions of women's (and men's) needs and what power relations determine the satisfaction of these needs, and instead holds out the illusion of a quick fix that would make the contextual problems disappear.

5. Many would argue that the exclusion of personal responsibility has gone too far, with medicalization being part of that exclusion. The acceptance of the insanity defence in law is an older example of this exclusion, and the introduction of post-traumatic stress disorder to describe behaviours observed in Vietnam war veterans is a more recent example. In both cases, individual responsibility for behaviour is displaced by a diagnosis. The person diagnosed no longer acts on his or her own responsibility, but is seen as acting out typical behaviour expected among a collective of those similarly "affected." Instead of the individual being punished, the collective type is treated. The humanity of this shift is self-evident, particularly in the contemporary case of post-traumatic stress disorder. However, like all instances of medicalization, the trend has multiple implications.

Technological solutions also minimize aspects of life that cause personal suffering, damaged expectations, and failed hopes. One gain of the Enlightenment was to institutionalize a degree of unwillingness to accept bad outcomes that are often inevitable; instead, we seek remedies. But for all that society does fix, other matters continue to go badly. Medical discourse

speaks heroically of "conquering" disease; however, sometimes such talk causes increased suffering among those whose condition cannot be conquered. Perhaps this unwillingness to accept suffering as natural also complicates our capacity to care for those who will continue to suffer. Medicalization too often supports an unrealistic assessment of what it is to be a human body, with all the limitation and vulnerability inherent in the flesh (Frank 1991b).

6. Medicalization is part of a general and problematic trend toward the commodification of social life in general and of the body in particular (Featherstone et al. 1991). Cosmetic surgery provides the most blatant example of medicalization furthering the body as commodity. The commodification of the baby becomes an obvious objection to surrogacy practices, fetal testing, and ultimately to fertility interventions in general (May 1991).

7. Medicalization is part of a general trend toward the surveillance of the individual. In the case of fetal monitoring this surveillance is literal (Rothman 1987, 1989). However, for most people, surveillance works not by direct observation but by setting regulatory norms (Gross 1980; Burchell et al. 1991). The medical construction of people with marginally high cholesterol levels as a "diseased" population has been questioned recently in debates over what routine medical tests could be eliminated. The definition of premenstrual syndrome as a disease is a case of medicalization in which personal anticipation of embodied experience is systematically altered, creating an expectation for medical intervention (Sherwin 1992).

   In such medicalizations, medical practice is the most common vehicle used by other interests to regulate populations toward some norm. Medically asserted norms are assumed to be in the interest of health alone and therefore morally neutral. But health itself is a social standard with implicit value commitments. This standard is debated in a social context that includes the importance of "health" to employers, governments, and health care providers.

8. As the above problems culminate, health ceases to be understood as a social value, subject to contest about what it includes as expectations and who has responsibility for these expectations. Instead, health becomes an unquestioned good, derived from the "neutral" ground of the body itself, and thus stands outside any process of political contest. Health is a claim that can stop any argument or silence any opposition.

The issue is not whether medicalization has brought more problems than benefits. What is involved is not a contest over comparative effect. As

stated earlier, medicalization is intrinsically part of contemporary culture. This cultural fabric is so dense that it is meaningless to seek to determine whether medicalization is the cause of any of the problems above, or a symptom of the problems.

Medicalization always involves social power, not just "scientific" benefits. Sawicki stated this core concern when she wrote that NRTs are "designed and implemented by experts in contexts where scientific and medical authority is wielded with insufficient attention to the prerequisites for democratic or shared decision-making" (Sawicki 1991, 91). There can be no Luddite agenda of doing away with science and medicine; even attempting to slow the pace of medical technology as a push for medicalization seems tenuous. What we should be attempting is to reform science and medicine to make them attentive to these "prerequisites for democratic and shared decision-making." Petchesky summarized, "We need to separate the power relations within which reproductive technologies ... are applied from the technologies themselves" (Petchesky 1987, 79). This separation is ultimately impossible (the technology exists only in its application), but such an idea at least clarifies the scope of potential intervention into NRT development and implementation.

Feminist Perspectives on the Medicalization of NRTs

Some of the strongest and most sustained criticism of the medicalization of NRTs comes from feminist analysts who have usually responded to these new technologies with alarm and distrust.[2] To understand and evaluate feminist critiques and come to grips with the sorts of alternatives they propose, it is important to understand the basis of their concerns. What is distinctively feminist about their evaluations of social practices is that they usually begin by exploring what effect a practice is likely to have on women's status in society, both collectively and with respect to specific groups (e.g., poor women). Feminism directs us to ask whether the particular practice investigated is likely to increase or decrease existing forms of oppression that women face.

Feminist suspicions of NRTs can be understood best by adopting a historical perspective when evaluating medicalized reproductive practices. Feminists perceive the context in which NRTs are now emerging as a long and ongoing pattern of increasing medical involvement in women's reproductive lives, which has resulted in increased medical control over them.

The History of Medicalization of Reproduction

The most obvious case of medical dominance in reproductive matters is represented by the virtual monopoly physicians have achieved over the events of childbirth (Arney 1982; Leavitt 1986; Bogdan 1990; Borst 1990; Mitchinson 1991). Not only have doctors claimed responsibility for childbirth and claimed the active role in the event — they are the ones who

"deliver" babies (Treichler 1990) — they have also determined the location in which childbirth must occur (hospitals); the position into which women must be manipulated (prone, to facilitate medical surveillance); the attendants at the birth (for decades it was only medical staff, now it is often the husband but still not a woman's larger support network); sometimes the timing of the birth (through induction of labour and the use of forceps); the use of anaesthetics according to the preferred practice of the day; the decision for or against Caesarian delivery; the use of electronic fetal monitors; and so forth (Bogdan 1990).

To a significant degree, women have welcomed medicine's promises for safe and pain-controlled childbirth and have encouraged medical involvement in an event that has often brought severe pain and serious risk of death or disability to mother and infant (Leavitt 1986; Bogdan 1990; Mitchinson 1991; Sawicki 1991). However, in the process of transformation of childbirth into a medical event, women's role has been made minimal: women often seem to be restricted to following orders as to when to breathe and when to push. Indeed, women have had to fight to establish "birthing" as a verb to describe their own active role in the process.

Ironically, women's initial shift to involving doctors in childbirth can be seen as their decision to consider childbirth as an event that could be controlled and modified (i.e., it was a deliberate attempt by women to claim and exercise power over a central event in their lives). However, medical participation in childbirth, as in most other forms of medical practice (Fisher 1986; Todd 1989), is usually experienced by both patient and physician as medical control (Treichler 1990; Sawicki 1991). When doctors moved women out of their homes and into hospitals, control became centralized in medical hands and women discovered that they no longer had much influence over the decisions that followed (Leavitt 1986; Garner and Tessler 1989; Kunisch 1989; Bogdan 1990).

In addition, despite the good intentions of doctors toward improving women's experiences of childbirth, it is also apparent that many obstetrical innovations over the years have eventually turned out to be harmful — sometimes dangerously so. The most notorious example may be Semmelweis's discovery of the role of doctors in spreading puerperal sepsis to women in labour and the long delay that followed before other doctors accepted the importance of practising hygiene when attending birthing mothers (Corea 1985a). Prominent among current concerns are the suspiciously high rates of Caesarian births found in certain regions and institutions (Marieskind 1980; Bogdan 1990); the recognition that squatting may be a better birth position for women, although it is less accessible to technological surveillance (Kunisch 1989); and the evidence that a more home-like birthing environment may reduce both stress and labour and lead to better post-partum conditions (Garner and Tessler 1989). Clearly, there is strong historical reason to distrust medical claims as to the benefit women derive from the preferred medical practice of the day (Arms 1977; Corea 1985a; Bogdan 1990). Yet it is difficult for most women to

contemplate, let alone execute, non-medical approaches to childbirth. To feminists, this history reveals the necessity of ensuring that medicalization of further aspects of reproduction does not lead to ever less personal control and autonomy for the women involved.

The Current Context

A need exists to find ways of returning control to women in the multiple decisions associated with reproductive matters (Ladd 1989). Feminists have offered various strategies for doing so. For example, they generally seek to establish respect for other sorts of knowledge in addition to technical medical knowledge, such as the experiential knowledge obtained through attentive midwifery practice (Bogdan 1990). Doctors might be seen as offering one form of expertise among many, constituting a valuable resource for women and providing particular knowledge and skills that are requested or required, rather than being considered the sole or even the primary source of authority about childbirth (Stanworth 1987; Bogdan 1990). It need not be a question of medicalization or not. Although the first option involves surrender of autonomy to physicians to make all further decisions (as things now stand) and the second precludes access to any medical advice or services, what feminists seek in this regard is to promote ways in which individuals can make use of medicine while maintaining personal control. However, restrictions on the medical role and respect for other forms of expertise in representing events have proven to be extraordinarily difficult transformations to achieve (Van Wagner and Lee 1989). Despite two decades of women's activism to return control to women in labour, most women still have little say about their medical care in childbirth (Corea 1985a; Ladd 1989).

Feminists see similar patterns of medicalization in the other aspects or phases of women's reproductive lives. For example, in the earlier stages of pregnancy, medical knowledge has helped to increase understanding of the health needs of the fetus, and medical monitoring of pregnancy sometimes detects and corrects dangerous problems and provides helpful guidance about reducing risk (e.g., through advice on diet and exercise). Such knowledge is usually welcomed by pregnant women, who are understandably concerned about ensuring the safe birth of healthy offspring. But, increasingly, medical advice is being translated into medical imperatives. Pregnant women and even potentially pregnant women often find themselves enjoined from smoking and drinking, not only by their doctors, but also by their family, friends, and perfect strangers.[3] Some jurisdictions have even instituted laws that make it a criminal offence for pregnant women to smoke or consume alcohol (Warren 1989).

In addition, prenatal screening techniques, which were initially introduced to provide medical information in cases where there is a substantial risk of preventable harm, often seem to become routine in all prenatal care — for example, blood tests, electronic fetal monitors (Kunisch

1989), ultrasound (Petchesky 1987), and, for many years, x-rays of fetuses (Oakley 1987). However, all of these tests are of mixed value to women: they often provide reassurance to expectant parents and sometimes help to correct or avoid preventable birth anomalies or make it possible to anticipate and prepare for dangerous circumstances, but some have eventually been proven unsafe (e.g., x-rays), and the safety of others is still being investigated (e.g., fetal monitors and ultrasound) (Kunisch 1989).

The virtually routine use of some technologies reduces women's sense of control by denying them any real opportunity to choose or refuse their use (Garner and Tessler 1989; Lippman 1991a). In addition, by stressing pregnancy's inherent dangers and ambiguities, such medical monitoring has trained women to qualify their sense of joyful expectation; many now relate to their developing fetus with a sense of anxiety and ambivalence (Rothman 1987; Green 1990). This is a significant cost that is seldom factored into evaluations of the technology.

Many observers anticipate that future advances in medical knowledge may one day make prenatal genetic testing affordable for all pregnancies. Feminists worry that broad prenatal screening will then become routine and essentially mandatory (Lippman 1989, 1991a). They perceive that "technical feasibility and the acceptability of the unit cost — rather than the acceptability to pregnant women — seem to be the two chief considerations in discussion of these proposals [for mass genetic screening]" (Rose 1987, 163).[4] Already, we can find in the bioethics literature arguments claiming that refusing technology that can prevent the birth of infants with severe anomalies should be treated as morally and socially reprehensible (Purdy 1978; Keyserlingk 1984). Some physicians prominent in the field of NRTs have fanned these anxieties by musing aloud about the advantages of *in vitro* fertilization (IVF) for all planned pregnancies because of the opportunity it affords for early embryo screening (Klein 1989). If and when such technologies become routine, women may no longer have any meaningful choice to opt out. However, there is substantial disagreement about the desirability of making prenatal genetic screening universal and automatic; certainly, some women do not wish access to this technology. Room for voluntary refusal must be ensured or non-screening may disappear as an option.

Also, routine use of existing technology has encouraged women to accept medical perceptions and definitions of their experience of pregnancy as more "real" and reliable than their own subjective feelings (Petchesky 1987). Women learn to accept the indirect, distancing, "objective" medical perspective of their body and their fetus as authoritative, and this attitude involves adopting a degree of alienation from their own embodied selves (Jacobus et al. 1990). Such a shift in perspective increases women's dependence on physicians not just to monitor their pregnancies, but also to name and confirm their own experiences; this dependence represents another form of the displacement of power and authority from women to doctors. Critics of medicalization perceive that restoring and preserving

women's power and control over their reproductive lives requires explicit recognition and respect for non-medical approaches and interpretations that exist alongside the more dominant medical orientations. They argue that a more restricted medical role, where medicine is viewed as one source of knowledge among equally valued others, would offer a less alienating and disempowering approach to reproduction than a predominantly medicalized approach.

In addition, critics see the increasing tendency of society to accept the medical view of the fetus as an independent entity, a subject of medical care in its own right often described as "the patient," as a particularly threatening example of the political significance of the shift to medicalized perceptions (Corea 1985a; Stanworth 1987; Overall 1987). This view not only distances the woman from the fetus she carries, it also supports a reductionist view of her as a "fetal container" or "maternal environment" — and often a "hostile" environment at that — obscuring the essential mother-child relationship and turning the woman into a medical problem to be overcome (Overall 1987; Morgan 1989). Such attitudes have social and political repercussions, transforming earlier understandings of pregnancy as a unique relationship between a woman and her fetus into a perception of an independent fetus whose needs can best be addressed by others (doctors, legislators, courts, fetal rights activists). Clearly, this social change is being accelerated with the advent of NRTs, in which the traditional understanding of biological mothering is being disrupted by technologies that have doctors transporting eggs, sperm, and embryos from one body to the next in pursuit of appropriate fetal environments without necessarily attending to the social, emotional, and political disruption such transfers may entail (Oakley 1987; Petchesky 1987; Stanworth 1987).

Contraception provides a particularly striking precedent for evaluating the evolution of NRTs. In contraception, as in the area of infertility, medical research has been concentrated almost exclusively on changing women's bodies and controlling women's fertility; comparatively little attention has been directed at finding ways of modifying men's fertility (Corea 1985a; McDonnell 1986). The contraceptive alternatives that have been most enthusiastically pursued have mostly been pharmaceutical or surgical (or both, in the case of implants) — that is, mechanisms that require medical supervision and approval (Yanoshik and Norsigian 1989). Feminist concerns about the safety of NRTs are deepened by the knowledge that even though many contraceptive technologies have, over time, proven hazardous to women (e.g., the Dalkon Shield® and the pill), adequate safety studies were not conducted before they were released for widespread use and warnings were only belatedly issued (Corea 1985a; McDonnell 1986).[5] Many women have been dismayed to find themselves victims of the iatrogenic effects of contraceptives that had been recommended by the doctors they relied on for health matters; medical advice has proven nowhere nearly as reliable a guide to health risks as patients have been conditioned to expect. In addition, in many parts of the world,

contraceptive technology has been employed coercively by governments to enforce population control policies (Duggan 1986; LaCheen 1986; Yanoshik and Norsigian 1989). Clearly, technology that is initially promoted as fostering individual choice for women can be transformed readily into an agent of enforced social control, so it is important to look beyond the short-term demand for NRTs and consider their medical, social, and political effects.

Historical Lessons

Critics of medicalization perceive widespread patterns of technology expansion in many areas of our "technophiliac"[6] society. In reproduction, as in most other areas of modern life, it is common for technological solutions that were developed to address specific urgent problems to become normalized and even mandatory eventually (Beck-Gernsheim 1989). Medicine seems to be a field particularly oriented toward technological favouritism, in that medical education, public policy, and the profit motive combine to ensure that technological innovation is seen as the measure of medical progress (Ratcliff et al. 1989). Yet such "progress" often carries with it the reduction of opportunities to pursue other options.

The rapid multiplication and expansion of NRTs leave little reason to believe that medical interventions in reproduction will stop at any foreseeable limit. History reveals that no sooner was medical control established over childbirth than it moved to the earlier stages of pregnancy and into the post-natal phases of lactation and child care. Contraception and abortion have also been defined as procedures that require medical expertise. More recently, menstruation and menopause have become designated as conditions that are subject to medical intervention.[7] Thus, even without the advent of NRTs, there is no time in a woman's adult life when she is medically perceived as healthy and not subject to medical care; women are placed perpetually in the role of patients and are subject to the medical control that role is thought to entail. NRTs seem to invite even greater opportunity for medicalized perception and control of the female body.

Thus, when feminists survey the emerging and expanding field of NRTs with this historical perspective in mind, they anticipate some familiar problems. In a culture they perceive as systematically devaluing women, it seems clear that medical practitioners have long been willing to take extraordinary risks with women's health (Morgan 1989). Time and again, physicians have made women and their children victims of poorly researched new technologies that were later proven ineffective, hazardous, or both (e.g., diethylstilbestrol [Bell 1989; Simand 1989], thalidomide, fetal x-rays). There is, then, good reason to fear that NRTs will be introduced and practised on women's bodies without adequate research into safety and effectiveness.[8] Evidence has shown that very few of the drugs and procedures administered to women to relieve infertility have undergone the

sort of testing ordinarily expected for new drugs or surgical techniques (Morgan 1989), and reports of serious side-effects often seem to be ignored or suppressed (Corea 1985b; McDonnell 1986; Klein 1989).

Balancing Access and Choice

Most feminists do not deny that medical technology has given many women options that might not be available otherwise and the opportunity to exercise choice and gain increased control over many aspects of their reproductive lives. In this sense, reproductive technologies can be seen as tools that increase women's sense of freedom and control in their lives (Stanworth 1990; Sawicki 1991). However, it is important to understand that the sense of freedom offered may turn out to be illusory for many women, for technology often has the effect of narrowing the sense of plausible alternatives and so, in practice, limiting the choices available to women (Garner and Tessler 1989; Morgan 1989).

Therefore, the question of where control over reproductive technologies is to reside is really central. Virtually all NRTs have been medically controlled. Only AI or contractual pregnancy can be practised without medical assistance (Wikler and Wikler 1991). Even here, medical monitoring is generally considered desirable to protect against STDs and unacceptably high genetic risks. Medicalization also provides a degree of legitimization that helps to pre-empt or subdue social and political critiques of these practices. Significantly, infertility treatments are provided by medical practitioners under rules of accessibility that they determine, and since these services are in high demand, medical experts can be quite selective in their choice of clients. The criteria they establish address not only such questions as age, marital status, sexual orientation and activity, socioeconomic class, and so on, but also the apparent commitment of applicants (Overall 1987; Nsiah-Jefferson and Hall 1989; Sawicki 1991). Potential clients feel pressured to fit themselves into the stereotypes promoted by providers of these services. Their sense of freedom to deliberate or show ambivalence is reduced by the perception of the long waiting list behind them and their fear of losing their place if they do not conform to the expectations defining who will be judged "deserving" of these highly prized opportunities (Pfeffer 1987; Beck-Gernsheim 1989; McCormack 1989).

In the area of childbirth, medicalization has superseded all other practices and made women excessively dependent on, and perhaps dangerously compliant toward, medical opinion. One clear threat of medicalized responses to infertility is that they, too, will supplant all alternative responses to infertility and become virtually irresistible to many women who are labelled with the medical condition of "infertility." Already, some women have reported that the very existence of these technologies makes their use seem inevitable (Rothman 1984; Overall 1987; Beck-Gernsheim 1989; Williams 1989). The development and social prominence

of some NRTs serve to reinforce the feeling that Kathryn Morgan has called "obligatory fertility" (Morgan 1989). It seems that the very terms of the debate have shut down the pursuit of alternative responses even before the search begins. We must remember that infertility is not simply a biological state; it is a socially defined and interpreted category that can be defined differently. Infertility can also be addressed through many distinct strategies in addition to medical responses (McCormack 1989). It is common for both proponents and opponents to grant that the strong demand for NRTs is a reflection of the "desperation" that involuntary childlessness often creates, but as Naomi Pfeffer (1987) has argued, this perspective is a caricature of the complex feelings actually experienced by infertile people. By characterizing women and couples who are involuntarily childless as "desperate," radical medical intervention is easily rationalized (ibid.). This way of conceptualizing the problem promotes a sense of urgency that precludes the investigation of other options.

Thus, alternative responses to involuntary childlessness are in danger of becoming totally eclipsed by the medicalized perspective. It is important to remember that other responses are possible. They include rejection of the label, grieving, acceptance of childlessness, adoption, foster parenting, change of partner, denial, finding a new job, moving to a new home, going on a long holiday (Woolett 1985; Pfeffer 1987; McCormack 1989). Other options include alternative family structures (e.g., multiple parenting) and, in some cases, eventual "natural" conception. At first, many of these alternatives pale in comparison with the powerful and apparently less disruptive resolutions promised by NRTs (where no big lifestyle changes are advertised), but in practice, NRTs can be disruptive of lives and relationships and may pose more threats than the non-technical choices (Williams 1989). That these alternatives are often quickly dismissed as inadequate can be seen as evidence of the power and authority vested in the medical routes by virtue of their status as medical. The technological approach that medicine has pursued leaves out broader social responses to the circumstances of infertility by making it into an individualized problem susceptible to individual solutions (Pfeffer 1987; Rose 1987; McCormack 1989; Wright 1989; Sawicki 1991).

Within medical contexts, clients are placed in the role of patients, and patients are generally expected or required to surrender large spheres of personal decision making to the authority of technical experts. Patients tend to be left with, at best, the opportunity to consent or refuse options presented to them but not to control actively the decisions made (Fisher 1986; Kleinman 1987; Todd 1989; Frank 1991b). Medical knowledge is defined as technical and scientific, and is considered more important and more powerful than other perspectives.[9] Since the scientific, objective, medical perspective is seen as more objective and reliable, it is considered more legitimate than women's subjective experience of their bodies, often even in the minds of women themselves (Petchesky 1987). Women learn not to trust their own sense of illness or well-being and not to rely on their

perceptions of bodily changes, and this alienates them from their own experiences. They are even encouraged to take a medicalized role in relation to their own bodies:

> Women are encouraged to check constantly on the normality of their procreative system events — onset of menstruation, birth control, pregnancy, abortion and miscarriage, labor, childbirth, postpartum conditions, and so on ... We [women] are acutely aware that something might go wrong and typically feel we need medical expertise to assess normality and to accomplish care. (Bogdan 1990, 103)

With NRTs, women experience a strong belief that not only their bodies, but also their minds and attitudes, must be made to conform. Linda Williams (1989) reported a strong consensus among participants in an IVF program that positive thinking is essential to a successful outcome.[10]

One of the more subtle, but perhaps the most powerful, ways in which medicalization reduces freedom is by controlling the language and conceptual scheme with which we approach problems (Treichler 1990; Sawicki 1991). Medical discourse and constructions have become dominant as a perspective for understanding women's bodies and thus have helped to shape women's direct experiences of their bodies (Jacobus et al. 1990; Stanworth 1990). But, as Kathryn Morgan observed, "internalizing the language, beliefs and values of the patriarchal reproductive technologists contributes to a profound experience of psychological oppression for women" (Morgan 1989, 61). Critics of medicalization recognize the need to try to gain control over the language, images, and understandings of motherhood and reproductive issues generally. They seek to transform discourse about reproduction and infertility into descriptions of women-centred experiences. They believe that if we are to restore choice to women, we must understand physicians as experts who can provide particular forms of support but who should not be granted the authority to define and determine women's understandings of infertility and procreation.

Because so many aspects of reproduction have been medicalized, women find themselves increasingly dependent on expert medical care. Although medicalization and the corresponding transfer of power from patient to doctor that medicalization has historically entailed can be problematic in any sphere, feminists see it as especially troublesome in the area of women's reproductive lives. They contend that since many women already experience a relative lack of personal power, any movement that involves transfer of what little power most women can claim over their own lives should raise concerns. Because so much of women's lives is connected, one way or another, with reproductive matters, medical control over reproduction is seen as helping to perpetuate an image of women as incompetent to make fundamental decisions in their lives without expert direction. Expansive intrusions of NRTs can be expected to exacerbate this

phenomenon. And since the distinctive power that women have traditionally been able to claim as their own is derived from their ability to bear children, technology that may transfer this power to others poses a significant risk to women's position in society.[11]

Infertility programs seem to rest on the assumption that failure to conceive or to be able to sustain a pregnancy is an intolerable burden for some women, and women's involuntary childlessness is therefore best categorized as an illness that medicine should strive to relieve. Although feminists do not deny that many women experience infertility as a medical crisis, they ask that we inquire into the effects that intense medicalized responses produce in terms of women's experiences of infertility. One such result is that a strong message is conveyed to all women — whatever their fertility status or preferences — that a woman's inability to bear children is a serious problem. The widely publicized, concerted medical efforts undertaken against this problem offer confirmation and hope to many infertile women, but they also reinforce an existing, dominant social message that bearing children is part of the meaning of being a woman in our society (Morgan 1989). Women's inability to fulfil this expected social role is defined as a problem of such severity that significant social resources are directed at relieving it, and the principal action available to affected women is to turn their bodies over to medical technicians for correction. Infertility becomes another medical war, akin to the ones against cancer and heart disease.[12] In the present social and political context, this image of women may overwhelm the basic feminist agenda of having society respect and value women not only as childbearers, but also as individuals with multiple dimensions worthy of respect.

Feminists ask that any social change that grants others a degree of control over women's reproductive lives be evaluated carefully to determine whether it helps to relieve women's oppressed status or whether it actually deepens it. The difficulty with NRTs is that they can be read as doing both — helping to empower some women while threatening others. Thus, it is essential to feminists that the power to define women's needs and desires and to choose the appropriate responses to them rests in women's hands. Such decisions must not be reduced to the status of technical, scientific problems (Ratcliff et al. 1989). Hence, they seek mechanisms that will help to ensure that medicalization of NRTs does not create a transfer of social power along with the limited transfer of authority necessary for effective treatment by physicians. Specifically, they seek to ensure that medicine is not granted a monopoly over questions about reproduction or the technology that affects it (Treichler 1990).

The Effects of Funding NRTs on Access and Choice

How the costs of NRTs are paid will also affect the degree and effects of medicalization of reproductive issues. Inclusion under the provincial health care insurance plans will probably provide the widest possible access to the medically defined and controlled technologies. It is important to evaluate different funding mechanisms to find the best balance of access and choice.

Is There a Right to Health Care Funding for NRTs?

The socialization of the costs of medicine implies a recognition of the special role of medicine in a society (Daniels 1985; Coburn and Biggs 1986). Public funding effectively grants the service the status of a right for citizens. Access to the service is construed as in some way central to the respect of those persons in need. We do not currently grant such a status to personal transportation and clothing, but health care and education are two services that have been so recognized. Access is enhanced through the reduction or elimination of direct personal costs, and through temporary relief from social obligations such as work or domestic duties, so that one may pursue the services.[13]

Following is a brief discussion of arguments for the public funding of health care in general, and then as applied to NRTs. It is important to establish that NRTs are a diverse set of services that cannot be treated as homogeneous for purposes of funding decisions. Funding NRTs may require a mix of health care coverage, market distribution, and perhaps other forms of subsidization.

Respect for persons as moral equals is the basis for any argument for a societal obligation to fund health care. Public funding through the health care system has the effect of making health care services more accessible than if they were distributed on the market, primarily because individual utilization of health services is without direct personal costs and therefore does not reduce other opportunities (i.e., work-, recreation-, or investment-related). Personal financial resources and priorities are therefore less influential on the use of health care.

Most socialized health care systems have not evaluated the ability of specific services to address particular goals of justice. Instead, these systems have funded any service that can be couched in appropriate health-oriented terms and provided through the traditional medical institutions. But neither health care services nor NRTs can be treated as a homogeneous package of services. Different services meet different health needs and are different for the purposes of society's obligation to fund. Health services for catastrophic illness are part of what is typically considered part of the package of health care services that merit funding. The same is true of inoculation programs, but not of non-restorative cosmetic surgery. The goals of justice that are served by the public funding

of health care must be understood before the appropriateness of funding a particular service can be determined.

Three arguments in support of public funding of health care support the claim that financial barriers to specific health care services should be removed.

The *compassion* argument claims that we should be the sort of society in which individuals who suffer from injury or illness have their needs for health care provided for independently of their economic status. The moral claim is that it is unjust to allow people to suffer when the means to avoid or alleviate suffering are available. This is of course intuitively plausible in cases of easily rescuable drowning people or when cardio-pulmonary resuscitation can restore full life function. A society may violate this principle if it allows individuals to be denied treatment because they cannot afford to pay for it. Limits to the obligation to provide particular types of assistance would be based on the available resources and the actual effectiveness of the health care service to prevent, alleviate, or eliminate the suffering.

The *equal opportunity* argument has been best described by Norman Daniels (1985). A simplified version of Daniels' position is that a just society removes barriers to equal opportunities for access to the marketplace upon which it depends for fair distribution of goods and services. Health is important for access to the market, and it can often be maintained, restored, or compensated for through the provision of health care services. A just society will therefore ensure access to these services, which are important to maintain or ensure access to the market. In addition, the need for health services is typically unpredictable, expensive, and urgent, which makes them difficult for most people to anticipate or afford. Even private insurance schemes with subsidies and public funding for the indigent and elderly have failed to meet the health care needs of many people in the United States (American College of Physicians 1990). Another buttressing argument is that poverty and unemployment are associated with poor health, and therefore the combination of these factors is individually crippling in terms of having equal opportunity in or access to the marketplace. The effect of health care services on society's obligation to maintain equal opportunity creates a moral obligation to provide health care services relevant to problems that limit equal opportunity.

The third argument in favour of public funding of health care services is based on the observation that it is in the *public interest* that people use certain kinds of health services. Examples are STD clinics and preventive services such as vaccination, screening, and counselling (e.g., dietary, family planning, lifestyle). The good to the public resulting from the use of such services may exceed the good derived by the individual using the service. Such health services are public goods; they are the ones that may not be given high enough value in the market either because individual consumers cannot perceive the need or because the value is more social than personal. In addition, in some cases the institutions necessary to

deliver such services probably could not be sustained on the funds generated through a market approach, so the public welfare would be lost. Consequently, these services require public funding either to make the costs of the services reasonable for the personal values they serve (e.g., family planning) or to remove any financial disincentives to pursue services that may be of limited immediate or long-term personal use but are important for the public (e.g., vaccinations, STD clinics, lifestyle counselling).

It is important to note that the decision to fund a service publicly may not require inclusion under the health care insurance plans. For example, NRTs might be subsidized through the limited underwriting of a contract that individuals would negotiate with groups offering approved services (e.g., fertility-enhancing drugs and counselling; counselling to decide whether to remain childless or adopt). This would promote greater flexibility in how individuals use a mixture of technologies and alternatives. This suggestion is similar to that made for people needing supportive services for home care (e.g., meals, housekeeping, daily nursing visits, medication delivery). In this context, the recommendation is that the client and family negotiate a contract of services with one or more of the various groups that deliver services approved and funded by the provincial government (Alberta 1989). This allows subsidization of health care services that promote access without forcing the client simply to accept or refuse the services that health care institutions or professionals recommend, preserving desirable elements of the market such as consumer choice and competition. The evaluation of each NRT should include determination of the appropriate mix of market, subsidization, and health insurance to achieve the particular goals of justice for that service. A weak contribution to the public interest or a claim based exclusively on compassion may need some subsidization for those in need (e.g., infertility services), while a claim based on equalization of access to the market might require full coverage under health insurance (e.g., prenatal screening).

Fertility services are a controversial example. It is compassionate to assist women and couples who are involuntarily childless; it is also compassionate to assist those who are reclusive due to their physical appearance. However, in both cases we are not sure how much prejudicial social pressures have shaped the desires that lead to the demand for the services. Neither are we sure that the technological response is socially or psychologically adequate. The fear is that funding out of compassion may seem to endorse the social norms that cause much of the suffering. The market makes such technological responses available to those who elect to use them and can afford them. Public funding may seem to endorse the social norms and the technological response. Finally, a limit to even a clearly compassionately required service such as critical care is whether the particular service is effective in alleviating the suffering. This is at least

controversial for infertility services whose success rates are below those required of many other health services.

The argument regarding equal opportunity does not support the public funding of fertility services. Assisting women and couples to fulfil procreative desires certainly promotes their life projects and goals. However, the equal opportunity argument supports public funding for services that restore or compensate for a health problem that undermines access to the market. The intention is not to supplement the market in its ability to provide services important to accomplishing personal goals. Instead, the justification is that without a particular service, one cannot get equal access to the market. The decision not to fund a service does not undermine reproductive rights, since they receive as much protection as any other liberty-based right, such as freedom of speech or movement.

Nor can the public interest justify the expenditure of public funds to supply fertility services. Professional services, including fertility, flourish in a free market system in Canada and the United States; public funding is therefore not needed to supply the necessary institution for the services. There does not appear to be any public interest served greater than the personal benefit derived from fertility services. Due to the intensely personal nature of the use of fertility services, the public interest argument cannot be invoked to justify public funding.

In contrast, consider the rapidly developing prenatal diagnostic technologies. Certainly, it is compassionate to avoid the birth of infants who can confidently be predicted to suffer intensely and to save women the risk of pregnancy for fetuses that cannot survive. In addition, the possibility of early intervention provides clear opportunities to prevent suffering.

Equal opportunity may be restored if a fetus or infant is diagnosed as having a condition that is amenable to effective treatment. This is perhaps most significant in the combination of monitoring and fetal therapies where otherwise severely compromised hydrocephalic infants are born normal due to early intervention. A more dramatic positive effect on equal opportunity to the market is difficult to find.

Although the technology and institutions necessary for prenatal screening and treatment flourish in the free market system, the public interest still mandates public funding to encourage use of the services. Although it is still in the individual interest of women to have healthy infants, it is of great moral and financial interest to society to promote healthy infants. Avoiding and reducing the personal and social distress of severely disabled people, and the financial costs of caring for them, is in the interest of society. Prenatal diagnostic technologies services have considerable effect on promoting this public interest. They therefore qualify for public funding to reduce the personal costs of use.

How Health Care Funding Increases Access and Limits Choice

Three elements of funding NRTs through the health care system affect the medicalization of reproduction and have the potential to increase access and limit choice. First, a central concern of funding health care services is ensuring appropriate use and quality control so that public resources, specifically taxpayers' contributions, are not squandered. This increases the authority of those who administer health services to define who qualifies for the services, to allocate resources, and to require compliance and monitoring. Second, public funding of NRTs through the health care system grants those services a status equal to that of other medical treatments. Special social and occupational support may accompany this status, so that one is often temporarily relieved of certain responsibilities to attend to the treatment of the condition. Although this permits more widespread and equal access to NRTs, it may also make them difficult to refuse. NRTs may be so socially advantageous compared to the alternatives that the latter are difficult to consider as viable options. Third, funding NRTs will extend access to the medical technologies. With the current emphasis on the reduction of health care costs, funded services that may reduce the birth of defective infants and related costs may be seen as obligatory. Funding could therefore lead to a social attitude that only irresponsible women will resist testing and "management" of all pregnancies, or at least those that begin with the involvement of fertility assistance (Ouellette 1988).

Quality Control and the Reduced Flexibility of Personal Choice

Public funding of NRTs through the health care system will require that medical authorities set standards and monitor the system to maintain responsible and effective use of public funds. This is additional to the professional and cultural authority these institutions have as a result of legal support for licensure and the setting of professional standards (Stevens 1971; Starr 1982; Azzarto 1986). People who cannot afford to purchase NRTs will use them once they are publicly funded; they clearly have their options increased by public funding. But there are also attendant benefits and costs of medicalization.

Public funding of health care services enhances some of the medicalizing effects. When women or couples seek assistance from NRTs, publicly funded or not, their problems are legitimized, they are provided with services on condition of adherence to medical advice, and various aspects of their lives are monitored. For reproductive issues, where the interventions are often powerful medications or complex procedures, the monitoring and adherence to medical advice are considerable. The supposed gain is risk reduction and sometimes the possibility of pregnancy, the assurance of having a normal child, or the avoidance of disabilities or at least time to plan for them in advance. The personal cost is loss of the uniquely personal nature of the reproductive experience (Oakley 1975) and

of decision-making control. Adherence and monitoring in a publicly funded system is given the special sanction of social responsibility. A non-compliant patient is not only a "bad" patient, but a "bad" citizen.

Thus, the funding of NRTs through the health care system would inevitably invest those who administer the system with the authority to define need, allocate resources, and require adherence to specific regimens (Basker 1986). This authority will also affect the degree to which alternative responses will be considered (e.g., avoiding prenatal screening, adoption). Assignment of responsibility to medical authorities to determine appropriate medical responses has been accompanied by a reduction in availability of the less prestigious non-medical services in areas of infectious diseases (Goodman and Goodman 1987) and of services to the elderly (Binney et al. 1990), to schizophrenic patients (McLean 1990), and to the mentally ill in general (Aviram 1990). NRTs funded through the health care system will likely show a similar increase in authoritative involvement (Eichler 1989), a consequent decrease in choice (Scritchfield 1989), and a decrease in attention to understanding and counteracting social factors that contribute to the problem of infertility (Warren 1988). The medicalization of reproduction, both in the sense of increased access to medical responses to problems and in medical regulation and domination, will thus be enhanced if funded through the health care system.

Another loss of control due to health authority over NRTs is the ability to tailor reproductive services to individual needs and desires. On the market, consumers of goods and services may select where and on what they choose to spend their money. If several outlets were available, a woman or couple might purchase a reproductive technology service from the centre whose staff had a similar attitude toward the use of the technology. Some might elect to use various folk methods in addition to AI, but forgo any monitoring of the pregnancy. Others might desire the full range of medical support and have no interest in supporting their efforts with less technological methods.

State funding and distribution of a service through the health care system protects the service and related goods from the pressures of the market. This means that outlets will tend to be distributed to maximize access to one of them but not competition among them. Nor will servicing the attitudes and needs of individual patients be important, since publicly funded professional services are to be provided only when professionals recognize a legitimate need for the service. In the effort to deliver an effective and economical service, there is a strong tendency toward standardization. Differences between outlets for medical care tend to be considered a problem; the least expensive delivery among those of similar efficacy is taken to be the norm. Individual idiosyncrasies are relevant only if they affect safety or effectiveness. Funding of NRTs through the health care system will likely promote widespread access to the standardized technologies through non-competitive outlets, which will be under pressure

to ensure adherence to a particular regimen so that high rates of efficacy may be achieved and maintained. This will also discourage treating NRTs either as a portion of a broader approach to reproductive issues or as a personally selective use (e.g., IVF without subsequent monitoring). As mentioned previously, some NRTs might be subsidized without inclusion under health insurance, preserving aspects of the market and promoting greater flexibility in how individuals use a mixture of technologies and alternatives.

Social Benefits for NRTs and the Eclipsing of Alternatives

Funding NRTs through the health care system will also bring social benefits for those who use NRTs. For example, abortion after prenatal screening creates the impression, whether accurate or not, that a fetal anomaly was the reason. Family and friends will often find this more palatable than an abortion that was not preceded by prenatal testing. The timing of embryo implantation for IVF may be acceptable to some employers as a medical excuse for absence from work. This benefit of legitimate time off does not accompany the timing of intercourse for ovulation cycles as determined at home by temperature readings. The increased status, benefits, and accessibility accompanying funded NRTs may have the effect of making them more attractive than non-medical alternatives. The increase in attractiveness is due to NRTs being perceived as a medical treatment. The legitimizing effect of medicalization is often enhanced when society decides to fund services to ensure access. The effect of funding NRTs through the health care system may be said to eclipse the alternatives by loading them with a social advantage that makes them more desirable.

There is evidence for the increased fiscal support for services defined as medical services. For example, social and supportive services for the elderly are better funded when labelled a medical problem or when medical professionals and hospitals are involved (Azzarto 1986; Binney et al. 1990). Women and couples who desire technological assistance with infertility claim that their needs are comparable to those of other non-controversial medical services such as gynaecological services. If this claim is accepted and medical assistance for infertility is considered to be a part of the health care plan, such services will be granted special status. The message is that infertility services are too important to be left up to individuals to purchase, at their discretion, on the market. The inclusion of medical assistance will eclipse those non-medical responses to infertility that are unfunded.

Special legal and social status are granted a "condition" and "treatments" that are publicly funded as medical services. The status is intended to increase access to health care services and often to assign social responsibility more appropriately. Abortion was not widely available in England until its medicalization under the rubric of therapeutic abortion (Grubb 1990). Suicide was less a punishable crime in the English courts as juries accepted the medical definitions (MacDonald 1989). Funding may

promote the ability to claim fertility treatments as qualifying for time off from work on the same basis as any other medical treatment. The actual status of infertility as a medical condition is still controversial, and so the right to time off from work is controversial. If the treatments for reproductive problems are funded as health care services, the controversy may be decided. Once a condition is recognized as "medical" and as requiring "treatment," it may be that human rights are violated under Canadian law when employers fail to recognize the condition and treatment as a legitimate excuse for absence and reduced performance. The funding of NRTs through the health care system fully establishes them as medical problems requiring medical treatment.

Medicine has long had the cultural authority to define health and illness, and to prescribe what constitute appropriate responses (Stevens 1971; Starr 1982). Public funding further legitimizes or authorizes professional definitions (Azzarto 1986). Medical responses to infertility, risks of pregnancy, and fetal anomalies are given explicit approval by state and medicine, recommending their use while rejecting non-medical responses as non-essential or not health services at all. Thus, the eclipse of alternative definitions of the problems and alternative responses by medical technologies is enhanced by funding through the health care system (Woliver 1989).

It is unclear to what extent alternative responses to NRTs are available to women or couples when NRTs are without direct cost and are accompanied by the benefits of the "sick role," such as time off from work to attend appointments. At a minimum, funded, medically appropriate services are likely to become the first approach to a problem, while others are ignored or left as alternatives when medicine fails (Kurz 1987; Morgan 1989; Wright 1989). The combination of the quick fix and no financial cost for medical approaches makes them attractive as the first choice, with other more long-term, less invasive, and often unsubsidized approaches (e.g., counselling, adoption) left as second or last resorts.

The inclusion of paternity leave benefits under unemployment insurance is an example of how certain benefits accompanying the sick role may be provided without the ascription of the sick role. Perhaps similar options could be found to supplement alternative approaches with some of the benefits of submitting to medical treatment. To the extent that these benefits are available without ascription of the sick role, it may be possible to permit alternative responses to NRTs, such as fertility services, to be equally valid social choices for individuals and disenfranchised social groups (Stark 1982).

Reducing Risks and Costs and the Elimination of Personal Choice

The public funding of NRTs will lead to more widespread use, the possibility of better data on safety and efficacy, and likely a significant increase in the number of available services and amount of research. For

example, it is inevitable that there will be a considerable increase in the number of services intended to assess fetuses *in utero*, to correct anomalies, and to reduce pregnancy-related risks to the fetus. Many services of this type are currently available under the various health insurance plans. Hesitation to include new services is usually based on concerns about the effectiveness of the service relative to its cost and possible utilization rate. Once these are settled, the opportunity to reduce the risk of suffering or "defective" infants is generally a compelling argument for the inclusion of the services under health care.

Such services are generally available to women if their physician considers the service appropriate, or if the woman requests the service and the physician does not consider it inappropriate. Women may still elect not to have amniocentesis or other procedures or, having had an anomaly diagnosed, women may elect to proceed with the pregnancy. The possibility of these procedures becoming mandatory to avoid the birth of severely "defective" infants and related costs was discussed earlier in this paper. Since prenatal services are currently funded, the point may be moot; however, public funding for fertility services might make a further contribution to the erosion of personal choice (Lauritzen 1990).

The elimination of direct costs may be a loss of the only socially acceptable reason a woman might give to avoid having her pregnancy and fetus assessed and monitored. Although legal protection may prevent women from being forced to accept procedures bearing personal risk (Keyserlingk 1984), procedures that do not bear significant personal risk and that are available at no cost to the mother may become both standard practice and part of what is considered the responsibility of childbearing. It is doubtful that abortion would ever be required of a woman who carries an imperfect fetus. But the increased monitoring deemed medically necessary for a "high-risk" pregnancy could become obligatory in a manner that could never be true of medical care for a patient who refused. This would represent not a reduction of choice for refusal or consent, but an elimination of even the requirement of consent for procedures medical authorities deemed important to the welfare of the fetus. What is important to recognize is that the shift to a moral imperative is partly prompted by the economic decision to fund such services. The last refuge for the woman to refuse these procedures may have been cost, but public funding removes the last socially acceptable excuse for a woman to refuse a medical intervention she may simply find offensive. The controversial issue of whether fetal welfare takes priority over maternal wishes may be pre-empted by the technological possibility and the elimination of personal cost. Public funding threatens to create a social situation in which fetal welfare takes unjustified priority over maternal wishes. The change in social attitudes toward "obligatory fertility" and the duty to use available technology (Morgan 1989) may be taught to a future generation as part of their reproductive responsibility (Beck-Gernsheim 1990) and may affect attitudes toward deformed fetuses (Retsinas 1991).

Summary of the Medicalizing Effects of Funding NRTs

Medicalization of reproduction and NRTs in response to reproductive problems provides greater access to technologies that benefit women, couples, future children, and society. The same social process also holds the potential to reduce choice in reproductive issues. The mechanisms that promote access to NRTs through health care funding are the same ones that bring about the social and personal problems referred to here as choice. First, the use of medical institutions and professionals to ensure quality of services delivered and responsible use of public funds will also reduce the degree to which reproductive experience and choices will be controlled by those who seek to reproduce, particularly women. Second, funding NRTs through the health care system will increase access by eliminating direct costs of utilization and increasing the social benefits accompanying the use of health care services. These benefits combine with other features of NRTs to magnify their value relative to the alternatives. This may result in the alternatives being reduced to "fringe" or "alternative" responses, which do not receive the same benefits as medical approaches, and are socially discouraged. Third, the availability of fetal and genetic assessments will reduce the number of infants born with congenital anomalies. However, the funded availability of such services may combine with pressure to contain avoidable health care costs and concern for the welfare of the fetus to place a heavy stigma, if not explicit social sanctions, upon women and couples who elect not to use the relevant NRTs. It is vital that decisions to fund NRTs be sensitive to the positive and negative social impact of those decisions.

Since NRTs are a diverse set of services that serve different functions, they must be evaluated individually to determine whether public funding is justified. It is easier to see how early detection of fetal anomalies to prevent suffering through therapy or termination of severe cases is a likely candidate for public funding directly through the health care system. Non-medical alternatives such as adequate maternal nutrition and programs to assist with substance abuse may be just as important to fund. It is more difficult to justify the inclusion of fertility services under health care plans when the non-medical alternatives seem to provide similar benefits and may be better for society, and when the suffering of couples or women who are infertile may be very different from those who are injured or ill.

Some of the social benefits that accompany publicly funded medical responses to reproductive problems may be available through other means for the alternatives. Re-evaluation of labour laws, for example, might provide the possibility of providing similar benefits for those who elect certain kinds of non-medical alternatives to respond to their concerns about infertility.

The issue of medicalization of reproduction as it is affected by health care funding illustrates how access may be promoted at the expense of choice. But understanding how this occurs creates the possibility of

combining public, private, and subsidized payment schemes, together with innovative approaches to social benefits, in a manner that might balance some of the concerns about losing choice to gain access. Each type of NRT must be evaluated to determine the proper mix of funding mechanisms and social benefit packages in a manner that is sensitive to the social viability of alternatives. Such an approach will permit the best balance of access and choice in reproductive issues.

Funding and Regulating NRTs

The medicalization of NRTs has been considered from a general conceptual approach and using feminist analyses, and the influence of public funding on medicalization has been appraised. It is not possible to make a general case for the funding or regulation of NRTs. The different benefits and risks of medicalization manifest differently for each technology and the purposes it serves. The most that can be said is that medicalization is a social process that always carries both benefits and social costs. The social benefits are typically various forms of improved access and recognition of suffering as socially legitimate. The social risks involve complicated social trends that at best direct and at worse coerce individuals, thus reducing choice to mere consent to medically proposed alternatives, or making refusal difficult. The following goals are intended to direct attention to the effects of medicalization for any particular NRT when considering the issues of regulation and funding.

Suggested Goals to Promote Access to NRTs Without Reducing Choice

1. NRTs must be evaluated on an individual service basis for each of the following concerns. For example, fertility technologies cannot be funded on arguments applying more to prenatal testing.
2. Each NRT should be evaluated for its role in meeting the requirements of justice in health care funding. Specifically, the service must offer reasonable prospects of alleviating suffering, promote equal access to the market, or promote specific public goods that might be lost if the service were available only on the market. The issue of suffering appears especially vexing, but it must be remembered that people desiring NRTs are basically healthy. They are not harmed in terms of access to the market by being denied funded access to many NRTs.
3. Professional autonomy, regulation, and funding should be evaluated for individual NRTs. The evaluation should assess reduction of individual risk for clients and overall public cost. These benefits must be weighed against possible losses of personal choice and the likely eclipse of less expensive and less invasive alternatives. Specifically,

the service should be funded or regulated in a manner that permits good risk information and cost control while promoting the client as the ultimate authority regarding whether to use the NRT or an alternative.

4. Each NRT must be evaluated for the social benefits that may accompany its use. Some of these social benefits are available because the service is medical and the woman is perceived as a patient in the sick role. Such assumptions reduce the role of choice for the woman and often provide benefits that the alternatives to the NRT do not have. For example, a couple may attempt to improve their chances of childbearing through temperature monitoring and timing intercourse. The use of AI through a clinic may provide an acceptable reason for time off from work, while being late because of the timing of intercourse is perceived as irresponsible. Mechanisms must be found to level not only the costs of using NRTs but also the social benefits attending their use.

5. Each NRT must be evaluated to anticipate the degree of voluntariness and how informed the consents are likely to be within the social and medical context. Specifically, people using a NRT should probably be considered properly informed for purposes of informed consent only if an unbiased source has presented the risks and benefits of the NRT and the alternatives. Since most NRTs will be distributed through the funded health care system or professional practices, special attention must be given to the fair representation of alternatives. Consent to clinical services is typically limited by disclosure of risks and benefits of the recommended service, inconsistent disclosure of medical alternatives, a short deliberation time, and little or no mention of non-medical alternatives. If this is the only source of information regarding alternatives, then consent will not be adequately informed, nor will choice be protected. It is likely that a "neutral" presenter, or both a medical and a non-medical presenter, will be important to ensure unbiased presentation of the medical and non-medical alternatives. Consent may be adequately informed if the client receives the information about alternatives from a knowledgeable non-medical source.

Notes

1. The present authors wish to express their appreciation to Professor Conrad for use of his unpublished materials. For specific studies, see bibliography in Conrad.

2. The many perspectives that exist among feminists generate a variety of concerns about NRTs. These differences are reflected in a complex debate about how to evaluate and respond to the divisive issues posed by NRTs, which makes it difficult

to isolate a single feminist perspective on this broad range of technologies; nevertheless, there are some common themes.

3. This trend is by no means restricted to pregnant women. As any smoker can testify, it is becoming more difficult to resist health promotion advice and make choices that endanger one's own health. The freedom of pregnant women is especially threatened in this regard, because they are seen not just as being irresponsible with regard to their own well-being, but also as recklessly risking the health of their fetus (Overall 1987; Corea 1985a).

4. See also Lippman (1991a), who documented routine use without informed consent of ultrasound screening as a form of prenatal screening and argued that this practice shows that the "consent" process for other forms of screening may be coercive.

5. In some cases (e.g., the Dalkon Shield®), deliberate decisions were taken to introduce technology known to be risky (Ratcliff 1989).

6. This is a term feminists have found helpful in describing the strong preference for technological solutions to problems we find expressed in our culture. It was introduced by Wright (1989).

7. Premenstrual syndrome is a condition whose symptoms are said to affect 95 percent of menstruating women (Zita 1988) and menopause has recently been defined by the World Health Organization as a deficiency disease (Martin 1987).

8. As Ratcliff argued, a market and social climate that encourages technology tolerates introduction of risky innovations: "this recklessness is fostered in a system in which dominating nature and technological tools to do so are presumed to be good" (Ratcliff 1989, 193).

9. Stanworth observed: "Perhaps most significantly, new technologies help to establish that gynaecologists and obstetricians 'know more' about pregnancy and about women's bodies than women do themselves" (Stanworth 1987, 13).

10. This is not an easy accomplishment, since the low success rates of IVF present women with the challenge of balancing a positive attitude with a protective defence against getting their hopes too high and hence finding their probable failure unbearable.

11. This is a complicated question, since many people, both feminist and anti-feminist, believe that women's distinctive reproductive role is at the root of their lesser status and power in society, in that it limits their freedom and opportunities and leads them to be economically dependent on men.

12. The "battlefield" for such wars is, of course, people who are ill or infertile.

13. Talcott Parsons first characterized the "sick role" to capture the temporary relief from social responsibilities in exchange for responsibilities to pursue medical care in an effort to recover one's health and be restored to full social responsibilities once again (Parsons 1951).

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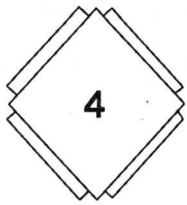

Prenatal Diagnosis and Society

Dorothy C. Wertz

Executive Summary

This paper provides a wide-ranging survey on societal attitudes regarding prenatal diagnosis (PND). According to opinion surveys, the public appears to approve overwhelmingly of prenatal testing. However, critics claim that prenatal testing is a form of quality control and could have negative effects on people with disability.

A large proportion of the population in Canada and the United States believes that abortion should be legal if there is a strong chance of serious defect in the child. However, the definition of "serious defect" is difficult. Conditions such as Down syndrome, spina bifida, and cystic fibrosis, which were once usually fatal in childhood, are now often medically treatable to the point that those affected reach adulthood. However, this increased life expectancy also increases the effect on the family, and elderly parents often have to care for middle-aged affected children.

This study reports extensively on surveys on the attitudes of parents toward PND. Generally, the parents of affected children are less receptive to PND and selective abortion than families without affected children. The higher the level of income and education, the more likely it is that women will have PND. One U.S. survey showed that most people support legal abortion for severe mental retardation in the first trimester (86%) and in the second trimester (76%), even though fewer (58% and 52%, respectively) would have abortions themselves. Many

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North Americans favour leaving abortion decisions to women, even if they personally would not abort in a particular situation. The factors that parents consider in choosing PND and abortion are also examined. Decisions are made in a social context and on the basis of how an affected child would affect their own and their family's quality of life.

Although public opinion appears to favour leaving decisions regarding PND and abortion to parents, the author cautions that there is potential for abuse. Decisions based on cosmetic factors, such as height, weight, obesity, and colour of hair, eyes, and skin, could be a consequence, and these could be extended to include an ever-widening range of genetic disorders or human differences.

Sex selection is a particularly controversial issue and is examined in length. Some geneticists believe that sex selection is a logical extension of parents' rights to choose the number, timing, spacing, and genetic health of their children. However, in a 1985 survey 66% of medical geneticists in Canada thought commercial PND laboratories should be legally prohibited from performing diagnosis for sex selection. Other issues discussed include prenatal paternity testing, tissue typing for organ or marrow donation, mandatory testing, and wrongful birth and wrongful life cases.

The paper concludes by offering recommendations on developing policy on PND and views of the future. Dangers accompanying PND can be avoided by careful application of policy guidelines. However, more research into the effects of PND on women's lives and on the lives of affected children born after PND is required.

Introduction

The public appears to approve the use of prenatal diagnosis (PND), both in Canada and in the United States (Singer 1991; U.S. Congress 1987), according to opinion surveys. This is in keeping with attitudes toward new developments in biotechnology generally; over 70% of the U.S. public regards these as more beneficial than harmful (U.S. Congress 1987). The increasing acceptance of PND in Canada (Baird et al. 1985; Dawe 1986, 1988; Hunter et al. 1987; Lippman et al. 1985; Lippman-Hand and Piper 1981; McDonough 1990b) documents this general approval. Yet many, including critics of PND and organizations for people with disabilities, have voiced concerns about the growing use of prenatal testing. Critics have claimed that such testing is a form of "quality control" that could lead to imposed eugenics (Beck 1990; Hubbard 1985, 1987, 1990; Hubbard and Henifin 1985; Lippman 1985, 1989, 1991a, 1991b, 1993; Rothman 1986), that it presents women with painful or even unwelcome choices (Rothman 1984, 1985, 1986, 1988, 1989), that it will be used for frivolous purposes unrelated to genetic disorders (Rothman 1989), and that it may have negative effects upon all people with disabilities (Asch 1989; Hubbard 1985, 1987, 1990; Kaplan 1989, 1993; Saxton 1987, 1988). The increasing use

and widespread public acceptance of PND are accompanied by rising fears and deep misgivings about its possible misuses and the potential coercion of women into testing and selective abortion. However, none of the social critics of PND would do away with it entirely. All believe that women should have freedom of choice.

The following essay examines the bases of these fears in a social context.

The Many Meanings of Eugenics

The underlying concern of those who criticize PND is often summarized in the word "eugenics." This word carries overwhelmingly negative connotations almost everywhere in the world, except in Greece, where it means simply having a healthy baby (Velogiannis-Moutsopoulos and Bartsocas 1989). Most modern authors associate eugenics with Nazi programs to eradicate Jews, Gypsies, and other "inferior" groups (Chorover 1979; Lifton 1986; Luria 1989; Müller-Hill 1988; Proctor 1988). Historians of the eugenics movements in Canada (McLaren 1990; McLaren and McLaren 1986), the United States (Kevles 1985, 1992; Ludmerer 1972), Germany (Adams 1990), France (Schneider 1990), the United Kingdom (Soloway 1990), and Latin America (Stepan 1991) remind us that genetics has been used to serve corrupt political and social ends in the past and warn of the possibility that it could do so again. Although some authors speak of a "new eugenics" (Kevles 1985) and almost everyone cautions about eternal vigilance, few, if any, historians expect that any Western nation will repeat the mistakes of the past (Lockwood 1985; Rosenberg 1986). It therefore remains unclear exactly what society should be on guard against. In seeking an answer to this question, many critics have seized on PND as the most obvious tool for the eugenics of the future, without considering what they mean by eugenics.

Eugenics has many meanings, so many, in fact, that the Commission of the European Communities has omitted it from its revised human genome proposal (1989) as lacking precision. According to Paul's (1992) excellent review, the various definitions of eugenics include the following dichotomies: (1) intention/effect; (2) science/social policy; (3) coercion/voluntary choice; and (4) individual/social.

Intention Versus Effect

Eugenics may apply to intentions, regardless of effects; it may also mean effects, regardless of intentions (Carlson 1984, 1986). If eugenics means intentions, it does not apply to most abortions after PND, because women do not abort with the intent of improving the gene pool. However, if eugenics applies to unintended consequences of individual decisions, PND and selective abortions could be considered eugenic (Wright 1990).

Duster (1990) believed that individual, private decisions are a "backdoor to eugenics," because their collective results will affect the genetic make-up of the entire population. According to this view, most individuals and families will make similar decisions because they subscribe to a unified ideal of human health and perfection. The sharp reduction in the incidence of certain birth defects, such as Tay-Sachs disease in the United States and spina bifida or thalassaemia in the United Kingdom, suggests that families are making decisions with regard to these disorders that decrease incidence of disease and therefore are "eugenic." However, for less serious disorders it is likely that individual decisions will differ in a pluralistic society. Individuals and diverse social groups usually have different ideas about what constitutes health, unless they are given biased information or are coerced by some social policy.

The Canadian College of Medical Geneticists (CCMG) has argued that "prenatal diagnosis in Canada has neither a positive nor a negative eugenic effect, because it does not seek to change the heritable characteristics of the species in any way or encourage any particular course of action by clientele receiving this service. Rather, prenatal diagnosis provides information to couples who elect to have the testing in order to make an informed choice concerning their reproductive plans" (CCMG 1991, 1129).

Science Versus Social Policy

Originally, eugenics was defined as a science rather than social policy. Francis Galton, who originally coined the term in 1883, described eugenics as

> the science of improving the stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognisance of all the influences that tend in however remote a degree to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had. (Galton 1883, 24-25)

Some modern definitions are so innocuous as to equate eugenics with the science of medical genetics itself (Haller 1984), in the absence of social policy.

However, most definitions assume an agent that promotes or interferes with a natural or social process to bring about a desired change in the population. Such definitions include "the promotion of reproductive options favoring desired human genetic traits, especially health, longevity, talent, intelligence, and unselfish behavior" (Carlson 1984, Glossary V) or "attempts to improve hereditary qualities through selective breeding" (Davis 1990, 283). These definitions assume that eugenics is a conscious policy of the State or of an organization that "promotes" or "attempts" such changes.

However, as noted previously, eugenics may be defined in terms of effects or consequences rather than intentions. Under this definition, the

agents may be individuals or families as opposed to (or in addition to) the State or other social institutions. The collective results of individual actions may be unanticipated by or even abhorrent to the individuals who made these decisions. A broad definition of eugenics that includes unintended consequences of individual actions will necessarily include ordinary acts of human reproduction and the use of new reproductive technologies (Carlson 1986). Families will choose the kind of children they want, and the result will be a form of "homemade eugenics" (Wright 1990) in the absence of direct social policy. It is exactly this kind of eugenics that critics of PND fear (Arditti et al. 1984; Corea 1985; Holmes et al. 1980, 1981; Hubbard 1985, 1987, 1990; Lippman 1991a; Rodin and Collins 1991; Rothman 1986, 1989; Spallone 1989; Spallone and Steinberg 1987). They have noted that (1) individual decisions are not always truly individual, but occur in a social context that may alter or limit choice (Lippman 1991a), and (2) the collective results of individual decisions may lead to social policies that discriminate against the minority who make different decisions and, especially, against persons with disabilities (Bayer 1991). This kind of "eugenic discrimination" could be particularly invidious in a democratic society, where it could occur by virtue of majority "vote" (or at least majority action) rather than by authoritarian decree.

Coercion Versus Voluntary Choice

Many people reject any definition of eugenics that includes the unintended consequences of individual actions, in favour of a definition that includes coercion and social goals. For example, Holtzman defined eugenics as "any effort to interfere with individuals' procreative choices in order to attain a societal goal" (1989, 223). What people are most likely to find objectionable in eugenics is not the goal, but the coercive means of achieving it. To this way of thinking, policies and practices designed to improve the health of the population do not come under the rubric "eugenic" unless they are coercive. Yet the history of the eugenics movement, especially in the United Kingdom, points to many non-coercive approaches that were acknowledged as eugenic (Hogben 1931). According to Ellis, the only compulsion we can apply in eugenics is the "compulsion that comes from within" (1912, 45). Instead of sterilizing people with mental illness or retardation, as occurred in the United States (Rafter 1988; Reilly 1991), the British eugenicists advocated public education and voluntary birth control for negative eugenics (reduction of undesirable traits) (Soloway 1990). A definition of eugenics that requires coercion as one of its elements would exclude most positive eugenics (increasing desirable traits instead of reducing undesirable traits), because most attempts at positive eugenics (except for the Nazi *Lebensborn* project) have been voluntary. (For example, the Repository for Germinal Choice, a sperm bank specializing in Nobel Prize winners and other leading scientists, is voluntary but openly claims to be for the betterment of the race.) A defini-

tion of eugenics that includes legal coercion would necessarily exclude PND, because nowhere in the world (with the possible exception of one province in China) is PND required by law.

A further problem with including coercion in a definition of eugenics is that it is not easy to decide what is meant by coercion. In the narrowest interpretation, coercion means legal compulsion or legal restraint; this is an inherently conservative definition. A decision is considered voluntary if there are no legal barriers to choice. According to this definition, women are free to choose whether or not to have PND and whether to abort or carry to term a fetus with a genetic disorder. Yet, other meanings of coercion depend on economics or social status rather than law (Lippman 1991a). These are described later under "The Social Context of Choice." With regard to PND, everyone agrees that coercion is bad, but many disagree about what coercion means.

Individual Versus Social: The Goals of Counselling

Individual/social is another dichotomy in definitions of eugenics. Actions may be defined as eugenic if their intention is social (such as preventing the costs to society of raising children with disabilities) and as not eugenic if their intention is to promote informed choices by individuals. For example, most genetic counselling around the world would be considered non-eugenic today because 99% to 100% of counsellors strive to be non-directive and to help individuals and couples achieve their parenting goals and understand their options and the present state of medical knowledge so they can make informed decisions (Fraser 1974; Sorenson et al. 1981; Wertz and Fletcher 1988a, 1988b, 1989d, 1989e). Counsellors tell patients that the decisions, especially reproductive ones, are theirs alone and refuse to make any for them (92%); they also claim to support any decisions patients make (94%) (Wertz and Fletcher 1988a, 1989a).

Bioethicists (Fletcher 1978, 1979, 1982, 1986, 1987, 1988, 1989; Fost 1989; Roy 1986), commissions (Knoppers 1991; Science Council of Canada 1991; U.S. President's Commission 1983; Institute of Society, Ethics 1972), and professional bodies (American College of Obstetricians and Gynecologists 1987; American Society of Human Genetics 1991; Society of Obstetricians and Gynaecologists of Canada 1983) have all agreed that the essence and goal of PND should be freedom of choice regarding congenital disorders.

According to the CCMG, "the objectives of prenatal diagnosis are fourfold: (a) to offer the widest possible range of informed choice to women at risk of having children with a genetic abnormality; (b) to provide reassurance and reduce the level of anxiety associated with reproduction, especially among high-risk women; (c) to enable high-risk women to continue a pregnancy by confirming the absence of the genetic disease in question; and (d) to facilitate optimal treatment of affected infants through early diagnosis" (CCMG 1991, 1129).

It is not only the non-directiveness, but the individual-versus-family focus of genetic counselling that places it outside most definitions of eugenics. However, as Kevles (1985) notes in his concluding chapter entitled "The New Eugenics," the shift of counselling during the 1960s away from concern with improving the welfare of the population to improving the welfare of individuals and families took place partly for political reasons. Many of the early post-World War II geneticists in Canada and the United States sincerely believed in improving the biological quality of the population but rejected any association with the eugenics movement (Paul, in press; Sorenson 1992). They focussed on voluntary, individual decision making. Reed (1974) coined the term "genetic counselling" to replace the earlier terms "genetic advice" and "genetic hygiene," which sounded too directive. Kevles believes that this shift in ethos to place the needs and rights of individuals and families above the welfare of the population or gene pool marked a decisive break with the past and that the so-called "new eugenics" is beneficial because it is devoted to the interests of individuals rather than society. Popular books that lionize the Human Genome Project, often rather uncritically, usually agree with Kevles that the old eugenics is gone forever (Davis 1990; Wingerson 1990). Yet the shift toward a more egalitarian form of counselling and away from outright directiveness retained some goals of the eugenics movement. Reed believed that directiveness was unnecessary because, given adequate information, most patients would make "rational" decisions (e.g., not to have children if they were at high risk for serious mental disorders). According to Reed: "If our observation is generally correct, that people of normal mentality, who thoroughly understand the genetics of their problems, will behave in the way that seems correct to society as a whole, then an important corollary follows. It could be stated as a principle that the mentally sound will voluntarily carry out an eugenics program which is acceptable to society if counselling in genetics is available to them" (Reed 1952, 43).

In addition, Reed believed that those who sought genetic counselling were so superior in intellect and character that they would, on balance, make a positive contribution to the gene pool even if their reproductive decisions were not always rational. In other words, genetic counselling could afford to be non-directive because:

1. most patients would make eugenically rational decisions on the basis of information provided; and
2. most patients who sought out the service were genetically superior in intelligence, moral character, and parenting abilities and therefore ought to have children anyway, even if some of their decisions were dysgenic for a single gene (Reed 1954).

In other words, Reed assumed that most patients who sought genetic counselling would be well educated and well-off, a prediction that proved true in early studies of genetic counselling (Sorenson et al. 1981).

Another reason for the shift described by Kevles stemmed from the professional locus of early genetic counselling. Many early counsellors were academic scholars rather than medical practitioners. Sorenson (1992) suggests that the ethos of non-directiveness emerged from the "value neutrality" of academics, which contrasts with the "activist-interventionist" bent of many clinical practitioners, who feel that they should offer advice on all subjects.

Ludmerer (1972) believes that there was no shift in ethos, and that the goals of the eugenics movement entered medicine, unpretentiously, through genetic counselling. The previous quotations from Reed suggest that Ludmerer and others (Margolin 1978) may be right. Most geneticists in Canada (68%), the United Kingdom (71%), the United States (78%), France (81%), and 15 other countries (74%) still believe that the eugenic goal of "improvement of the general health and vigor of the population" is important, but it is not the primary goal of counselling (Wertz and Fletcher 1988a, 1989e). Fewer geneticists in Canada (51%), the United Kingdom (48%), the United States (47%), France (50%), and 15 other countries (54%) believe that another goal of Kevles' "old eugenics," namely "reduction in the number of carriers of genetic disorders in the population," is an important goal of counselling. Most geneticists in Canada (98%) and 18 other countries (97%) believe that "the prevention of disease or abnormality" is an important goal of counselling; and 11% in Canada, 69% in France, 19% in the United Kingdom, and 7% in the United States believe that this is "absolutely essential" (Wertz and Fletcher 1988a, 1988b, 1989e). There may be less difference between the goals of the "old" and the "new" eugenics than Kevles believes (Kessler 1989, 1992).

Some would argue that the term "new eugenics" is a misnomer, because technologies that increase choices cannot be eugenic (Fletcher and Wertz 1992c). The prevailing view in biomedical ethics is that needs and rights of individuals should take precedence over the needs of society (Beauchamp 1988; Beauchamp and Childress 1989). Yet, it is not clear that all "good" is on the side of individuals, or that all evil is on the side of society.

Feminists, believing that individuals must be seen in a context of relatedness, argue that technologies must be judged on the basis of their social consequences, especially their effects on women, minorities, and people with disabilities (Hubbard 1985, 1987, 1990; Lippman 1991a). According to these critics, individual choices in PND have social consequences and are therefore eugenic; however, they are somewhat uncertain about what to do beyond labelling and urging caution. Most would like to see women retain freedom of choice with regard to abortion in general, including abortions for genetic disorders or fetal malformations. However, some (Asch 1989; Hubbard 1990; Kaplan 1993; Lippman 1991a; Rothman 1986, 1989; Saxton 1984, 1987, 1988) regard abortion after prenatal diagnosis of a severe congenital disorder as ethically more problematic than abortion of a healthy fetus for even the most "frivolous"

reason. Although this argument may appear illogical at first, the deeper reasoning is based on the social outcomes of individual decisions. By aborting fetuses with certain characteristics, women and families are labelling certain kinds of people as not worthy of life and are deciding what sort of people should inhabit the world. Assuming that most individuals make similar choices, that these choices will be influenced by prevailing economic and social standards, and that PND will become routine in most pregnancies, they judge we will sooner or later arrive at a eugenic society. The critics would like to see women retain absolute rights of choice, but at the same time they would like to see these choices tempered by compassion. Overall, they subscribe to the prevailing ethic of radical individualism and autonomy prevalent in Western medical ethics.

One reason that eugenics has such a negative connotation is that all eugenicists, whether radical, liberal, or conservative — including Francis Galton (1883), Madison Grant (1916), George Bernard Shaw (1905), Bertrand Russell (1929), and Jane Clapperton (1885) — believed that individual desires must be sacrificed to the public good. Even John Stuart Mill, who believed in the widest possible scope of individual choice, thought that the State should take responsibility in regard to reproduction. Urging "responsible parenthood," he argued that "to undertake this responsibility — to bestow a life which may be either a curse or a blessing — unless the being on whom it is to be bestowed will have at least the ordinary chances of a desirable existence, is a crime against that being" (Mill [1855] 1991, 120). (Echoing Mill's statement, Hungarian obstetrician/geneticist Andrew Czeizel (1988) argues that children have "the right to be born healthy" and the State has the moral and legal responsibility to ensure their healthy birth. Czeizel is the last geneticist to advocate this kind of eugenics openly, but others may tacitly support this view.) Feminist critics of new reproductive technologies are uneasy with statements such as Mill's. They reject interference with women's choices, but are at the same time uncomfortable with both the existence and the social outcomes of these choices. As Fox-Genovese writes, feminist theory includes an "uneasy coexistence of communitarian and individualistic commitments" (1991, 41).

Labelling a technology as eugenic does little to clarify these issues. In view of its multitudinous and sometimes contradictory meanings, it would clarify discussion of the word if it were dropped from discussions of PND altogether.

There remains the problem of defining what it is that people fear when they use the word "eugenics." The basic fears, discussed later, appear to be (1) coercion into having PND and abortion; (2) exploitation of women for the benefit of medical or social institutions; (3) excesses or misuses of PND for purposes such as sex selection; and (4) discrimination against people with disabilities, especially if their births could have been prevented. Underlying this latter fear is a sense that there may be public feeling that it is better if individuals with severe disorders are not born, sometimes voiced as a belief that "some people should not have children." For

example, when a television newscaster with a genetic disorder affecting her fingers and toes recently announced that she was pregnant, there was a public outcry from listeners that she was unfair to the child. Genetic counsellors may be non-directive, but the public, in this case, was not.

Issues such as the redefinition of health or normalcy or the definition of personhood play a lesser role in such critiques, though they are important in religious or philosophical discussion of the issues. Perhaps the real threat is the free-market system. Privatizing reproductive decisions can lead to "commodification" (Rothman 1986, 1989) or "commoditization" (Paul 1992). Nozick (1974) spoke of a "genetic supermarket" in which parents would order children with the characteristics they desire. Wright argued that the real danger "isn't that the government will get involved in reproductive choices, but that it won't. It is when left to the free market that the fruits of genome research are most assuredly rotten" (1990, 27). Instead of using the word "eugenics" to create anxiety, society might pay more attention to the effects of market forces on individual decisions.

Positive Eugenics: Enhancement

PND is more readily applicable to negative eugenics (elimination of characteristics deemed undesirable) than to positive eugenics (promotion of characteristics regarded as desirable). At present, it is not scientifically feasible to use PND as a method of enhancing the characteristics of individuals or populations. However, in the future it may be possible to identify fetuses with above-average qualities of certain kinds, such as resistance to specific diseases, mathematical ability, or higher general intelligence. If this ever becomes possible, some families may wish to use PND to select only "above-average" children for birth, rejecting those that are merely normal. The first such selections would most likely creep in under the guise of promoting children's health, by selecting for birth only those with above-average resistance to fatal and untreatable diseases. Subsequent selections would involve cognitive abilities, which are thought to be the route to success in modern cultures.

There are ethical and social objections to use of PND for enhancement, in addition to what may be insurmountable scientific problems. First, such uses would increase social inequality. Families with more education and income would be more likely than others to demand and obtain such services. Second, selection of a fetus on the basis of certain genetic qualities does not guarantee that the child will be loving, successful, or happy. High intelligence does not necessarily lead to "success." Most of the qualities needed for success in work or in human relationships are learned socially rather than transmitted genetically. Selection on the basis of a particular characteristic, such as predicted high intelligence quotient (I.Q.), could mean overlooking characteristics that are far more predictive of a child's ultimate welfare, such as ability to relate to others. A "smart" child is beneficial to neither family nor society unless the child has

interpersonal and social abilities, which may have both genetic and environmental components. What most parents want is not a genius who does well on I.Q. tests, but rather a child who is loving, happy, normally intelligent, and able to live and work successfully in society. It appears highly unlikely that there will ever be a genetic formula for identifying such children in the womb. Even selection for above-average resistance to disease has pitfalls. For example, suppose one could select for resistance to old-age pneumonia and subsequently found that people outlived their brains, bones, or other parts of their bodies. Selection on the basis of single characteristics or even clusters of characteristics that exceed the normal has dangers for both the individual and society. Fortunately, it seems unlikely that PND will be used for this purpose.

The Social Context of Choice

Some feminists have claimed that women say they "have no choice" about having PND (Lippman 1991a), implying that they have been pressured into it. Yet when asked in surveys or interviews, most women say that they had a free choice, without interference from their partners, family, or doctors (Evers-Kiebooms 1987; Evers-Kiebooms et al. 1990; Frets and Niermeijer 1990; Sjögren and Uddenberg 1988; Swerts 1987). Both statements may be true, depending upon the meaning of "choice." If choice is the absence of legal coercion or coercion by partner or family, clearly women have a choice. However, if choice is interpreted in the broader context of economic and social realities, many women may believe that the possible alternative to PND — raising a child with a disability — is so unattractive that it does not present a real choice. In the liberal tradition (Green 1889) or to socialists, freedom of choice means the practical ability to act upon one's decision. If freedom of choice means the absence of legal coercion (or, by extension, coercion by husband or family), a woman carrying a fetus with a severe genetic disorder is free to abort or carry to term. If choice means being able to live with the consequences of this decision, many women may feel that they "have no choice," because the economic and social costs of raising the child could be unbearable.

It is important to remember that the abortion controversy arose just as women were gaining a new measure of dignity and self-respect as people, aside from their role as mothers. Luker (1984), in her excellent book on pro-life and pro-choice activists, argues that the modern abortion debate would not have arisen except for the change in women's roles. Although abortion was common in the nineteenth century, women felt far less conflict about it than they do today (Mohr 1978). Women's entry into the paid workforce has led to their empowerment and to a new self-definition. Instead of regarding themselves first as wives or mothers and only secondarily as workers (who justified their work by its economic

benefits for their children), many women now identify themselves first as people who have an occupation, and secondarily as mothers (Luker 1984). In this context, the cost of children to women is higher than ever before (Wertz and Sorenson 1989). Each child means an economic loss of time in the workforce (or an economic loss for day-care to replace oneself at home), a loss of years in job or career advancement, and a tremendous drain on energy for women, who often still take major responsibility for the home in addition to working. Women are taking less time out for childbearing. Over half of the mothers with children under one year of age are now in the workforce full time. Women are also having fewer children and spending more time to advance the educational and career prospects of each one. In return for all of this effort and loss of wages, families expect more from each of the few children that they do have. Zelizer (1985) described the changing social value of children. Whereas in the nineteenth century a child was valued in terms of earning potential (usually wages shared with the parents), today children are valued for their emotional rewards. Children are supposed to be loving, to relate well to others, and to have some achievements (in school, athletics, the arts) of which the parents can be proud. Children should be evidence of the parents' earnest efforts at child rearing, at providing all of the advantages — spiritual and material — that they can reasonably afford.

Parents do not necessarily strive for the "perfect child," but probably most would prefer a child who is healthy and also "above average" in some respect. Many parents, especially those with only one or two children, may consider each child a "work of art" upon whom they lavish resources. These attitudes are not new; they go back at least to the beginning of this century, when doctors experimented with new methods of childbirth that were to protect the baby's brain or to prevent criminal tendencies that medicine associated with damage during natural birth. The use of episiotomy and outlet forceps, now routine in most hospital births, arose around 1920 from a desire for healthier children and a distrust of natural processes, a view shared by both women and doctors at the time (Wertz and Wertz 1989). PND is, in a sense, an extension of earlier methods to ensure a "better quality" baby, that is, a baby without detectable disorder. It belongs alongside other, more commonly used methods, such as the Caesarian sections that now account for about one-quarter of births in the United States. As long as these methods appeared to produce a better outcome, or at least healthy babies, few women complained. Fewer still decided to give birth outside hospitals, where they could avoid the use of high technology. Despite the plethora of books on natural birth, independent (lay) midwifery, birthing centres, or home birth, most women continue to give birth in hospitals. Perhaps 1% of North American women give birth at home, and most of these are Mexican-Americans living along the Texas-Mexico border (Pearse 1987). Home birth and lay midwifery are choices that few women have made. A major reason is that most women fear that something could go wrong for the baby if they give birth in the

absence of high technology, despite considerable evidence that home is as safe as hospital for low-risk women and newborns (Wertz and Wertz 1989). If something were to go wrong, if the baby were to be deprived of oxygen at birth and suffer mental retardation, however mild, most women would never forgive themselves for having made the "wrong" choice. Perhaps there is an analogy here with choices about PND. The choice exists, but the possibility of having a child with a severe birth defect, if the birth could have been prevented, weighs so heavily on some women's minds that it is as if they had no choice.

If the economic and social cost of having a healthy child is greater to women than ever before, on account of women's entry into the workforce, the cost of having a child with a disability is enormous. The irony is that women who have invested heavily in their education or careers and who have postponed childbearing until their late thirties or early forties face the highest risk for chromosomal abnormalities. These are the women who have the most to lose, economically and socially. Most of the care for children with disabilities falls on the mother (Byrne and Cunningham 1985; Marcenko and Meyers 1991; Thompson and Walker 1989). Not only must she give up much of her paid employment, but she must often adopt motherhood as her primary self-identification. To identify oneself first as a mother, in a world where most women identify themselves as workers, places a woman in a position of relative isolation. Also, she may be a mother for the rest of her life. Medicine has greatly extended the lives of people with disabilities, so that most people with retardation now live a nearly normal lifespan. It is not uncommon for parents who are in their eighties to be caring for children with Down syndrome who are in their fifties (Janicki and Wisniewski 1985; Krauss and Seltzer 1993). When the elderly parents die, care usually falls on the siblings (Seltzer and Krauss 1993). Some siblings have expressed resentment at the extra attention given to the affected person and their own corresponding neglect in childhood (Drotar and Crawford 1985; Lobato 1983; Seltzer and Krauss 1993).

Most people with mental retardation, perhaps 80%, live at home under the care of parents or relatives (Fujuira et al. 1990; Meyers et al. 1985). This has always been so. Institutions were for those who had no families, or who were violent or profoundly retarded (and almost half of those with profound retardation lived at home). Society has never provided either institutional care or in-home care for most people with mental disabilities. In 1967, the peak year for institutionalization in the United States, 197 000 people with mental retardation or developmental disabilities were institutionalized out of an estimated one to two million. In 1990, 82 000 were institutionalized. Cost is not the only reason. Advocates of de-institutionalization and many child psychologists have argued that children with retardation or developmental disorders are more likely to develop to their full potential at home, under the care of their parents, than in an institutional setting. It is now virtually impossible for parents in many

areas to place a newborn or infant in an institution, no matter how severe the retardation. In-home care, even occasional "respite" care, is difficult to obtain. Under these conditions, the choice of not having PND appears to be no choice at all, unless a woman is opposed to abortion under most conditions (Petchesky 1990).

Advocates for people with disabilities argue that women can make meaningful choices about PND only if economic and social supports for families affected by disabilities are increased to the point of adequacy (Asch 1989; Degener 1989, 1990; Finger 1984, 1990; Hubbard 1990; Kaplan 1989, 1993; Lippman 1991a; Saxton 1984, 1987, 1988). Although increased support is necessary in the interests of social justice, it may not present an alternative to PND and selective abortion in all cases. Much of the literature on the effects of PND on attitudes toward people with disabilities regards all disabilities as a generic class and treats them as if equal. This approach is not realistic. Most physical and some mental disabilities can be overcome with social support and changes to the physical environment (Carrier 1986). However, some mental and neurological disabilities require lifetime care and overwhelm the parents' lives. Such disabilities may never be overcome, even with massive economic and social support.

The writings of parents of children with disabilities present a mixed message. Although generally intended to inspire by presenting triumphs over adversity, many such biographies describe the immense effort and sacrifice on behalf of the parents (Deford 1983; Dorris 1989; Forecki 1985; Fraiberg and Fraiberg 1979; Spradley and Spradley 1985). There is no clear outcome that might be labelled "joy" (Retsinas 1991). Instead, many parents write as if the grieving process that began at the child's birth continues throughout the child's life, as a never-ending sense of loss (Simons 1987; Wikler et al. 1981). Parents' accounts represent after-the-fact, largely successful, attempts at coping. (Parents who do not cope usually do not write about their failures.) Those whose children have mental retardation or behavioural problems have described the immense difficulty of daily life. We do not know what these parents might have done if they had had a choice. Probably, many would prefer not to think about the possibility, because to negate the birth of a child like theirs is to devalue both their child and their own coping efforts. However, studies in England have shown that from two-thirds (Simms 1986) to four-fifths (Pahl and Quine 1984) of parents of young adults with severe mental disabilities say that they definitely would have had an abortion had they known what awaited them and had the option of abortion been legal at the time.

Increased social and financial supports for children with disabilities may offer a realistic alternative for some parents, but not for all. Medical treatment itself has resulted in many of the problems that parents face, by extending life for people with serious mental retardation. It is impossible to return to a "natural" state in which women do not have to face the possibility of PND and abortion. Although some critics of PND imply that

such a return to nature would be desirable (Rothman 1986), medicine has so transformed nature that we can no longer refer to nature or to "what nature intended" as a guide for either prenatal or post-natal decisions.

North Americans lost the sense of nature in childbirth sometime in the nineteenth century (Wertz and Wertz 1989). We must face the fact that we live in a technological age that women themselves helped to bring about (Cowan 1992, 1993; McDonough 1990a). Parents have always made choices — often negative ones — about infants with disabilities; for centuries Europeans exposed or abandoned such newborns, usually placing them where they would not be found by kindly passers-by (Boswell 1988). The Catholic church made no effort to eradicate this custom. Many of these infants would no doubt have died before the advent of modern medicine. Although some (Glover 1984; Kuhse and Singer 1985) would argue in favour of allowing newborns with severe disabilities to die, legal or hospital regulations, together with the almost automatic urge of perinatologists to save life, effectively prevent it. Modern medical care has pushed decisions that were made after birth into the period before birth. It is no longer possible for parents to decide whether or not to have a lifesaving operation on a newborn with mental retardation; in most cases, the hospital will overrule the parents and proceed with the operation (Fletcher 1982; Guillemin and Holmstrom 1986). The parents could, of course, decide to place the child for adoption, but few do so, even though there are waiting lists of people willing to adopt children with Down syndrome. (Adoption is less likely for infants with profound mental retardation or likelihood of death within the first few years.) Most parents apparently consider giving up a child with a disability for adoption as the most socially "deviant" course of action they could take. Many doctors do not even mention this possibility. If there is a choice that parents feel they really do not have, it is probably giving up their baby for adoption, an alternative that receives little social support.

For most parents, choices are now limited to the pre-conceptional or pre-birth period. Having foreclosed choices that once existed post-natally, medicine now offers new choices prenatally. It appears that most women accept these choices. The increase in the use of PND in Canada (Hunter et al. 1987; McDonough 1990b; Roy and Hall 1989), Denmark (Therkelsen et al. 1989), Germany (Schroeder-Kurth and Huebner 1989), the United Kingdom (Farrant 1985; Harris and Wertz 1989; Terzian et al. 1985), and the United States (Adams et al. 1981; Hook and Chambers 1977; Hook and Schreinemachers 1983; Marion et al. 1980; Mulvihill et al. 1989) suggests rapid adoption of the new technologies. Women who have had amniocentesis and have aborted fetuses with Down syndrome write of their relief at being able to make this decision (Brown 1989; Eichholz 1989; Green 1992; Hodge 1989; Rapp 1984; "When Risk Factors" 1989). Even though the decision was often difficult and psychologically stressful, these authors believe that PND freed them to go on with their lives, to continue their careers, and to have healthy children. Although sensitive to the need to

provide adequate support for those with disabilities, they believe that PND will continue to offer the best alternative for many women carrying fetuses with serious mental retardation (Rapp 1984, 1992, 1993).

Why, then, do some authors argue that women have no choice about having PND, or that women are coerced into it? Rothman, for example, argues that "amniocentesis and selective abortion, like embryo transplants, surrogate motherhood, and other new reproductive technology, are all being used to give the illusion of choice ... we should realize ... that human beings living in society have precious little choice ever ... The social structure creates needs — the needs for women to be mothers, the needs for small families, the needs for 'perfect children' — and creates the technology that enables people to make the needed choices" (1986, 14). Hubbard (1985, 1987, 1990) argues that both women and their doctors are pawns of larger economic, class, and patriarchal forces. Women may think that they have a choice in PND, but their actions are determined by social class interests and by society's rejection of persons with disabilities. Although Hubbard believes that PND and abortion should be available, she believes that, on balance, PND presents more problems than promises of liberation. She points to a "technological imperative" in birth that blames women who fail to make full use of available technologies. According to Hubbard,

> such tests may be helpful to that rather small number of women who, for reasons of personal or family history, know that their future children are at greater than usual risk for a particular disability ... However, on balance, I believe that the very existence of such tests makes life *more* difficult for the vast number of women who have no specific reason to anticipate problems. The point is that once such a test is available and a woman decides not to use it, if her baby is born with a disability that could have been diagnosed, it is no longer an act of fate but has become her fault. (1985, 567)

She argues that women should have an unqualified right to abortion, but that abortions on the basis of fetal conditions have a different moral quality from abortions performed for other reasons or even for no reason at all except the mother's whim. If a woman does not want to be pregnant at all, so be it. But to not want to continue a pregnancy after positive prenatal diagnosis of a disorder is to commit a eugenic act parallel to Nazi selection processes (Hubbard 1985, 1987). Hubbard claims that most women would not terminate pregnancies after prenatal diagnosis of congenital disorders if they had a real choice, namely the choice of raising the child in a supportive and accepting society. Along with many others (Beck-Gernsheim 1989; Birke et al. 1990; Bradish 1987; Bush 1983; Tymstra 1989), she argues that there is now a technological imperative to use PND.

Rothman (1986, 1988, 1989) believes that women's choices are dictated by the economics of a free market society: "now we see the commodification process enter all pregnancies, as society encourages the development of prenatal diagnostic technology. This process ... the screening and testing of fetuses, serves the function of 'quality control' on

the assembly line of the products of conception, separating out those products we wish to develop from those we wish to discontinue" (1986, 97).

Lippman argues that the technological and social imperatives favouring PND amount to having no choice. "With prenatal diagnosis presented as a 'way to avoid birth defects,' to refuse testing, or perceive no need for it, becomes more difficult than to proceed with it. This technology perversely creates a burden of not doing enough, a burden incurred when the technology is *not* used" (1991a, 28).

In a footnote commenting on this burden, she writes: "The degree of this burden is demonstrated by the frequency with which women queried about their reasons for having prenatal diagnosis say that they 'had no choice'" (Lippman 1991a, 28, fn. 61).

However, studies of women having PND clearly indicate that they believed they had a choice (Adler et al. 1991; Frets and Niermeijer 1990; Rapp 1988b, 1990, 1992, 1993; Sjögren and Uddenberg 1988, 1989; Swerts 1987), even if some felt social pressure (Sjögren and Uddenberg 1988). This is more than "false consciousness." The fact that about 7% in the United Kingdom and in California have refused maternal serum alpha-fetoprotein (AFP) screening or PND on moral grounds, even when the tests are offered free of charge under national or state health care systems, suggests that some women are making choices instead of acting as the puppets of larger social forces (Harris and Wertz 1989; Richwald et al. 1990).

The history of PND also points to women's active and personal choices. In contrast to other areas of experimentation in the history of obstetrics, where poor women especially were exploited as research subjects (Oakley 1980, 1984; Wertz and Wertz 1989), the history of PND suggests that women actively encouraged research in this area. Women who participated in experiments with amniocentesis tended to be white, middle class, well educated, and vocal — characteristics that encouraged physicians to pursue this line of research with more vigour than they might have otherwise (Cowan 1993). When PND passed beyond the experimental stage, it was women's intervention that helped it become routinely offered to all women at high risk. The actions of individual women, such as Dolores Becker, in suing physicians for not offering PND have ensured that it became a routine part of obstetrical practice (Andrews 1987a; Cowan 1993; Elias and Annas 1987). Courts in the United States have held physicians liable for a child's special medical care for life if the problem could have been diagnosed prenatally and the procedure was not offered (Andrews 1987a; Elias and Annas 1987). The women (and their husbands) who initiated these suits were not acting as the pawns of social class interests; many would have sued even if there were optimum social supports for their children, because such support still does not provide them with the child they wanted.

It therefore appears that women do have a choice, although there is social pressure to use new technologies. The choice, as noted above, is

within the context of other choices about childbirth technologies, such as hospital birth, fetal monitoring, episiotomies, and vaginal birth after Caesarian section. It is extremely difficult, if not impossible, for women to choose to reject technologies approved by the obstetrical profession. Once tests are offered, to reject them is a rejection of modern faith in science and also a rejection of modern beliefs that women should do everything possible for the health of the future child. However, women may have more choice about PND than about most other childbirth technologies, largely because they are not confined to a hospital at the time of testing and because many groups provide strong religious and cultural support for carrying a child with a disability to term.

According to one line of argument, it is doctors and genetic counsellors who inadvertently "coerce" women into having PND and abortion (Clarke 1990). Patients' interpretation of risk, for example, can easily be influenced by doctors' presentations (Marteau et al. 1991), by the type of professional the patient sees (Harper and Harris 1986; Holmes-Siedle et al. 1987), and by whether the professional uses ultrasound to show a visible anomaly (Drugan et al. 1990). Winner (1986, 1990) notes that our concepts of what constitutes a risk are often determined by our social situation.

According to Clarke,

> an offer of prenatal diagnosis implies a recommendation to accept that offer, which in turn entails a tacit recommendation to terminate a pregnancy if it is found to show any abnormality. I believe that this sequence is present irrespective of the counsellor's wishes, thoughts, or feelings, because it arises from the social context rather than from the personalities involved — although naturally the counsellor may reinforce these factors. Thus the Holy Grail of non-directive counselling is unattainable, because the counsellor's conscious or even unconscious motives are irrelevant: the offer and acceptance of genetic counselling has already set up a likely chain of events in everyone's mind. (Clarke 1991, 1000)

Clarke suggests that clinical geneticists may take a more pessimistic view of many genetic conditions than do the paediatricians actively involved in caring for children with these conditions. So far, little research has compared the views of these two groups. That some people with genetic disorders support PND and termination of pregnancy may, according to Clarke, simply mean that "their lives are blighted by social, as much as medical, factors." He compares their support for PND with the support of some elderly people for euthanasia, and claims that it "does not refute the charge that social pressure could induce some elderly people to undergo assisted death" (Clarke 1991, 1000).

Underlying the allegations of Clarke, Lippman, Rothman, Hubbard, and others that women have no choice is a basic conflict in the stated and unstated goals of genetics. As Tesh (1988) states, there are often "hidden arguments" behind public health programs. For example, the focus of today's public health campaigns on changing individual lifestyles may shift

attention away from social and cultural causes of disease. An "individualizing ideology" makes the individual "the supreme arbiter of morality" and blames the individual for ill health. Instead of asking "structural" questions, such as "Why do large numbers of people continue to smoke?," researchers in public health ask, "Why do these particular people continue to smoke?" "The first question directs attention to the tobacco culture in which everyone lives ... The second question directs attention to the psychology and physiology of individual people within that culture. Prevention concerned solely with these individuals conceals an endorsement of the structure" (ibid., 163). A similar analogy may apply to PND. By focussing on preventing genetic disorders in individuals and families, the medical profession may lose sight of the social conditions that help to make some of these less severe disorders into problems. More importantly, the profession, in concentrating on professional-patient relations, may ignore the potential of PND to redefine "normalcy," to upset the sex ratio, or to promote "choices on the basis of 'fashion.'" Clarke (1990, 1991) argues that the traditional public health goal of prevention of disease or abnormality, as espoused by the Royal College of Physicians of London (1989) and as subscribed to by 98% of geneticists in Canada (Wertz and Fletcher 1989e), is itself inimical to choice and implicitly contradicts non-directive counselling.

There may be another hidden agenda behind prevention; namely, saving public money by reducing the number of births of children with disabilities. To obtain public funds for programs in genetics, public health officials must usually speak a language of "cost-benefit" rather than "non-directive counselling" (Conley and Milunsky 1975; Duster 1990; Hagard and Carter 1976; Sadovnick and Baird 1981). Thus, they weigh the cost of lifetime care for an affected child against the cost of detecting the presence of that child in the womb. Cost-benefit analyses usually assume that all affected fetuses will be aborted. Such arguments have a similar ring throughout the world. Some examples include:

- From Israel: "The total cost of the program for the detection and prevention of birth defects for the fiscal year 1985/86 was approximately $370,000 ... Among the interrupted pregnancies there were 37 cases of Down syndrome. The calculated cost of their management was almost $5,000,000" (Chemke and Steinberg 1989, 274-75);
- From Switzerland: "The cost of thousands of prenatal tests, of which fewer than 2% will result in the detection of abnormalities, is only a fraction of the money that would necessarily be spent if these methods of prenatal detection were not available ... The bill for institutionalization of a child in Switzerland is about $4,000 per month, which represents an annual sum of some $48,000; if this figure is multiplied over 30 years (a common lifespan figure in Down syndrome), it easily reaches one-and-a-half million

dollars for each institutionalized individual. In economic terms, then, the sums of money invested to permit this type of prenatal testing are quite justified" (Engel and DeLozier-Blanchet 1989, 362);

- From Denmark: "Prenatal chromosome investigation of women ≥ 35 years of age for Down syndrome alone would give a benefit of around ... ($555,000) per year. Adding the benefit caused by the concomitant diagnosis of other chromosome abnormalities and neural tube defects, prenatal investigations are very attractive from the economic point of view" (Therkelsen et al. 1989, 146); and
- From the United States: "The cost per NTD [neural tube defect] detected would be $87,274, which is far less than the projected costs of lifetime care for an affected child" (Wertz and Fletcher 1989e, 425; Meister et al. 1987, 81-83).

The health policy planners and economists making these statements clearly expect most women to abort for Down syndrome or spina bifida, and most do. Parents make their own cost-benefit calculations using social and emotional costs and benefits, and come to the same conclusion as the economists; namely, that PND and selective abortion offer the "least lose" alternative. Some cost-benefit analyses in genetics also consider emotional costs, as do the parents themselves (Drummond 1980; Modell 1990; Modell and Kuliev 1991; U.S. Congress 1992). Cost-benefit analyses do not necessarily negate parental choices, but most such analyses are made on the basis of costs and benefits to society rather than to individuals. Modell and Kuliev (1991) argued that there are also benefits to individuals, families, and entire groups of people at genetic risk, because those who would otherwise have forgone having children entirely may now reproduce, using PND to ensure that they have only healthy offspring. This is what has happened among Cypriots at risk for having children with thalassaemia major in Britain (Kuliev et al. 1985; Modell and Mouzouras 1982; Modell and Petrou 1988; Modell et al. 1980). (Modell discounted the increased numbers of births of children who are carriers of thalassaemia, arguing that in the absence of an environmental advantage for carrier status, the proportion of carriers in the population will not increase.)

In contrast to Modell's experiences with thalassaemia, parents of children with cystic fibrosis in the United States have generally so far preferred to curtail reproduction rather than use PND (Wertz et al. 1992). However, the diagnostic testing here is not as clearcut.

Some authors have argued that doctors themselves are coercing women into having PND and selective abortion by providing directive or slanted counselling (Hubbard 1985, 1987, 1990; Lippman 1991a). There is little evidence of this in Canada. In a 1985-86 survey to which 47 of the 73 members of the CCMG responded, 91% said that they would counsel non-directively about an XYY fetus and 9% would advise carrying to term

(Wertz and Fletcher 1989e, 1992; Wertz et al. 1990). In the case of a 45,X fetus, 98% would counsel non-directively and 2% would advise carrying to term. In the case of a fetus with a possible small neural tube defect, 94% would counsel non-directively, 2% would advise carrying to term, and 2% would advise abortion. Overall, the percentage of those in Canada who would be non-directive in these three cases slightly exceeds the percentage who would be non-directive in the United Kingdom and United States, and exceeds by a considerable margin the percentage who would be non-directive in France (35%, 82%, and 56%, respectively, for the three cases in France). Women geneticists, who comprised 42% of the Canadian respondents, were three-and-one-half to six times as likely as men to be non-directive, according to a multivariate analysis (stepwise logistic regression) that included all professional and personal characteristics. In the case of an XYY fetus, 26% in Canada, 18% in the United Kingdom, 23% in the United States, and 0% in France would discuss the emotional difficulties of termination. In the case of a 45,X fetus, 28% in Canada, 24% in the United Kingdom and United States, and 18% in France would do so. Although geneticists in Canada appeared to be largely non-directive, there nevertheless remained a small percentage who would give directive advice. Perhaps the greater failing was that almost three-quarters would not prepare women for the emotional results of abortion carried out for "genetic" reasons. The grief after the abortion of a wanted pregnancy can be quite severe (see "How Parents View Selective Abortion" in this paper).

The results of an earlier study of 1 369 genetic counselling cases in the United States suggest that although nearly half of those counselled said they had been influenced by counselling, they were no more likely to change their reproductive decisions than those who had not been influenced (Wertz and Sorenson 1986). About one-third came to and left counselling uncertain of their reproductive plans (Wertz et al. 1984).

Although most geneticists seem to follow the principles of non-directiveness, no one knows how other physicians or health professionals (such as nurses or social workers) counsel. Much genetic information is conveyed by paediatricians, obstetricians, and family or general practitioners. In one study, only 17% of parents of children with cystic fibrosis had ever seen a genetic professional; 40% had received their genetic counselling from the child's cystic fibrosis doctor (Wertz et al. 1992). In this study, 43% of parents thought that their cystic fibrosis doctor would be neutral toward PND and abortion for cystic fibrosis, 42% thought their cystic fibrosis doctor would disapprove of abortion for cystic fibrosis, and 15% thought the doctor would favour carrying a fetus with cystic fibrosis to term. Paediatricians, who struggle to keep children with genetic disorders alive, may be more optimistic about some disorders than are geneticists, but as yet there is no research to substantiate this supposition.

On the other hand, obstetricians have a long history of directiveness in pregnancy and birth (Leavitt 1986; Oakley 1980, 1984; Scully 1980; Wertz and Wertz 1989). Obstetricians provide the primary counselling for

many women having PND for advanced maternal age. North American obstetricians generally favour the use of high-tech methods in birth, including fetal monitors (Ruzek 1991; Wertz and Wertz 1989). There is no reason to believe that they would feel otherwise about high-tech methods applied to pregnancy, if such methods promised a better outcome, meaning a healthier baby. Therefore, by virtue of their training and professional culture, it is reasonable to expect that obstetricians would favour the use of PND and that they might actively encourage women to have it. In one study, they were also more pessimistic than other practitioners about sex chromosome anomalies (Holmes-Siedle et al. 1987).

Lawsuits act as a further driving force behind obstetricians' use of PND. Under "wrongful birth" suits, parents of affected children have recovered the costs of the child's extraordinary medical care for life (though they have not, as yet, recovered damages because the child was born) (Andrews 1987a). Some obstetricians may fear that to avoid lawsuits, they must not only suggest PND when it is medically indicated (in the sense of informing patients about the procedure and standing ready to perform it), but they must also actively encourage or urge patients to have it. Other obstetricians may feel that they are not providing adequate prenatal care if they do not use all of their high-tech professional expertise.

Some women may feel coerced by their obstetricians, totally apart from any contact with a genetics professional. However, as stated earlier, there is no hard evidence showing coercion by obstetricians to make women have PND, although there is a host of literature from the natural childbirth and women's health movements (Arney 1982; Boston Women's Health Book Collective 1984; Rothman 1982; Ruzek 1991; Wertz and Wertz 1989) reflecting women's experiences of loss of control over pregnancy and birth. Women may actually exert more control over decisions about PND and abortion than they do over most other aspects of pregnancy and birth. Studies have indicated that PND is one procedure that some women have consistently refused (Harris and Wertz 1989; Mulvihill et al. 1989), usually on the basis of personal values or religious beliefs about abortion. If obstetricians are using coercion, they have not been entirely successful. Interview and questionnaire studies in Sweden point to the absence of coercion (Sjögren and Uddenberg 1988, 1989); unfortunately, there are no comparable studies in North America.

Failure to inform women adequately may be a greater danger to decision making than coercion (Chervenak et al. 1989; Faden 1991). Canadian studies have suggested that although most women know PND exists, some are reluctant to ask for it or even to mention it unless their doctor suggests it (Davies and Doran 1982; Dawe 1986, 1988). Until lawsuits made PND a standard of care for women over 35 years of age, some doctors did not mention it. In one U.S. study, the most important variables affecting women's use of PND were the knowledge, interest, and attitudes of obstetricians (Bernhardt and Bannerman 1982); however, some have not suggested it. In a study of 520 women who had had amnio-

centesis, 36% had learned of the procedure from their obstetricians and 36% had learned of it from the media (McGovern et al. 1986). Under-referral accounts for much underutilization in Canada as well (Lippman-Hand and Piper 1981).

In a country without national health insurance, such as the United States, poor or less educated women are less likely to receive information about, or to have, PND than better educated women (Bannerman et al. 1977). For example, in a study in Georgia of women over 40 years of age, 60% of whites in urban areas and only 0.5% of African-Americans in rural areas used PND (Sokal et al. 1980). Although no similar data exist for minorities in Canada, there are strong suspicions in Canada and other countries that use of PND is correlated with education and social class (Harris and Wertz 1989; Schroeder-Kurth and Huebner 1989; Therkelsen et al. 1989). Educated women are better able to make requests and to insist upon their rights. Counselling sessions with educated patients show higher levels of communication and of counsellor satisfaction (Wertz et al. 1986, 1988a, 1988b). Ironically, educated women are more likely than others to report that they were influenced by counselling (Wertz and Sorenson 1986).

Counselling less educated patients and ethnic minorities regarding PND can bring special problems of communication (Murray et al. 1980; Nsiah-Jefferson 1989). According to Rapp (1987, 1988a), 50% of patients (mostly African-American or Hispanic) at publicly supported clinics in New York City break their appointments for counselling, and 20% to 50% of those who are counselled decide not to have PND, largely because of religious and cultural beliefs. (In contrast, only about 10% of patients in private care break their appointments for counselling.) Sometimes low-income and minority groups do not receive counselling at all (Roghmann et al. 1983). When counselling and PND are provided to minority groups, it is sometimes done paternalistically or autocratically, for example, by refusing PND to carriers of sickle cell trait if their partners cannot be located (Bowman 1991). Rural patients and Native American women also tend to be underserved (Coffman 1993). Some hospitals have made special, successful efforts to introduce PND to low-income women (Marion et al. 1980).

Asian patients frequently expect directive counselling and become confused by non-directiveness (Pedersen 1987; Sue 1990; Wang and Marsh 1992; Yuen 1987). Some look to the counsellor's non-verbal gestures for clues to the counsellor's intentions. There is no easy solution to the problem of communication between a majority culture that believes in patient autonomy and minority cultures that believe doctors should be authority figures and that decisions — including decisions about PND and abortion — are the responsibility of extended families rather than individuals.

There is considerable room for improvement in communication generally, even with patients from cultural majorities. For example, some

maternal serum AFP screening programs do not tell patients that having their blood drawn may be the first step on the road to PND and abortion (Press and Browner 1993). Some genetic counselling sessions fail to address patients' primary concerns. In one study of 1 369 counselling sessions, in 47% of cases neither client nor physician was aware, after 45- to 60-minute sessions, of the topic the other party had most wanted to discuss (Wertz et al. 1988b). Both parties were aware of what the other had wanted to discuss in only 26% of sessions. Yet counsellors said they were satisfied with 95% of sessions (Wertz 1988a). Their level of satisfaction was based on their own inaccurate perceptions that they had successfully communicated information about risk, etiology, and prognosis to the client, but these perceptions had no relation to actual client learning (ibid.). It would appear that communication is a bigger problem than "coercion."

To summarize, the evidence is that (1) women exercise choice in regard to PND; (2) there are social pressures to use PND in a technological culture, just as there are pressures to give birth in hospitals and to use other birth technologies; (3) women probably have more power over choices about PND than they do over other technologies used in birth; (4) the greatest threat to choice may be failure to inform women about PND, leading to under-utilization; (5) there are hidden arguments in public health programs, including genetic screening programs, that shift attention away from social and cultural causes of ill health or definitions of ill health; and (6) the goals of disease prevention or cost-benefit arguments may be at odds with the goals of genetic counselling that stress helping individuals come to decisions that are best for them.

The Exploitation of Women

Exploitation is not the same as coercion. As Feinberg (1983) noted, exploitation can exist in the absence of coercion, as long as one party benefits disproportionately from an interaction. Critics of all the new reproductive technologies argue that such technologies exploit women and aggrandize the medical-scientific establishment or the biotechnology industry. At the extreme, feminist critics claim that all modern technology is a manipulative patriarchal plot against women (Arditti et al. 1984; Corea 1985; Rothschild 1983; Spallone 1989; Spallone and Steinberg 1987). They direct most of their attention against reproductive technologies. This is exemplified in the following statements from the FINRRAGE Conference held in Sweden in 1985:

> We ... declare that the female body, with its unique capacity for creating human life, is being expropriated and dissected as raw material for the technological production of human beings ... Genetic and reproductive engineering is another attempt to end self-determination over our bodies ...

> We know that technology cannot solve any problems created by exploitative conditions. We do not need to transform our biology, we need to transform patriarchal, social, political, and economic conditions ...
>
> We call on women to resist the take-over of our bodies for male use, for profit making, population control, medical experimentation and misogynous science. Life for us always means risk. It cannot be programmed or perfected ...
>
> We condemn the use of women from exploited countries and poor women by men and international conglomerates in the interests of global capital and patriarchy ...
>
> We support the recovery by women of knowledge, skill, and power that gives childbirth, fertility, and all women's health care back into the hands of women. (Cited in Spallone and Steinberg 1987, 211-12)

In the same vein, Rothman (1989) and Whitbeck (1973-74, 1984) describe the "flower-pot theory" of conception and pregnancy whereby the man plants his seed and the woman provides only the container for a child that is a totally separate being-unto-itself, devoid of relationship to her. Rothman argues that new technologies reify this being and provide a "quality control" to help ensure that it will meet patriarchal specifications. Margaret Atwood, in her futuristic novel *The Handmaid's Tale* (1986), describes a society in which fertile women have become the unwilling vehicles for a quality-controlled state reproductive system in which newborns are divided into "keepers" and "shredders," and a special semi-slave class of women (handmaids) must produce at least one "keeper" to save their own lives. (Ironically, it is worth noting that there is no reproductive technology in this book — the ends are all achieved by tyranny and political coercion.)

The concern underlying these statements becomes more understandable in the light of the history of childbirth in developed nations, especially in North America. For at least 200 years, some doctors have exploited pregnant women and women giving birth, displaced midwives, and built a lucrative profession for themselves. In the United States, especially, medicine was a business throughout its formative years — conducted in an entrepreneurial style similar to that of small shopkeepers, without effective regulation. To demonstrate their superiority to midwives and sometimes to make up for their own lack of experience (until 1852 American medical education included no clinical teaching), some nineteenth-century obstetricians used and over-used whatever medical technology was at hand — ergot, forceps, bleeding, mercury — in spite of the warnings of the very best physicians of the day. The trend toward use of technology continued in the twentieth century, with episiotomies, outlet forceps, use of analgesics, induced labours, high Caesarian section rates, and fetal heart monitors. Throughout most of this history, women and families not only acquiesced in the increased use of technology, but often actively sought it. Women, including feminists, campaigned for the use of

a "twilight sleep" in the 1920s. Women were not coerced into giving birth in hospitals earlier in this century. Although hospitals did much to lure them in (partly for economic motives), women made the choice themselves. Under the circumstances of the 1920s and 1930s, the hospital seemed the best choice, both in safety and in comfort. After a while, there was no realistic choice left for most women except the hospital. Once inside "the doctor's castle," the cascade of interventions in birth could begin in earnest. As early as the 1950s, women began to complain that they were treated as machines on an assembly line and that birth was utterly dehumanized. Early attempts at "natural childbirth" were quickly co-opted by obstetricians. Not until the women's movement of the 1970s gained momentum were there large-scale attempts to re-humanize hospital births. Much of the reform in birth (birthing suites, the presence of husband and other children) was spurred by economic competition among hospitals and also by fear on behalf of hospitals that a newly vocal home birth movement or out-of-hospital birthing centres might take away their business.

Birth remains stubbornly technical, and few women have taken the option of home birth, though more might do so if the cultural climate were more favourable. Most would feel guilty if they refused a birth technology or a hospital that provided such a technology that could have prevented problems. The entry of women into medicine will not necessarily re-naturalize birth. Even though women have at long last been allowed into the profession of obstetrics in recent years, and now comprise perhaps 30% to 50% of residents, these women are trained to rely on high technology. Whether they will use more or less of it than their male counterparts is not yet known.

This story is not pretty. Doctors have in the past exploited women. Medicine has been a business. Technology has been over-used in birth, to the detriment of women and infants. Poor women in clinics have served as research subjects, usually unknowingly until the Nuremberg Code established the concept of informed consent. If some women now regard all technology as a patriarchal plot against women, their anger is understandable in view of this history. Their attack on PND must be seen in the context of the larger history of overuse of technology in birth and the history of women's loss of control over birth. PND, like other birth technologies, leads women away from trust in their own bodies (Leuzinger and Rambert 1988). Most women can no longer trust their own feelings that the baby is healthy.

To reject all technology is unfair, however. Doctors' motivation to use birth technologies was never solely economic or self-serving; the safety of mother and baby was usually a primary concern. The history of PND in itself does not suggest that the technique was developed primarily to aggrandize doctors, either monetarily or professionally. As Cowan (1993) notes, the research history of amniocentesis points to an unusually eager and informed, totally voluntary participation, largely by middle-class white women. In societies with national health insurance or a national health

service, doctors gain little or nothing monetarily by doing many prenatal diagnoses. It is unclear whether they gain professionally, but hospital or clinic rules can prevent abuses. In Canada, chorionic villus sampling (CVS) contrasts with many birth technologies (such as fetal monitors) in that it underwent a randomized controlled clinical trial (Canadian Collaborative CVS-Amniocentesis Clinical Trial Group 1989) before becoming a standard of care.

Why, then, do feminist critics fasten on new reproductive technologies as exploitative of women? They do so partly because feminism seems to have some ambivalences within itself. The feminist movement of the 1970s was not prepared for the "infertility crisis" of the 1980s. Contraception and abortion rights were the battles of the 1970s; many feminists perhaps envied women who could not have children and who did not have to worry about unwanted fertility. Many of those who fought for women's control over their fertility in the 1970s find it difficult to empathize with infertility; they argue that women who cannot have biological children by the usual means should simply give up the attempt and go on with their lives. Not surprisingly, the strongest feminist attacks have been upon *in vitro* fertilization (IVF) and other methods of "assisted reproduction" rather than on PND, though in the latter case there is also a general mistrust of technology and a feeling of "male meddling" with women's bodies.

PND itself takes on new meaning in the context of infertility (Borg and Lasker 1989; Sandelowski et al. 1991). The babies of previously "infertile" women who struggled to achieve pregnancy are "premium babies." Women perceive both the risks and the benefits of PND as being higher in the context of infertility. Recognizing that they may have few children, or perhaps only one child, they are especially concerned that each child be, if not "perfect," at least as healthy as possible. Infertility is the spectre that stalks most educated, professional women today. These are the women who have put off childbearing to have careers and who hear their "biological clocks" ticking. These are also the women who have the most to gain from PND, in terms of maintaining their own careers and quality of life. They do not understand why critics within the feminist movement, which earlier urged them to postpone childbearing and to have careers, sometimes show little sympathy with their infertility or their desire to avoid caring for a child with a serious birth defect.

Some feminists have recently begun to show unease about abortion, especially abortion for reasons of "fetal quality" (see "Feminist Views"). In siding with people who have been "victimized," such as battered women and children, many feminists have taken up the cause of people with disabilities, including those whose births could have been prevented by PND. Empowering those formerly oppressed or victimized has become the slogan of the day. "Ablism," the dominance of the able (or "temporarily able," since many of us will become disabled by age or accident) over people with disabilities, has joined racism and sexism as an evil to be overcome. Many people with and without disabilities have felt a contradiction between

empowerment for people with disabilities and selective abortion of fetuses with disabilities (Asch 1989; Henifin et al. 1989; Hubbard 1987, 1990; Lippman 1991a; Rothman 1986, 1989; Saxton 1987; Wexler 1989; Zola 1972, 1975, 1977). However, there is another contradiction, the one between women's new self-image of themselves primarily as people rather than mothers (Luker 1984) and their identification with affected fetuses as victims of ablism, as they themselves have been victims of sexism. It is not possible to resolve this contradiction without considerable rethinking.

These ambiguities are not sufficient reason to label PND as exploitation. However, there is another reason that merits close attention. PND is big business for the companies that manufacture the equipment and conduct the laboratory tests. This may be less of an issue in Canada. Under national health insurance, the hospital and the laboratory do not make a profit, but the physician may earn a fee. Although many geneticists in Canada are salaried, most obstetricians are not. Women who do not qualify for PND under guidelines generally accepted in Canada (CCMG 1991, 1992) can go to the United States, where laboratories are competing for business. Glossy brochures advertising "prenatal paternity testing" ("most men will provide support if they can be sure a child is their own"), "19 mutations for cystic fibrosis," or "embryo diagnosis for cystic fibrosis" arrive regularly in doctors' mail. Occasionally, an enterprising American doctor, catering to minority groups, may advertise PND for sex selection, conveniently located close to the Canadian border. PND in the United States has been commercialized, along the lines of the commercialization of other medical technologies. Patients become the ultimate consumers, though they need the collaboration of doctors.

PND in the United States is no longer a scarce resource. Laboratory capacity has increased to the point that the original recommendations of government bodies (U.S. National Institutes of Health 1979) or professional organizations (CCMG 1991, 1992) about maternal age, which were recognized at the time as arbitrary, have been relaxed. It appears that most geneticists would perform PND for any anxious woman, even without indications of age or family history. In 1985, 55% of Canadian geneticists would be willing if resources were available to perform PND for an anxious woman at 25 years of age with no medical or genetic indications for its use, and an additional 15% would offer a referral (Wertz and Fletcher 1989e). Performance of PND solely for maternal anxiety is against CCMG guidelines. In the United States, 78% would perform PND and 11% would offer a referral for it. In the United Kingdom, the figures are 79% and 9%, respectively. In France, where some regard PND as a scarce resource, 38% would perform it and 19% would refer for it. Around the world, those who would perform PND for anxiety were 7.3 times more likely than others to say they would also perform it for sex selection. More female (76%) than male (61%) geneticists would perform PND for anxiety alone.

Most geneticists who would perform the procedure believed that they were alleviating anxiety. Socially speaking, they were opening the door to

making PND a routine procedure in prenatal care. Most pregnant women are anxious. Most geneticists said that as long as they had the laboratory capacity, they would do the procedure. Commercialization creates laboratory capacity, and it may become necessary to increase consumer demand to keep the laboratory working at capacity. Therefore, it seems reasonable to expect that, in the United States, PND will be used on women of younger age groups for less severe conditions, and also for non-medical reasons such as paternity testing. Tests need not be invasive or risky; the so-called "triple test" (AFP, estriol, and human chorionic gonadotropin [hCG]) may be applied to most pregnancies as a routine blood test to determine which women should have CVS or amniocentesis. Having had a positive blood test, many women will find it difficult to decline further testing.

This seems to be what critics mean by exploitation. The biotechnology industry is making large sums of money and women are having more tests, which become more difficult to refuse. That most women probably welcome the tests does not change the facts of commercialization. PND is already one of the most frequently used procedures in prenatal care (Blatt 1988; Nightingale and Goodman 1990) and could become routine in most pregnancies unless CCMG guidelines are followed.

It is the possibility of routine PND, applied to all or most pregnancies, that feminist critics find most objectionable, because it would add yet another technological requirement to pregnancy and would place more control in the hands of professionals. Routine PND available on patient demand would appear to be a compromise between routine PND applied by physicians and CCMG guidelines for medical and genetic indications. Some geneticists have argued that some affected fetuses are found in non-risk groups and that sometimes women request PND because they sense that something is wrong (Wertz and Fletcher 1989e). By acceding to women's requests for PND in the absence of medical indications, as would 55% of Canadian and 78% of U.S. geneticists, or by offering referrals (as would an additional 15% of Canadian and 11% of U.S. geneticists), they believe that they are identifying substantial numbers of fetuses with abnormalities (ibid.). There are several problems with routine PND on demand. First, it is inherently unfair to many social groups. Women with higher education, income, and occupational status are more likely than others to request PND and to engineer physician compliance with their requests. Second, PND available on demand is likely to become routine PND for all, as increasing numbers of women make requests and physicians begin to suggest to their patients that such requests are in order. If a majority of women request PND, the remainder may feel social coercion to have the procedure even if they do not have personal anxiety. Third, if PND on demand evolves into routine PND, this could become enormously expensive for the health care system. For these reasons, adherence to professional guidelines about indications is the preferable approach; this could prevent overuse or misuse of the more invasive tests, although commercial pressure would remain.

To summarize, allegations that PND exploits women do not seem pertinent to most individual doctor-patient relationships. Nevertheless, such allegations are historically based and reflect the entrepreneurial quality of medicine in earlier periods and the overuse of technology in childbirth. Charges of exploitation reflect deep ambivalences within feminism, but also describe the commercialization of genetic testing.

Selective Abortion

An estimated 1% of all abortions in the United States occur after PND (Henshaw and Van Vort 1992; Henshaw et al. 1987). This figure is 0.03% in British Columbia (Roy and Hall 1989), 1% in Australia (Rogers and Taylor 1989), 0.003% in Denmark (Therkelsen et al. 1989), 1.3% in the former Federal Republic of Germany (Schroeder-Kurth and Huebner 1989), 0.15% in Israel (Chemke and Steinberg 1989), 0.002% in Norway (Berg and Tranøy 1989), 0.003% in Sweden (Bischofberger et al. 1989), and 1.34% in the United Kingdom (United Kingdom, Office of Population Censuses and Surveys 1987). However, many people believe that these abortions deserve special consideration. A recent trend in the criticism of selective abortion after PND is: Abortion should be available to all women for any purpose of their own choosing, but abortion done because of fetal characteristics has a different moral quality from other types of abortion. Women should be especially thoughtful before deciding to abort for fetal conditions because they are making judgments about the kind of people who should inhabit the world and are implicitly judging living persons who have disabilities (Hubbard 1987).

The strongest criticisms of selective abortion have come, not from religious groups, but from a small, articulate group of feminists who concentrate their efforts on limiting the use of new reproductive technologies (Hubbard 1987; Rothman 1986; Spallone 1989). Their views may not be representative of feminists as a whole. Many women who use or advocate PND and other new technologies would score high as feminists on other issues, such as equality in employment. The critics, although vocal, represent only one wing of the feminist movement.

Although most feminists in North America would stop short of legally restricting selective abortion, some in Europe would prefer to see abortion remain easily available for reasons of the woman's personal choice (or even for no reason at all) but would like to see restrictions on abortions after PND (Hansen and Kollek 1985). Although this point of view may seem illogical, what these women are stressing is a fundamental distinction, in personal experience, between unwanted and wanted pregnancies. Most pregnancies that proceed as far as PND are wanted, if not in their original plan or intention, at least by the time the procedures are performed. Abortion of a wanted pregnancy differs in psychological, and, some would

argue, moral quality, from abortion of an unwanted pregnancy. To understand the complex views surrounding selective abortion, it is necessary to describe the spectrum of views on abortion in general and selective abortion in particular. These include religious views, traditional bioethical views, and more recent feminist views. Finally, it is important to describe how families themselves have decided about PND and abortion.

Religious Views

According to a recent survey in the United States, most religious or voluntary organizations take no position on PND (49%), or approve its use (37%), or "do not know" (24%) (Singer 1992). Only 2 of 265 voluntary organizations surveyed qualified their approval (neither was a religious organization), and none disapproved. Some statements by church bodies regarding genetics have avoided taking a position on PND, while recognizing the ethical problems involved (Church of the Brethren 1987; United Methodist Church 1992). Others have affirmed the use of PND (Evangelical Lutheran Church in America 1991; United Church of Christ 1989). However, if PND will be followed by abortion, the position of most religious denominations follows the position of the denomination on abortion in general (Atkinson and Moraczewski 1980; Bouma et al. 1989; Brown 1990; Bueche 1986; Campbell 1982; Congregation for the Doctrine of the Faith 1987; Duke 1985; Dunstan 1988; Fineman and Gordis 1982; Pellegrino 1987; Santurri 1985; Zakut et al. 1989). These writings reflect wide cultural differences. The Catholic tradition regards the fetus as a person from the moment of conception, though a few moral theologians would permit genetic abortions for "fetal deformity ... of such magnitude that life-supporting efforts would not be considered obligatory after birth" (McCormick 1981, 200). Historically, however, penalties applied to abortion have never been as severe as penalties applied to murder, and for centuries very early abortion was not considered destruction of a person. Following Aristotle, many early Christian theologians believed that "ensoulment" of the fetus did not occur until a certain period had passed (40 days for a boy and 90 days for a girl). In classical and mediaeval times, people knew little about the exact time of conception or the characteristics of the embryo, so it was easier to disregard the beginnings of life. It was not until the late nineteenth century, when medical science was finally able to describe the timing of conception and the development of the early embryo, that both the Catholic Church and the emerging medical profession became concerned about early abortion as a moral problem (Mohr 1978). Our increasing knowledge about the fetus, and our ability to see it on ultrasound, have tended to reinforce religious views that point to its essential humanity. Other religious traditions, including the Mormon Church and conservative Protestant groups, also oppose abortion except to save the mother's life. Orthodox Jewish tradition opposes abortion, but holds that during the first 40 days after conception there is nothing present but "water"; therefore,

very early CVS might be acceptable (Zakut et al. 1989). Orthodox Jewish communities in North America often try to avoid the births of children with genetic disorders such as Tay-Sachs disease by carrier screening and arrangement of marriages so as to avoid marriages between carriers, because the community does not approve of PND and selective abortion.

Religious arguments in favour of termination are usually based on prevention of suffering for the child. Most such arguments come from liberal Protestant denominations or Conservative or Reform Jewish traditions. Usually, their authors would prefer to see selective abortion used only for serious or grave fetal conditions that would offer the child a poor quality of life, but these are difficult to define. Dunstan (1988), speaking from an Anglican point of view, regarded abortion for severe disability as an extension of natural processes. Denominations that favour PND have generally not actively supported it except when abortion rights are called into question by others. Most denominations, although tacitly in favour, have been reactive rather than active.

Religious groups opposing selective abortion have been far more vocal. In 14 of 19 nations surveyed in 1985, religious opposition was the main challenge to PND (Wertz and Fletcher 1989e). In Norway, religious opposition influenced public policy in 1983 (Berg and Tranøy 1989), when Parliament set up a special commission to monitor PND and set a quota on amniocenteses. In 1987, the quota was 800 per year in a nation of four million. As Norway already had passed a law permitting abortion on demand, this step implied that selective abortion was different, and of higher moral concern. No other country has a "watchdog" commission for PND.

Religion affects decisions to have PND and abortion in North America, with fundamentalists of all religions less likely than others to choose PND at all (Seals et al. 1985).

Bioethical Arguments

Most writings about PND in the secular bioethics literature focus on selective abortion. Of 853 entries on PND since 1985 in *Bioethicsline* and the references from 19 countries in Wertz and Fletcher (1989e), 455 have selective abortion as their major topic.

The usual argument in bioethics is based on the "increasing moral status of the fetus." The early embryo, while recognized as having human potential, is not considered a "person." However, as the pregnancy progresses the fetus gains in moral status and has increasing moral claims on society (Sumner 1981). These gains in moral status coincide with the fetus's increasingly human appearance, but do not coincide with viability. Moral status is based on abstract, metaphysical criteria of personhood (Tooley 1972; Warren 1973) or on biological criteria such as the ability to feel pain (Botkin 1990; Reiter et al. 1991). Those who use moral status as a criterion seek to find some feature by which the world can be divided into

"persons" who should be valued and protected and "others" who are not entitled to the same protection.

The increasing moral status argument sees little or no moral difference between the third-trimester fetus and the newborn (Royal College of Obstetricians and Gynaecologists 1987). The difference between the two is seen as merely "geographical." Thus, D. Callahan (1987, 1990), although pro-choice, wrote that women must regard the fetus in terms of the fetus's prospects apart from the mother. Chervenak and McCullough (1990a, 1990b) reported that third-trimester abortion should be recommended only if the fetus has a lethal condition and the only choice is between abortion and non-aggressive care at birth. Others see little ethical difference between third-trimester abortion and planned non-treatment at birth (Fletcher and Wertz 1990, 1992a, 1992b, 1992c).

Traditional bioethical arguments, like most modern medical texts, reify the fetus as an entity separate from the mother. The fetus becomes an "unborn patient" (Harrison 1982; Harrison et al. 1991) and the mother becomes a container (Annas 1986) or, in medical jargon, "the maternal environment." Ultrasound, although increasing a mother's attachment to the fetus (Fletcher and Evans 1983), also reifies the fetus for her by placing it on a TV screen outside her body (Black 1992; Martin 1987; Petchesky 1987). Few women can identify this picture as a baby — the doctor "makes it real" for them (Rapp 1988a, 1988b).

Bioethics in North America has emerged from the discipline of philosophy and has remained largely philosophical. The social sciences have played almost no role in the development of bioethical thinking (Fox 1990). This may explain why many ethical arguments that emphasize the moral status of the fetus ignore the relational aspects of pregnancy by treating mother and fetus as separate atoms in a Kantian sense. Certainly, they overlook much of women's experience of pregnancy (Addelson 1987).

Arguments based on increasing moral status of the fetus also have failings from the public health point of view. The embryo and fetus are in greatest need of protection from environmental hazards precisely at the earliest stages of development, when according to traditional ethical arguments they have the least ethical status. Some legal experts such as Margery Shaw believe that a fetus that will be carried to term deserves full protection from the moment of conception (Robertson 1983, 1989; Shaw 1980). In a counter-argument to Shaw, Eisenstein (1988) stated that pregnancy (real or potential) has historically been an agent in the subordination of women. If the law regards all women as potentially pregnant, they will be without freedom to work or to lead normal lives.

Feminist Views

According to feminist views, "value" or "status" of a fetus is conferred by a relationship with the mother, the family, or society, rather than by some intrinsic metaphysical quality that somehow increases throughout pregnancy (Overall 1987, 1989).

Recently, feminists have started to redefine their views of abortion to reflect women's experiences of pregnancy and motherhood. Starting with Thomson's (1971) classic article, feminist thought has stressed the need for abortion rights. (A few exceptions, such as S. Callahan (1979, 1987), are outside the mainstream of feminism.) However, this does not mean that abortion is an easy decision, especially for a wanted pregnancy. Feminist thinkers try to take into account women's actual experiences. It appears that many women regard an embryo or fetus as a "baby" from the very beginning. Women speak not of their fetus, but of their baby or unborn baby. Although more are willing to abort during the first trimester than the second, these differences are less than might be expected, averaging about 5% in one study of the attitudes of parents of children with cystic fibrosis (Wertz et al. 1991). Especially in a wanted pregnancy that has proceeded to PND, women see themselves as related to another being. McDonnell (1984) has urged feminists to develop a "morality of abortion" that is openly feminist.

According to Sherwin's excellent summary of feminist views,

> Focus on the fetus as an independent entity has led to presumptions that deny pregnant women their roles as active, independent, moral agents with a primary interest in what becomes of the fetuses they carry. The moral question of the fetus's status is quickly translated into a license to interfere with women's reproductive freedom.
>
> Because the public debate has been set up as a competition between the rights of women and those of fetuses, feminists have often felt pushed to reject claims of fetal value, in order to protect women's needs ...
>
> On a feminist account fetal development is examined in the context in which it occurs, within women's bodies, rather than in the isolation of imagined abstraction. Fetuses develop in specific pregnancies that occur in the lives of particular women. They are not individuals housed in generic female wombs or full persons at risk only because they are small and subject to the whims of women. Their very existence is relationally defined, reflecting their development within particular women's bodies; that relationship gives those women reason to be concerned about them ...
>
> On this view, fetuses are morally significant, but their status is relational rather than absolute. Unlike other human beings, fetuses do not have any independent existence; their existence is uniquely tied to the support of a specific other. (Sherwin 1992, 108-109)

According to this way of thinking, personhood is based upon relationship (Baier 1985; Gilligan 1982; Held 1987; Lebacqz 1973; Petchesky 1985). Fetuses are unique entities in that they cannot freely form relationships with others; all relationships are mediated through the mother. Fetuses are not persons because they cannot form social relationships, and others (except the mother) cannot form relationships with them; in this sense they differ from newborns.

Feminist views of selective abortion probably reflect the experience of many women faced with such decisions. In a wanted pregnancy (or at least a pregnancy that would ordinarily go to term), women tend to see themselves as mothers from the beginning. An abortion breaks a relationship that they have already established with the unborn baby. If the abortion takes place because there is "something wrong" with the baby, the mother is placed in the role of judge rather than nurturer. She is judging her own baby in terms of quality and acts as the gatekeeper to life by virtue of conscious decision. Many women making these decisions feel an affront to their own self-images as mothers, nurturers, and women. If a woman also sees herself as a victim or a member of an oppressed group (by virtue of sex, ethnicity, or social class), she may also feel a special empathy with people with disabilities (Addelson 1987; Banks 1981; Kaufmann 1988; Kenen 1981; Samuelson 1986; Sherwin 1984-85). Abortion of a fetus with a disability may contravene her basic view of motherhood as caring and also self-sacrificing. Some feminists have argued against unrestricted procreative liberty in this regard (Ryan 1990).

On the other hand, the women's movement fought long and hard to gain a self-image for women apart from their biology and their capacity to bear and rear children. Women who were raised to be self-effacing and to devote their lives to their children learned, in the 1970s, that it was not necessarily selfish to take some space for themselves instead of putting the needs of others first. Selective abortion stands at the centre of a conflict between women's needs to live as full persons in the modern world of work, and their own moral construction of the world in terms of caring relationships, including relationships with unborn babies. This may explain why many women are willing to have an abortion of an unwanted pregnancy on the basis of their own needs, without knowing anything about the fetus, but are reluctant to abort solely on the basis of fetal characteristics. They must make their decisions in a culture that does not regard suffering as ennobling or of spiritual value. For most North Americans, suffering that can be avoided is seen as stupid and without value (Luker 1984).

Following the "ethics of relationships," some feminists would like to see abortion re-thought in terms of some form of collective decision about the definitions of life or personhood and some collective responsibility for children. Rejecting the view of Harrison (1983) that abortion decisions should be a matter of individual conscience, Fox-Genovese argued for a collective set of values. Survival of newborns with serious disabilities (among others who are gravely ill)

> depends upon a massive expenditure of social resources. In a society in which people no longer agree on a single religious definition of life, such a definition must be a collective decision that risks a considerable measure of arbitrariness. For if we leave the definition of life to individual conscience or convenience, we open ourselves to the worst consequences of atomization.

> Abortion confronts us with a collective social, economic, political, and moral problem that we can only solve collectively and in frank acknowledgement that no solution will escape intellectual inconsistencies and some unresolved moral tensions. Abortion forces us to recognize provision for children as a collective responsibility. (Fox-Genovese 1991, 85)

Fox-Genovese also advocated greater social responsibility for *all* children.

How Parents View Selective Abortion

Between 1972 and 1990, the National Opinion Research Center's (NORC) yearly General Social Surveys (GSS) reported that about 79% of the U.S. population thought that legal abortion should be available "if there is a strong chance of serious defect in the baby" (University of Chicago, NORC 1991). In 1972, the last year that the survey asked about personal choices, 71% said that they would have an abortion if their child would have a serious defect. The GSS did not define "serious defect" for its respondents, nor did it examine acceptance of abortion for particular disorders.

The literature indicates that most women choose abortion for the most serious mental and physical conditions, but are less willing to abort for less serious conditions. Families who have intimate experience with a disorder, such as in a child or other relative, are frequently ambivalent toward selective abortion, regarding it as a rejection of their affected child or relative. The findings of some studies have suggested that most parents of affected children do not consider selective abortion acceptable for the disorder in question (Elkins et al. 1986).

Abortion Decisions: A Review of the Literature

Responses to routine screening programs are perhaps the best indications of the general public's views on abortion for fetal defects. Most women accept prenatal screening, if offered at no cost (Frets and Niermeijer 1990; Richwald et al. 1990). In public health screening programs in Europe, 60% to 90% of pregnant women accept PND (Cao 1991; Cao et al. 1981, 1987, 1989; Swerts 1987). The most common reason for not having PND is because it is too late in pregnancy to have an elective abortion. In Britain, only 7% of pregnant women now decline testing on moral grounds (Cuckle and Wald 1987). A California study reported a similar figure (Richwald et al. 1990).

Table 1 shows the percentage of women who have chosen abortion for some common genetic disorders after receiving prenatal diagnosis of an affected fetus. Usually, these are women who do not have children with genetic disorders. Most chose abortion for severe mental retardation, death in early childhood, or substantial physical disability. For example, among the first 7 000 women receiving PND under a public health program in New York City, 97% of those receiving a "positive" diagnosis aborted for Down syndrome and two other disorders with even more severe retardation, and

all aborted for anencephaly or spina bifida, regardless of race or income (Benn et al. 1985).

Occasionally, the cumulative effects of women's choices have been so great as to reduce dramatically the incidence of some common "birth defects." Thus, geneticists have reported a 94% decline in births of children with anencephaly in England and Wales between 1964 and 1972 and a 68% decline in spina bifida (Cuckle et al. 1989). Geneticists have attributed most of this decline to PND and termination of pregnancy (Carstairs and Cole 1984; Laurence 1985; United Kingdom, Northern Regional Health Authority 1988).

For thalassaemia, a blood disorder that leads to death in adolescence or early adulthood after years of increasing pain and disability, the birth incidence declined by 90% in 10 years in the Ferrara region of Italy; only about four families a year did not choose abortion (Lalatta and Tognoni 1989). In Sardinia, and in Greek Cypriot communities in England, close to all women have accepted screening, and about 90% with affected fetuses chose abortion (Cao et al. 1987; Modell and Mouzouras 1982; Modell and Petrou 1988). Most people in these close-knit communities have seen a child with thalassaemia and have no wish to confer this kind of suffering on a child.

Although there are no national figures for reductions in the number of births of children with disabilities in the United States, the results of a study in metropolitan Atlanta revealed that in 1986 PND and "genetic elective interruption" led to an estimated 63% reduction in births of children with Down syndrome to women over 35 years of age and to an estimated 26% reduction in births of children with Down syndrome to women of all ages. Using the language of epidemiology, the authors concluded that "in a surveilled community, ... prenatal monitoring for chromosomal anomalies is used by an 'at-risk' population" (Priest et al. 1988, 1307). Mikkelsen et al. (1983) claimed a reduction in Down syndrome in Denmark. However, Motulsky and Fraser (1980) thought that any future reduction will be modest.

The U.S. President's Commission (1983, 18-20) has estimated that as a result of screening in Ashkenazi Jewish populations, the incidence of Tay-Sachs disease was reduced from 50 to 100 births per year in 1970 to about 13 in 1980. Almost all women with fetuses that have Tay-Sachs disease have chosen abortion. There has also been a reduction in thalassaemia (Pearson et al. 1987).

The longer a screening program has existed, the greater the acceptance of both PND and selective abortion. For example, in Scotland the percentage of women choosing abortion for spina bifida rose from 21% in 1976 to 74% in 1985 (Ferguson-Smith 1983a; Harris and Wertz 1989).

Table 1. Abortion Choices After PND

Disorder	Effects	% choosing abortion	Area	Source
Chromosome abnormality: trisomy 13, 18, or 21 (Down syndrome)	Severe mental retardation; for 13 and 18, death in infancy	100%	Switzerland	Engel and DeLozier-Blanchet 1989
		94%	U.S.	Golbus et al. 1979
		97%	New York City	Benn et al. 1985
		73%	Atlanta	Priest et al. 1988
		79%	Maryland	Faden et al. 1983
		100%	U.S.	Faden et al. 1987
		95%	England & Wales	Golbus et al. 1974
Metabolic disorders accompanied by severe mental retardation (e.g., Tay-Sachs disease)	Profound mental retardation; death before age 5	100%	Australia	Rogers and Taylor 1989
		close to 100%	U.S.	U.S. President's Commission 1983
Anencephaly	No higher brain function; brain stem only; death soon after birth	100%	Wales	Cuckle et al. 1989
		100%	New York City	Benn et al. 1985
Spina bifida	Open spinal column with nerve damage; usually some paraplegia; sometimes mild retardation	74%	Scotland	Ferguson-Smith 1983b
		close to 100%	Wales	Cuckle et al. 1989
		100%	New York City	Benn et al. 1985

Thalassaemia	Blood disorder usually leading to death by age 20 after increasing pain and disability; found among Greeks, Italians, other Mediterranean people	95% 90% close to 100% 100% 99%	Australia United Kingdom Sardinia U.S. Ferrara, Italy	Rogers and Taylor 1989 Modell and Petrou 1988 Cao et al. 1987 Pearson et al. 1987 Lalatta and Tognoni 1989
Sickle cell anaemia	Blood disorder; decreased life expectancy; painful crises; found in people of African descent, also some Greeks and South Asians. Prognosis considerably better than for thalassaemia	39% 54%	U.S. U.S. (New York City)	Rowley 1989; Rowley et al. 1991 Driscoll et al. 1987
Sex chromosome abnormality (XYY, XXX, XXY, 45,X, etc.)	Various; possible infertility, failure to mature sexually, extremes in height (unusually tall or short), sometimes learning disorders	79% 62% 38% 63% 67% 89%	Switzerland New York City Denver England & Finland 24 published studies U.S.	Engel and DeLozier-Blanchet 1989 Benn et al. 1985 Robinson et al. 1989 Holmes-Siedle et al. 1987 Verp et al. 1988 Golbus et al. 1974
Blindness		62%*	Maryland	Faden et al. 1983

* Attitudinal study only; does not report actual choices after PND.

Using a public health model of prevention, some epidemiologists would seriously suggest widespread use of carrier testing and PND to reduce neonatal and infant mortality rates (Dalgaard and Norby 1989; Powell-Griner and Woolbright 1990; Saari-Kemppainen et al. 1990; Scriver et al. 1984; Stone et al. 1988). However, all stress that such programs be voluntary.

Many genetic disorders are not accompanied by severe mental retardation or physical disability. For most sex chromosome abnormalities (e.g., XYY, XXY, 45,X, XXX) the major disabilities are social: the child may not reach puberty without hormonal treatment, may be infertile, may be too tall or too short, or may have a learning disorder. In these cases, fewer families choose abortion: 62% in one U.S. study (Benn et al. 1985) and 79% in a Swiss study (Engel and DeLozier-Blanchet 1989). The sex chromosome disorders most likely to be aborted involve infertility; namely, XXY (Klinefelter's syndrome) and 45,X (Turner syndrome) (Verp et al. 1988). Often, parents fear that children with these disorders, especially boys, will be homosexual (Robinson et al. 1989). Parents are more accepting of disorders involving possible learning disorders but no sexual dysfunction (XYY or XXX).

Parents of affected children (Breslau 1987; Cooley 1988; Elkins et al. 1986) and parents who are themselves affected (Czeizel 1988) sometimes regard a disorder as less disabling than do those with no experience of the disorder. Table 2 describes attitudes toward abortion among the parents of affected children. (For Huntington disease, which develops in middle age, the table shows the attitudes of the adult children of affected parents, who may pass the disease on to their own children.) A comparison between Tables 1 and 2 may suggest that people with experience of a genetic disorder in the family are less willing to use selective abortion than are members of the general population. However, direct comparison between the tables is misleading. Most disorders in Table 2 are not comparable in severity to those in Table 1. Huntington disease, although severe and incurable, usually appears only after 40 or more years of healthy, productive life. Cystic fibrosis and haemophilia involve neither mental retardation nor (in most cases) serious limitations on physical activity. Most of the conditions listed in Table 1 involve retardation, early death, or physical disability.

The two tables are also based on different kinds of studies. Table 1 reports the actual behaviour of women who have had PND, while Table 2 (with one exception) reports the attitudes of *all* parents at risk, including those who have *not* had PND. Many parents who object to aborting a fetus with their child's disorder choose not to have PND. An interest in PND usually implies a willingness to consider abortion. Studies reporting attitudes of *all* parents usually show less approval of abortion than studies of women who have chosen PND and discovered that they were carrying an affected fetus.

Table 2. Attitudes Toward Abortion Among Families with Affected Members

Disorder	Effects	% who say they would abort	Area	Source
Cystic fibrosis*	Enzyme deficiency affects lungs and digestive system. Median life expectancy, 28 years in U.S. in 1990, about 32 in Canada	95%	France**	Boue et al. 1986
		52%	Wales	al-Jader et al. 1990
		20%	New England	Wertz et al. 1991
		42%	Belgium	Evers-Kiebooms 1987
		65%	Belgium	Denayer et al. 1990
Haemophilia A*	"Bleeder's disease." Absence of blood-clotting factor, requires frequent medical treatment. Risk of HIV from transfusions and blood products	46%	Australia	Rogers and Taylor 1989
		100%	U.S.	Miller et al. 1987
		43%	England	Evans and Shaw 1979
		40%	Scotland	Markova et al. 1984
		43%	Canada	Markova et al. 1984
Huntington disease***	Severe mental and motor deterioration ending in death; first symptoms usually appear at about age 40	71%	U.S.	Kessler et al. 1987
		43%	U.S.	Markel et al. 1987
		33%	U.S.	Schoenfeld et al. 1984
		35%	England	Craufurd and Harris 1986
		30%	U.S.	Meissen and Berchek 1987

* Respondents are parents of affected children.
** Study represents actual decisions after a positive PND, rather than attitudes.
*** Respondents are adult children of affected parents.

In the one study in Table 2 that reports the decisions of parents of children with cystic fibrosis who actually had positive prenatal diagnoses for cystic fibrosis (Boue et al. 1986), 95% chose abortion. This compares with the 20% to 65% of all parents of children with cystic fibrosis who say that they would abort for this disease. The 95% who aborted in the Boue et al. study may also reflect a difference between France and North America with regard to attitudes about abortion of affected fetuses.

The few studies that make scientifically valid comparisons suggest that for some disorders the parents of affected children are more receptive to PND and selective abortion than are families without affected children. Parents of boys with fragile X syndrome (moderate to severe retardation) or Duchenne muscular dystrophy (a severe physical disorder that usually puts the boy in a wheelchair by about the age of 12) are more likely to favour abortion than are people with no personal experience of the condition (Beeson and Golbus 1985; Meryash 1989; Meryash and Abuelo 1988). One study revealed the perceptions of women who had lived with affected children as "clear and concrete," full of "intimate detail about the realities of care and the experience of those affected," while the perceptions of women without affected children were "vague and abstract" (Beeson and Golbus 1985, 110).

The demographics of abortion suggest that women with lower income and less education are less likely to have PND than women with higher incomes and more education. Rapp, in her excellent anthropological studies of genetic counselling among New York City minority groups, claimed that about half of minority women do not keep their appointments for counselling or PND, compared to 10% for white patients in private care (Rapp 1988a, 1988b). She attributed this to failures in communication between hospital (or counsellor) and patient, to patients' logistical problems (e.g., transportation, babysitting), to out-of-pocket costs, and to different world views, rather than to moral objections. Even a small amount of money can be an insurmountable barrier to poor women; in California, a $49 payment for spina bifida screening (which included ultrasound and amniocentesis, if necessary) deterred one-quarter of clinic patients from screening (Richwald et al. 1990).

Some studies have showed that college-educated, upper-income career women are less willing to risk having a child with a disability than women with less education and lower income (Beeson and Golbus 1985; Beeson et al. 1983; Luker 1984). In Wales, however, neither education nor social class was related to attitudes toward abortion among parents of children with cystic fibrosis (al-Jader et al. 1990), possibly because of greater acceptance of selective abortion among all social classes in the United Kingdom.

Religion is often associated with abortion attitudes, with Catholics less likely than non-Catholics to accept abortion (Beeson and Golbus 1985; Kyle et al. 1988; Markel et al. 1987; Meryash and Abuelo 1988). Women who attend church often or who believe that the Bible is the literal word of God

are less likely to approve of abortion (Faden et al. 1983, 1987). In some studies, women who have had previous elective abortions (not necessarily for fetal defects) are more willing than others to have selective abortions (Faden et al. 1987), but in other studies there are no differences (Holmes-Siedle et al. 1987).

Table 1 raises some other demographic questions. Thalassaemia is a blood disorder affecting mostly whites; sickle cell anaemia affects mostly African-Americans. Why, the reader may wonder, are the abortion rates so different? There are several possible explanations: first, thalassaemia is a more severe disorder than sickle cell anaemia and has fewer treatments. Children suffer more and die earlier. Second, about 60% of African-American women (compared to 20% of white women) in the United States receive prenatal care too late to have PND. Third, failures in communication occur more often in counselling minority women (Rapp 1988a, 1988b). Fourth, some clinics offer PND for sickle cell anaemia only to women whose partners agree to be tested and who are found to be positive. In about 45% of cases, the partners of women who carry the sickle cell gene are unavailable or unwilling to be tested (Anionwu et al. 1988; Rowley et al. 1991). In these cases, the woman is not offered PND, even though she is at risk for having a child with sickle cell anaemia. The reasoning in such programs is largely paternalistic; PND is routinely offered to women who are carriers of genes for other recessive disorders even if their partners refuse testing (Bowman 1991).

There is no evidence that African-American women are more opposed to abortion per se than white women (Wilcox 1990), but they are more strongly opposed to abortion of a wanted pregnancy. In fact, there were proportionately more elective abortions in 1987 among African-Americans (56 per 100 live births) than among white women (30 per 100 live births) (U.S. Department of Health and Human Services 1991).

Readers may wonder at the acceptance of abortion for thalassaemia in predominantly Catholic Italy, France, and Belgium (Table 1). In these countries, most people separate their personal morality from their religion. For example, in Italy there is a

> profound dissociation between the Church's influence in shaping society's institutions and the influence of society itself on moral behavior and attitudes. The vast reach of this dissociation ... is well illustrated by the fact that in 1974 and 1978 two laws which introduced divorce and voluntary abortion were passed, first in Parliament and then through popular referendums (1975 and 1981, respectively). These laws placed Italy among the most liberal countries in these areas. (Lalatta and Tognoni 1989, 290)

Catholic institutions, including the Papal University in Rome, perform PND without hindrance. (They do not perform selective abortions, which are available elsewhere.)

Long-Term Follow-Up Studies

No one knows how many parents subsequently regret their decision. It is easier for parents to acknowledge that abortion was the wrong decision for them and then to go on with their lives than it is for parents of a living affected child to admit that they may have made the wrong decision. Consequently, there are many studies of depression and other psychological sequelae of abortion for fetal defects (Blumberg et al. 1975; Donnai et al. 1981; see also section entitled "Psychological Issues: Anxiety and Grief" below) and support groups for families that have made the abortion decision, but there are no long-term studies of families that have carried affected fetuses to term. The possibility of PND and selective abortion is almost never mentioned in support groups for families with children with disabilities; it is too threatening to parents who are in the process of coping with a disorder. However, parents occasionally openly express regrets. "I'd have euthanasied [*sic*] her if I'd have known," said one parent of a child with Down syndrome (Shepperdson 1983).

Conclusions from a Study of Parents of Children with Cystic Fibrosis

A study of the views of 271 parents of children with cystic fibrosis about abortion for 12 maternal/family situations and 11 different fetal conditions showed that although most favoured abortion rights for others, in all situations described, most would not themselves abort except in the most extreme circumstances (Wertz et al. 1991, 1992) (Table 3, Figures 1 and 2). A full description of the study appears in the Appendix.

Parents' ratings of the personal acceptability of abortion for fetal characteristics suggest that most would themselves be reluctant to abort unless extremely severe mental or physical disability or death in early childhood were involved. The questionnaire described the extreme limiting situations ("unable to speak or understand," "bedridden for life").

Severe mental retardation (defined as "child would be unable to speak or understand") was the only fetal characteristic for which the majority (58%) would themselves abort (Figure 2). For cystic fibrosis itself, 20% would abort in the first trimester and 17% in the second trimester. In interviews, many said that after visiting paediatric clinics where they saw children with retardation, they were thankful that their child "only had cystic fibrosis." Most were highly optimistic about their child's future and expected the child to live to at least age 40 (the highest age listed on the questionnaire) and to participate in most activities of "normal" life.

Many families who have experienced life with a child who is ill, but not retarded or severely disabled, due to a genetic disorder are reluctant to abort a fetus with the same disorder. At the same time, as many families said in interviews, they are hesitant to risk conceiving another child with the same disorder. For these families, PND is not the answer to their quest for a healthy child. They would prefer to wait — for a treatment, a cure, or a reproductive technique that avoids abortion, such as preimplantation diagnosis, a possibility that several families mentioned spontaneously.

Few would abort for severe adult-onset disorders starting at age 40 to 60. Even fewer would abort for genetic susceptibility to alcoholism, an area now receiving much attention. Although their overall responses suggest that most parents would not use abortion frivolously, 12% would abort for severe obesity. Responses to the obesity question should give readers pause. Although obesity is a medical condition with potentially serious consequences, most North Americans think of it primarily in terms of appearance (though they may use "medical" reasoning to justify an abortion choice). Apparently, there is a not insubstantial minority who would abort for cosmetic purposes if a prenatal assessment were possible.

The trimester of pregnancy had less relationship to personal willingness to abort than might be expected, given the public policy debates over second-trimester abortions. For most fetal conditions, only 5% fewer women would abort in the second trimester than in the first. This suggests that newer methods of PND, such as CVS, that make first-trimester abortions possible may have relatively little effect on deeply held attitudes.

The attitudes of respondents' own siblings, spouses, and parents toward abortion for cystic fibrosis were among the strongest predictors of the respondents' own attitudes. Sociodemographic variables, including religiosity, education, and income, also played an important role in personal attitudes toward abortion (see Table 3). Religious background itself was related largely to maternal/family situations, where traditional Catholic social values may remain, rather than to abortion for fetal characteristics. For some fetal conditions, those with higher education, income, and occupational status were more willing than others to abort. This finding reinforces concerns that differential use of selective abortion by different social groups could lead to discrimination against people with disabilities.

In many maternal or family situations, men were more likely than women to say that they would abort. Men were also more likely than women to say that abortion should be prohibited by law. Men eschewed the middle ground of not themselves aborting but permitting it for others. Gender was not related to any responses with respect to fetal characteristics.

If these results are in any way indicative of views of the general population, they should give pause to efforts to ban abortion for specific purposes or for specific fetal conditions. A large percentage of North Americans may favour leaving abortion decisions to the woman, even if they themselves would not abort in a particular situation. In this study, most would support the right of others to abort, including for their child's illness.

The results suggest a wide range of variability among families in terms of what they themselves will accept in a child. This points to the need to protect freedom of choice.

Table 3. Psychosocial Characteristics Associated with Personal Willingness to Abort in Selected Situations

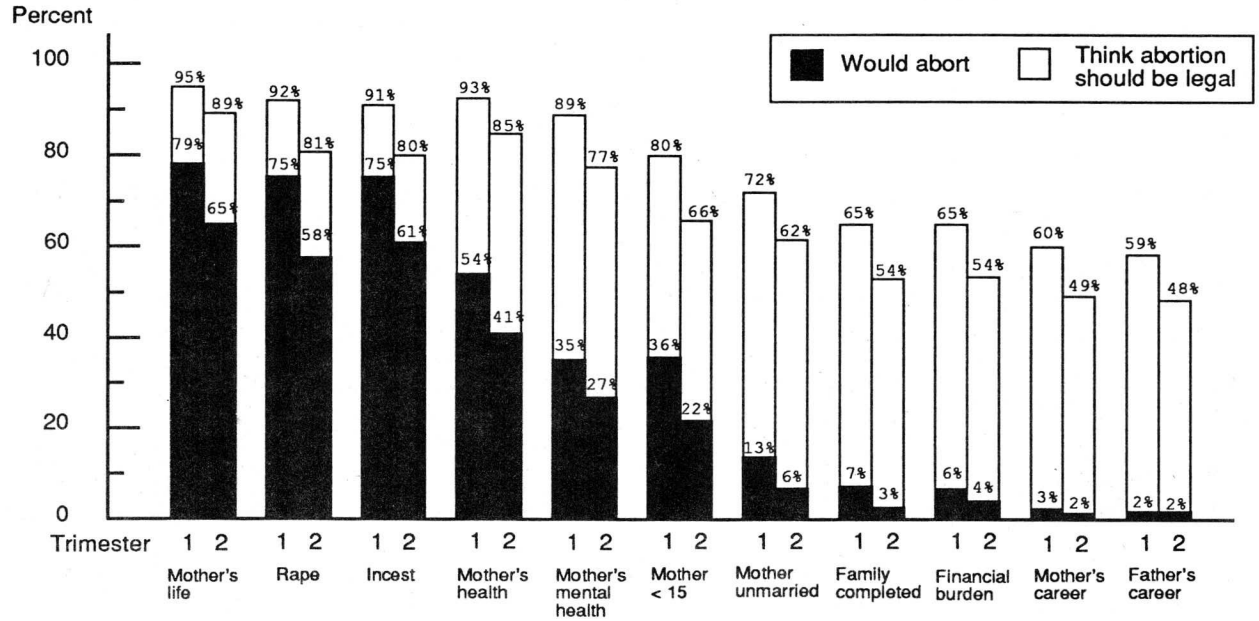
	Abortion situation						
Psychosocial characteristics	**Mother's life**	**Rape**	**Mother's health**	**Mother's mental health**	**Mother under age 15**	**Mother unmarried**	**Family completed**
Religion[1] (non-Catholic)	**	**			**	**	*
Infrequent attendance at religious services	**	**	*	*	*	*	*
Higher education (years)	**	*	**	**		**	**
Higher income[2]	*	**	*	*	**	**	*
Occupation[3] (professional)							
Respondent's sex							
- Female				**	*		
- Male	*		*			*	*
Previous elective abortion	**						*
Approval of abortion[4] of cystic fibrosis by:							
- Spouse	*	*	*	*	*	**	**
- Respondent's siblings	*	*	*	*	*	*	*
- Respondent's mother	**	**	**	**	**	*	*
- Respondent's father	*	*	*	*	**	*	*

[1] 4-point scale: once a year or less to weekly or more.
[2] 8-point scale: 0-$10 000 to $50 000 +.
[3] 6-point scale: unskilled to professional.
[4] 3-point scale.

Financial burden	Severe mental retardation	Bedridden for life	Death before age 5	Cystic fibrosis	Moderate mental retardation	Mild mental retardation	Severe disorder at age 40
*				*			
*	**	*	**	**	*	*	**
		*	**		**	**	**
*		**	*	*	*	*	*
	*	*	*	*	*	*	
*	**	**	*	*	**	**	
*	**	*	*	**	*	**	**
*	*	*	*	**	**	*	*
*	**	**	**	*	**	**	**
*	*	*	*	*	*	*	*

n = 271 parents of children with cystic fibrosis (Wertz et al. 1991).
* = associated at zero-order level, $p < 0.05$.
** = associated in stepwise logistic regression, $p < 0.10$.

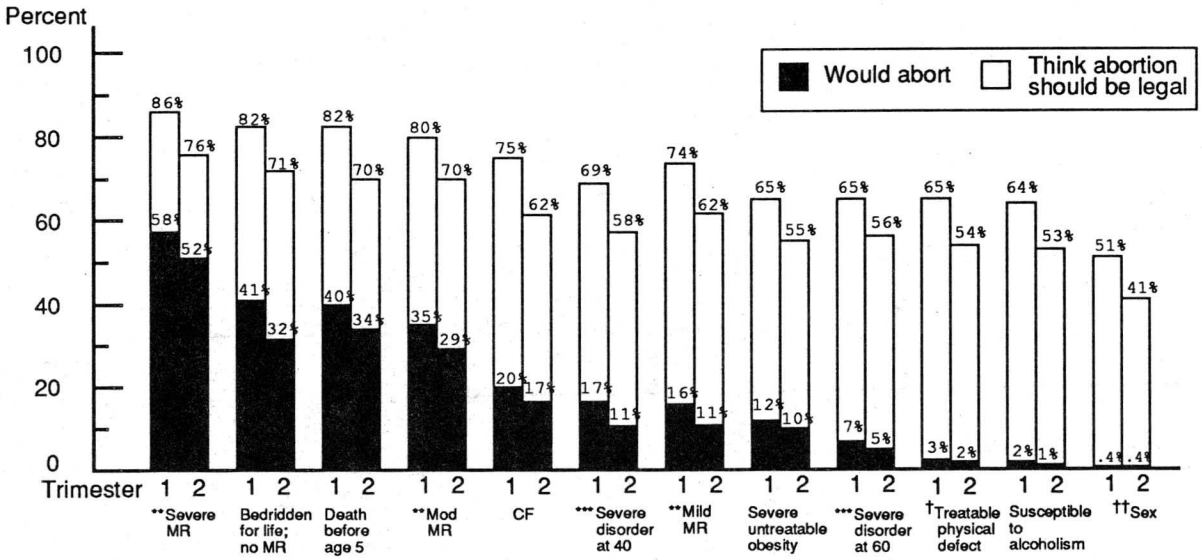
Figure 1. Abortion for Maternal/Family Situation (N = 271)*



* Due to missing data, actual n's varied from 240 (mother < 15, 2nd trimester) to 253 (mother's life, 1st trimester).

Source: D.C. Wertz et al., "Attitudes Toward Abortion Among Parents of Children with Cystic Fibrosis," *American Journal of Public Health* 81 (1991), 993.

Figure 2. Abortion for Fetal Characteristics (N = 271)*



* Due to missing data, actual n's varied from 237 (CF, 2nd trimester) to 246 (severe MR; sex, 1st trimester).
** Severe MR: unable to speak or understand; moderate MR: could communicate, not live independently; mild MR: could hold job and live independently.
*** Develop severe painful disorder, incurable.
† Cleft palate, nearsightedness.
†† Child is not sex desired by parents.

Source: D.C. Wertz et al., "Attitudes Toward Abortion Among Parents of Children with Cystic Fibrosis," *American Journal of Public Health* 81 (1991), 994.

Choice in Social/Cultural Context

Parents make their decision, not on the basis of odds or medical information alone, but in a context of perceived social consequences. The interviews with parents, the experience of genetic counsellors, and some published reports have described the major factors affecting their decisions. These include the following:

Guilt at Rejecting Their Own Child with a Disability

According to social workers, guilt at rejecting their own child with a disability is the major reason why parents of children with disabilities are reluctant to abort. "How could I throw away someone as lovable as you?" However, the Wertz et al. (1991) study did not support this reasoning. No parent of a child with cystic fibrosis gave this response, although the investigators tried to elicit it in both questionnaires and interviews. Those who were considering PND said they would not tell their children about their plans. Concealing both pregnancy and abortion from the affected child, who is usually very young at the time parents attempt another pregnancy, would be relatively easy. With CVS in the first trimester of pregnancy, the whole matter could be concealed even from the family's adolescent children. Studies of women who have undergone PND for other conditions show that most families tell their unaffected children about prenatal tests and selective abortion (Ashery 1981; Black 1991, 1993; Black and Furlong 1984; Green 1992; Tunis 1993). No research has yet been done into what families tell their affected children.

Quality of Life: Self, Child, and Marriage

Parental guilt over rejection of their existing child does not seem to be the major factor in decision making. Instead, parents use a complex balance of social, psychological, and moral factors, which they sum up as "the kind of life the child would have" or "what our life would be like," in other words, quality of life. Women speak of their own quality of life, the family's quality of life, and the child's quality of life as parts of an inseparable train of thought. Usually, they mention their own quality of life first, closely followed by considerations about the potential child, the marriage, and the rest of the family. Women often use the word "selfish" to describe what they wish to avoid or to condemn. In women's ethical reasoning, selfishness (i.e., acting without consideration of others) is the worst sin (Gilligan 1982). Some women carry this to extremes; they believe that for a woman to have a life of her own or to do anything for herself is selfish. Many think that if they fail at being "superwomen" or "supermoms" who can cope with any disability they will be regarded as selfish. Often they preface their decisions with "This may be selfish, but" and then go on to confess that they couldn't cope with a child (or another child) who is sick or has a disability. Conversely, some use the word "selfish" to condemn women who have made decisions to which they themselves object. One woman, speaking of an acquaintance who had carried a child with cystic fibrosis to term after PND, said, "She did that for herself. She didn't think

of the child at all. She just wanted another child and she didn't think about what the child's life would be like." The speaker said that she would have PND in her next pregnancy, and would abort a fetus with cystic fibrosis, because "it wouldn't be fair to the child to be born with that."

Married women or women living in a long-term relationship always consider the possible effects of a child with a disability on the marriage or relationship. Some think they could accept the child, but "this isn't the kind of child my husband wants." This line of reasoning occurs most often with regard to milder disorders, such as mild retardation, and especially with sex chromosome anomalies where the child will not mature sexually or will be infertile. Men find it more difficult than women to accept a boy who will not turn out to be a "man" according to accepted social definitions. (They are somewhat more willing to accept the infertile girl, as long as she appears normal.) Faced with this situation, the woman must weigh her belief that she could cope with the child's disability against the fact that she will have to live with a man who may continue to reject the child. Under such circumstances, the child's chance for a normal life and the marriage's or relationship's chance for survival are greatly diminished. When weighing the alternatives, many women decide to concede to the husband's or partner's view to protect the best interests of all concerned. These women's moral reasoning is based on a network of relationships rather than on the "rights" or interests of individuals (Gilligan 1982; Sherwin 1992). They do not regard their own, the child's, and the family's quality of life as separate entities.

When parents speak of the child's quality of life, their perceptions tend to follow the logic presented in Figure 2. Although much disability is "socially constructed" (Asch 1989; Saxton 1984, 1987; Wexler 1989) and could be eliminated or greatly reduced by social changes such as laws guaranteeing fair employment, education, access to buildings, and so on, some conditions are so severe that no amount of social change or social services could guarantee entry into the wider society. Even in the presence of outstanding social services, many parents will have to make considerable personal and financial sacrifices. Many parents believe that a child who will die in infancy or early childhood or will be severely retarded does not have a real chance at life. A child who will be bedridden for life but not retarded gives mothers a peculiar horror. They dread having to care, perpetually, for a sound mind in a paralysed body. Women in the cystic fibrosis study said "I find this really difficult" or "I don't want to think about this." Some found this situation the most unnerving of all the fetal conditions described. On the other hand, if a disorder is treatable, or occurs only after 40 to 60 years of productive life, most would regard the individual's quality of life as good. Parents are reluctant to acknowledge the concept of socially constructed disability. They often describe these disabilities, such as obesity, in medical terms (higher risk of heart disease, shortened life expectancy), rather than in social terms.

When speaking of a fetus, parents almost never use ethical, legal, or religious terms such as "rights of the fetus," "right to life," "rights of the unborn child," or "personhood." These terms reify the fetus into a separate entity, while pregnant women feel its "connectedness" with their own bodies. Women feel that the fetus is a potential person, not merely "a collection of cells that made a mistake" (doctor quoted in Rapp 1988b, 103). Women think in terms of the child that the fetus could become, rather than in terms of its present stage of development. Often, they envisage the child over its entire life. However, few seek out and talk with other families who have raised such children to adulthood when counsellors refer them to such families. Most women, faced with a decision about abortion, wish to make the decision as quickly as possible, even if they are still within the first trimester. They do not wish to delay their decision by taking time to talk to other families.

In the Wertz et al. (1991) study on cystic fibrosis, the trimester of pregnancy made little difference in views. As the public learns more about the fetus and embryo, and as PND assigns individual characteristics to fetuses earlier in pregnancy, more women have come to regard the fetus as a potential human being from the beginning of pregnancy (Fletcher and Evans 1983; Imber 1986, 1990; Rapp 1988b), regardless of their religious beliefs. Making selective abortion possible in the first trimester of pregnancy does not alter women's fundamental beliefs that they are making a decision about a potential child, though it does make the abortion procedure much easier.

Although religious beliefs play a large part in their decisions, those who do not abort rarely use religious or ethical terms. They say simply, "I couldn't go through with that [selective abortion]." Those who are religious and who nevertheless choose to abort say that they believe God is forgiving; if Catholic, they go to confession and may have the aborted fetus baptized (Rapp 1988b, 112-13).

"Wantedness" of the Pregnancy

Perhaps the most important factor in abortion choices, after quality of life, is the degree to which a pregnancy is wanted or unwanted. Families with unwanted or semi-wanted pregnancies usually do not hesitate to abort, even for relatively minor abnormalities. It is as if a diagnosis of a disorder gives them a morally acceptable way out of an undesired situation. On the other hand, families with wanted pregnancies find the decision extremely difficult, even for severe abnormalities. Sometimes, they have tried for years to achieve this pregnancy or have a history of miscarriages. Even if the woman becomes pregnant without difficulty, abortion means abandoning hopes and dreams for a much-wanted child.

Optimism

Most parents who consider having more children after the birth of a child with a genetic disorder are coping well because the affected child is probably still quite young and has not yet exhibited major symptoms of the

disorder. Even with severe disorders, an infant or small child may appear close to normal. The differences appear later, when the child's age-mates start to mature. Parents of small children, finding that the child seems healthier and more normal-appearing than they had expected, and feeling a sense of achievement because they have been able to cope, are frequently optimistic about the child's future. In the cystic fibrosis study (Wertz et al. 1991), most parents thought that their children would reach age 40 (the oldest age listed in the questionnaire), even though few people with cystic fibrosis have lived this long. Most expected their children to live independently, hold full-time jobs, marry, become parents (if boys, through artificial insemination, because men with cystic fibrosis are infertile), travel, engage in sports, and do whatever else is associated with normal life. In the interviews, many said that they expected science to find a cure before their children started to experience severe symptoms. A typical statement was: "It would be really hard to think about that [abortion] right now. She's doing so well. I know I'll think about it when she's a teenager and maybe starts getting real sick, if they still haven't found a cure" (mother of a four-year-old with cystic fibrosis).

Optimism is pervasive among parents of children with disabilities. Optimism is part of the "denial" that goes with normal psychological coping mechanisms; parents find it easier to cope day to day if they believe that the worst symptoms will never appear or that science will find a cure in time. Optimism, much of it unrealistic, accompanies many disorders. For example, one-quarter of adults at risk for Huntington disease think that science will find a cure before they develop symptoms (Kessler et al. 1987), although no cure is in sight. "Can't you fix it?" is a common refrain from patients who receive a diagnosis of an affected fetus. Even if every cell in the child's body has an extra chromosome (a situation that most geneticists despair of ever rectifying), parents expect science to find a remedy.

However, some expectations of cure, or at least treatment, may be realistic. For example, 25 years ago children with cystic fibrosis lived to the age of about 7; in 1990, the median life expectancy was 28 in the United States and 32 under Canada's national health care system, and rising. Children with cystic fibrosis often live for long periods — 10 years or more — with no symptoms.

Spouses and Compromises

Most people choose spouses or partners with similar underlying values about abortion. Often, entire extended families share similar views. In the Wertz et al. (1991) study, there were strong correlations between women's own attitudes and their perceptions of the attitudes of partners and extended family networks. Nevertheless, some studies have shown that in many marriages — up to two-fifths — spouses hold somewhat different views about aborting fetuses with abnormalities (Beeson and Golbus 1985; Sjögren and Uddenberg 1988) or about the burden of raising an affected child (Sorenson and Wertz 1986). Men do not experience pregnancy and

do not usually take primary responsibility for children's daily care. They have a certain emotional distance from the pregnancy, and find it considerably easier than their women partners to decide what should be done. In the Wertz et al. (1991) study, men tended toward the extremes, saying either "I would have an abortion" or "abortion should be prohibited by law," while women preferred the middle ground, "I would not have an abortion but it should not be prohibited for others." Often, when a family comes in for PND after having had a child with Down syndrome, it is at the insistence of the husband or partner, who has made it clear that he does not want another such child. However, when a man who has held rigid anti-abortion views receives a positive diagnosis of abnormality, it is emotionally upheaving because his world view has been threatened.

Who compromises when spouses or partners differ? Counsellors report that often the woman's view prevails because she is carrying the pregnancy and will later care for the child. On the other hand, sometimes the woman, after considering the effects on the relationship, yields to the man's point of view. According to a woman who carried a fetus with cystic fibrosis to term after receiving the diagnosis only a week before the time limit on abortion elapsed,

> I wanted to have an abortion. I didn't want to bring a child into the world to see it suffer. But my husband, he was brought up Catholic, though he isn't religious anymore. But he was bothered by the idea of abortion. He said to me, "How many more times are you going to go through this?" That really got me thinking, because I knew if I had an abortion I would have to do this again. So I went ahead and had _____, and then I had my tubes tied. If I'd really insisted on it he would have let me have an abortion. I know if I'd had more time [to decide], I would have had an abortion. (Wertz 1992, 180)

This woman, after considering the quality of life with a potentially disgruntled husband, the certainty that she would have to go through PND on the next pregnancy, the possibility that the next pregnancy might also be affected, and the fact that her previous child with cystic fibrosis was doing well, opted to have a second child with cystic fibrosis. For her, this was the least-lose option, there being no real most-win option in her situation.

Finances

Financial considerations play a role in most decisions, and are part of quality of life. Although parents do not make financial cost-benefit statements, they do think about costs. Both low-income and upper-income families use cost as a rationale.

According to Rapp:

> One genetic counselor encountered two patients, each of whom chose to abort a fetus after learning that its status included XXY sex chromosome (Klinefelter's syndrome). One professional couple told her, "If he can't grow up to have a shot at becoming the President, we don't want him."

> A low-income family said of the same condition, "A baby will have to face so many problems in this world, it isn't fair to add this one to the burdens he'll have." And a Puerto Rican single mother who chose to continue a pregnancy after getting a prenatal diagnosis of Klinefelter's said ... "He's normal, he's growing up normal. As long as there's nothing wrong that shows, he isn't blind or deaf or crippled, he's normal as far as I'm concerned." (Rapp 1991, 147)

Lower-income women sometimes note that parent support groups and social activists for children with disabilities are usually upper middle class. They cannot count on the same level of support for their own children with disabilities. According to one woman who was a member of a minority group,

> All those groups, those films and stuff, I don't know if that really helps Malik. In fact, it *don't* help Malik. What good does it do to put all those fancy white kids on television? Oh sure, it's an inspiration. I bet the Reagans, they sit home nights watchin' it. Gives them a good excuse not to worry when they cut the social services back. Those films don't say that the kids got parents who can pay for speech therapists, foot doctors, special computer tapes in their homes. Not my son, why don't they put my son on the television? Then people would see what it's really like. (Leila Robertson, mother of a seven-year-old with Down syndrome). (Rapp 1993, 70)

Risk

Risk itself is less important than what is risked. Of course, families do want certainty. Many genetic counsellors have encountered the proverbial patient who is not satisfied with 99.4% certainty and wants the test done again to try for 100%. Studies of hypothetical behaviour show that if a risk for spina bifida is raised from 95% to 100%, far more women say they would abort (Faden et al. 1987). Nevertheless, in practice many decisions follow severity of disorder rather than degree of risk. Many parents find even a small risk of retardation unacceptable.

> We were told of a possible 10% risk of mental retardation in our child; the degree of impairment could not be predicted. We clutched at straws. The baby was moving and growing normally; two ultrasound scans had been normal. Were not these important signs? But then the baby would be physically normal even if mentally retarded. No comfort there ... It seemed crazy that although we had not been prepared to risk a chance of one in 200 of having a child with Down's syndrome we were now in an agony of indecision over a one in 10 risk of mental retardation. ("When Risk Factors" 1989, 1599-1600)

This family decided upon abortion. A similar risk for a sex chromosome abnormality would have led many families to a different decision (Robinson et al. 1989; Verp et al. 1988).

Parents who decide on the basis of risk alone may regret their decision if the result is the birth of an affected child.

> The couple in our study [of Duchenne muscular dystrophy and hemophilia] who was perhaps most unprepared for the birth of an affected [child] both had graduate training in mathematics. In their decision making process they focused heavily on the probabilities and decided the odds were in their favor. They plan a different course of action in their next pregnancy. (Beeson and Golbus 1985, 113)

Other Children

According to some, simply being a parent of a normal child makes women less willing to abort, especially a wanted pregnancy (Black and Furlong 1984; Rothman 1986). However, some women choose to abort a fetus with an abnormality largely because of their normal children.

> Our first child and her welfare became a major factor in the equation. Not only were we aware of the possible effects on her of having a mentally retarded sibling but also we were continually thankful for her existence. It would have been much worse if it had been our first pregnancy. ("When Risk Factors" 1989, 1599-1600)

Adult and adolescent siblings of affected children are usually quite accepting of PND and often plan to have it themselves (Miller et al. 1987). Affected children themselves may accept the idea, even though in principle it negates their own existence. In one study, most of the adolescents and young adults with thalassaemia said that they wished their parents had had PND and selective abortion before their own births, even though they would not have been born (Schiliro et al. 1988).

Fetal Sex

Sex alone, in the absence of risk for an X-linked disorder, plays a minor role in most parents' decisions about fetuses diagnosed with abnormalities. The exceptions are cases when there is a risk, rather than a virtual certainty of a disorder, of about 10% to 12%. Then, parents, in an effort to grasp anything that might help them decide, may take into account the fetus's sex, especially if all of their living children are of one sex.

Reproductive Alternatives

Some families could avoid the abortion decision by adopting or using artificial insemination by a donor or a donated egg and IVF. Few do. Adoption has become both difficult and expensive, with an average payment in the United States of about $14 000 to agencies, lawyers, and hospitals; that is, if a healthy infant can be found (Caplan 1990; Bartholet 1993). If at all possible, most families prefer to have their own children. As one couple in the cystic fibrosis study said, "An adopted child wouldn't really be our own" (Wertz et al. 1992).

Many people, especially women, might favour donor insemination (McCormack et al. 1983) if a "risk-free" donor could be found. Several families in the Wertz et al. (1992) cystic fibrosis study said that they had considered and rejected donor insemination because at the time (1989) it was impossible to be certain that the donor did not carry the gene for cystic

fibrosis. Discovery of the gene for cystic fibrosis and the development of carrier tests have since made donor insemination a stronger possibility, though current tests leave a small, but real, possibility (perhaps 1 in 650) that the woman could still have a child with cystic fibrosis after donor insemination.

Another possibility, spontaneously mentioned by several families interviewed, was IVF and selection of a healthy embryo for implantation. Although the cystic fibrosis study did not ask about reproductive alternatives, some couples had read about embryo selection and were enthusiastic. "I'd be willing to go from door to door and take up a collection for [research on] this," said one man whose wife opposed abortion and who had been unable to adopt. No one interviewed regarded embryo selection as abortion, because there was no pregnancy. They did not see the embryo as a human being and were not concerned about destroying or freezing defective embryos. Women clearly regarded pregnancy as a process taking place inside their bodies and abortion as removal of something from them. What happened in a petri dish, before implantation in the womb, was another matter entirely. When it becomes possible to select embryos free of cystic fibrosis or other disorders, many families at risk will see this as a least-lose alternative, in spite of the high costs of IVF and success rates that many families may consider low. Robertson (1992) thought that because of its high out-of-pocket cost to patients, preimplantation diagnosis will be little used, at least in the United States. However, Bonnicksen (1992) thought that it will become the driving force behind IVF and that commercial IVF laboratories will use it as a lure to attract patients.

Pluralism

Canada and the United States are pluralistic societies, which are now moving toward multiculturalism, meaning the incorporation of the views and traditions of different cultural groups into the mainstream of society. Individuals, families, and cultural groups have different thresholds of acceptance for different kinds of disability. Responses to the Wertz et al. (1991) study of families of children with cystic fibrosis show wide variation in acceptance of various conditions. What one person could accept, another could not. It is appropriate that the person who will raise the child make the decision, whatever that decision may be; usually, this is the mother. Social workers, doctors, and ethicists should not interfere with parents' decisions, unless they themselves intend to raise the child. (Although carrying the child to term and placing it for adoption is usually a possibility, few women are willing to turn over a wanted baby to someone else.) It is probably better to allow some parents to make frivolous decisions (e.g., aborting a fetus with a treatable problem) than to interfere legally and thereby jeopardize the entire structure of patient autonomy.

In reality, most parents find decisions about selective abortion of a wanted fetus difficult. Their decisions are made in a social context and on

the basis of how an affected child would affect their own and their family's quality of life. Practically speaking, it is impossible to separate their own quality of life from the child's quality of life in trying to assess the consequences of having such a child. Most use a least-lose pattern of reasoning. Women stand to lose, whatever decision they make. A woman who chooses abortion has to give up the "Madonna" image of the long-suffering mother who nurtures without conditions; instead, she may feel like an "agent of quality control in the reproduction production line" (Rapp 1988b, 115) or she may wonder if the baby will be "good enough for us."

On the other hand, a woman who chooses to carry an affected fetus to term may be "a mother forever," losing out on the new job or career opportunities available to other women, and often raising the child without adequate social and financial support. She may also be accused of selfishness for bringing a child into the world without thinking of the child's quality of life.

In a multicultural society, it is important to respect the choices of people who make different, even diametrically opposing, decisions.

Opponents of Selective Abortion: Comparison of Lifestyles

Anti-abortion groups are most adamant in regard to selective abortion, more so than for any other type of abortion. Luker (1984) found that this was the one area where pro-life groups were the least likely to compromise. They believed fetuses with disorders or malformations were the most in need of protection. According to Luker, "to defend a genetically or congenitally damaged embryo from abortion is, in their minds, defending the weakest of the weak" (ibid., 207-208). They speak of amniocentesis as "search and destroy missions" or "selective genocide against the disabled" (Schaeffer and Koop 1979). Luker explained that pro-life activists identify themselves with the "deformed" fetuses found by amniocentesis. Pro-lifers are defending an earlier set of values and beliefs no longer held by most North Americans, about 79% of whom approve abortion for serious fetal defects (University of Chicago, NORC 1991). Pro-lifers feel that they are an embattled minority in need of protection, like fetuses found to have serious problems. Luker reported that pro-life activists in her survey had considerably less education and income than pro-choice activists. Sixty percent of pro-life women finished college, compared to 94% of pro-choice women, and only 37% of pro-life women worked in the paid workforce, compared to 94% of pro-choice women. According to Luker:

> The average pro-choice activist is a forty-four-year-old married woman who grew up in a large metropolitan area and whose father was a college graduate. She was married at age twenty-two, has one or two children, and has had some graduate or professional training beyond the B.A. degree. She is married to a professional man, is herself employed in a regular job, and her family income is more than $50,000 a year. She is

> not religiously active, feels that religion is not important to her, and attends church very rarely if at all.
>
> The average pro-life woman is also a forty-four-year-old married woman who grew up in a large metropolitan area. She married at age seventeen and has three children or more. Her father was a high school graduate, and she has some college education or may have a B.A. degree. She is not employed in the paid labor force and is married to a small businessman or a lower-level white-collar worker; her family income is $30,000 a year. She is Catholic (and may have converted), and her religion is one of the most important aspects of her life: she attends church at least once a week and occasionally more often. (Luker 1984, 197)

Pro-life women and their husbands believed that a woman's primary role was motherhood and that the financial sacrifice of keeping the wife and mother at home was well worth it in terms of their own values. "Pro-life people have relatively fewer official achievements in part because they have been doing what they see as a moral task, namely, raising children and making a home; and they see themselves as becoming handicapped in a world that discounts not only their social contributions but their personal lives as well" (Luker 1984, 207). It is small wonder, then, that they have chosen to identify with fetuses with disabilities. They see themselves as part of an oppressed minority (full-time wives and mothers) whose values are no longer respected and who are in danger of obliteration in a changing society.

PND Without Abortion

PND can be used to prepare for the birth of a child with a disability instead of making a decision about abortion. Some families use it for exactly this purpose. In a recent study of parents of children with cystic fibrosis, 44% of those who would use PND would do so "to prepare myself for the birth of a child with cystic fibrosis," 28% would use PND to get information so they could make a decision, and 28% would abort (Wertz et al. 1992). Tables 1 and 2 show that some women do not abort after positive findings, even for conditions involving mental retardation. Medical professionals now regard this as a legitimate use of PND. Most geneticists in Canada (87%), the United Kingdom (91%), and the United States (96%), but fewer in France (56%), would perform PND for a couple at 42 years of age, with a previous child with Down syndrome, who say they oppose abortion but would like to prepare themselves for the birth of another child with Down syndrome (Wertz and Fletcher 1989e). Many geneticists said, in giving reasons for performing PND in this case, that willingness to abort should not be a pre-condition for PND or that PND should be offered "with no strings attached." Many geneticists (34%) believed that these patients might change their minds about termination after a positive diagnosis, and that a possible change of mind justified performance of the procedure. Few

mentioned any medical risks to the mother or the fetus. The only countries where PND professionals would refuse to use such testing for this purpose were those with limited laboratory resources and Norway, which has legal limits on the number of procedures. Individual hospitals within a country may also have limited laboratory capacity and may have to turn away some women who oppose abortion.

Most women who seek PND to prepare themselves for the birth of a child with a disorder are really seeking PND in the hope that they will find out that the child will be healthy. After receiving favourable results, they can continue the pregnancy with greatly reduced anxiety. Professionals in North America believe that this is a justified use of PND. Helping families to prepare themselves for the birth of an affected child is now an ethically accepted use of the procedure (Clark and DeVore 1989).

However, most families probably associate PND with at least a willingness to consider abortion. This willingness was the characteristic most strongly related to intentions to use PND among families of children with cystic fibrosis (Wertz et al. 1992).

Use and Effects of PND

Effects of Differential Use of PND by Different Social Groups

Women who have PND tend to be better educated and to have higher incomes than those who do not have PND. In one study in the United States, 60% of urban white women over 40 years of age in Georgia, but only 0.5% of African-American women over age 40 in rural areas, used PND (Sokal et al. 1980). Rapp (1988b) noted that half of minority women visiting clinics in New York City do not keep their initial appointments for genetic counselling, and 20% to 50% of those who are counselled decide not to have PND, largely because their world views differ from those of the counsellors. In contrast, 10% of patients in private care in New York do not keep their appointments for counselling. These differences result from inequities in the U.S. health care system (in 1988, 39% of African-American mothers and 39% of Hispanic mothers did not receive prenatal care in the first trimester [U.S. Department of Health and Human Services 1991]), and also from difficulties in communication between medical professionals and patients with less education. Studies of communication in genetic counselling have found greater awareness, among both professionals and patients, of what the other party wanted to discuss, if the patient were better educated (Wertz et al. 1988b). Genetics professionals were more satisfied with counselling if patients were better educated (Wertz et al. 1988a). Educated patients were also more likely than others to report, six months after counselling, that the counselling had influenced their reproductive plans (Wertz and Sorenson 1986).

However, even in countries with a national health service or national health insurance, genetics professionals are concerned that those who are better off and better educated are using PND at rates disproportionate to other classes. In the United Kingdom, "The two-income family that has postponed child-raising until their mid-thirties would become the primary customers for chromosome analyses. This prospect challenges the British sense of fairness and the belief that health care is a right rather than a privilege" (Harris and Wertz 1989, 415). One early Canadian study suggested that PND was being used primarily by college-educated women (Bannerman et al. 1977).

Different social groups also use PND at different rates on account of their personal and social values. For example, the family with two pay cheques is more likely to favour abortion rights, especially if the woman has a college or graduate school education, than the family with a full-time wife and mother who stays at home. African-Americans, while using abortion in general at somewhat greater rates than the U.S. white population, use selective abortion comparatively rarely, probably because of strong values about protecting a wanted pregnancy (Bowman 1991; McCormick 1975).

The women who receive PND are not necessarily the women who most need it. Two-career couples in their late thirties are not the only families who could benefit. The age distribution in childbearing suggests that minority women, especially African-Americans and Hispanics, account for a disproportionate share of the births to women over 40 years of age. In most of Latin America, the distribution is even more skewed. An estimated 10% to 12% of all births south of the U.S. border are to women over 40 years of age, most of whom are poor and almost none of whom have access to PND or legal abortion (Penchaszadeh 1993). People from lower socioeconomic groups are also at greater risk for exposures to environmental hazards, both at home and at work, that may cause fetal malformations. Substance abuse and battering of pregnant women occur in all social classes, but such problems are less likely to receive consistent treatment among poor women. Although poor women appear to be at greater risk than others for bearing children with genetic disorders or fetal malformations due to continued childbearing over age 40 and greater exposure to toxic substances, no evidence shows that they have more children with such disorders than do those who are more economically advantaged. The effects of social inequality are demonstrated primarily by higher rates of prematurity and low birthweight among disadvantaged groups.

Nevertheless, in the future, differential use of PND and selective abortion by different social groups could lead to an unbalanced distribution of genetic disorders among social classes, although the impact will be limited since most causes of handicap are not genetic and PND is done only if there is an increased risk, often because of an already affected child. It is possible that lower classes could be looked down on if they continue to

have children with mental retardation and do not use PND. "It will be the educated, articulate, vocal, and economically privileged who will use the system most effectively and for whom there will be the most marked fall in births of affected children. Further, the burden of caring for handicapped children might increasingly fall on those who can least afford it and are least able to press for better services" (Harris and Wertz 1989, 405).

Use of PND for "Less Serious" Conditions

Although about 79% of the U.S. population believe abortion should be legal "if there is a strong chance of serious defect in the baby" (University of Chicago, NORC 1991), a percentage that has changed little since 1972, there is no precise societal definition of "serious." Nor is there any definition of what may be considered serious in the future. Conditions that were once frequently fatal in childhood (Down syndrome, spina bifida, cystic fibrosis) are now medically treatable, so that most of those affected reach adulthood, but still have the underlying condition. Some people with Down syndrome hold jobs. Most people who would once have been bedridden can now propel themselves in wheelchairs. People with hearing, visual, or motor disabilities can now enter most public buildings, apartments, and businesses, as the result of laws requiring accessibility. In other words, many disabilities are less "serious" than they were formerly, due to medical, legal, and social advances.

On the other hand, medicine has often extended life without being able to treat the basic mental or neurological problems. Parents age while still caring for an adult child with a mental disability.

PND reveals disorders that most medical professionals might not consider serious, such as sex chromosome abnormalities, but that society continues to stigmatize. Many parents who want small families of one of two children may decide that a boy with an XXY chromosome complement (Klinefelter's syndrome), for example, is not the son they want. Although the boy will reach puberty with proper treatment, he will be infertile (a condition that many fathers associate, falsely, with impotence), may look different from his peers, and may have learning or behavioural problems. A family may decide that they do not wish to invest their resources in this child if they could choose otherwise. Or, a family belonging to a cultural minority that places a high value on a woman's ability to bear children may decide that a girl with an absence of the second sex chromosome, 45,X (Turner syndrome), would be an economic disaster. On account of her infertility, no one in that cultural group will marry her and the parents will have to support her for the rest of her life. In India, 46% of geneticists would advise abortion for a 45,X fetus, as would 40% in Turkey (Wertz and Fletcher 1989e). Parents vary greatly in their perceptions of seriousness. What one family finds acceptable, another may find extremely serious in terms of their personal expectations for the child, their culture's expectations, their economic situation, or their goals for their own lives.

Although use of abortion may follow a range of perceived seriousness that starts with severe mental retardation (total inability to communicate), early death, or extreme physical disability as the most serious (see Figure 2), a small percentage of families might consider, for example, development of Alzheimer's disease at age 60 a condition that warranted termination before birth, especially if they themselves had cared for a parent with such a disease. (Even though they might not be living to care for the child when the child reaches 60 years of age, they might consider the suffering for the child extreme.) Other parents might decide that the 5- to 10-point deficit in I.Q. that often accompanies treated phenylketonuria (PKU) is something with which they would prefer not to deal. Some have warned that if enough parents make such choices regarding I.Q., the norms themselves could change (Genetic Screening Study Group 1988).

It is probably best to let parents decide what they consider serious, even if most people would not agree with some decisions. There are both cultural and individual differences in how people define health and disease (Ekwo et al. 1985, 1987; Payer 1989). Unless society is willing to raise the child (something neither society nor the parents would wish), the decision is best left to the people who will raise the child. Only they can define the word "serious."

It would be dangerous to create medical, legal, or social definitions of serious because they could infringe on families' lives in several ways. First, as mentioned earlier, a disorder now considered serious, such as Down syndrome, could become less serious in its effects because of improved education and training. If Down syndrome were to be redefined as no longer serious, anti-abortion activists could promote legislation making legal abortion difficult. (A similar pattern has already occurred with the post-natal treatment of Down syndrome; the disorder was once, but is no longer, considered serious enough to warrant non-treatment of affected neonates (Fletcher 1982; Guillemin and Holmstrom 1986).)

At the other extreme, a cultural majority could define a condition as serious, when it is treatable. This majority could enforce its views on people who hold minority views by refusing social supports for children with this condition. This is the situation that concerns most people who try to equate PND with eugenics. To accommodate minority and majority views in a pluralistic society, it is best to leave all such decisions to the parents, even if some decisions appear to be made on frivolous grounds. However, accommodating all views leaves the door open to some relatively trivial reasons, for example, with regard to height and weight. In one study, 12% of parents said they would abort for "severe, untreatable obesity," almost as many as would abort for mild retardation and more than would abort for susceptibility to alcoholism (Wertz et al. 1991). Although some of these parents may have considered obesity a medical condition, in a society that values thinness, obesity would be one of the first conditions selected against on social grounds. Short stature would be another cosmetic condition against which some families would select. So would unusually

tall stature in a girl. Both weight and height are in a sense "medical" conditions and doctors would probably be legally obligated to disclose variations from the norm, if these conditions were to become prenatally diagnosable. If many parents were to act upon such information, the norms themselves would change.

The best approach to PND for so-called less serious conditions in a pluralistic society is to provide the most complete, unbiased education possible. This is especially important if parents have no experience with the disorder in question. What parents do after a diagnosis has been made depends largely on what the doctor, counsellor, or genetic support group tells them. For example, fewer parents decide to abort for sex chromosome disorders if provided with thorough, unbiased counselling (Holmes-Siedle et al. 1987). This is particularly important for male fetuses, because many parents associate a sex chromosome abnormality with homosexuality, but do not discuss their fears with the counsellor.

Some parents will consider cystic fibrosis a less serious condition, especially as the media continue to report new treatments and hopes of cure. What members of the general population do with carrier screening and PND for cystic fibrosis will depend almost entirely on what the media and the medical profession tell them. Most people have never seen anyone with cystic fibrosis. Educational materials for screening programs in some countries in Europe describe cystic fibrosis as an extremely serious disorder leading to death in the late teens. Conversely, materials to be distributed by the consortium of seven cystic fibrosis carrier screening pilot studies in the United States, funded by the National Institutes of Health (NIH), say that people with cystic fibrosis go to college, work full time, live independently, marry, and lead generally normal lives (U.S. Congress 1992). The NIH-funded consortium further explains to people to be screened that with advances in medical treatment, children born with cystic fibrosis today can reasonably expect to live to 40 or more years. Parents who are told that children with cystic fibrosis are likely to die in their late teens after a long, serious illness are likely to respond differently to offers of PND than are parents who are told that their child will probably live to age 40 and have a productive life.

It is imperative that society provide educational materials and resources (including referrals to individuals and families with the disorder in question) that describe the entire range of phenotypes associated with a given condition, throughout the individual's lifetime, and, if necessary, how the disorder affects the next generation (e.g., birth defects resulting from maternal PKU, or increased length of mutation and severity of disorder in fragile X syndrome and myotonic dystrophy). Although education may cause stress for some parents (as noted in the NIH consent form for cystic fibrosis education and screening), it is absolutely essential for decision making. Thorough education is also likely to reduce the number of abortions for less serious conditions, as parents realize that they can cope

with the situation. The major problem will be to avoid bias; this may mean presenting a variety of different and even conflicting opinions.

Education holds the potential for creating more loving and better informed choices. According to Asch, speaking on behalf of those with disabilities,

> Seeking to avoid the experience of raising disabled children is no crime or callous, selfish statement, as some may claim. It is an honest, understandable, if perhaps misinformed, response to the fears that a disabled child will not fulfill what most women seek in mothering — to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud. Let us frame our thinking about prenatal diagnosis and selective abortion in a sincere discussion of what we long for in the experience of having children. Let us then ask how a child's disability will compromise that dream. Such discussion will help us to answer the question of whether it is disability inherently that pains or the consequences of disability that might be changed with genuine societal commitment to change them. If we believed that the world was a problem to the child and not the child a problem to the world, we might be better able to imagine how raising a child with a disability could give much the same gratifications as raising another child who did not start life with a disabling condition. (Asch 1989, 86)

Effects of PND on Societal Attitudes Toward People with Disabilities

Many people fear that increased use of PND will shift social resources away from people with disabilities (Harris and Wertz 1989; Holder and Henifin 1988; Hubbard 1990; Hull et al. 1984; Johnson and Elkins 1988; King's Fund Forum 1987; Lippman et al. 1985; Motulsky and Murray 1983; Rothman 1986, 1989; Schroeder-Kurth and Huebner 1989).

There are several important points to remember in approaching this topic. First, most disabilities are not genetic in origin. Genetic disorders, diagnosed prenatally, account for 1% or less of all abortions and are never the leading cause of infant or toddler mortality. The most common causes of birth-associated disability are prematurity, low birthweight, and environmental exposure — none of which is preventable by PND.

Most disabilities result from accidents, aging, viral or bacterial diseases, birth traumas, acts of violence, or environmental exposures. Although some of these, such as disabilities resulting from cardiovascular incidents, may have genetic components, the genetic contribution is only part of the origin of multifactorial disabilities, which also depend on the environment. It is unlikely that PND will ever have predictive value for most multifactorial disorders.

Genetics does not even account for most severe mental retardation. Altogether, chromosomal disorders (e.g., Down syndrome), single-gene disorders (e.g, Tay-Sachs disease, fragile X syndrome), and developmental

malformation syndromes (e.g., neural tube defects) account for about 40% of individuals with I.Q.s under 50 (U.S. National Institutes of Health 1979). Accidents at birth, prematurity, low birthweight, environmental or substance exposures, and unknown factors account for the remaining 60%. Genetic disorders do account for substantial numbers of deaths at early ages, including perhaps 20% of all infant deaths. They are second only to prematurity and birth injuries as causes of perinatal mortality. They are estimated as the second leading cause of death in the 1- to 4-year age group and the fourth leading cause in the 15- to 24-year age group (ibid.), behind accidents, suicide, and homicide (U.S. Department of Health and Human Services 1991). Many fetal malformations, including some congenital heart defects, cannot be diagnosed prenatally. Even disorders that can be diagnosed prenatally, such as Tay-Sachs disease, will not be tested for in low-risk groups and will continue to appear. Other disorders, such as neurofibromatosis, have a high new mutation rate. This means that disability will always be with us, regardless of what we do with PND. Society needs to be prepared to offer support to people with disabilities. Even if every pregnancy underwent chromosomal PND and testing for neural tube defects (an unlikely event, given the negative risk-benefit ratio for younger women) and every woman agreed to abortion (also unlikely), society would still have children with birth defects of genetic origin (e.g., from unsuspected inborn errors of metabolism, new mutations, heart defects). Most birth defects would still originate from prematurity, low birthweight, and environmental exposure, as they do now (Yankauer 1990). This argues for preventive measures that aim at the social and environmental causes of birth defects. There is no reason why social and economic programs cannot go hand in hand with public education about genetics and use of PND, if desired. There is also no reason why prevention of disabilities — through adequate maternal nutrition, prenatal care, prevention of substance abuse or physical abuse, and PND — must be at cross-purposes to support people living with disabilities. It is illogical to argue that supports for living people with disabilities will be reduced if there are fewer such persons.

Second, it appears unlikely that society will have fewer people with disabilities in the future. As society ages, we can expect more, rather than fewer, people with disabilities of all types, including mental disabilities; thus, it is important to increase, rather than to contemplate decreasing, supports for people with disabilities.

However, those who are concerned about the effects of PND on attitudes toward disabilities do have some legitimate fears. Sooner or later, as health care budgets are rationed, perhaps according to the Oregon model, taxpayers may decide that they do not wish to provide extraordinary support for a child with very limited potential if the birth could have been prevented. (This is not to say that most people lack all sympathy for those with disabilities or that this is the beginning of a Nazi-like extermination program.) When treatment is not effective and the state underwrites the

cost of care, at some point there must be a limit to the amount expended, so that funds can go toward patients whose treatment may be successful. Thus, Oregon has decided not to give extraordinary treatment to children with acquired immunodeficiency syndrome (AIDS). This decision was made after statewide public forums and public discussion. Some serious and untreatable genetic disorders will probably fall similarly low in the scale of triage, and probably most of the public will concur. This is the area where majority views are most likely to impinge on those with minority views. If a woman has PND and then decides to carry to term a baby with a serious and costly problem that cannot be treated successfully, she may indeed face social disgrace (Billings et al. 1992; Natowicz et al. 1992). (She could, of course, have refused PND, but may still be considered socially irresponsible for doing so.) She may also face loss of social benefits. The U.S. Office of Technology Assessment, in a survey of geneticists, found instances where health insurance companies attempted to withdraw insurance in such cases (U.S. Congress 1992). This type of discrimination may be more likely under a national health insurance system, where insurance is centralized and the only appeal is to the legislature and ultimately to the voters. Some national systems of maternity benefits, as in France, make all benefits dependent on women's compliance with a regimen of prenatal and post-natal visits, which include some tests. It would be comparatively easy under such a system to require a woman to have certain non-invasive tests, such as maternal serum AFP, the triple test, ultrasound, or (in the future) a test for fetal cells in maternal blood and then to encourage her to abort, for the good of society, if a serious, costly, and untreatable condition is found. What could prevent this in pluralistic societies such as Canada is legal protection for the views of minorities who believe in the protection of all life. This does not mean that society should offer extraordinary support when treatment is ultimately futile; withholding such support is not the beginning of a program of extermination.

It is important not to let the availability of genetic tests lead us to the false illusion that most disabilities are avoidable and thus unacceptable to society. As a Protestant theologian and a geneticist from Germany have stated:

> This would create a "duty to have a normal (nonhandicapped) child." This position no longer recognizes the "diakonic" task of the handicapped in society. By "diakonic task" we mean that the handicapped, by their presence, perform a real social service. Diakonic comes from the Greek word for servant, and is used in the New Testament to describe the Order of Deacons who cared for the poor, sick, and elderly in the early Christian Church. The handicapped are deacons in a symbolic sense. Their presence serves to make us reflect on what it means to be human. Their presence also serves to draw communities together in making sacrifices to provide for their well-being, and thereby enriches the fabric of human relationships. A society without the handicapped would lose

> its sense of community and its willingness to care for others. The ideal of perfect health sacrifices the reality and complexity of life and human relations, which do not exist without suffering. At risk is humane solidarity with the sick and handicapped and their families. (Schroeder-Kurth and Huebner 1989, 169)

PND for Reasons Not Related to the Health of the Fetus

The indications for PND set forward by a joint committee of the Society of Obstetricians and Gynaecologists of Canada, the Canadian College of Medical Geneticists, and the Canadian Paediatric Society (CCMG 1991, 1992) include maternal age over 35, family history of genetic disorders, exposure to teratogens, previous birth or miscarriage accompanied by a genetic disorder, and abnormally high or low maternal serum AFP. Others (Fost 1989; U.S. National Institutes of Health 1979) have suggested similar guidelines. In addition, PND can be used for reasons unrelated to the health of the fetus. These uses include sex selection in the absence of an X-linked disorder, prenatal paternity testing, and tissue typing to see if a fetus can be a compatible organ or marrow donor after birth. All of these uses are ethically controversial.

Sex Selection

Sex selection may be morally justifiable in some cases to prevent serious X-linked disorders that a healthy mother can transmit to her sons but not to her daughters; these include haemophilia and some forms of muscular dystrophy. A male fetus whose mother carries a gene for an X-linked disorder has a 50% chance of having the disorder. Some X-linked disorders cannot be diagnosed before birth. Identification of fetal sex and selective abortion of male fetuses who are at 50% risk may enable the parents to prevent the birth of a child with severe medical problems. This use of PND falls within ethically accepted uses of prenatal testing to prevent serious genetic disorders.

Most sex selection has no relation to genetic disorders; it is solely for the sex desired by the parents. Two ethical issues are involved. The first is whether families should be able to choose the sex of their children, and if so, under what conditions. The second is whether abortion is justified as a means to this end. Although about one-third of the U.S. public favours use of pre-conceptional methods of sex selection (Dixon and Levy 1985), relatively few (5%) approve of prenatal testing and abortion for this purpose (Singer 1991). However, more than one-third (38%) would approve the use of abortion for sex selection if a couple already had three children of the same sex, regardless of whether they were boys or girls (ibid.).

Direct requests for PND for sex selection are likely to be few in Western nations, in view of the absence of a strong cultural preference for children of a particular sex and personal and cultural objections to use of abortion for this purpose. Although most North Americans believe that abortion should be available to others in a wide variety of situations, including sex

selection, few would use it themselves (Wertz et al. 1991). Regardless, the numbers of requests for PND for sex selection cannot be documented in Western nations because few parents make open requests. However, medical professionals in Canada and the United States appear increasingly willing to perform PND for those making such requests. According to a 1975 survey of 149 clinically oriented geneticists and counsellors, 15% would recommend amniocentesis for sex selection in general and 28% would do so for a couple with one girl who wanted to have only two children and who wanted to be sure that their final child would be a son who could carry on the family name (Fraser and Pressor 1977). In 1985, 47% of doctoral-level geneticists in Canada would either perform PND (30%) or offer a referral (17%) for a couple with four daughters who desired a son and who would abort a female fetus (Wertz 1992; Wertz and Fletcher 1989a, 1989b, 1989c, 1989e, 1989f, 1991a, 1991b, 1992). In the United States, 34% would perform and 28% would offer a referral. A substantial percentage in some other countries would also perform PND for this couple, including 60% in Hungary, 52% in India, 38% in Sweden, 33% in Israel, 30% in Brazil, 29% in Greece, and 24% in the United Kingdom. Few in France would perform PND for this purpose (1%) or offer a referral (6%). A 1990 survey, using the same question, revealed that 85% of master's-level genetic counsellors in the United States would either arrange for PND or offer a referral (Pencarinha et al. 1991, 1992), although when interviewed, most counsellors said they oppose sex selection (Burke 1992). In Canada, 66% of medical geneticists in 1985 thought commercial prenatal diagnostic laboratories should be legally prohibited from performing PND for sex selection (Wertz and Fletcher 1989e).

In giving reasons for acceding to parents' requests, many geneticists in the 1985 survey said that sex selection was a logical extension of parents' acknowledged rights to choose the number, timing, spacing, and genetic health of their children (Wertz and Fletcher 1989c, 1989e). These geneticists regarded withholding any service, including sex selection, as medical paternalism and an infringement on patient autonomy. Those who would refuse PND said that it was a misuse of scarce medical resources designed to look for serious genetic abnormalities, that sex was not a disease, or that they disapproved of the abortion of a normal fetus. Most regarded sex selection as a private matter between doctor and patient. Few, except for geneticists in India, mentioned the societal implications of sex selection. Women, who comprised 42% of doctoral-level geneticists in Canada and 35% in the United States, were twice as likely as men to say that they would perform PND for the couple with four daughters in the case previously mentioned (Wertz and Fletcher 1989a, 1989e).

Most requests for sex selection in developed countries are probably covert, with women requesting PND on the basis of anxiety about the health of the fetus. Most geneticists in Canada (70%), the United States (89%), and around the world (73%) would perform PND or offer a referral for an anxious woman 25 years of age with no medical or genetic indications for

its use (Wertz and Fletcher 1989e). Fewer would do so in France (56%) or the United Kingdom (43%). Information about fetal sex is usually communicated to parents if they wish to know, though some clinics do not provide the information unless specifically requested (Hulten et al. 1987; Wertz and Fletcher 1989f). In effect, sex selection by PND is therefore available to most families. For some women having PND for medically indicated reasons, such as maternal age over 35, knowledge of fetal sex may present a troubling or even unwelcome possibility for choice. For example, a woman aged 40 with three sons, whose pregnancy is unexpected and who has always wanted a daughter, could decide to have PND, which is medically indicated by her age and genetic risk, and to find out the fetus's sex before deciding whether to continue the pregnancy. Knowledge about fetal sex affects abortion decisions among some women (about 16%) having PND on the basis of advanced maternal age, especially if the pregnancy was not intended (Sjögren 1988). To some, the choice itself parallels Sophie's choice, in William Styron's novel, because the woman herself must make the decision.

The major use of PND for sex selection occurs in those developing countries where there is a strong preference for sons. In some countries, such as India, most prenatal diagnostic procedures are performed for sex selection rather than detection of fetal abnormalities. Ultrasound, although not always accurate, is affordable even to villagers and poses no risk to the mother. In China, some families are turning to PND to ensure that their one child, under the official "one-child policy," will be a son (Moen 1991). In many nations of Asia, sex selection contributes to an already unbalanced sex ratio caused by the neglect of female children. An estimated 60 million to 100 million women are missing from the world's population (Coale 1991; Sen 1989, 1990), including 29 million in China and 23 million in India. In the United States, United Kingdom, and France, there are 105 women to every 100 men, and in Africa and Latin America the proportions of women and men are almost equal; in much of Asia, including Pakistan, Afghanistan, Turkey, Bangladesh, India, and China, there are fewer than 95 women for every 100 men (United Nations 1991). Families desire sons for economic reasons. In these countries, where most people have no social security or retirement pensions, sons are responsible for caring for parents in their old age. Daughters usually leave the parental family to live with their husbands and to help care for their parents-in-law. Even if a daughter stays in the parental home, she seldom has the earning power to support her parents. In some countries, a daughter represents a considerable economic burden because her family must pay a dowry to her husband's family to arrange a marriage. A son's religious duties at his parents' funerals, although often cited as a reason for son preference in India, are of lesser importance than economic factors. These religious duties can be performed by other male relatives.

When minorities from Asian nations emigrate to North America, they sometimes bring with them their son preference, even though the socio-economic conditions in North America do not support such a preference.

Ethical arguments in favour of sex selection in general, including pre-conceptional selection, are that (1) sex choice would enhance the quality of life for a child of the wanted sex; (2) sex choice would provide a better quality of life for the family that has the sex balance it desires; (3) sex choice would provide a better quality of life for the mother, because she would undergo fewer births and her status in the family would be enhanced; and (4) sex choice would help to limit the population (Warren 1985a, 1985b, 1987, 1989). According to these arguments, families that have the sex balance that they desire would be happier. Children of the unwanted sex, usually female, would be spared the abuse, neglect, and early death that is their documented fate in some developing nations (George et al. 1992; Verma and Singh 1989), and that may occur to a less obvious extent elsewhere. Women would not be abused by their husbands for not bearing children of the desired sex. Women would not have repeated pregnancies and births to produce at least one child of the desired sex, usually a son. Families would not have more children than they could afford, in order to have a child of the desired sex. Many families in developing nations would prefer to have at most two children. These couples could limit their family size and still have a son to support them in their old age, instead of continuing to have children until they have a son. The threat of world overpopulation might recede.

Each of the arguments above can be effectively countered. Arguments that sex selection will lead to a better quality of life for families, children, or women are comprehensible only in the context of a sexist society that gives preferential treatment to one sex, usually the male. Instead of selecting sex, it should be possible to improve quality of life by making society less sexist (Holmes 1985, 1987; Hoskins and Holmes 1984, 1985). Although sex selection could prevent some abuse of unwanted female children and their mothers in the short run, it does not correct the underlying abuses, namely the social devaluation of women in many parts of Asia and the stereotyping of children of both sexes in the rest of the world.

There is no good evidence that sex selection will reduce population growth in developing nations, as Postgate (1973) claimed it could. Most families try to have the number of children that is most economically advantageous. If they could select sex, and if one sex presented an economic advantage over the other, some families might have more children — all of the advantaged sex — than they would have had in the absence of sex selection. Education of women in developing nations and increased opportunities for their employment outside the home are more effective means of reducing population growth than sex selection. In developed countries, sex selection will likely have no effect on population size because

most families will not have more children than they wish in order to have a child of a particular sex (Dixon and Levy 1985).

Arguments against all types of sex selection are based on the premise that all sex selection, including selection for the balanced family desired in Canada and other Western nations, helps to perpetuate sex stereotyping and sexism (Overall 1987; Ullman and Fidell 1989; Warren 1985a, 1985b). Sex selection violates the principle of equality between the sexes (U.S. President's Commission 1983). In a non-sexist society, there should be no reason to select one sex over the other. Bayles (1984) examined concerns that might be posed for sex preference, including replacing oneself biologically, carrying on the family name, rights of inheritance, or jobs requiring either men or women. He noted that none of these reasons is valid. A child's sex does not make that child biologically any more "my" child than a child of the other sex. In modern societies, women and men can carry on the family name, inherit estates, and perform most jobs. Conversely, men can care for children, elderly parents, or relatives with disabilities, tasks that are usually the woman's responsibility in developed nations and that could in the future lead to a preference for daughters. Warren (1985a, 1985b) noted that even in a non-sexist society, there would remain a natural desire for the companionship of a child of one's own sex. Although this may be the strongest argument in favour of sex selection, any normal pleasure that a parent can enjoy with a child of one sex, such as sports, vacations, or hobbies, can be enjoyed with a child of the other sex.

Another argument against sex selection is that it could increase inequality between the sexes, even in developed nations where parents usually regard sons and daughters more equally. Although the preference for a boy or a girl is slight, there is evidence that North American families would prefer that the first-born be a boy or that they have two sons and a daughter if they are to have three children (Pebley and Westhoff 1982). Although there is no firm evidence that first-borns receive more economic advantages than later-borns (Warren 1985b), some social scientists and feminists believe that a society in which first-borns tended to be sons would tend to give more power to boys and men (Steinbacher 1983).

There are additional arguments against sex selection if it takes place after conception. PND for this purpose is a misuse of costly and, in some countries, scarce medical resources. Sex selection negates the medical uses of PND to detect serious disorders in the fetus and undermines the major moral reason that justifies PND and selective abortion — the prevention of serious and untreatable genetic disease. Using PND to select sex could lead to a "slippery slope" toward selection on cosmetic grounds, such as height, weight, or eye, hair, or skin colour, if ever technically possible. Some parents would select for such purposes, especially for weight (Wertz et al. 1991). Such "genetic tinkering" could in time change the human gene pool.

Laws prohibiting sex selection would not necessarily prevent the practice, because parents could conceal their real reasons for requesting

PND. Such laws could lead to further interference with reproductive freedom. A better approach would be to work toward equality of the sexes and against sex stereotyping, including the stereotyping of fetuses (Rothman 1986), and to establish a moral climate against sex selection of any kind. Sex selection is not a medical service; doctors do not have to accede to patient requests or offer referrals. Doctors could also consider withholding information about fetal sex, although this puts control into the hands of doctors and could lead to a resurgence of medical paternalism. The legality of withholding this, or any other information, is also doubtful, even though the information is not related to the health of the fetus.

Prenatal Paternity Testing

An estimated 3% to 5% of all children born in North America are not fathered by the mother's husband or partner (Sing et al. 1971, esp. 167, 195; A. Beaudet, pers. comm., 16 March 1992; F. Greenberg, pers. comm., 16 March 1992; P.R. Reilly, pers. comm., 21 February 1992). In cases where paternity is uncertain, the woman or her partner(s) may request PND solely for paternity testing. If only two men are involved, the cooperation of only one is required in testing. Prenatal paternity testing can also be used for forensic purposes, if pregnancy occurs after rape.

Most women requesting prenatal paternity testing intend to make a decision about abortion on the basis of paternity. A typical situation could be: "A pregnant woman requests tests to find out who the baby's father is. She is involved with two men: Joe, who wants children, and Bill, who does not. If Joe is the father, she will have the child. If Bill is the father, she will have an abortion. If she cannot find out who the child's father is, it is not clear what she will do."

The number of requests, and the potential market, have reached the extent that at least one commercial laboratory in the United States has advertised prenatal paternity testing to all members of the American Society of Human Genetics. Wherever regulations permit it, and patients can pay for it, genetics units in the United States will probably perform PND in such cases, though not without some ethical qualms about their own role in the woman's life situation. Withholding PND would seemingly offer little benefit in such cases, especially if post-natal paternity testing is available. It is not clear whether withholding prenatal paternity testing would reduce or increase the number of abortions in situations where paternity is dubious. Withholding prenatal testing could increase interpersonal dishonesty; a woman could conceal the existence of additional mates and try to persuade the man of her choice that he is the only possible father. Openness is probably the best alternative, especially in view of the child's future relationships with others. If it is possible to determine the father's identity before birth, at least interpersonal decisions can be made with full knowledge.

In cases where the pregnancy may have resulted from criminal assault, it is especially important to know the truth about paternity so that

the woman can make a decision about abortion. Probably few would question the use of PND if rape or incest has occurred.

Tissue Typing for Organ or Marrow Donation

Sometimes a couple who have a living child with leukemia wish to know whether their fetus, once born, will be able to be a donor for marrow transplants for the living child. Information about the fetus would enable them to make plans for the living child's future. However, this information would also enable them to "save time" by aborting a fetus with an incompatible tissue type and conceiving another fetus that might have marrow suitable for a transplant. Professionals sometimes suspect that the latter motive underlies requests for PND. Parents are understandably concerned over the health of their living child and deserve sympathy in these situations. They fear that time will run out before they can find a suitable marrow donor. Nevertheless, if they are considering the fetus primarily as a marrow donor, they are using that fetus as a means to an end rather than as an end in itself. There is something inherently disturbing in the thought of a fetus carried to term as a tissue preparation for someone else, even though the transplant procedure itself is harmless to the donor. Caution would be advisable in providing PND for tissue typing because of the temptation that it provides to think of a fetus largely in terms of benefit to someone else (Clark et al. 1989, 1990). This is especially so in cases where the fetus was purposely conceived to provide marrow. Of course, some parents requesting PND for tissue typing have conceived primarily because they desire another child; they may be curious to know whether the new baby can be of help to their living child.

The problem of requests for prenatal tissue typing will increase in the future, as marrow transplants become acceptable for treatment of a variety of genetic disorders such as Hurler syndrome.

Social, Ethical, Psychological, and Legal Issues

Full Disclosure of Prenatal Test Results

Sometimes, prenatal tests have results that are ambiguous, conflicting, or controversial. Rothman (1986) described the anxiety caused by disclosure of such results and suggested that it might be better if women did not know them. Making a decision on the basis of a test result that says, for example, that there is an abnormality in 5% of the cells and that the child *may* have mental retardation (as opposed to definitely having retardation) places an enormous burden on the mother. Rothman further suggested that many women probably do not want to know about ambiguous or conflicting test results, though she has no evidence to support this conjecture. She believed that women should have the opportunity, before PND, to check off, on a list, all the kinds of results that

they do not wish to be told, including not only ambiguities but also the presence of "milder" anomalies such as sex chromosome abnormalities. At the same time, she realized that such a checklist is probably impractical, given the sheer number of possible disorders that are prenatally diagnosable.

Full disclosure of test results is now the norm among geneticists and will probably remain so for legal and ethical reasons. Given a case where amniocentesis suggests that the fetus may be a trisomy 13 mosaic, but where this result may also be an artifact of culture, 98% of Canadian geneticists would provide full disclosure, as would 97% in 18 other countries (Wertz and Fletcher 1989e). Fewer (66% in Canada, 75% in the United States, 52% in the United Kingdom, and 47% in France) would also tell the woman that their colleagues had disagreed about the meaning of the results in this case. Those who would not disclose colleague disagreement believed that this was unnecessary and gratuitous information that would only upset the mother. However, most did not consider disclosure of the test results themselves as harmful in any way; fewer than 1% around the world saw any harm from full disclosure.

In a second case, where maternal serum AFP, AFP, ultrasound, and karyotyping produce conflicting results that suggest the possibility of a small neural tube defect, all geneticists in Canada, and 94% to 98% in the United Kingdom, France, and the United States, would tell the woman that the test results conflict and that there may be a small neural tube defect (Wertz and Fletcher 1989e; Wertz et al. 1990). In Canada, 94% would follow this disclosure with non-directive counselling, compared to 95% in the United States, 84% in the United Kingdom, and 56% in France. (In France, 38% would advise carrying to term or would tell the parents that there was no major abnormality.)

A third type of case that raises problems of full disclosure involves new or controversial interpretations of test results. For example, in 1985 the interpretation of low AFP as suggestive of Down syndrome was still controversial, and geneticists were not in agreement about how a low value should be interpreted. At that time, 96% of Canadian geneticists would tell the mother about the results, and 83% would be non-directive in counselling her about whether or not to have PND. In the United States, 97% would disclose and 89% would counsel non-directively. In the United Kingdom, 84% would disclose and 78% would counsel non-directively. In France, 88% would disclose and 65% would counsel non-directively about whether to have PND.

Geneticists would disclose in these three cases for both moral and legal reasons. Most said either that patients had a right to know or even a "duty to know," or that they themselves had an obligation to tell the truth. In North America, lawsuits are undoubtedly one of the driving forces behind full disclosure in these cases. Anything less than full disclosure has become impractical for legal reasons.

Privacy Versus Duties to Third Parties

Pregnancy is a uniquely private condition and is recognized as such by the courts. As long as the fetus remains within the mother's body and is dependent on the mother, information about its medical or genetic status is part of the mother's medical record and therefore confidential.

Nevertheless, the father (or fathers, if there is a difference between the biological and social fathers) has an interest in the health of his potential offspring. He will be responsible for supporting the child. He may have sound reasons for wishing to know about the child's health before birth in order to make life choices (such as choice of employment) that will maximize the child's support. However, if the parents are on the verge of divorce or separation, the mother may be reluctant to divulge a positive prenatal diagnostic finding to the father, for fear that he will try to get a reduced settlement for child support or try to pressure her to have an abortion. (He may also pressure her to carry the fetus to term if he opposes abortion but she does not.) In such cases, the information from PND should be the mother's alone, to do with as she wishes. Although openness with the father is desirable in most situations where child rearing will be a shared activity, sometimes it may be necessary for the mother to protect her own and the fetus's privacy to avoid harm from a partner whose ideas about the kind of child he wants differ from her own.

Prenatal testing raises other concerns about privacy. As with many new genetic tests, unanticipated and unwanted information may emerge. Prenatal testing that is based on deoxyribonucleic acid (DNA) diagnosis (e.g., for Huntington disease, for cystic fibrosis in some families with affected members) will reveal non-paternity because it compares fetal and parental DNA. In these cases the professional faces the dilemma of whether or not to reveal non-paternity to a husband or partner who has himself been tested as a prelude to PND. The finding is unexpected; the test was carried out for a purpose other than determining paternity. Non-paternity is a classic case in medical ethics. Most bioethicists argue that the doctor should tell the husband or partner that he is not the father of a child or fetus, even if he does not ask, simply because he is also the doctor's patient and patients should be told all test results. In fact, most geneticists in Canada (96%) and 18 other countries (96%) would not tell a woman's husband or partner that he is not the father of a living child with an autosomal recessive disorder (Wertz and Fletcher 1989e; Wertz et al. 1990). In Canada, 87% would tell the mother alone without her husband or partner present, and let her decide what to do with the information, as would all geneticists in France, 84% in the United States, and 81% in the United Kingdom. As reasons for their answers, 58% said they wished to preserve the family unit, 30% cited the mother's right to decide, and 13% cited the mother's right to privacy. Most believed that there was no medical reason for the husband or partner to know in this case; they either would instruct the mother to tell him that the disorder would not recur in future

children, or would allow the family to go through the charade of having PND for the disorder in future pregnancies.

In DNA-based PND, it would be more difficult to keep this secret from the woman's partner, especially if the testing had been preceded by full informational counselling. It would be appropriate, therefore, to inform couples before initial DNA tests that PND will reveal non-paternity. Ideally, the mother should be informed of this privately, before counselling the couple together and before the formal informed consent, so that she will have an opportunity to decline testing if she thinks there is a possibility of non-paternity. If she decides to proceed with testing, the professional can then inform both parties that the test will reveal non-paternity. In this context, full disclosure of non-paternity to both parties would be appropriate, after forewarning and in the context of family counselling.

Other relatives may have a stake in prenatal diagnostic results. For example, a finding of Down syndrome and subsequent testing of the parents may reveal that one parent carries a balanced translocation. That parent's siblings have some risk of also carrying a translocation that would put their future children at risk. The person who carries the translocation clearly has a moral duty to tell her or his relatives so that they can decide whether to be tested. Genes are shared among family members; in a larger sense the true patient in genetics is the family (Berg and Tranøy 1989). Wertz and Fletcher (1989e, 479) have argued, following the President's Commission's recommendations, that doctors should be legally permitted (but not legally required) to disclose genetic information to family members at risk if a patient refuses to do so, provided that four conditions are met:

> A professional's ethical duty of confidentiality to an immediate patient or client can be overridden only if several conditions are satisfied: (1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability both that harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed. (U.S. President's Commission 1983, 44)

These recommendations applied only to situations where there was high risk of serious harm (e.g., an autosomal dominant disorder). It is highly unlikely that the President's Commission's criteria for disclosure would apply to most findings from PND. Most disorders that present a high risk of serious harm are likely to be known, *before* PND, in living family members, either through carrier testing (e.g., for cystic fibrosis or sickle cell anaemia) of the parents or through a family history of symptomatic disease. Prenatal testing for these disorders is conducted only if there is reason to believe that they exist in the family. Most chromosomal abnormalities discovered by routine PND for advanced maternal age or for risk factors discovered by biochemical screening present such a low recurrence risk for other family members that it would probably not provide legal or moral

justification for disclosure against a patient's wishes, even after the child is born. The risk to relatives for Down syndrome or spina bifida discovered through PND in the absence of family history is too low to warrant disclosure against the parents' wishes.

There is a danger in the President's Commission's arguments; they set a precedent for other kinds of disclosure. Unfortunately, it is possible to do harm by intending to do good; disclosure can have unintended side-effects, especially if a relative subsequently tells an institutional third party. In the extremely rare cases where relatives may be at high risk of serious harm, disclosure of PND results against a patient's wishes should be delayed until after the child is born or the pregnancy has been terminated. Eventually, most patients will be persuaded that the ethical course of action is to tell other family members who may be at risk. However, pregnancy is not the time to do so unless the patient is willing. Pregnancy is a uniquely private relationship between mother and fetus that should remain private. Employers, insurers, government agencies, and welfare departments should have no access to the results of prenatal tests. The possibilities for coercion and for denial of benefits are too great.

Non-Disclosing (Exclusionary) Tests

DNA-based PND, used for disorders where the gene has not yet been cloned, offers the possibility of testing a fetus without revealing the parent's own genetic status (Wertz 1990).

A non-disclosing test, also called an exclusionary test, provides information about the fetus without revealing the parent's genetic status. Non-disclosing tests are of two types. In the first, DNA is not available from enough family members to provide full information about a proband, but the proband wishes to know whether a fetus has the gene for the disease. In these cases, a proband whose parent has an autosomal dominant disease and who is therefore at 50% risk can have the fetus tested and receive risks of about 1% or 49%. In other words, the fetus either is free from risk or carries the same risk as the parent. A peculiar ethical problem ensues if an at-risk fetus is carried to term. If the parent subsequently develops the disease, the child is destined to develop the disease and will, in effect, have been tested without giving consent (Huggins et al. 1990). This contravenes the recommendation of the President's Commission (1983) that children not be tested. Nevertheless, some probands who request PND have no other choice except a non-disclosing test, on account of their family constellations. In these situations, most professionals and ethicists believe that testing should be allowed, provided that, before testing, there is a full discussion of the possible consequences of carrying an at-risk fetus to term. However, care must be taken to ensure that all decisions remain the patient's.

The second type of non-disclosing test involves a proband who could learn whether he or she carries the disease gene, but does not want to

know. Instead, the proband wishes to have the fetus tested without being tested personally. Again, the fetus either will be virtually free of risk or will carry the same risk as the parent. Greater certainty for the fetus is not possible without testing the parent. This type of non-disclosing test is ethically controversial. However, permitting non-disclosing tests only if parents agree in advance to abort at-risk fetuses would be an infringement on the rights of individuals to make their own decisions.

PND for Reduction of Multi-Fetal Pregnancies

Ethical problems arise after prenatal diagnosis of one abnormal twin or in multi-fetal pregnancies where the number of fetuses threatens the mother's ability to carry them to a point of survival. In the former cases, parents want to have a normal child but cannot bear the burden of caring for an abnormal child. The latter cases usually follow infertility treatments (Berkowitz et al. 1988; Evans et al. 1988a, 1988b, 1990). Both situations call for a position that does least harm in a type of "life-boat" ethical emergency. The principle of justice is clearly relevant here.

First reports (Aberg et al. 1978; Kerenyi and Chitkara 1981) of selective termination of an abnormal twin drew sharp ethical and legal criticism (Hagen 1981; Hecht 1981; Matthews 1981; Somerville 1981). Somerville argued that the principles governing abortion did not apply to "killing a fetus in utero without its evacuation." She tried to draw a moral and legal line between justified abortion — defined as evacuation of the uterus with a "secondary effect" of fetal demise — intended to meet a need of the woman, and an unjustified selective termination aimed "simply to destroy the fetus," premised on (to her) an unjustified "right to kill the fetus ... directly." She believed that the "final results" are the same in both cases (Somerville 1981, 1218).

Selective termination of one twin with a disorder or malformation is ethically more complex than selective abortion of a single fetus. The need to avoid causing harm to the presumed normal twin and the mother (through clotting, haemorrhage, and shock) increases the risks. However, the means are the same in each case — the prevention of birth of an affected infant by killing the fetus (i.e., justified feticide). The act of termination is not morally different, in kind, from selective abortion, although the considerations are more complex. Somerville's position permits emotion to overwhelm reason, possibly because putting a needle directly into the fetus appears more "direct" than death by "evacuation of the uterus." The "directness" or "indirectness" argument seems beside the point. The goal of selective termination is to save a pregnancy if the risks are acceptable (Evans et al. 1988a, 1988b). This goal is different from the goal of abortion, which is to end an unwanted pregnancy. The goal of fetal reduction is also to save a wanted pregnancy.

A survey of practitioners of PND and other professionals shows that this view is widely shared among doctors and clergy (Evans et al. 1991).

Responses showed that the acceptability of abortion in singletons increased with the severity of anomalies involved and decreased with advancing gestation, bearing out influence of a "graded" theory of the moral status of the fetus discussed earlier in "Bioethical Arguments." The same trend was observed in twins, although the acceptability of selective termination of the affected twin in the second and third trimester was lower than for singletons. Overall, professionals' acceptance of selective termination was strongly associated with the trimester of pregnancy, indication for selective termination, and fetal number, whether it be a singleton or twin gestation. There is as yet no research on women's perceptions of fetal reduction or of selective termination of an affected twin. Some women have preferred to terminate the entire pregnancy rather than selectively reduce the number of fetuses. To them, fetal reduction may appear to be a Sophie's choice that they do not wish to consider. Others have requested reduction of twins to a singleton. The latter request sometimes comes from single mothers who believe that they could not cope with twins. The ethical issues in these situations do not differ from the ethical issues of abortion in general, and women's requests should be respected.

Psychological Issues: Anxiety and Grief

Anxiety

Concern about anxiety accompanying PND began in the early 1970s (Fletcher 1979). Since then, many psychological studies have been done of women undergoing various forms of PND. Most of these studies conclude that many women experience increases in anxiety at two times: immediately before the prenatal diagnostic procedure, and while waiting for the results. However, after receiving a favourable diagnosis their anxiety decreases to the same level as or a lower level than that of women not having the procedure (Beeson et al. 1983; Fava et al. 1982, 1983; Marteau 1991; Marteau et al. 1989; Phipps and Zinn 1986; Silvestre and Fresco 1980). Excellent reviews of the psychosocial literature may be found in Adler et al. (1991); Green (1990); Tunis (1993); Tunis and Golbus (1990). Women having CVS experience similar peaks in anxiety to those of women having amniocentesis, except that these occur earlier in the pregnancy (Robinson et al. 1988). Tunis et al. (1990) concluded that women's overall pattern of mood states (measured by the McNair et al. "Profile of Mood States," 1971) exhibits relatively little distress. Most women in the various psychological studies think of PND favourably (Chervin et al. 1977; Evers-Kiebooms et al. 1988; Finley et al. 1977; Gregg 1991; Kolker 1989; Kolker and Burke 1987; Lippman-Hand and Fraser 1979a, 1979b; Michelacci et al. 1984; Nielsen 1981; Pauker and Pauker 1979; Reading and Platt 1985; Scholz 1992; Verny 1986; Zuskar 1987). Their anxiety while waiting for the results focusses on the possibility of having to make a decision about abortion (Beeson and Golbus 1979; Beeson et al. 1983; Blumberg et al. 1975; Chervin et al. 1977; Dixson et al. 1981; Finley et al. 1977;

Golbus et al. 1974; Kolker et al. 1991; Robinson et al. 1975; Roghmann and Doherty 1983; Silvestre and Fresco 1980; Spencer and Cox 1987, 1988; Tabor and Jonsson 1987; Tunis et al. 1990; Verjaal et al. 1982). Women cope with this anxiety either by avoidance (which includes repression) or by focussing attention on the potential problem. Avoidance measures of coping include not telling others about the pregnancy, not wearing maternity clothes until the results are in, and, at the extreme, not feeling fetal movements or "quickening" until receiving favourable results (Black 1989, 1992; Rothman 1986). "Attention" methods of coping include information seeking and development of approaches to future anticipated decisions. Both methods of coping have advantages and disadvantages. Tunis (1993) suggested that avoidance may be the more functional strategy for the majority who ultimately receive favourable results. However, for those who receive "bad news," avoidance and repression earlier in the pregnancy can ultimately increase the emotional pain and grief after selective abortion (Green 1992; Marteau et al. 1989).

Although the overall results of studies of PND suggest that most women experience no drastic or permanent changes in mood, and that most women are subsequently glad they had the procedure, the aggregate results conceal the very real distress of a small number of women (Tunis 1993; Tunis and Golbus 1990; Tunis et al. 1990). Some women tend to blame themselves for all negative life events. These women are especially likely to become depressed. Women who lack adequate social support or support from spouses or partners experience more anxiety while waiting for test results (Adler and Kushnick 1982; Adler et al. 1991; Black 1989; Blumberg et al. 1975; Cohen and Wills 1985; Emery and Pullen 1984; Kelly 1977). Such women frequently experience greater anxiety than others during pregnancy in general, regardless of whether they have PND.

Men also experience an increase in anxiety while waiting for test results, but their anxiety levels are considerably lower than women's. In one study, the level of men's anxiety was most strongly related to the earning power of their wives (Evans et al. 1993). This supports Luker's (1984) argument that upper- and middle-class families believe that they have more to lose through the birth of a child with a disability.

As yet, no studies have been done of the long-term effects of PND on women's lives or on their relationships with their children. It has been difficult to assess the effects, if any, of other uses of high technology in pregnancy and birth on long-term relationships between parents and children (Wertz and Wertz 1989). Perhaps such effects are ultimately few. Although many have said that PND places a "quality control" upon children and that this may cause parents to see their children differently (Lippman 1991a; Rapp 1992; Rothman 1986), the quest for healthy children long predates PND. Early in this century, middle-class parents expressed a desire for children as perfect as possible and would willingly undergo early experiments at induced labour. These were cultural beliefs that obstetricians and their patients shared. PND is only one more in a long list of

technologies developed to produce "better" babies. It is unlikely to change most women's views of their children, with the notable exception of those who carry a pregnancy to term after unfavourable findings.

Historically, most women have approved of birth technologies, including PND. What they have objected to is overuse of high technology, notably Caesarian operations, and dehumanization of birth. Most women not only have accepted PND, but appear glad to have the opportunity for some relief from the normal anxiety of pregnancy. For most women, PND is reassuring. Although one could argue that the procedure is merely allaying anxieties that would not have existed in its absence (Lippman 1991a), it is not now possible to return to the pre-PND era.

Grief After Selective Abortion

Most studies have shown that women having selective abortion of a wanted pregnancy experience a grief that may be comparable to loss of a child (Friedman and Gradstein 1982; Panuthos and Romeo 1984). The mother's relationship to her unborn baby starts as soon as she knows she is pregnant. To break this relationship intentionally may be the cause of intense pain. This contrasts with elective abortion of unwanted pregnancies, where the literature consistently reports that few emotional problems result (Dagg 1991; Figà-Talamanca 1981; Nadelson 1978; Smith 1973; Stotland 1991).

Women who electively abort for reasons unrelated to fetal characteristics have not developed a relationship with the fetus; they have simply chosen not to become mothers. In contrast, in abortion on genetic grounds, the woman has previously chosen to be a mother (even if she did not originally choose the pregnancy). In the case of selective abortion, she has revoked that choice. Selective abortion is similar to miscarriage in its emotional results. For many years, miscarriage was seen by most men as a "non-event" (Osterweis et al. 1984; Reinharz 1988). There was "nothing to show," no body to bury. Yet, for those women who wanted the pregnancy, miscarriage could be devastating (Neugebauer et al. 1992). The privacy of pregnancy loss makes it difficult to receive the social support that would exist for the death of an infant (Green 1992; Vachon et al. 1982).

Many studies have reported moderate depression in the first few months after selective abortion on genetic grounds (Black and Furlong 1984; Blumberg et al. 1975; Donnai et al. 1981; Jones et al. 1984; Leschot et al. 1982; Lloyd and Laurence 1985). Although an early termination, after CVS, is easier emotionally for many women than a termination following amniocentesis, the loss is still very real. Ultrasound has changed the nature of pregnancy (Cox et al. 1987; Drugan et al. 1990; Field et al. 1985; Hegge et al. 1988; Hyde 1986; Milne and Rich 1981; Sparling et al. 1988; Villeneuve et al. 1988). Lippman (1991a) said that ultrasound is PND without consent because women sometimes undergo the procedure without being asked whether they want it. Instead of the traditional milestone of

quickening, which marked the reality of "life" or "the presence of another being" for most women (and which until the mid-nineteenth century also marked the definitive presence of pregnancy), women now see ultrasound as the "new quickening." Instead of feeling the baby move within them, they see it on a TV monitor. (Usually, medical personnel must interpret this new wonder for the woman: otherwise, she will be unable to discern the various parts of the baby. As one woman said, "They made the baby real for me" [Rapp 1990].)

Women having CVS will usually have ultrasound and will see the baby's image on the screen; this makes it difficult to maintain emotional distance. Women having abortions after CVS may therefore face the same level of emotional distress as women having abortions after amniocentesis. Grief may be accompanied by guilt. Some women blame themselves for the genetic disorder and for the abortion decision.

Fathers "distance" the event and put it behind them much sooner than mothers (Jones et al. 1984). Most families who have unaffected children will tell at least one unaffected child about the tests and will give at least a partial explanation for ending the pregnancy (Black and Furlong 1984; Green 1992).

In the long run, most women seem to cope with pregnancy loss without significant dysfunction. Most return to work, resume sexual relationships, and plan future pregnancies within a month after the abortion (Tunis 1993). Nevertheless, some women continue to exhibit severe distress. Lack of social support or support from spouse or partner, a history of infertility, a previous child with a genetic disorder, or a history of miscarriages may all contribute to continued grief. In order to minimize the effects on such women, it would be advisable for centres doing PND to follow up all women who lose pregnancies, whether by selective or spontaneous abortion or miscarriage, in order to assess psychosocial distress, to assess social support from others (including partners), and to arrange for psychological counselling if necessary. It would be helpful to provide information, before PND, about the range of grief reactions experienced by those who have selective terminations, so that those whose grief is unusually greater or is persistent will have been prepared for this outcome (Elder and Laurence 1991; Forrest et al. 1982; Magyari et al. 1987; White-Van Mourik et al. 1990).

Although grief accompanies selective abortion, most women recover without permanent effects. It is not possible to compare the grief accompanying abortion on genetic grounds with the more permanent psychological effects of raising a child with a genetic disorder. Some parents of such children apparently grieve throughout their entire lives (Wikler et al. 1981).

The Place of Genetics and PND in Health Care: Priorities

About 3% of all pregnancies result in the birth of a child with a significant genetic disorder or disability. An estimated 5% to 10% of paediatric hospital admissions in North America are for clearly genetic disorders (Hall et al. 1978; Scriver et al. 1973). These include 0.4% to 0.6% for chromosomal disorders and 4% to 7% for single gene disorders. When disorders that may have a genetic component (such as some types of childhood cancers, asthma, and diabetes) are added in, disorders of inherited origin account for 36% to 53% of all paediatric hospital admissions (ibid.). Perhaps 10% of all adult hospital admissions are due to clearly genetic disorders (Gelehrter and Collins 1990). A study of one million births in British Columbia showed that about 1 in 20 people (5.3%) under 25 years of age had a disease or disorder with a genetic component (Baird et al. 1988). Even in developing countries, genetic disorders account for an estimated 25% of childhood mortality (Penchaszadeh 1993; Verma and Singh 1989). Clearly, genetics deserves a high priority in health care budgets.

Nevertheless, the strongest predictors of health and disease in modern societies are socioeconomic. Mortality and morbidity follow class (and sometimes also racial/ethnic) lines. Social problems, such as child abuse, homicide, avoidable accidents, and alcohol or drug addiction, are the major causes of death in certain age groups. For example, in the United States, accidents are the leading causes of death for all races between 1 and 14 years of age. Between ages 15 and 44, accidents are the leading cause of death among whites and Asian-Americans, homicide is the leading cause of death among African-Americans, and suicide is an important cause of death for all races (U.S. Department of Health and Human Services 1991). None of these causes of death is genetic. What this means is that societies must continue to give the highest priority to removing social causes of illness, including poverty, homelessness, and addiction, and to the preventive medical care that would ameliorate their effects, such as maternal/infant nutrition, routine prenatal care, and home visits for new mothers. Elaborate and costly procedures should have lower priority than basic preventive medical and social care. It would be wasteful of social resources to spend large sums of public money on preimplantation diagnosis, for example, until all pregnant women receive early prenatal care, have a roof over their heads, and are assured of adequate nutrition and protection from harmful substances or sexually transmitted diseases. Preventive care seldom makes the headlines but saves many lives. However, advances in genetics need not be at cross-purposes with basic medical care.

There is no reason why a developed society such as Canada cannot have both a comprehensive program of genetic services and a comprehensive program to combat the social causes of illness. It is a false dichotomy to speak of genetic determinism versus social determinism. Illness has both social and genetic causes. Just as it is a grave mistake to look for a

"genetic fix" or "technological fix" for social problems such as crime or addiction (Etzioni 1976; Hubbard 1990; Lippman 1991a; Loomis and Wing 1990), it is also a grave mistake to expect social transformations alone to prevent or cure most diseases. Social changes and preventive medicine could lead to greater equality in the distribution of health and illness, but could not eliminate retardation, genetic disorders of adult onset, or the common diseases of aging; thus, research into genetic medicine must go hand in hand with basic preventive care in setting health care priorities.

What priority should PND receive in a health care budget? In setting priorities, it is important to remember two things: first, chromosomal PND and ultrasound, even if applied routinely in all pregnancies, would not detect all potential "birth defects" and might not even detect most problems. Scientifically (leaving ethical concerns aside), it would be a mistake in health care planning to rely on PND to eliminate most disabling conditions. PND should be seen as a means of enabling women and their families to make choices, rather than as a search and destroy mission that will reduce the health care budget. The second point to remember in policy planning is that PND has the capacity to prevent much family suffering. For this reason, it deserves a priority within the larger system of prenatal care.

This does not mean that expensive or invasive procedures should be offered routinely in all pregnancies. To do so not only would further "technologize" pregnancy, but would shift necessary resources away from more vital areas of preventive medicine and social care. The only way to incorporate PND fairly into a national health care system is to limit its use to situations where medically indicated by the mother's age or genetic history. Thus, Oregon, which has recently adopted a system of rationed health care that assigns priority to each procedure, includes PND as part of prenatal care, but only if indicated by age or genetic history (Hadorn 1991; E.P. Kirk, pers. comm., 28 June 1991). This means that PND would not be offered for maternal anxiety in the absence of medical indications, would not be used solely to detect the sex of the fetus in the absence of X-linked disease, and would not be used for treatable conditions such as cleft lip, for solely cosmetic conditions such as birthmarks, or for conditions commonly regarded as falling within the normal range of human variation, such as webbed toes. Women should be legally free to seek PND outside a national health care system for any of these uses, though public education should discourage such actions. Legal restrictions (except for laboratory quality control and availability of genetic counselling) would set a dangerous precedent for further restrictions that could limit reproductive choices. However, a national health care system should recognize that the primary purpose of PND is to ameliorate parental and family suffering by enabling women and families to make choices about conditions that cannot be completely cured.

In cases of questionable paternity, where lack of certainty about the child's paternity would have a profound effect on the child's treatment (if born) and the family's quality of life, PND for paternity testing should be

offered within the health care system to prevent suffering. For example, if a woman were raped while attempting to become pregnant by her husband or partner, carrying the pregnancy to term could cause immense mental anguish. PND could ease decisions about terminating or carrying to term, by establishing paternity. By extension, PND for paternity testing could alleviate emotional suffering and promote informed decisions in less extreme cases, and would therefore seem justified as part of health care. Anxiety over paternity (or for morbid anxiety of any kind that a psychiatrist or clinical psychologist would judge clinically significant) should be distinguished from the normal anxiety of pregnancy. To allocate resources fairly, and to maintain a balance between high technology and routine care, it may be necessary to withhold CVS or amniocentesis from women who request them solely on the basis of normal, albeit exaggerated, anxieties of pregnancy. However, if a mental health professional judges the anxiety clinically significant, or if the anxiety is based on the question of paternity, which may affect the family's future quality of life, it would be appropriate to offer PND within the context of a national health care system. Whatever the indication, PND should be offered with no strings attached about the woman's eventual decision. Women who claim that they oppose abortion under any circumstances should have an equal right to PND and an unqualified right to maintain their stand, if they desire, after receiving the results. Sometimes, women do not know how they will act until they actually receive unfavourable results. It would be unfair to prejudge their decisions and thereby deprive them of the right to make a choice.

Protecting the Rights of Those with Minority Opinions

There is much concern that in the rush to adopt prenatal technologies society will impinge upon the rights of those who hold different or unpopular values. Sometimes, the discussion is couched in terms of the woman who, after PND, carries to term a baby with a severe neurological problem and is subsequently shunned by her neighbours or (in the United States) refused insurance coverage for her child. It is important to recognize that different groups and individuals have very different and deeply held values about personhood, about nature, about what is meaningful in life, and about the will of God. It is absolutely essential, in a democratic society, to maintain respect for these differing views as long as they are not destructive. For children who are carried to term, parents' views are deserving of respect even if the majority disagrees with these views. Carrying a child to term is not destructive or oppressive; the parents who will raise this child have made their decision in view of their own values, so the decision is the best one for them. Without inhabiting the child's body, it is essentially impossible to judge what would have been best for the child, as many courts have noted in wrongful life cases. Therefore, society should not pass negative judgment upon women who reject PND or who knowingly carry fetuses with severe disorders to term, provided that

these women made their decisions without coercion from their partner, extended family, religious authority, or religious/social group. A decision made with full knowledge of the consequences, without coercion, and with careful reflection on one's own values and beliefs should always be respected, provided that it does not do harm. When carrying a fetus with a genetic disorder to term, the woman has willingly assumed whatever harm may result to her, and the harm, if any, to the child is impossible to measure against the state of non-existence. Most people with very severe disorders, especially mental retardation, are unable to reproduce, so there is no harm to the gene pool. The only harm, therefore, would appear to be to society, if society is responsible for the individual's support. It is here that the majority may exert its wrath on those with minority views — by withholding public support for medical care, education, housing, and even subsistence itself. Eventually, most taxpayers may argue that they should not be forced to support people whose care is costly, who have little intellectual potential, and whose births could have been prevented. This is a dangerous view; it could be extended to include an ever-widening range of genetic disorders or human differences. Although health care planners might well consider limiting the use of some extraordinary or costly procedures — as ethicists have proposed in other situations, as for the terminally ill or those at the extreme limits of old age (Callahan 1990) — to withhold usual care or support is to make a judgment about what constitutes a person. Recognizing that people hold different values in this regard, a just and democratic society should maintain full support for those who choose to have children with serious disabilities and also for their children. Public forums and public education about the views of others could help to reduce stigmatization.

The more difficult dilemmas with regard to minority views pertain to situations where a woman or family seeks PND and abortion for reasons not accepted by the majority culture. Sex selection is a prime example. Those who would condemn sex selection as immoral or who would withhold PND are open to accusations of ethnocentrism or of not respecting cultural differences. On the other hand, those who make a business of sex selection may justify their actions by referring to respect for cultural minorities. In a multicultural society, where people of different cultures are in the process of learning to respect and value each other's traditions, it becomes increasingly difficult to condemn the practices of other cultures without being labelled ethnocentric. "Post-modernism" in social theory extols the unlimited and unrestricted expression of diversity. However, is it necessary to accept the practices of others uncritically to respect their cultures? Fletcher (1989) argued that there are non-negotiables that transcend cultures. At its extreme, cultural relativism can lead to a destructive position that says "anything goes." Deconstructionism, which originated in literary theory, takes relativism a step further, by denying the existence of objective reality and by claiming that language is the only reality that we can hope to know (Fox-Genovese 1991). Thus, to deconstructionists (or

post-structuralists, as social scientists more usually describe themselves) "male" and "female" are linguistic constructions rather than natural or scientific realities. Deconstructionism rejects even naming an absolute, such as justice or equality, because these categories were constructed by authority (usually male) (Scott 1988). By reducing reality to language, deconstructionism moves "toward the repudiation of any notion of right beyond that of personal experience" and effectively undermines concrete arguments that would make a case against oppression of minorities and women (Fox-Genovese 1991). Thus, this extreme form of relativism becomes destructive to the cultural minorities it presumes to protect.

Sherwin (1992) has developed an approach that she calls "feminist moral relativism," which steers between ethical absolutism (ethnocentrism) and extreme or irresponsible relativism. Using as an example clitoridectomy and other genital mutilations of women in some non-Western cultures, Sherwin argued that the rightness or wrongness of a practice can be judged on the basis of whether it constitutes oppression. The fact that the majority of a community, including its oppressed members, believes in a practice does not make it right. The entire community may be oppressive of women or of its own minorities, and therefore its entire moral system may express oppression. Sherwin believed that it is possible to evaluate a community's moral system on the basis of how the system evolved (its history), whose interests it serves (its power structure), and whose interests are sacrificed. The fact that those whose interests are sacrificed — usually women — often concur in a community practice (such as sex selection or genital mutilation) does not establish ethical validity for that practice. In the history of oppression, including slavery, the oppressed often identified with the values of the oppressors. Sherwin argued that, "Unless there is evidence that women would agree to this practice if they were free of patriarchal coercion, we cannot treat it as an acceptable local custom, even if the majority of citizens in areas where it is customarily practiced now approves of it" (Sherwin 1992, 74). She continued, "A feminist moral relativism demands that we consider who controls moral decision-making within a community and what effect that control has on the least privileged members of that community. Both at home and abroad, it gives us grounds to criticize the practices that a majority believes acceptable if these practices are a result of oppressive power differentials" (ibid., 75). Sherwin argued that we should not feel embarrassed at condemning some practices of other cultures on this basis, though preferably we should do so with the support of some people within the other culture. According to Sherwin's criteria, sex selection in Asian cultures is wrong because it results from and contributes to the oppression of women. Sex selection is wrong even if the woman herself requests it without direct coercion from her husband or partner, because her request emanates from a coercive culture. Therefore, in this case the majority culture should not respect requests for sex selection and should not consider itself ethnocentric for doing so. Rejecting

requests for sex selection does not denigrate an entire culture, only its oppressive aspects.

In refusing such requests, members of the majority culture can also point out that the economic situations that underlie sex selection in other cultures (lack of social security and need for a son to provide care in old age; exorbitant dowries as pre-conditions of marriage for daughters; patrilocal residence and loss of any economic contribution from a daughter to her parents) do not apply in North America. If Asian minorities remain here, they have no justification for son preference except tradition. If they return to their countries of origin, most will be sufficiently well off economically as to eliminate monetary need for a son. Although sex selection should remain legal, because laws could set dangerously restrictive precedents, there is no obligation to respect it or to subsidize it.

However, in condemning practices of a minority culture, the majority culture should be aware of and should attempt to eliminate patriarchal biases within itself. It would be hypocritical, especially in a multicultural society, to prohibit the practices of minorities as oppressive while retaining a patriarchal basis of oppression in the fabric of majority culture.

Are there other minority views besides sex selection that need not be respected? Probably, yes. By analogy, Sherwin's arguments about the oppression of women can also be applied to the oppression of people who have different prevailing views of beauty or fashion. Requests for PND for cosmetic purposes unrelated to human functioning need not be respected, even if an entire cultural group were to say, for example, that they would not accept girls over six feet tall or boys who wore glasses. A culture that set these standards would be victimizing its members through stereotyping. Such requests not only should not be honoured, but should be counteracted through public education.

Readers will note that the ethical arguments concerning minority views of use of PND for abortion differ somewhat from arguments about minority views of carrying to term fetuses that will be severely disabled. In the latter case, there is usually no discernible harm to parent or child (it is difficult to make a convincing case that non-existence would be preferable from the child's point of view), though there may be monetary harm to society. However, in the former case, considerable potential exists for harm through honouring minority views. If all minority views were respected, including sex selection and cosmetic use, PND could harm the entire structure of society by redefining normalcy, continuing the oppression of women, and unbalancing the sex ratio in some communities; thus, it becomes necessary to draw a line against respect for such uses.

Some feminists (Hubbard 1987; Lippman 1991a) would extend Sherwin's argument about cultural oppression of women to include oppression of people with disabilities. According to this view, the majority or ablist culture oppresses those who are less able and uses PND as an instrument of oppression. This argument stands on questionable ground. Although many problems, such as deafness, blindness, or paralysis, can be

overcome, it requires considerable effort to raise children with these conditions. Not all parents are able or willing to assume the added sacrifices and responsibility. If they do so, it is often the woman who pays the price by giving up other potential life opportunities. The birth of children with disabilities all too often leads to the further oppression of women. Many feminists would argue that in a truly just society a mother would not have to sacrifice herself to care for such a child, because the entire society would assume this care. According to this argument, a woman should not have to choose between her own oppression and the elimination of a fetus that belongs to another oppressed group, those with disabilities. This is utopian thinking. No society is likely to assume the major proportion of care for children with disabilities, and it is also unlikely that most parents (with the exception of those whose children have severe retardation) would want society to do so. Most parents want economic and social support, but they also want to take primary responsibility for raising their own children. Not all parents wish to take on added and difficult responsibilities, nor should they be forced to do so. A woman who aborts a fetus that will be deaf or blind is not necessarily contributing to the oppression or stigmatization of living people who are deaf or blind. The ethical approach in these cases would be to discuss the alternative option of giving up the baby for adoption instead of terminating the pregnancy. Nevertheless, this option in itself means sacrificing the interests of the birth mother; few women want to have a baby for someone else, and many would consider this option oppressive. Thus, with regard to use of PND for less severe conditions, there seem to be no clear demarcations as to what is ethically permissible.

The converse of this problem may occur if parents who themselves have disabilities would like to have children who are like themselves. For example, suppose a couple with achondroplasia asks for PND with the intention of aborting a fetus who will be of "normal" height. They say that they do not wish to have a child who will tower over them, and would prefer to have a child of their own height. Although most of the population could disagree with this choice, it should be allowed in the interests of fairness. If "normal" parents can abort a fetus who will have a disability, it is only fair to allow parents with disabilities to abort a "normal" fetus, provided that (1) the parents are mentally competent; (2) they understand the medical and social implications of their choice, including possible stigmatization of themselves and the child; (3) the disability will not cause the child pain, severe retardation, or significant reduction in lifespan; (4) the parents are able and willing to care for the child; and (5) they are aware of the possibility of carrying a "normal" fetus to term and placing it for adoption. Although selective abortion of a "normal" fetus may repel most people, it would not be fair to allow parents to abort fetuses whose disabilities can be overcome (such as deafness, blindness, short stature) while not allowing persons with such disabilities to reject fetuses with so-called normal characteristics. Deafness may be normal within a deaf

family or community, and hearing may be deviant. It is to be hoped that the parents' motives in such cases would be to promote greater love and communication with a child like themselves, rather than to tailor-make the child to their standards. PND should be allowed in such cases because (unlike sex selection) it would be performed for the detection of abnormality.

In summary, it seems best, in a multicultural society, to let people proceed according to their own views, even if the majority population finds some choices offensive. The only clear ethical prohibitions would be: (1) sex selection; (2) selection by "normal" parents against a characteristic generally acknowledged to fall within the range of "normal" human variation; (3) selection against characteristics whose adverse effects can be entirely overcome without extraordinary measures (e.g., near-sightedness); and (4) use of PND to select fetuses with some "superior" characteristic such as I.Q. or resistance to cancer. These four kinds of selections have the power to change both society and the human gene pool in unforeseeable ways and may have unintended negative consequences. It is important, in attempting the almost impossible task of defining human normalcy, not to change the definition over time so as to make it more restrictive. Extensive use of PND could theoretically lead to a narrower definition of normalcy if enough fetuses with some characteristics were eliminated. Although most people may consider some choices wrong (e.g., abortion of a fetus with PKU because the family does not wish to assume the burden of keeping a child on the special diet), society should respect the rights of those who hold such views, provided that they have full information and are acting without economic or social coercion.

Legal Issues: Mandatory Testing, Wrongful Birth, Wrongful Life, Full Disclosure

Legal issues surrounding PND include possibilities of mandatory testing; wrongful birth (a suit brought by parents who argue that a child, or a child with a particular condition, would not have been born if the doctor had provided adequate testing and information); wrongful life (a suit brought by, or on behalf of, the child for damages associated with a disabling condition); and suits related to the quality and extent of information provided in counselling. Although these types of suits originated in the United States, doctors practising under national health insurance systems or even in the United Kingdom's National Health Service are not immune to legal actions. Andrews (1987a) and Elias and Annas (1987) have presented comprehensive overviews of the situation in the United States. Clayton (1993) has compiled a summary of state-by-state legislation addressing genetic services and abortions for fetal defects, both before and after the time of viability. She has also compiled a summary of damages in wrongful birth and wrongful life cases.

Mandatory Testing

PND is not mandatory anywhere in the world, nor are there any serious suggestions that it should become mandatory. However, in countries without national public health insurance, such as the United States, there is concern that insurers and employers (who pay for employee health insurance) may someday require genetic testing as a precondition for insurance or employment (Holtzman 1989). Although no institution has yet suggested this, PND could become part of a package of tests required for maintaining insurance coverage, at least for some women at high risk. This is unlikely in Canada or any country with universal public health insurance.

Geneticists, ethicists, and the public agree that all types of genetic screening should be voluntary (Singer 1991, 1992; Wertz and Fletcher 1989e). The only exception is screening for newborns, if, and only if, early treatment is available that would benefit the newborn. In this case, the U.S. President's Commission (1983) believed that mandatory newborn screening was ethically justified because it would benefit the newborn immediately and directly, and the newborn could not seek out screening of its own accord.

Wrongful Birth

Wrongful birth suits originated in the late 1960s from failures of sterilization or contraception arising from professionals' negligence. Most courts have allowed some damages in these cases. Although the children were normal, their births were unplanned and unwanted and placed a financial burden on the parents. Courts have varied widely in the amounts of damages awarded in such cases.

Early on, parents also attempted to sue for the special costs arising from birth defects. Parents have argued that physicians have failed to inform them of their risks of having an affected child, have failed to inform them about prenatal tests, have performed tests negligently, or have failed to refer them to a specialist who could perform a test. The parents have argued that they were deprived of information on which they could decide to terminate a pregnancy. Historically, the success of these cases has hinged on the availability of legal abortion for fetal defects. In 1967, the New Jersey State Supreme Court denied both parents and child the right to sue, after the child was born blind and deaf due to maternal rubella (*Gleitman v. Cosgrove* 1967). Even though the physician had intentionally withheld information about risk, the court denied the parents' claim because, in the absence of legal abortion, there was no way of avoiding the child's injury. After the U.S. Supreme Court *Roe v. Wade* (1973) decision made abortion legal, state courts ruled that physicians are negligent if they deprive "parents of the right to make an informed decision concerning continuation of the pregnancy" (Elias and Annas 1987, 110). Two landmark cases, *Becker v. Schwartz* and *Park v. Chessin*, reached the New York State court in 1978. Dolores Becker, age 37 at the time of her pregnancy

in 1974, stated that her physician did not tell her about the availability of amniocentesis. The Beckers sued for lifetime institutional care of their child with Down syndrome. The court upheld their right to sue, but the case was settled out of court. Although the media had predicted a multi-million-dollar verdict, the actual amount was small — $2 500, the amount they had spent on foster care. The Beckers had given the child up for adoption and had no financial obligations for care. This case raises some important issues that point to the reasons for another type of suit, wrongful life. First, the courts have generally measured damages in terms of lifetime care. Awards are often large. For example, in one case, parents of a child with Down syndrome were awarded $1 533 000 (*Phillips v. United States* 1981). Although the mother, age 23, had a sister with Down syndrome, she was offered neither genetic counselling nor PND. The child had an I.Q. of 56 and a life expectancy of 50 years, during which he would need 24-hour supervision. Second, parents are not legally obligated to spend any of the money awarded on the child's actual care. For example, if the Beckers had waited until they received a multi-million-dollar award before placing their child for adoption, they could have kept the money, and the adopting parents would have had no claim to the funds. This type of outcome could be prevented by legislation or by allowing the child to sue on its own behalf.

Wrongful Life

Wrongful life suits have not fared as well in courts as wrongful birth suits. Courts have hesitated to compare the state of non-existence with an existence of even the most impaired quality. The New York Court of Appeals rejected the Beckers' request to permit their child with Down syndrome to sue on its own behalf. The court argued:

> Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians ...
>
> Simply put, a cause of action brought on behalf of an infant seeking recovery for wrongful life demands a calculation of damages dependent upon a comparison between the Hobson's choice of life in an impaired state and nonexistence. This comparison the law is not equipped to make. (*Becker v. Schwartz* 1978, cited in Elias and Annas 1987, 113)

The court raised the further concern that wrongful life suits might be brought every time a child was less than "perfect."

Wrongful life suits have enjoyed somewhat greater success in the intervening years, and some legal experts predict that they will eventually find close to universal acceptance (Andrews 1987a; Elias and Annas 1987). Courts have begun to shift away from attempting to compare non-existence with impaired existence. Capron stated that it is quite logical for a child to say "I would have preferred not to exist. But since I'm here, I want to be compensated for my handicap" (Elias and Annas 1987, 114). The first successful case, *Curlender v. Bio-Science Laboratories* (1980), occurred in

California. Sauna Tamara Curlender, the plaintiff, had Tay-Sachs disease. Her parents had had carrier testing for Tay-Sachs disease and the results were negative. The child sued the laboratory for emotional suffering and the loss of 72.6 years of life. (Her life expectancy was 4 years as opposed to about 77 years had she not had Tay-Sachs disease.) The court declined to enter into meditation on the mysteries of life or to be concerned with non-existence. The fact that the child suffered on account of someone else's negligence was sufficient to allow damages. However, the court did reject the claim for lost years of life because Sauna never had a chance for a 77-year life expectancy. Damages were limited to her actual 4-year life span. According to Elias and Annas (1987), the case was settled for $1.6 million. In 1982, the California Supreme Court, using Capron's (1979) reasoning, formally recognized the tort of wrongful life (*Turpin v. Sortini* 1982). The child was conceived and was born deaf after an expert incorrectly diagnosed an inherited condition in her older sister. The court ruled that the child had the right to sue, but doubted that a jury would consider life with deafness as worse than not being born. The court further limited potential damages to medical and special care (special damages) but denied damages for pain and suffering (general damages), perhaps because the latter would require an evaluation of impaired existence versus non-existence.

Wrongful life suits, although accepted, will probably have limited use. The major use would be when parents have lost their right to sue, for example, if the statute of limitations has expired (and if the child has a longer period of time to file a claim), if the child has been placed for adoption and neither the birth parents nor the adoptive parents can sue, or if the child is under the legal guardianship of someone other than the parents.

The *Curlender* decision left parents themselves open to wrongful life suits from their natural children. In other words, a child born with an impairment could sue its mother for negligence if she decided to carry it to term knowing that it would be impaired. Shaw (1980) argued that women who "abandon their right to abort" after positive prenatal diagnostic findings incur a "conditional prospective liability" for negligence toward the fetus. She would permit children to sue their mothers for failure to abort them and would also permit children harmed by their mothers' health behaviours during pregnancy (including alcohol and drug use) to sue their mothers. Shaw argued that children have a right to be born physically and mentally sound.

This point of view turns a right to have an abortion into a duty to have an abortion and limits free choice. Elias and Annas (1987) argued that there is no legal right to be born physically and mentally sound and no right to be born. This is not to say that the parents and society have no moral obligations toward the developing fetus; they have a moral duty to protect it from harm insofar as possible. Feinberg argued for a "plausible moral requirement that no child be brought into the world unless certain

very minimal conditions of wellbeing are assured" (1984). This does not constitute a legal right to be born mentally and physically sound, though it may argue for a moral right. The California legislature, after *Curlender*, passed legislation that would prohibit children from bringing wrongful life suits against parents for conceiving them or failing to abort them (Elias and Annas 1987). At least 21 other states have followed suit (Glantz 1989).

Full Disclosure or "Quality of Information"

Some types of full disclosure cases have been discussed previously. However, there are other disclosure issues, including those raised by false positives. Sometimes, a normal fetus is aborted after false-positive findings. Although there is a clear moral duty to disclose, there is controversy in the legal profession about whether the parents should be told. However, as case law pushes physicians toward disclosure of the fact that some treatments are unsuccessful (Andrews 1987b; LeBlang and King 1984), it is likely that there will be a similar push for disclosure of inaccurate PND. If an abortion decision is made on the basis of erroneous information, the physician or laboratory should be liable, according to Andrews (1987a).

If a professional provides information in a manner that the patient cannot or does not comprehend and the patient bears an affected child on the basis of this information, the professional could be held liable. A suit would be most likely if: (1) the information is provided in such a way that a "reasonable person" would not understand it, or (2) a "reasonable person" could understand the information, but this particular patient clearly does not understand it. Although physicians in other medical settings have usually not been held liable for conveying information in an incomprehensible manner, provided the information was accurate (Andrews 1987a), geneticists and genetic counsellors may be in a special situation. Their stock in trade is information rather than treatment, and they could reasonably be expected to provide this information in such a way that it can be understood. Sending out written summaries of the counselling sessions that take place before and after PND would both increase comprehension and reduce liability. In the future, written summaries in lay terms could become a "standard of care."

The future may also see lawsuits for failure to provide "complete" information about the full range of variability in genetic disorders discovered by PND. For example, a woman who carries to term a fetus with cystic fibrosis after being told that the median age of survival is 32 years might decide to sue if her child died at 7 years of age, arguing that she made her decision on the basis of misleading information. Although such suits have not yet occurred, and may not succeed, it is probably only a matter of time before patients make such allegations. The importance of comprehensive and comprehensible information cannot be underestimated.

In general, thoughtful analysts have suggested avoiding legislative restrictions as setting undesirable precedents for the limitation of freedom

(Blank 1990; Charo 1993; Eisenstein 1988; Gallagher 1987; Glantz 1989; Nelson and Milliken 1990; Rothenberg 1993).

Summary and Policy Recommendations

PND has the potential to benefit women by freeing them to some extent from the capriciousness of nature. By being able to make informed decisions about their future children, women become empowered and gain a measure of control over their quality of life. In all, PND represents an advance for women toward control of their own reproductive capabilities. It also has the capacity to prevent the family suffering that often accompanies serious disabilities. Even its staunchest critics believe that it benefits some women.

However, PND carries with it some dangers, including possible social, economic, or political coercion upon women to use it for social goals, and exploitation of women for the professional or economic purposes of others. It is our considered opinion that although the benefits outweigh personal and societal risks of PND, public policy should be sensitive to the dangers. Accordingly, public policy should try to counter each of the following problems:

Public Fears About Eugenics

As explained in "The Many Meanings of Eugenics," eugenics has many meanings, ranging from legal coercion of individual actions to attain societal or political goals to individual actions, freely undertaken, which nevertheless change the structure of the gene pool or society. What the public fears most is coercive eugenics that favours the ends of those in power. It is highly unlikely that PND can or will be used for coercive eugenics in a democratic society. It is important that policy makers make the public aware of this, by (a) public education stressing freedom of choice in decisions about whether to have PND; (b) public education about the scientific limits of PND, namely that it does not guarantee anyone a "normal" baby; (c) education for medical personnel outside the field of genetics (obstetricians, paediatricians, family practitioners, nurses, social workers), stressing women's rights to choose; and (d) regulations forbidding use of publicly financed PND for enhancement of normal human characteristics, such as I.Q. It is highly questionable whether the second type of eugenics, namely an alteration in human characteristics through uncoordinated and uncoerced individual choices, will occur, especially in a multicultural society where different social groups may have different values about the characteristics they desire in their children. In any case, this "backdoor eugenics" is not what the public really fears. Many fears about eugenics are inchoate and uncoordinated; they reflect a lack of understanding of human genetics and a distrust of scientific "experts" rather than an

awareness of political realities. Education about genetics, including its limits, its benefits, and its potential misuses, could greatly help alleviate public fears.

Choice in Social Context

Although everyone agrees about maintaining freedom of choice, legal rights alone are not enough. Choice can be subtly or not-so-subtly dependent upon economic or social pressures, including those exerted by family or community. It makes little sense, for example, to claim that a woman has a choice about PND or termination of pregnancy if society does not provide support for children with disabilities, or if her community shuns her for having a child with a disability (or sometimes merely a child who is "different"). To make choices real, it is necessary to provide full and ongoing support for people with disabilities of all kinds and for their parents. It is also necessary to educate the public, preferably from an early age, about the range of human diversity to counteract stigmatization.

Non-directiveness in genetic counselling has an important role in facilitating freedom of choice. This means providing full and fair information about the entire range of expression of a genetic disorder, throughout the child's lifetime and in adulthood; it also means helping the family to work through their decision without influencing it toward what the counsellor considers the proper goal. Non-directive counselling means genetics should not be used as preventive medicine but should have the goal of informed decision making.

Most geneticists in Canada espouse fully non-directive counselling. However, there is still a potential for directiveness from other types of professionals, especially obstetricians, who will do most of the actual prenatal diagnostic procedures and will be the gatekeepers for genetic counselling. It will be important, as a policy priority, to educate obstetricians about non-directiveness. A more attainable goal may be to educate patients about how to recognize and counter directiveness in their obstetricians.

Abuse can occur from failure to offer or discuss PND when medically indicated. There may be more complaints about failure to provide PND than about pressure to submit to it. PND, if medically indicated on the basis of maternal age or genetic history, should be offered regardless of the use that parents intend to make of it. This means that PND should be offered to, and discussed with, women who oppose abortion, so that they can have the opportunity to prepare themselves for the birth of a child with a disability, if they so desire. This should be a standard of care. Special precautions should be taken, in offering PND to such women, not to appear to exert pressure toward reconsidering abortion.

The Exploitation of Women

Much of the attack on PND and other new reproductive technologies stems from the history of "over-technologized" childbirth and obstetrical paternalism. In the past, some doctors have used women patients for their own professional or economic aggrandizement and have also depended overly on high technology and medical heroics to save mothers' and infants' lives, while overlooking the necessity of routine preventive care. If many women are now angry at the use of high technology in reproduction, they have sound historical reasons for their anger. Nevertheless, history does not always repeat itself. The influx of women into medicine and the "consumer movement" among patients have led to more egalitarian doctor-patient relationships, even if they have not led to less use of technology. However, the critics of technology sometimes forget that throughout the history of birth, doctors and patients shared the same basic goals (healthy mothers and babies) and that patients usually collaborated in (and sometimes even promoted) the use of sophisticated technologies. The history of amniocentesis suggests that most research subjects were far from exploited; they were white, middle-class, and eager participants. There is no evidence that PND was developed mainly for the economic or professional benefit of doctors. In a national public health system, it is unlikely that PND will become exploitative.

The commercial sector, on the other hand, has a real possibility for exploitation. Commercial laboratories need large volumes of tests to make their operations profitable, and many are competing in the market for physicians' and hospitals' business by offering special tests or savings-by-volume. The effect could be to increase the number of tests performed, for example, by lowering the limit for advanced maternal age or by offering PND to any woman who claims to be anxious. It is important, in setting government or hospital policies, to resist these temptations because they will have the effect of making PND routine in most pregnancies, with the major benefits occurring, not to the women, but to the companies that manufacture equipment or process laboratory tests. Adhering to the CCMG guidelines for indications for PND offers the best defence against exploitation.

Views on Abortion After PND

Many Protestant denominations have supported the moral rights of parents to abort fetuses with severe defects to prevent human suffering, though none has defined "severe." The Catholic Church continues to oppose such abortions. The tradition in secular bioethics, also reflected in the legal regulations of many countries, is to regard the fetus as acquiring greater moral stature or moral worth as it progresses in development. The theory is that as the fetus comes to look more human and acquires more human capabilities, it deserves greater protection; thus, many countries permit abortion for any reason in the first trimester of pregnancy, but closely regulate it in the second trimester. Many countries forbid it in the

third, after the fetus may be viable outside the womb, albeit with extraordinary technical support. However, pregnant women probably do not see abortion primarily in terms of the "increasing moral status of the fetus." If a pregnancy is wanted, or is at least intended to go to term — and by the time a pregnancy progresses to PND it usually fits these criteria — the woman sees herself as a mother from the outset. She does not reify the fetus into an object that increases in value, but thinks of it as a potential child as soon as she knows that she is pregnant. Feminists have described the ethics of abortion in terms of the mother's relationship with her potential child. Abortion breaks that relationship. A woman may choose not to be a mother at all, but to choose not to be a mother after originally having chosen to be a mother is particularly painful. Many women resent the possibility of having to make this choice. The very existence of PND places on them a peculiar burden; nevertheless, most do not wish to return to the days before PND.

In making choices, most women do not separate their own and their family's quality of life from their conceptualizations of the child's quality of life. Some believe that it is impossible to judge the child's quality of life without being inside the child's body, and therefore decide on the basis of their own and their family's quality of life. Decisions are quite various; what one family considers serious, another would willingly accept.

In making policy, it is important not to try to define "personhood" or "serious disorder" because there are no truly objective definitions. It would be wisest to allow the parents who will raise the child to make such definitions for themselves, after receiving full information about the disorder and its effects on family life.

Differential Uses by Different Social Groups

Equal access is of the utmost importance. This includes access to information about genetic disorders, diagnostic procedures, and treatments for children. It is important that PND not become a white, middle-class people's antidote to disability, while other social groups assume the burden of caring for children with disabilities. The actuality in medicine, even under national health insurance, is often that educated, articulate people use the latest technology at disproportionate rates. If this continues to be so with PND, genetic disability could in time become a mark of low social class, adding further to the burdens of those already disadvantaged. This would increase the stigma of genetic disability because it would mean that the parents of those with disabilities were too ill-educated or socially irresponsible to prevent their births.

Equal access (in the sense of making available free medical care) may not be sufficient to prevent class disproportions in use. Communication of medical information often suffers when presented to ethnic minorities or less educated patients; it is necessary to establish the equivalent of an affirmative action program in regard to communication with these groups.

It will also be difficult to do this without appearing to impose PND on low-income people. Fully comprehensible information must be provided in such a manner that patients do not perceive it as advocating PND.

Use of PND for "Less Serious" Conditions

Regulations that would delineate "seriousness" would probably be impossible to establish and could do considerable harm by setting precedents for further regulations that would limit freedom of choice. Although some parents may not share prevailing social values about what constitutes a serious condition, they should be able to have PND and termination for any condition that they consider too serious to accept, provided that (a) they have received full information about the condition and its effects on the child's and family's functioning; (b) they have understood this information; and (c) they have been presented with the option of placing the child for adoption instead of terminating the pregnancy.

However, there are some conditions for which PND should not be offered under a national health care system: (a) sex selection in the absence of X-linked disorders; and (b) selection of cosmetic characteristics if within the range of normal human variation, such as height, weight, or eye, hair, or skin colour, if ever these become technically possible. (However, these procedures should remain legal; professional codes of ethics and public opinion could prevent commercial abuses.) With these exceptions, use of PND for non-disabling genetic conditions is better approached through public education than through regulations.

Effects of PND on Attitudes Toward People with Disabilities

Many people with disabilities fear that PND will serve as a search and destroy mission to prevent the existence of people like themselves and that use of PND will shift societal resources away from support for those with disabilities. This should not be so. Most disabilities are neither genetic nor prenatally diagnosable. Instead, they result from accidents, aging, environmental exposure, low birthweight, or drugs. It is difficult to see how the existence of more people with disabilities (if PND were to be restricted) would add either to the favourable perception of disability or to its support. Instead, the birth of fewer people with disabilities, especially those with severe mental retardation who use a large share of resources, could enable society to provide better for existing people with disabilities.

The perceived threat of PND to people with disabilities could be largely overcome by public education about the true sources of disabilities. Most disabilities are not exclusively genetic in origin. This education could also help to prevent our seeking a "genetic fix" for social problems.

Uses of PND When Not Medically Indicated Under CCMG Guidelines

Adherence to the guidelines will help to prevent many social and political problems associated with PND. Under a national health care program, PND should not be used for sex selection in the absence of X-linked disease. Sex selection, whether for girl or boy, is inherently sexist in origin and helps to perpetuate sexism because it is based on the premise that only one sex is capable of certain social actions. Sex selection has the power to unbalance the sex ratio or to change the composition of families (e.g., if all families acted on preferences that the first-born be a boy). Sex selection could start a trend toward fetal selection on cosmetic grounds. For all these reasons, it is important to refuse such requests. If sex selection appears to be the patient's primary goal when PND is medically indicated on the basis of age or family history, it would be reasonable to withhold information about sex until the third trimester. Legal regulations should not prohibit use of PND for sex selection by private practitioners because such regulations would restrict women's freedom of choice. It is hoped that social disapproval will prevent widespread use. However, if sex selection were to become widespread, it might become necessary to consider regulations that would prevent its becoming a social problem.

When parents intend that a fetus, after birth, become a potential tissue donor for another child, there is usually no medical reason to perform tissue typing on the fetus before birth. An exception would be a situation where early knowledge of the fetus's potential to act as a marrow donor (after birth) would help the already born child who needed the transplant (e.g., a partial match from an unrelated donor might be available, but doctors might want to know whether the unborn baby will be a better match). If PND is performed in these cases, care should be taken to prevent the possibility of aborting a fetus solely on the basis of having an incompatible tissue type.

PND for paternity testing, although not a medical indication, should be allowable under a national health care system if knowledge of paternity will have a profound effect on the family's future relationship to the child. This would include fetal paternity testing in cases of rape and in all other cases where the woman would probably abort in the absence of certain knowledge about paternity.

Full Disclosure of Test Results

All medically relevant risks and test results should be disclosed, including results that are conflicting, ambiguous, or have new or controversial interpretations. Almost all geneticists say that they already disclose such results. Guidelines for other physicians and health care professionals should also highlight the requirement for full disclosure.

Errors in diagnosis (false positives or false negatives) should also be disclosed, even if painful for both patient and practitioner. Disclosure of

an error may be vital to a patient's future reproductive plans, and is owed her as part of respect for the patient as a person.

Disclosure to Relatives and Other Third Parties

Disclosure to spouses or partners is inherently troubling because it poses a dilemma between respecting the man's interest in his future offspring and protecting the woman's privacy. It seems best, in view of protecting the unique relationship between mother and fetus, to allow no one access to prenatal test results without the mother's consent. When test results produce unexpected social findings, such as non-paternity, it seems best, in the interests of protecting socially vulnerable women and children, to tell the mother alone without her partner present. This is what most geneticists now claim to do. Ideally, guidelines for practice would avoid this situation by telling the mother privately before testing that tests will reveal paternity (allowing her to withdraw from testing), and (if she decides to go ahead) subsequently telling both the woman and her partner that tests will reveal paternity.

Similar guidelines for practice could also cover situations in which medical information from prenatal diagnostic results would be useful to patients' relatives at risk for genetic disorders. To prevent situations in which the parents refuse to convey useful information to relatives, professionals should discuss this possibility before testing and get agreement to disclose medically relevant information.

Guidelines should prevent medical personnel from disclosing test results to institutional third parties, such as employers, insurers, and schools, without authorization from the mother (before the child is born) or from a parent (after the child is born). Regulations should prevent institutional third parties from coercing parental consent.

Non-Disclosing or Exclusionary Tests

Non-disclosing or exclusionary tests, which provide genetic risk information about the fetus without disclosing the genetic status of the parent, should be avoided unless no feasible alternative is available. Those who perform such tests should keep in mind that if a fetus at risk is carried to term, a child will have been tested without consent.

Reduction of Multiple Pregnancies

Reduction of multiple gestations should be a woman's right; this is in keeping with rights to abortion in general. Often, reduction is the only way to ensure that any children from a multiple pregnancy will be born alive. Recognizing that an increasing percentage of mothers are single and will struggle to raise children without adequate support from a partner, reduction from twins to a singleton should also be permitted. However, planners should not expect reduction to be an automatic or easily accepted answer to the problems of multiple gestation as a result of taking fertility drugs.

Anxiety and Grief

Many studies have shown that the anxiety caused by PND dissipates rapidly after favourable results. There appear to be no longer-term unfavourable effects for most women. Most women who undergo abortion after PND experience grief somewhat akin to the grief following the loss of a child; however, most recover completely after a few months. A small percentage of women do experience grief that is not only intense but long lasting. Guidelines for practice should include long-term follow-up of all women receiving unfavourable results from PND, and should include grief therapy if necessary.

The Place of PND in Health Care Priorities

Ultimately, health care in many developed countries will probably move toward a rationed system along the lines being tried in Oregon, with priority given to preventive care and to illnesses that are treatable. Such a system will necessarily depend on community consensus about what (and who) should be treated.

Genetic counselling and PND, where indicated medically under CCMG guidelines, should be given priority as an integral part of routine prenatal care. (This does not mean that PND should be routinely applied in all pregnancies, only that it should be offered if medically indicated.) Prenatal care in itself should carry a high priority in any health care system because it can identify and ameliorate social and medical problems that cause mortality and morbidity. In Oregon, prenatal care comes close to the top in priority ranking, and PND (if medically indicated) is included in prenatal care.

However, in setting priorities, it is important to remember that many of the major causes of ill health are social rather than genetic. Although genetic discoveries may hold out great hope for humankind, it would be illusory to expect them to solve the social problems that cause or contribute to much disease. We should not expect a genetic fix for social ills. Disabilities will always be with us, and society should be prepared to offer full support to people with disabilities.

Protecting the Rights of Those with Minority Views

In a multicultural society, it becomes essential to try to understand the views of those who differ from the majority. In regard to those who elect not to have PND or who elect to carry a fetus with a serious condition to term after receiving full and fair information, society should respect deeply held values, which are often religious. In regard to those who, after receiving full information, elect to have PND and to abort for a condition that the majority would consider acceptable, society should respect the right to make such choices.

Not all minority views need be respected. An entire community can base its moral structure upon the oppression of one group. Often that group is women. It is not necessarily ethnocentric to reject a moral system that favours sex selection because that system is based on oppression of women. Rejection of sex selection does not mean rejection of the entire minority culture that uses it, but only of particular practices. To approve all practices of other cultures in the name of multiculturalism could lead to a destructive ethical relativism that has no limits.

Need for an Expanded Code of Ethics

In summary, it appears that societal dangers accompanying PND can be avoided by careful application of policy guidelines. There is a need for long-term research into the effects of PND on women's lives and on the lives of the children born after PND (Gates 1993). Until we know the ultimate effect of PND on women, we cannot take the most appropriate steps to prevent abuses.

Finally, a comprehensive and up-to-date code of ethics for professionals would help to stress the basic goals of free choice. The CCMG (1992) already has a code of ethics for its members. A portion of this should be extended to include all people who provide PND (including maternal serum AFP and ultrasound), including those who provide the pre- and post-procedure information. Obstetricians, family or general practitioners, nurses, social workers, and others who come into contact with women having PND would be covered by the code. Several documents exist as possible outlines for such a code ("The Declaration of Inuyama" 1991; "The Declaration of Inuyama and Reports" 1991; Fletcher and Wertz 1990, 1991, 1992a; Wertz 1991).

Codes of ethics need not be mere props to bolster the self-images of professional societies. International codes, such as the Nuremberg Code (United States 1949), have been highly influential in restructuring research ethics (Berg and Tranøy 1983) and rules for informed consent. However, general codes require implementation through professional advisories and guidelines regarding specific issues (American College of Obstetricians and Gynecologists 1987; American Society of Human Genetics 1991; CCMG 1991, 1992), which may be revised from time to time as scientific and social realities change. Codes of ethics should provide a framework for policy recommendations. It is essential that elements of any code be carried out in public policy, lest the code remain unused and in the realm of philosophical generality.

A Prediction for the Future

In the past, risk and cost have determined whether a prenatal diagnostic procedure became routine. Ethical and social considerations have held secondary importance. The advent of tests on fetal cells in maternal blood effectively removes the factor of risk to the fetus, leaving

only cost as a barrier to routine use in all pregnancies. If the new tests are accurate, meeting accepted levels of sensitivity and specificity, and if the cost is low enough, PND will become part of routine prenatal care. To most women, the health of the fetus is the paramount consideration in pregnancy. Most women do not side with the feminist critics of PND; if a riskless, inexpensive test becomes available, they will want it. Availability and use of such a test will change the character of pregnancy irrevocably. The history of ultrasound is illustrative here. Ultrasound, a seemingly riskless and relatively inexpensive procedure, gradually became routine without much comment from feminists, ethicists, or religious bodies. There was no mechanism for either information or consent. The fetus became a "patient" in its own right. Mothers developed a new quality of attachment to the creatures that they viewed, from a distance, on television monitors, while doctors took charge of interpreting these pictures for them. Ultrasound changed many women's definitions of life from the traditional quickening of the fetus in the womb to the appearance of a picture of the fetus on the TV screen. Ultrasound also placed pregnancy more firmly under medical control. Early diagnosis through fetal cells in maternal blood will carry the process further by endowing fetuses with human characteristics, including sex, early in pregnancy. CVS does this today for some women, but future methods of PND may do it for all. This means that many women may have to face decisions about their pregnancies. The challenge to society will be to provide full, balanced information about the medical and social meanings of disabilities and to prevent discrimination against those whose choices differ from the majority.

Appendix. Views of Parents of Children with Cystic Fibrosis on Abortion in 23 Situations

Since late 1985, accurate PND has been possible for families who have a living family member with cystic fibrosis. The availability of this technique has presented parents with the possibility of new and potentially troubling decisions about selective abortion. Parents of children with cystic fibrosis at 12 centres in six New England states were asked about attitudes toward abortion in 23 situations, including 12 maternal or family situations (Figure 1, p. 238) and 11 conditions affecting the child (Figure 2, p. 239). For each situation and for each of the first two trimesters of pregnancy, respondents were asked to respond "I would have an abortion," or "I would not have an abortion, but it should not be prohibited for others," or "I think abortion should be prohibited by law" (Wertz et al. 1991).

Questions included situations frequently described in opinion polls (e.g., mother's life, rape, incest), or used as rationales for abortion (e.g., low maternal age, mother's career, financial burden, family completed). Questions describing characteristics of the potential child avoided listing names of specific disorders and instead briefly described the child's condition (e.g., instead of trisomy 18, "severe mental retardation: child unable to speak or understand"; instead of Tay-Sachs disease, a "severe genetic disorder leading to death before age 5"; instead of Huntington disease, a "severe painful disorder starting at age 40, incurable"). Several disorders or susceptibilities that are not currently diagnosable prenatally were also included, such as susceptibility to alcoholism, "severe, incurable disorder at age 60" (Alzheimer's disease), and "severe, untreatable obesity," in order to see how many respondents thought these warranted selective abortion. Obesity was included because of concerns that, if ever given the opportunity, some parents may make prenatal selections on "cosmetic" grounds, such as stature, or the colour of hair, eyes, or skin. In a country obsessed with thinness, obesity would be one of the first characteristics selected against. Finally, there was a question about abortion for sex selection because, despite much publicity and two recent surveys of physicians (Evans et al. 1991; Wertz and Fletcher 1989e), there are no published surveys of parental attitudes. In addition to the abortion questions, there were questions about sociodemographic background, child's health, future expectations for the child, knowledge about new genetic tests, reproductive plans, and the attitudes of spouses and members of the extended family toward abortion for cystic fibrosis.

Starting in January 1989, anonymous questionnaires were distributed by all 12 cystic fibrosis centres in New England to parents of children enrolled as patients. Questionnaires were returned directly to project staff. Of 395 parents asked to participate, 271 (68%, 227 families) responded. All 120 families who volunteered were interviewed briefly, and 17 who were still fertile and at risk for having children with cystic fibrosis were

interviewed in depth. For the entire group of 227 families, the children's health status corresponded generally with the national clinical profile of cystic fibrosis (Boat et al. 1989). The children's median age was 7; 90% had pancreatic involvement; 73% required chest physical therapy, including 46% who required it from one to five times daily; and 42% had been hospitalized within the last year. The parents' median age was 35; 73% were female; and 78% were living with the affected child's other parent. In all, 52% had been surgically sterilized; 15% were over 45, widowed, or divorced; and 33% were still fertile and at risk for having another child with cystic fibrosis.

College graduates (36%) and Catholics (57%) were represented to a greater extent than in the white New England population generally. The higher proportion of Catholics has been observed in previous studies of cystic fibrosis and perhaps results from greater frequencies of the cystic fibrosis gene in the Irish, Italian, and French populations found in New England. Median household income ($30 000 to $40 000), occupational distribution (38% professionals or managers, 25% clerical, 12% blue-collar workers, and 25% homemakers), and weekly church attendance (38%) paralleled the white New England population.

Most of these married, majority Catholic, middle-class white parents supported legal abortion in the first trimester for all 23 situations described and for 20 of the 23 in the second trimester (Figures 1 and 2). Substantial minorities (41% to 49%) thought second-trimester abortion should be legal in the remaining three situations. The percentages of parents favouring legal abortion for mother's health, rape, mother unmarried, family completed, and financial burden exceeded those for comparable questions in the 1991 National Opinion Research Center's (NORC) General Social Surveys by 5% (mother's health) to 29% (mother unmarried) (University of Chicago, NORC 1991). The 86% (first trimester) and 76% (second trimester) who supported legal abortion for severe mental retardation closely paralleled the 79% supporting it for "serious defect" in the baby in the 1989 General Social Surveys and the 80% supporting it in a previous study (Faden et al. 1987).

Although in all situations fewer supported legal abortion in the second trimester than in the first, the differences were not great, averaging 11 percentage points for maternal/family situations, and 5 percentage points for fetal characteristics.

Figure 2 shows a steady gradient of parents' perceptions about severity. The majority who would abort for a given fetal characteristic would also abort for the characteristics in the bars to the left. For example, of those who would abort for cystic fibrosis (fifth set of bars from left), 86% would also abort for moderate mental retardation (fourth set of bars from left), 88% would abort if the child would be bedridden for life (third set of bars from left), and all would abort if the child would die before age five or have severe mental retardation. Of those who would abort if the child

would be bedridden, 80% would abort for death before age five and all would abort for severe mental retardation.

Characteristics associated with personal willingness to abort in multiple situations included religiosity (church attendance), education, income, and the spouse's and extended family's attitudes toward abortion for cystic fibrosis (Table 3, p. 236).

For all maternal/family situations and all fetal characteristics except sex selection, attitudes toward abortion were associated with respondent's perception of the attitudes of spouse, mother, father, and siblings toward abortion of a fetus with cystic fibrosis (Table 3). Most thought that their spouses or partners (65%), mothers (60%), fathers (55%), and their own siblings (51%) would disapprove. These views were closely interrelated, with correlation coefficients of >0.6. The respondents' perceptions of their mothers' views were especially important in relation to abortion for maternal/family situations. At least for spousal views, respondents' perceptions were accurate in the 43 families where both responded.

In addition, the following variables (not reported in Table 3) were associated with abortion for cystic fibrosis: perceived approval of abortion for cystic fibrosis by father-in-law, mother-in-law, affected child, other children, cystic fibrosis doctor, and genetic counsellor, and perceived absence of support from spouse or partner, family doctor, or cystic fibrosis doctor for carrying a fetus with the disease to term. Parents' perceptions of the views of the cystic fibrosis doctors toward abortion for the disease were among the factors most strongly related to their own attitudes toward abortion for cystic fibrosis. These perceptions may reflect in part the clinically necessary optimism conveyed by many paediatricians in their interactions with parents; we did not survey physicians' personal attitudes toward PND or abortion for cystic fibrosis.

Not associated with any attitudes toward abortion, including abortion for cystic fibrosis, were parents' age, fertility status, marital status, number of children, the health of the child with cystic fibrosis, future expectations about such a child, cost of the child's illness, knowledge about PND, interpretation of genetic risk, and reproductive intentions. No variables were significantly related to abortion for obesity, a severe disorder at age 60, susceptibility to alcoholism, a treatable defect, or sex selection.

Interestingly, although an earlier study (Kaback 1984), conducted before PND was possible, suggested that 83% of parents would consider PND an "important reproductive option," the 12 participating clinics in our study reported no PND for cystic fibrosis among families affected by cystic fibrosis during the 12-month study period.

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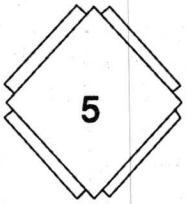

Roles for Ethics Committees in Relation to Guidelines for New Reproductive Technologies: A Research Position Paper

John B. Dossetor and Janet L. Storch

Executive Summary and Conclusions

This study reviews the ethical issues arising in new reproductive technologies (NRTs) in relation to the interests of eight particular groups: (1) society in general (and certain important subsets of society in particular, such as ethnocultural groups, women's groups, minority groups, the disabled, those at increased genetic risk, etc.); (2) governments (legislative and administrative interests); (3) religious groups; (4) children-to-be (resulting from NRTs); (5) prospective or would-be parent(s), women and their partners; (6) scientists, physicians, and other health care professionals who seek to do research and/or provide services; (7) the judiciary; and (8) the health care system.

The composition, function, and *modus operandi* of two types of ethics committees, the institutional ethics committee (IEC) and the research ethics board (REB), are described. IECs and REBs are then placed within the context of ethics committees of various types of professional organizations in Canada. Two national ethics agencies are singled out, the National Council on Bioethics in Human Research (NCBHR) and the Canadian Bioethics Society (CBS). They differ in

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important details, but the possibility is raised that the developing role for NCBHR in relation to REBs might be paralleled by a comparable role for CBS in relation to IECs. Consideration is also given to the possible role of departmental ethics committees at the local level, and provincial or regional bioethics initiatives at a level between the institutional and national levels.

We characterize the varieties of research reviewed by REBs, and describe the somewhat more variable functions of existing IECs, apart from their widely shared function of reacting to ethics dilemmas arising in particular clinical cases. Attention is also directed to programs, procedures, and devices that could be introduced into clinical practices that do not receive ethics reviews. One particular example of this is "innovative therapy." We draw attention to another type of hospital committee, which we term the New Program and Technologies Committee (NPTC). This committee is responsible for all new programs and is mandatory for new practices; at present, such committees require REB clearance for new research, but do not necessarily require IEC clearance for new practices, new procedures, or introduction of new devices. For the field of NRTs, we believe that such a mandated IEC clearance is essential.

A first draft of this document was distributed to 70 individuals whose opinions we felt would be valuable to our deliberations. Although it was not possible to make this representative of the Canadian public, we believe it was a significantly important sample of unusually well-informed opinion across Canada. More than half of those canvassed sent detailed replies. These were personal opinions and not necessarily positions of the organizations in which many of these individuals are prominent. (We had promised these individuals both anonymity and confidentiality for their views.)

The objective in preparing this document was to share our experience with IECs and REBs with the Royal Commission on New Reproductive Technologies. However, we also presume that the Commission might be interested in the conclusions that we, as researchers, have drawn as a result of this research. Many of these came to us during the five months of the project.

Conclusions

1. Many of the ethical issues raised by NRTs are wider and more profound than those normally raised by research proposals to REBs or clinical situations presenting to IECs.
2. No better system exists for analyzing the ethics of the more specific issues raised by NRTs than IECs (for dilemmas of practice, or new devices) or REBs (for research).
3. For NRTs, we favour other options:
   (a) ethics review at the level of departments of obstetrics and gynaecology, in certain instances; at the level of departments of paediatrics or perinatology or genetics, in others.

(b) an advisory ethics body, or an NRT subcommittee of a centre at a provincial or regional level.

(c) an ethics entity at the national level that complements, for IECs, the role now being played for REBs by NCBHR. This role would involve networking, communication, and education (including a journal and/or workshops, etc.). CBS is one body to be explored in relation to this. If this new national ethics agency were to materialize, we believe it should interact strongly with NCBHR in the area of NRTs, where research and practice are not always sharply differentiated.

4. The ethics entity envisaged in Conclusion 3(c) would draw up more specific guidelines for the roles of IECs than currently exist.

5. While professional judgment and freedom of decision making are important aspects of clinical practice and must be preserved, in NRTs, where uncertainty so often interacts with lack of knowledge and prognostic desperation, we also hold that "innovative therapy" must have ethical review. For NRTs, such decisions are seldom urgent and seldom require precipitate action.

6. We do not have a firm position on legislation versus guidelines for control of IECs and REBs in relation to NRTs. There are advantages to both routes. At present, we favour staying with the *guideline* option, but that could change if significant research or new NRT practices develop in the private sector (outside the purviews of existing IECs and REBs) and if circumstances reveal that ethics review is being undertaken by private consulting firms with insufficient integrity.

7. We strongly support the concepts of provincial or regional ethics centres even if they were not envisaged as playing a critical advisory role in relation to NRTs, as described in 3(c) above.

8. We strongly support the concept of monitoring ethical undertakings promised by researchers. This should be more searching than annual ongoing reports by principal investigators or practitioners. The emphasis here is on maintaining professional integrity and establishing accountability, not on the concept of an "ethics police." We are not sure how best to carry this out. The process may be better termed *quality assurance in research ethics*.

Introduction and Objectives

This research paper stems from an invitation from the Royal Commission on New Reproductive Technologies, in the summer of 1991, expressing interest in receiving a paper outlining the organization in Canada of hospital ethics committees and institutional (especially university) research ethics committees and their potential to address the

ethical issues of research and clinical practice related to new reproductive technologies (NRTs). The paper was also to deal with the possible role of various types of ethics committees at the local level in implementing recommendations and/or guidelines that might subsequently be made by the Commission. Not excluded, however, was the possibility that local committees might need to be supplemented and supported by other ethics decision-making bodies at provincial, regional, or federal levels.

A first draft was circulated to over 70 individuals (specialist physicians, family physicians, philosophers, ethicists, health law experts, nurse ethicists, nurses, and theologians) to obtain their personal opinion. We specifically excluded obtaining organizations' official positions. Nor did the distribution include the public at large, women's groups, or professionals of reproductive health care facilities, or their clients — mainly because of their lack of experience with ethics committees, an abbreviated time frame in which to complete the report, or because a group would be receiving attention from Commission researchers exploring other initiatives.

In the first draft we raised the following questions:

1. What are some of the moral dilemmas faced by Canadian society with respect to NRTs?
2. What are the various types of ethics committees in Canada and what connections link them — extrinsically, to other ethics committees, and intrinsically, to other committees in the institution (such as quality improvement committees).
3. What are the nature and function of institutional ethics committees (IECs) and research ethics boards (REBs), including:
   (a) their composition, including variations in composition and the factors accounting for the variability;
   (b) their workings — for example, whether they are proactive or reactive and whether they are widely used for new practices;
   (c) their primary focus — for example, whether their primary duty is to the hospital board, individual research subject or patient, researcher or clinician, or society; whether they safeguard the public; and whether they represent the public;
   (d) the evidence available regarding their ability to meet perceived needs and address ethical problems and issues;
   (e) issues that ought to get to ethics committees but fail to do so — for example, whether the mandates of IECs are defined so that all new practices will pass before them in the same way that all clinical research is passed before REBs; and
   (f) questions of access, especially by the unempowered.

4. How is research in the private sector (doctors' offices) and within private health care facilities and industry regulated? Is there adequate ethics review?
5. What are the feasibility and utility of provincial, regional, and federal multidisciplinary bioethics centres and advisory and educational groups?
6. What are the feasibility and utility of a federal NRT committee or group to advise or provide education on ethics issues and other aspects of NRTs?
7. Is there a need for enacted regulation, as in the United States — for controls that are more than guidelines?

In this final report we do not identify the individual views of those who responded to the first draft. However, certain individuals who gave us unique viewpoints are identified as personal communications (with permission).

It should also be borne in mind that this research paper attempts to deal with the ethical issues of NRTs only. We are not competent to address the technological aspects of these services.

Ethical Issues Inherent in New Reproductive Technologies

This section reviews ethical dilemmas in the field of NRTs, the details of which are listed in the Appendix. In this section, using criteria based on the ethical acceptability of NRTs in society and their fiscal feasibility as health care services, we speculate on the categories into which they might be placed.

Ethics dilemmas with respect to NRTs are categorized in the Appendix under groups of persons whose interests they principally affect. We see eight main interest groups of affected persons:

1. society in general (and certain important subsets of society in particular, such as ethnocultural groups, women's groups, minority groups, the disabled, those at increased genetic risk, etc.);
2. governments (legislation and administration);
3. religious groups;
4. children-to-be (resulting from NRTs);
5. prospective or would-be parent(s), women and their partners;
6. scientists, physicians, and other health care professionals who seek to do research and/or provide services;

7. the judiciary, provincial bar associations (health law sections), and various health law institutes; and
8. the health care system.

Our ambition is to integrate the fields of activity identified by the Commission with the principal issues affecting these eight interest groups, keeping in mind the criteria of social acceptability and feasibility. The Commission's fields of activity are:

1. causes and prevention of infertility;
2. assisted human reproduction;
3. prenatal diagnosis and genetics; and
4. embryo and fetal tissue research.

The ethical issues pertaining to the eight groups are listed in the Appendix to enable readers to judge whether they differ significantly in degree from those usually dealt with by IECs and REBs. Most of our first-draft advisors believe they are significantly different.

There are many similarities between the Appendix and issues already identified by the Commission in the document *What We Heard: Issues and Questions Raised During the Public Hearings*.[1] Regrettably, however, it is not likely that the issues listed in the Appendix will be resolved in the short term. Yet they seem crucial to planning, and it may be assumed that resolving at least some of them is the Commission's major preoccupation. We can do no more than place them in the context in which they seem most meaningful to us, and press on — but before doing so, we reiterate the fundamental problem of how to develop a system of ethics for a pluralistic society, such as Canada is today. Engelhardt has made a recent attempt to do this,[2] in the context of entitlement to dialysis and transplantation, viewed internationally. He compares the ethics shared by "moral friends" with what is available for sharing by "moral strangers." He finds that, in the second instance, one can only claim three shared principles: (1) the principle of authorization — focussing on the right to individual choice; (2) the principle of limited societal protection; and (3) the principle of limited social solidarity. He outlines a case by which these three principles can be used to build a moral framework for dealings among moral strangers, but it would be idle to pretend that even this analysis would be acceptable to all. As noted by many respondents, Canada does not have a reasoned, universally accepted, shared system of ethical principles — a fact that makes ethical planning all the more difficult — though an important foundational document exists, the *Canadian Charter of Rights and Freedoms* (1981).

Since this is so, we find ourselves focussing on the following combinations of criteria of partial acceptability and feasibility and wondering if such a pragmatic approach might be valuable for handling NRT issues.

Activities in Society Classified by the Criteria of Ethical Acceptability

Activities in society fall into different classes of ethical acceptability or rejection. It is likely that recommendations of the Commission would follow this classification, which is as follows:

(a) *ethically unacceptable for the whole of our society* at this time (i.e., could/should certain activities even be made illegal?) — for example, human cloning
Such an injunction might also make research directed toward such a goal unethical (and possibly illegal)

(b) *not ethically acceptable to all, but permitted by society for those who wish to use it* outside *the framework of the health care system*
Such research or practice might be expected to fall into a subgroup, such as:
    (i) biomedical research
    (ii) innovative practice
    (iii) regulated non-standard practice

(c) *not ethically acceptable to all, but permitted by society* within *the health care system* for those who wish to use it
Such practice would fall into the subgroup of:
    (i) standard health care practice

(d) *ethically acceptable to all and also considered to be established* normal health care
Such practice would fall within the subgroup of:
    (i) standard health care practice

(e) *ethically acceptable to all, but not appropriate for* medicalization
Such a practice might fall into one of the following subgroups:
    (i) social ethics discussion and planning
    (ii) individual social counselling
    (iii) family and child welfare, and child adoption
    (iv) reproductive health education at all levels

At present, practices such as artificial insemination by donor (AID), artificial insemination by husband (AIH), *in vitro* fertilization (IVF), and gamete intrafallopian transfer (GIFT) would come under category (b)(ii), as they are not ethically acceptable to all but are permitted by society to those who can afford them. Such practices are essentially unregulated and are not currently looked upon as biomedical research. Abortion falls into category (c)(i) (not ethically acceptable to all, but permitted as an option

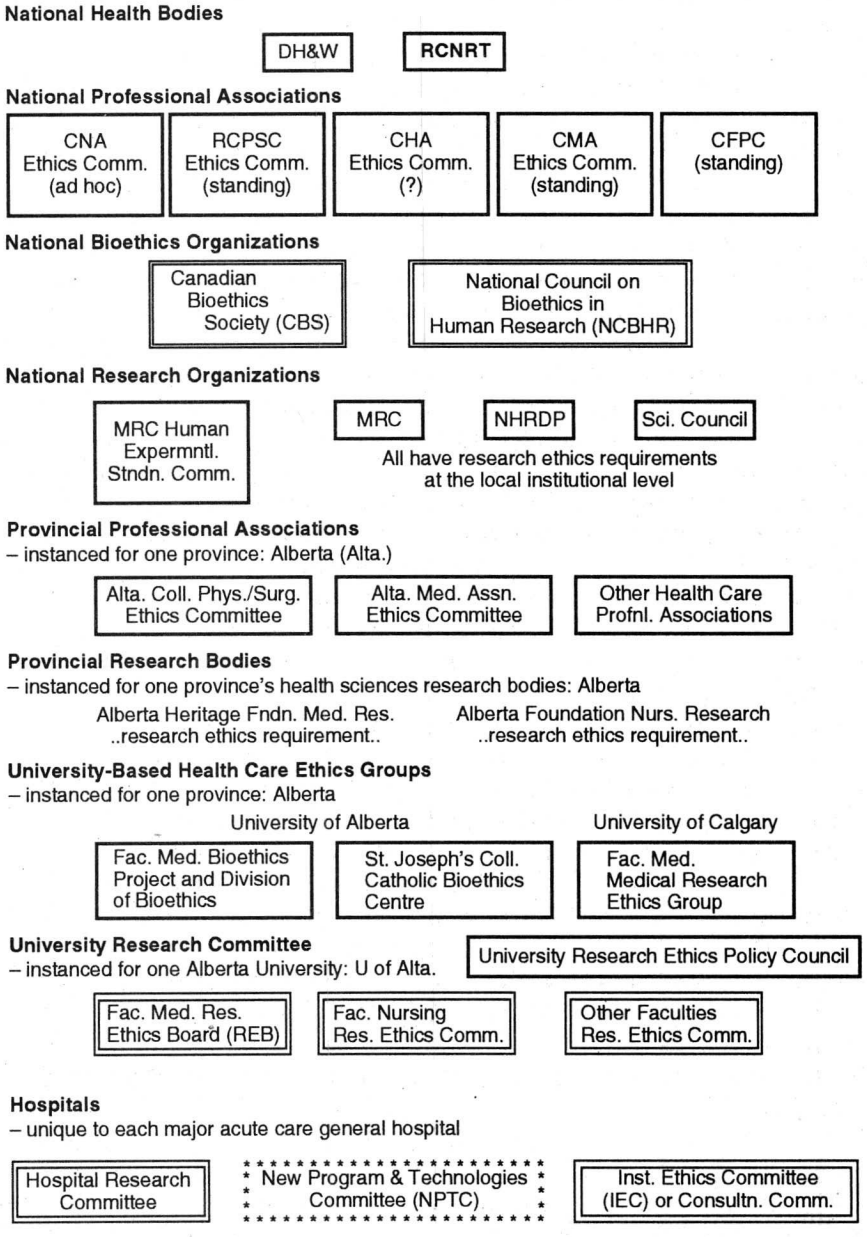
under certain circumstances and under regulated conditions) as well as such anti-conception practices as ligation of fallopian tubes or the vasa deferentia. Under (b) would fall research practices that have not yet reached the point where they have application. It is not clear where *surrogate gestation* or *sex selection by abortion* fall — probably in category (b).

Figure 1 summarizes the variety of ethics committees in Canada. Public and voluntary funding agencies (not shown in Figure 1 are organizations such as the Kidney Foundation of Canada, Cystic Fibrosis Foundation, etc.) require research ethics review before they will consider funding research. The Medical Research Council (MRC) has a standing committee on human experimentation, but it does not review ethical aspects of research proposals. Professional bodies have standing or ad hoc ethics committees responsible for periodic review of their professional codes of ethics and consideration of certain national or local issues important to the professionals concerned. Although they currently do not undertake ethics review for research, there is some question as to whether or not the College of Family Physicians of Canada (CFPC) Ethics Committee will review non-institutional research proposals in the future. The provincial colleges of physicians and surgeons do not review non-institutional research proposals, although several have considered the possibility. Most major clinical institutions (hospitals) have ethics committees (IECs) for research review and to address ethics issues in clinical practice. Each university has its research ethics review board or committee (REB).

There is little communication among the various groups involved in ethical reflection. They are not in a formal relationship (except, horizontally, between university REBs and local new program and technologies committees [NPTCs] or IECs). There is no provincial or national link-up of IECs, nor a journal that gives accounts of common problems. The linkage among university REBs is also very loose. However, because of its prestige and the central role it plays in funding medical research, the MRC represents an authoritative national body. Also, more recently, the NCBHR — jointly sponsored by the Royal College of Physicians and Surgeons of Canada (RCPSC) and the MRC — has begun to function as the voluntary and unofficial standard-setter for university REBs, although it does not cover all faculties' research (for example, faculties of nursing are not included under the NCBHR mandate, but this may be changing). It seems that NCBHR could become the principal agency linking REBs and thus may be important to interests of the Commission.

The Canadian Bioethics Society (CBS) is a multidisciplinary national society whose main activity has been an annual meeting. Its current membership is about 400 (350 individual and 50 institutional members) and its annual meeting draws 100-200 registrants. Its membership includes those who serve on both IECs and REBs, as well as ethicists from the fields of law, philosophy, and theology. To date it has not performed a role in linking IECs, but this is another option that the Commission might

Figure 1. The Broad Range of Ethics Committees in Canada



consider. Perhaps associations such as the Canadian Medical Association (CMA), Canadian Nursing Association (CNA), and Canadian Hospital Association (CHA) would be interested in supporting such a function for the CBS in a similar manner to the support of the NCBHR by the RCPSC and the MRC.

There is a need for individual IECs and REBs to be linked with other committees of like nature; such linkages are essential if IECs and REBs are to implement recommendations of the Commission.

Not indicated in this review is the role played by the pharmaceutical and medical device industry in organized medical research. When research funding comes from industry, researchers respond to the ethics demanded by industry. Local university REBs are then required to review both the scientific validity and the ethics of new research proposals, as most of these proposals do not require funding from national agencies and therefore are not subject to a national scientific peer review by a body such as MRC. This places a demand for scientific knowledge on the REB, which its members (often appointed for their interest in ethics) are not always able to meet. This additional requirement leads to considerable variability in REBs — some will handle scientific review, others will not.[3] This variation is problematic because industry-funded research constitutes over 75 percent of all research proposals, and the percentage is rising.

More significantly, any industry-sponsored activity (e.g., new device or praxis) could be carried out by physicians in private facilities without any IEC or REB ethics review. According to responses to a recent questionnaire from NCBHR, it seems there may be a move in Canada (as already occurs in the United States) for non-institutional health science research conducted in physicians' offices or private health care facilities to obtain ethics review from private ethics consultant companies.[4]

In addition to IECs and REBs, some institutions (hospitals especially) have committees that investigate the fiscal and resource allocation implications of research projects, new practices, and new devices. We label these NPTCs.

It is not clear whether there should be legislation to regulate the function of IECs or REBs. In the United States, institutional review boards (IRBs) are regulated by the Office for Protection from Research Risks of the National Institutes of Health (NIH), Department of Health and Human Services (DHHS).[5]

The Growth and Nature of Institutional Ethics Committees and Research Ethics Boards

Two main types of ethics committees exist: IECs and institutional research ethics boards (REBs in Canada, IRBs in the United States). Both serve institutions with respect to ethics problems — in clinical practice and research, respectively. For purposes of this paper, the historical evolution of these two types of committees is deemed not to be important. Their

evolution has been summarized for the United States[6] and for Canada.[7] The journal *IRB, A Review of Human Subjects Research* describes various roles and responsibilities for IRBs in the United States, and Cranford and Doudera have addressed the question of effectiveness of IECs in the United States up to 1984.[8] Two studies in English Canada and one in Quebec, referenced below, have addressed the question of IECs, but there is virtually no study yet on the effectiveness of REBs, though the matter is under current study by the NCBHR.[9]

In addition to their IECs, many hospitals have another committee (not primarily for ethics) that examines each research project from many hospital viewpoints (including ethics). This type of committee we have termed the hospital NPTC. Although the NPTC usually requires REB approval before considering any clinical research project, it is this committee, not the IEC, that reviews new practices and the introduction of new devices in many institutions (if review is deemed necessary by the practitioner or his/her department chair). For example, an expensive device, the lithotripter, can be introduced without formal IEC or REB ethics review, even though it might never have been subjected to a randomized controlled clinical trial. Indeed, the whole process by which devices are introduced in Canada[10] is flawed.

Both IECs and REBs are committed to protecting the rights of patients and subjects and to ensuring that ethical concerns are addressed. As society has become more litigation-conscious, the goals of the committees may change subtly to reflect researchers', practitioners', and institutions' concerns about liability. This shift is most apparent in the United States, although Canadian institutions struggle with similar tensions.

In the United States, the legal framework for ethics committees evolved in ways that Canada has not followed. For example, U.S. IRBs have legislated authority. Also, for certain clinical cases, mandatory review has been required by U.S. IECs or by certain U.S. courts in ways that are foreign to Canada.

In Canada, hospitals have been stimulated to form IECs as a result of a 1986 recommendation of the CHA and the 1986 Guide to Accreditation of Canadian Health Care Facilities. The latter stipulated that "the facility should address the need for policies on the following biomedical ethics subjects" and further specified that "this process may be facilitated by the creation of a multidisciplinary ethics committee." A 1989 Canadian survey[11] of 142 English-language hospitals with over 300 beds revealed a dramatic increase in the formation of IECs, from 26 in a 1984 survey[12] to 70. Findings from a Quebec study were similar, with 25 IECs developing between 1985 and 1989, and notice being given of 26 more intended for 1990, which would make a total of 120 ethics committees of all types in 96 Quebec institutions.[13]

For Canadian research involving human subjects, in 1972 the MRC instituted local ethical review before consideration for funding, and in 1978 it issued its first set of ethics guidelines for the protection of human

subjects in research. These guidelines, revised in 1987,[14] are used as a model by university medical school REBs, most large institutions that review ethics issues for human research, and funding agencies.

The basic premise of ethics committees has been the need for a neutral "outside" group to ensure that scientist or practitioner fervour is not detrimental to patient or subject welfare. Hospital ethics committees (IECs) were developed to deliberate on and make recommendations in three spheres: (a) ethically difficult clinical situations; (b) ethical aspects of hospital policies; and (c) proactive bioethics education or discussions. It is notable that, unlike the role of REBs in advance of new research, IECs were not created to be concerned with the ethical review of all new practices or devices prior to their introduction. University REBs were developed to examine ethical considerations in research projects including: the validity of the scientific question and the methodology by which it is to be answered; the wider social implications of the research; the adequacy of information to subjects in obtaining informed consent; rules about stopping the study; the ratio of risk to benefit; provision for subject withdrawal without detriment; preservation of patient privacy and anonymity; researchers' professional integrity in relation to the perquisites and other compromising rewards offered in the course of industry-sponsored research; legal liability to various parties (including the funding agency and the institution), etc.

To ensure some degree of objectivity, health professionals other than physicians and frequently persons from outside the hospital, such as lawyers and theologians or bioethicists, are included as members of ethics committees. Similarly, on research review committees, "neutral" individuals are involved in adjudicating the ethics of proposals by examining them with regard to procedures for obtaining consent, confidentiality, and other ethical requisites.

It is not easy to strike a balance between committee members who are knowledgeable in medical sciences and those whose main concern is patient care. Further, delays while the committee decides on the acceptability of a research proposal or innovative treatment plan are not welcomed by the researchers involved. Thus, in addition to dealing with challenges to their authority, committees often struggle with problems of timing, insufficient expertise, and politics unique to their settings. Seldom, if ever, does either type of ethics committee feel totally competent to address the difficult issues that can arise. Committees wrestle with decisions over ethics approval and, if circumstances permit, may choose to reflect on a matter for days or weeks before a recommendation is made. An extreme example was the committee at the Victoria General Hospital in Halifax, dealing with the questions of the use of fetal tissue for Parkinson's disease. This committee decision involved an 18-month process of national opinion sampling and many half-days of debate.

It should be noted that in a number of institutions a single committee is responsible for both clinical and research ethics. However, in Quebec,

for the 94 committees whose function is known, there are 38 clinical ethics committees, 41 research ethics committees (not known as REBs in that province), and 15 ethics committees that serve both functions.[15] The proportion may be significantly different elsewhere in Canada, but there are no conclusive data on this point (see Table 1).

IECs: Present Functioning and Future Potential

Given the dramatic increase in numbers of IECs in hospitals in Canada since 1984-85, it should not be surprising to find considerable unevenness in their development. This variability relates to the different functions of consulting, developing policy, and providing bioethics education, the manner in which the IECs have been established, and the means of access to them.

IECs have developed via two main modes loosely called *bottom-up* or *top-down* in the jargon of organizational structures, though the two approaches may be termed *patient-oriented* or *mission-oriented*, using another paradigm. IECs that developed from within the organization as an outcome of the expression of needs by various health professionals in the organization would constitute the bottom-up or patient-oriented style of development. Although we have few data on this approach to IEC establishment, there is some evidence to suggest that this approach brings with it a healthy commitment to the ethical nature of the endeavour and to meeting clinical needs, but may run into problems of continuity. On the other hand, IECs established by administration to meet an accreditation standard or to provide evidence that the hospital is concerned about addressing ethical issues appear to have been less successful in commanding early commitment, encouraging access, and being perceived as more than just another hospital committee.

This is not to suggest that the potential for an effective IEC cannot be realized without a populist approach to its development, but rather to note the realities of any bureaucratic solution to what is seen to be a professional and human value problem. In that regard, IECs in religious hospitals may experience an easier acceptance and commitment simply because of a long-standing commitment to examining ethical issues, albeit largely from a theological perspective. There is also a longer history of *medical moral committees* in such institutions as compared to non-sectarian or secular ones.

IEC acceptability can also be directly related to the manner in which IEC members are appointed, and the authority to whom they report. If IEC members are perceived to be knowledgeable, informed, and unbiased individuals, they are likely to achieve a greater degree of respect and use by *users* of the service — whether that be through consultation, policy discussions, or educational programs. However, there appears to be a serious difficulty in the definition of knowledgeable by members of the hospital community. For some specialists, knowledgeable tends to be

Table 1. Comparison of IECs and REBs

	Institutional ethics committee	Research ethics board
Reporting authority	Variable: usually the board or CEO, sometimes through pastoral care or a less formal route; occasionally to a medical advisory committee (MAC).	Appointment by the Dean, or VP Research, often on suggestion by the Chair.
Function	Consultation on selected cases; involvement with hospital policies; bioethics education. No primary ethics involvement with research projects.	Intimate review of all research proposals, including scientific validity, harm/benefit ratio, confidentiality, informed choice and informed consent; rarely, social impact.
Usual size	5-25, average 13.	Average 15.
Usual composition	Physicians, nurses, administrators, and pastoral care (often more than one of each); independent lawyer or legal ethicist; bioethicist (40%); member(s) of public; other hospital employees; other resource persons — patients or relatives.	Scientists, clinicians, nurses, statistician, ethicist, independent lawyer, member(s) of public, academic administrator, other resource persons.
Method of appointment	Variable: request of CEO, request of the Chair, appointed representative of specific group.	Usually after request by the Dean, VP Research, or the Chair. Confirmed by Dean.
Individual responsibilities	Attend meetings; develop ethical arguments; visit with patients, relatives, or family; visit with specific physician or nurse.	Attend meetings monthly, having spent several hours critically examining 2-6 projects and being familiar with 6-12 others.

Table 1. *(cont'd)*

	Institutional ethics committee	Research ethics board
Frequency of meeting	6-8 meetings yearly.	10-12 meetings yearly.
Usual pressure of business	Usual demand on committee members.	Usually very heavy. Preparatory time for meetings usually 4-8 hours.
Usual duration of individual commitment	Variable.	Seldom more than 3 years.
Committee's resources	Co-opted secretary to take minutes.	Requires administrator and full-time secretary, as a rule.

restricted to a physician in one's own specialty who possesses the requisite medical knowledge in the area; for others, knowledgeable refers to a person with expertise in ethics. Between these two extremes are those who take the position that it is the consumer of service who is the knowledgeable IEC member.

Likewise, IECs that report to medical advisory committees (MACs) may be seen as too medically oriented and too restrictive of other input, while those that report directly to the chief executive officer (CEO) or board may be seen by physicians as usurping some of their power. Perceived and real access to these committees may also be restricted by the reporting relationship. IECs reporting to the MAC may be seen to be focussed on medical practitioners' needs and inaccessible to the average nurse, physiotherapist, or social worker, while IECs reporting to the CEO or board may be perceived with suspicion by physicians and used only by non-physician health professionals.

Another phenomenon noted in IECs is that committees that spend their early months engrossed in study and discussion about bioethics are later sometimes perceived as being too insular, while those with rotating memberships, where members learn as they go, are perceived as not sufficiently knowledgeable to be worthy of consultation or to give valuable educational offerings in bioethics.

In some instances physicians have ignored IECs, preferring to consult their colleagues in difficult instances. In other instances IECs appear to have bent over backwards to meet physicians halfway by structuring mini-consultation teams composed mainly of knowledgeable physicians/

specialists and/or bioethicists. These mini-teams may report back to the parent IEC (for information only), or may bring back the issues for discussion and wider consultation or to provide an opportunity for reflection on similar cases that might arise in the future.

The present variability and apparent shortcomings in IECs should not be taken to suggest there is no potential for IEC involvement in addressing ethical issues surrounding NRTs. We would stress that attention be paid to the material presented earlier, namely, that IECs in Canadian hospitals are in the process of development, with many beginning to manifest a considerable degree of maturity in their deliberations and grasp of clinical ethical issues.

The majority of IECs, whether mature or developing, subscribe to a set of ethical principles at a level above individual interests: principles to benefit patients, minimize harms to patients, respect client autonomy, and provide fair and just care for patients and clients in care or seeking care. One of the benefits of IECs is that these principles are perceived differently by health care professionals, chaplains, bioethicists, consumers, and others, thus providing a means by which these different perceptions can be expressed, debated, and brought to bear in decision making. However, perhaps the least well expressed of all perceptions is that extremely elusive viewpoint — the perception of society at large.

This interdisciplinary perspective on ethical issues and the ethical principles that aid in addressing these issues must not be lost. An example of differing perspectives on these matters is those of doctors (family practitioners and specialists) and nurses. For example, specialists may be oriented more toward treatment of illness and disease — the *cure perspective* — while nurses are often more oriented toward understanding and ministering to human responses to illness and assisting patients to articulate the meaning of illness — the *care perspective.* Both are committed to advocacy of patient needs yet, when ethical issues arise in clinical settings, these two different but complementary perspectives may be critical to understanding the facts of the case. If to this dyad one adds the perspectives of other health professionals — especially family physicians (who may bridge between both individuals in the dyad), but also pastoral care chaplains, bioethicists, the family, and the patient where possible — the ethical debate may be profound.

The Role of the IECs in Addressing the Ethical Issues of NRTs

Given that NRTs are mainly "new" and rapidly evolving, is it likely that IECs can meet the ethical challenge of their increasingly pressing demands? If IECs are to meet this challenge, it is essential to ensure that new NRT practices are vetted by an interdisciplinary group of dispassionate experts, and not just by scientists, clinical specialists, and health care providers. There is also a pressing demand for IEC members to become

knowledgeable and conversant on the ramifications of these complex issues.

With respect to the practice aspects of these technologies, we believe there is a need to look at different levels of consultation and decision making. We suggest that the following IEC hierarchy might be considered: a local IEC on the obstetric and gynaecology (O & G) service, with connections to the hospital IEC (perhaps as its subcommittee). The hospital IEC, in turn, should have links to a national body similar to an Advisory Council on Biomedical Ethics for Canada, as proposed by the Law Reform Commission of Canada,[16] or to a provincial or regional bioethics centre, as has been previously suggested to the Royal Commission on New Reproductive Technologies[17] and as recommended in the Alberta Rainbow Report.[18] Our view is that, while decision making should remain at the institutional level, the advisory/educational level would enable additional ethical reflection and foster consistency in decision making. The rationale for this approach is that: (a) NRTs pose serious and complex ethical issues requiring the best available minds (health professional, ethical, theological, etc.); (b) to address the ethical issues in a comprehensive manner, NRTs require a relatively sophisticated understanding; yet (c) responsibility for ethical issues, both for individual clinical dilemmas and for institutional policy, must remain at the local or "grass-roots" level.

It is our view that, contrary to the situation 10 years ago when clinicians involved in AID and IVF pioneer work were reluctant to hear from others, clinicians practising NRTs today are more ready and willing to receive consultation from a wider group of "experts" or "knowledgeable others," including consumers. Thus, a local IEC specific to O & G might be composed of experts in NRTs, experts in bioethics who understand the principles at stake, nurses and social workers involved with clients, chaplains and others who have a special interest and knowledge in NRTs, plus one or more public representatives or consumers of care. This "expert" group would be involved in consulting on cases, developing policies surrounding various types of cases, becoming better educated about these issues, and promoting education of professional staff. Depending on the question under discussion, this specialized NRT committee or IEC subcommittee would report to the hospital's IEC or REB, to educate about and to seek wider opinions and analyses of these matters. Both the main committee and the NRT subcommittee would have counsel available from an outside group (the provincial, regional, or national advisory body). The NRT subcommittee would also serve as a resource regarding ethical issues arising from NRT research and practice in Canada and abroad.

The Problem Posed by Innovative Therapy and New Practices

There is a serious problem relevant to NRTs stemming from the difficulty in clearly distinguishing that which is an *innovative therapy* from that which is *clinical research* (Table 2). In the context of transplantation

Table 2. Comparison of Innovative Therapy and Clinical Research

Innovative therapy	Clinical research
1. Patient's MD is the therapeutic innovator.	1. Patient's MD may be both in charge of treatment and conducting research as principal investigator.
2. Clinical situation often desperate; other therapy not available, or has failed.	2. Clinical situation suitable for asking standard research questions to increase knowledge.
3. Directed at treating specific patient; result not likely to be generalizable.	3. Directed at testing a hypothesis to obtain knowledge, which should be generalizable.
4. Ethical focus is derived from the MD-patient relationship and trust, and patient's *informed consent* and desire.	4. Ethical focus is that of clinical research — to research subjects and funding agent — with subjects' *informed consent.*
5. Ethical accountability to individual patient, chief of service, administration of hospital, and provincial colleges of physicians/ surgeons.	5. Ethical accountability is to groups of patients, IRB/REB, and funding agency.
6. Protocol: optional Scientific review: optional Ethics review: optional	6. Protocol: mandated Scientific review: mandated Ethical review: mandated
7. Institutional clearance: needed because of unusual demands on staff and resources.	7. Institutional clearance: mandated because it involves research.
8. Outcome: success may lead to pilot study (clinical research); failures often not reported.	8. Outcome: research question is answered and may lead to generalizable benefit to others; also, failures are reported.

medicine, one of the authors has attempted to defend the principle that innovative therapy should be allowed to continue, as, on the whole, it has served patients well.[19] But there are problems, and these may be even more significant in the realm of NRTs.

Two logistical problems should also be recognized: (a) research on NRTs may have been conducted elsewhere, and thus their introduction to a new Canadian institution may not be considered research; and (b) introduction of the NRT may not involve significant resources (e.g., differential centrifugation of donor sperm) and therefore may not need external funding. Therefore, such a practice might well be introduced without the need to make more than a local departmental (medical) decision.

New practices, if based in private facilities, may not need ethics clearance for their introduction. Practitioners may also introduce new clinical practices or devices (developed or tested elsewhere) with scrutiny limited to peer (medical) consent and approval at the division or department level. Most IECs do not function to review ethics in relation to new clinical practices within the hospital, or the ethical implications of new devices. As noted earlier, the IECs' mandate is usually defined as being more for the review of difficult clinical cases, ethical discussion on hospital policy, or proactive ethics education. Newly introduced practices are not clinical research and, to date, do not have to go the REB route of research proposals. Thus, the work that led to the first IVF baby, Louise Brown, was carried out without ethical review and (unbelievably) was considered just a new method for treating infertility — not research. For most institutions there are no guidelines or rules ensuring that new practices are reviewed by IECs.

NRTs, both as practices and as research projects, have a greater impact on society and therefore require greater multidisciplinary input than do most other clinical innovations. It is because of this wider social and ethical perspective that we believe the concept of innovative therapy, in the context of NRTs, merits greater concern.

REBs in Relation to Ethical Issues Inherent in NRTs

For clinical research the rules are much clearer. Broadly viewed, the REB reviews the following classes of quantitative and qualitative research:

1. *Proposals for research requiring funding from national, provincial, or disease-related research agencies:* For these the REB reviews such aspects as method of patient recruitment, determination that financial compensation is not acting as inducement, a realistic account of possible benefit and detailed account of possible risk, the use of language uncluttered by technical jargon on consent forms, clear differentiation between the patient's physician and the principal investigator, provision for opting out without penalty of any sort, the maintenance of anonymity and

confidentiality, etc. While some REBs deal with the validity of the scientific question, others leave scientific validity to the granting agency's expert peer review process. Such studies may involve new therapies, new uses of established therapies, or introduction of new procedures, or may be directed at elucidation of the processes of disease.

2. *Proposals that do not require funding after competition at the national level as they will be funded from the pharmaceutical industry:* These are often multi-centre trials (often randomized controlled trials (RCTs)) of new therapies, where most of the protocol design and consent form development stems from industry's research division. The objective is often more to meet Health Protection Branch (HPB) requirements before marketing rather than to ask a serious scientific question. In addition to the ethics review as noted for category (1), the REB needs to examine the extent to which consent documents are merely protecting industry, institution, and investigator versus protection of the research subject. As there will be no independent scientific review, the REB is also the court for establishing validity of the scientific question — a function for which it may be inadequately qualified. The REB must also look for inappropriate recompense or rewards that threaten the objectivity and integrity of investigators.

3. *Proposals for small-budget, local research projects:* These may be performed on patient populations by means of questionnaires, or may be concerned with ethical concerns about existing devices or the introduction of new ones. They will not be concerned with new therapies, but may involve simple measures (taking blood samples from patients) to study mechanisms of disease or the effects of standard therapy, for example. Of great concern at this level, as in the preceding categories, are proposals involving children or incompetent adults.

4. *Qualitative research proposals:* Most medical REBs are not being presented with qualitative research proposals for ethics review. In qualitative research, investigators probe the meaning of individual experiences with small numbers of subjects. This form of research provides perspectives that do not emerge from quantitative research questions, even when such research is directed at peoples' attitudes or opinions. Qualitative research, increasingly conducted by nurses and social scientists, holds great potential for uncovering the meaning of various NRTs for the woman and her partner in the experience. Such research usually receives ethics review in nursing, the social sciences, and the humanities.

Although most REBs include members from nursing, law, bioethics, hospital administration, and the general public, the majority of members are physicians from various disciplines (paediatrics, obstetrics, psychiatry, oncology, surgery, and internal medicine subspecialties). As committees, most REBs would not feel competent to deal with broad societal ethics issues or with the ethics of qualitative research. The volume of work generated by proposals of the (1), (2), and (3) types, above, creates a heavy demand on these individuals for which there is little reward beyond academic satisfaction. Thus, a proposal for IVF research, fetal tissue transplantation, or fetal reduction *in utero* as part of an IVF innovative practice or research would likely be seen as falling outside the normal REB responsibility of committee members. This would be especially so if the proposer did not view the proposal as clinical research.

Neither clinical IECs nor REBs are oriented toward the views of members of Canada's first nations, women's groups, or new Canadian immigrants — the tapestry of pluralistic multiculturalism that constitutes Canada today. Also, only those in denominational institutions would be oriented toward religious perspectives. Members of both types of ethics committee have a deep commitment to ethical decision making but also have local loyalties and professional interests. Most would not deem that they qualify to bear the wider responsibility involved in many of the issues of NRTs as outlined in the Appendix of this document.

The Role of Ethics Committees in Monitoring Ethical Undertakings

An aspect of the work of ethics committees that has received little attention is the monitoring of ethical agreements after they have been undertaken by investigators or practitioners. Monitoring may be perceived as smacking of "surveillance by the ethics police." Not surprisingly, the notion of *downstream* monitoring of ethical agreements has met with little enthusiasm by researchers and perhaps even less by members of ethics committees (IECs or REBs). It is not surprising that this resistance occurs when one considers that committee members are living in a milieu of academic, institutional, and professional collegiality. Yet in our opinion there is a clear duty to the public to ensure that ethics agreements are being carried out. One advisor suggested that investigators themselves be required to propose feasible methods of independent verification of conformity to ethical commitments in their proposals. This suggestion seems eminently feasible.

The MRC, in drawing up its 1987 Guidelines, noted that monitoring of ethics obligations was desirable but left it to the local level for consideration and possible action. So far no publications have signalled attention to this matter. Another advisor recommended (1) an annual statement

from each investigator that ethics undertakings have been fulfilled, (2) annual ethics reviews of ongoing projects, or (3) both, and that this include all innovative therapy. Yet another respondent stated that an annual declaration of conformity should not be deemed to be sufficient.

It is not clear in the field of research or practice of NRTs to what extent it is desirable to monitor to ensure that ethical obligations are being observed. But those whose advice we sought on this question were strongly of the opinion that monitoring of ethics in NRT research ought to be undertaken. Another area of research ethics monitoring would focus on the adequacy of information for patients or subjects enrolled in research. Do these subjects/patients know they are in a research protocol? Do they understand what it is all about? How long do they retain the information from the explanation on which they based their consent?

Responses from Advisors and Consultants

Note 1: Not every question originally asked in the draft is analyzed below, but only those that elicited wide differences of opinion. Others, with less divergence, are included in the preceding sections of this paper.

Note 2: A few respondents pointed out their perception that the questions were a thin veil for a secret agenda, which lent bias to the questions. This bias was perceived as being anti-industry and anti-libertarian. We make no apology for this, but feel that the observation should be acknowledged at the outset of our analysis.

1. **Do you agree with the statement that the ethical issues arising from NRTs are *significantly different* from those that normally present to IECs and REBs?**

   Replies: Yes: 58% No: 23% Yes/No: 19%

   Yes: because they are made *without* the normal guidelines of previous well-articulated positions, professional codes, consensus, or legislation; committees would sense the lack of the usual "reference points"; they involve proactive decisions; the societal impact is much more profound; the very fact of the Royal Commission testifies to the uniqueness of the issues.

   No: they are not dissimilar from other issues affecting the beginning and end of life; even some of those have wide societal impact (see Nancy B., or adolescent's right to abortion despite parental objections, etc.); we cannot have separate ethics review processes for each special interest area; committees must recruit whatever resources they need, including wider consultation, but basically must be deemed capable of handling every NRT issue.

Researchers' conclusion: The issues are significantly different and merit special attention at least for an interim period until these issues are better understood and there is a greater collective experience in addressing them.

2. **Do you agree with the classes of interest groups/bodies whose interests are particularly impacted by NRTs, or have significant ones been missed?**

   Replies: Yes: 45% No: 41% Yes/No: 14%

   Significant groups that were later added to the original five impacted groups are children-to-be, government (legislative/administrative), and religious groups, to give eight in all. Several thought the interests of parent(s)-to-be should be replaced by interests of women, but these were not enough to convince the researchers. This is controversial.

Researchers' conclusion: With the additional three groups added, the classes of interest groups/bodies are reasonably represented.

3. **How important is a *multidisciplinary approach* to addressing ethics issues in IECs and REBs?**

   Replies: Yes: 83% Equivocal yes, or but ...: 17%

   Most respondents thought this was extremely important, and were very emphatic.

   Yes, but ... refers to those who pointed out the difference between multidisciplinary and interdisciplinary (the latter being preferable). Another claimed the process of decision making is better described as *discernment*, implying that there is interdisciplinary work to be done in coming to conclusions. Another stressed that multidisciplinary must include different races and ethnic groups, not just various disciplines of privileged whites. Another: it all depends on which disciplines ...

Researchers' conclusion: An interdisciplinary (collaborative) approach is essential and, inasmuch as possible, should involve lay persons of various ethnic groups.

With regard to *research* that might involve NRTs:

4. **Do you agree that, by and large, the REB process gets to review the ethics of all *institution-based research* proposals?**

   Replies: Yes: 66% No: 11% Don't know: 23%

   If not: What type of institutional research are REBs failing to review?

   Nearly all of those who replied "Don't know" are not in institutions involved in research using human subjects. Of those who said "No," the greatest concern was with innovative therapy (which they believe should always go through REBs). Some student projects may not be

reviewed. There is no disclosure of REB decisions; some feel there should be. Only a small proportion of REB members have specific training in bioethics.

Researchers' conclusion: Innovative therapy appears to be a major concern, i.e., where the ethics review loophole is greatest.

5. **Do you agree that, when it comes to *research that is intra-mural to industry* (though possibly leading to an NRT), existing ethics committees are useless?**

Most respondents agree that the REBs are of no use in affecting intra-mural research, though some believed that adequate control was exerted when industrial research is "driven to access the ordinary system." One believed ethics committees should not play the role of ethics police. Another saw the role of the Royal Commission as extending beyond universities and requiring industry involved in NRT research to establish links with appropriate REBs extra-mural to their operations. Another pointed out that to get the first REB review as a human experimental trial is quite late in the life of a protocol.

If so:

5.1 **How might industry be held accountable for the ethical implications of its research?**

Only by legislation, financial penalty, or withholding of HPB approval. The U.S. federal regulation of industrial research should be examined, as in the silicon breast implant issue. It might help to distinguish macro-ethical from micro-ethical, suggested one. Generally, there was a wish to see ethics review of this level of research but no concrete idea about how it might be done. A first step would be to name instances "where unchallenged research has resulted in projects which have been quite unethical." Problem: make it difficult to do a certain type of research in Canada, and the company will just decide to do it elsewhere, in another country.

5.2 **How might a royal commission approach the problem?**

Acting proactively, a royal commission might list areas where industry-based research would be ethically problematic and "require" or "urge" that ethical review take place before initiation of protocols. Other measures: insistence on full disclosure of data; ethical review from within industry but involving independent outsiders representing certain societal interests; stronger legal protection of the consumer (in the thalidomide instance, parents had to finance their own legal battles to obtain [inadequate] settlements, years later). Serious attention should be paid to pushing back the ethics review process to the early stages of research, before it reaches human subject experimentation. Once practices get to the point of human use, government licensure could be considered. To be effective, most advise that

controls would have to be legislated (though some still prefer guidelines).

Researchers' conclusion: Guidelines for ethical review of industry-based research should be developed, with monitoring through a body such as NCBHR.

6. **The *animal husbandry industry* would seem to be an area where gamete, embryo, and fetal research is carried out, which later becomes transferable to human practice or research. Do you perceive this as a special problem?**

   Replies: No, not a problem: 60% Yes, a problem: 40%

   If so: Do you have additional advice, as regards ethics review and NRTs?

   Most of those who perceive that there is a problem (e.g., could current animal cloning practices be done on humans?) would be content to leave ethics review to the point of entry into the arena of human use. A few respondents see this as a big problem but are not sure how it may be addressed; they suggest that perhaps the first step would be to list the areas that should not be researched — e.g., fusion of human and animal gametes.

Researchers' conclusion: Adequate review of research at the transfer point of animal to human should be the first area on which to focus attention.

7. **When industry seeks the *research collaboration of institution-based clinical researchers*, are the REBs adequate to protect the interests of the five (now eight) classes identified?**

   Replies: Yes, adequate: 66% No, inadequate: 26%
   Can't say: 8%

   If not adequate: Do you perceive a role for IECs or REBs in this question?

   Several respondents see such a power imbalance between researchers and industry as to flaw the integrity of researchers — integrity could perhaps come from using independently funded regional or national advisory bodies, perhaps jointly with representatives from industry. Committees, at this interface, should have legal input, preferably from lawyers with a feminist perspective. Several see inadequate representation of the interests of society-at-large, compromised as it may be by the career interests of researchers and practitioners. IECs and REBs need strengthening, perhaps by regional ethics advisory centres.

Researchers' conclusion: Involvement of national or regional ethics advisory bodies in monitoring industry-institution research collaboration would enhance protection of the interests of the eight classes identified.

8. **Do you agree that certain research projects that might involve NRTs may be carried out by *physicians and other practitioners in the private sector*, outside government-supported institutions, and that such a process would not receive ethics review at present?**

   If so:

   8.1 **How do you think ethics reviews in these areas might be accomplished?**

   8.2 **Could extended mandates for IECs and REBs help to bridge the gap?**

   Replies: Most respondents saw this as a "loophole" in ethics review. One claimed that a responsible industrial firm would have no problem, as it would require REB approval from researchers — but this observation does not cover those researchers who do not have affiliation with institutions that have REBs (i.e., most family physicians). Others see the lead coming from (a) provincial colleges, (b) district health councils, or (c) to-be-created provincial ethics advisory centres — to establish or carry out functions of REBs or IECs for both industry and non-institutional researchers or practitioners.

   There would be a time problem in obtaining commitment from REB members to do non-institutional reviews; most would not want to spend the time unless the contract with an outside agency made it very worthwhile. There would be important questions of remuneration, liability, and accountability in extending the existent IEC or REB mandates.

   Provincial colleges already have standing ethics committees. Could these, with some restructuring, also act to review non-institutional research in some provinces? Ontario and Quebec would need several such non-institutional REBs, for example.

   There was no specific question in the distributed draft addressing the possible role for private REB/IEC initiatives in the non-institutional sector, such as has developed in the United States.[20] It is one way to go, though some respondents are very wary of this because of the profit motive built into such private ethics review enterprises.

Researchers' conclusion: Although a reasonable solution might be to make such a review the responsibility of the provincial college of physicians and surgeons, this fails to capture researchers who are not physicians, such as nurses in the community of social workers. Thus a provincial ethics review board might be more suitable.

With regard to *innovative therapy or practice* (in relation to possible NRTs):

9. **In addition to research and new clinical practices, is there a valid area of clinical activity where MDs traditionally have been free to act according to conscience in the interest of a particular patient — subject only to their code of ethics, the college disciplinary process, and hospital regulations?**

Replies: A large majority of respondents (73%) agree there is such an area, the rest (27%) do not. One (who has studied the question) believes it is always research. Another is very wary of the word "conscience" in this sort of context. Several have concerns about policing "innovation," as it impedes new knowledge.

10. **Do you believe that *innovative therapy* (which might involve an NRT) should have formal ethics review by REBs or IECs?**

Replies: Yes: 87% No: 13%

One felt that REBs can stifle innovative ideas (citing an IVF program with so many locally imposed constraints that it could not operate). Most (87%) felt that innovative therapy for NRTs must go through the same process as research.

If so:

10.1 **Are you concerned about restricting physicians from carrying out innovative therapies in unusual situations when acting on serendipitous hunches for individual patients, etc.?** [Louise Brown's conception was in this category, supposedly.]

Replies: Yes: 37% No: 63%

The majority believe that possible restriction of physicians' freedom to act is outweighed by the obligation to consult others via recognized IEC or REB routes. The motivation is not to establish "policing," but "ethical accountability." As urgent immediate medical need is unlikely in the NRT field, time can be taken to review and reflect on the ethics implications of innovative therapy.

10.2 **How would you see such a regulation being imposed on physicians?**

Replies: Opinions differed. Some see it as a function of the local college; others via a regional or provincial ethics advisory board; others through amendment to professional codes; and still others through MAC policies to require innovative therapy (in relation to NRTs) to be reviewed by local REBs. "Imposed" is perceived to be the wrong word; rather, it should be seen as self-regulation to maintain professional accountability, and the college should decide how to do it.

Researchers' conclusion: Since many innovations are unlikely to be captured by a clinical research review (REB), guidelines in professional codes of ethics, enforced by the appropriate professional bodies, are

critically important. Leaving such review to an individual department is not appropriate.

With regard to *new clinical practices and/or devices* (such as might relate to NRTs):

11. **Are there *significant gaps in ethical review by IECs and NPTCs* when new practices or devices are introduced clinically?**

    Replies: Varied. Yes: 57% Not sure: 43%

    If so:

    11.1 **Is this mainly due to the limitation of the usual mandate for IECs (clinical ethics crises, review of hospital policies, and bioethics education)?**

    11.2 **If the IEC mandate is formally extended to conduct ethics review on all new practices and devices, will this adversely affect its current role as a responsive consultation body for crises in clinical ethics?**

    11.3 **Or, is the problem that federal regulations with respect to new devices are totally inadequate, unlike those for new pharmaceuticals?**

    There was no clear message from the replies to these three questions except that an extended mandate for IECs would have a detrimental effect on their ability to conduct ethics analysis on cases, which was perceived to be their main purpose.

With regard to *new concepts* for handling the ethics issues of NRTs:

12. **Do you think it helpful to insist that there be no difference between an innovative practice and clinical research?**

    Replies: Yes: 50% No, it is not helpful: 50%

    The question was not well worded. However, from the text of the replies it may be concluded that many people see a difference between these two activities, but a large majority believe there should be no difference in the accountability of the physician to an IEC or REB for ethics review.

13. **What do you think of the idea that *all NRT clinical practice and research be handled by a three-tier process:*** (a) departmental review (of a multidisciplinary type), (b) institutional review (multi-disciplinary, equivalent to the NPTC, IEC, and REB processes), and (c) federal or national? [Note: the possible option of a provincial or regional third level was not included in the question. It emerged later. Also, it was not made clear in the question whether the third level was conceived as being regulatory or purely advisory.]

Replies: Varied. Many (55%) thought the three-tier idea was excellent, good, or reasonable. A minority (27%) thought it too cumbersome, one vehemently so. Several more approved the first two levels, but were indecisive about the third. Several thought the first level was not necessary, but approved the other two. Other comments included the following. The process of triple-level review might be expedited by advance "letters of intent" and selected "facilitated review," etc. Communication between a central (or regional) body and the IECs and REBs would be an important aspect (various respondents stressed this aspect). The role and responsibility of the third-level (national or regional) body would have to be well defined; without that definition it is difficult to be specific. It is the best way of protecting the interests of all eight groups (previously identified). It is essential to maintain full legal safeguards for patient autonomy and privacy, and meaningful representation for minority group rights.

If so:

13.1 **What would you recommend for the structure, method of appointment, accountability, composition, and method of communication (with local levels) of such a body?**

13.2 **What would be the drawbacks and problems with such a proposal?**

Replies: Costly, time-consuming, time lag for approval would be much increased (for NRTs this might be beneficial). Not necessary. Politicized appointments to the national level inevitable. National body might pressure institutions to act against their own policies.

Researchers' conclusion: Pursuit of a three-tier system is urged. The highest level (the third) could be split, with the provincial (regional) level acting in an advisory, educational, and consultative role, and the national level acting in a coordinative, inter-communicative, and reflective capacity. Neither component of the third tier would be seen as regulatory. E-mail could be used extensively. A high degree of trust and respect will be necessary to make this voluntary linkage workable.

14. **What other strategies would you offer to supplement the present function of IECs, NPTCs, and REBs for the ethics issues of NRTs?**

An educational process for top-level decision makers (suggested by several respondents). Seminars on philosophical issues related to genetics and NRTs for those serving in IECs and REBs (suggested by several respondents). The question of licensure (see the new U.K. Commission) was raised.

Researchers' conclusion: Education and inter-professional and public discussion are critical.

With regard to the need for "downstream" monitoring for integrity of ethical undertakings:

15. **Do you believe that research involving human subjects should be *monitored for the performance of ethical undertakings*?**

    Replies: Yes: 96%

    The form that monitoring should take was varied, as one would expect. Most thought it should involve more than a periodic report by researchers on their own projects. Several stressed it must be at the divisional or departmental level.

    One should encourage acceptance of an ethos of "ethical uncertainty" in human research. Another expressed the idea of "quality assurance in research" as the underlying philosophy for monitoring. Indeed, *the term "quality assurance" should be used instead of "monitoring"*; emphasize it is establishment of accountability and protection of subjects against the unexpected, not the search for blameworthiness, that underlies the thrust toward downstream monitoring. Several suggested that the institutional quality assurance committee should assume this responsibility jointly with the IEC or REB.

    Input from researchers for monitoring their own projects might be a good approach. The experience of subjects for NRTs must be taken into account. Other strategies: reviewing records, interviewing subjects, interviewing and observing practitioners or researchers randomly (after prior discussion).

Researchers' conclusion: The concept of quality assurance in research ethics should be promoted as the highest priority.

Appendix

Ethical issues relating to NRTs, listed by the group in society whose interests are principally affected:

1. The ethics interests of **society in general**, and of certain subsets in particular (ethnocultural groups, women's groups, minority groups, disabled groups, groups at increased genetic risk, etc.):

   Critical questions that have to be addressed and continuously kept in mind include:

   (a) Is technology accelerating out of societal control? If so, what can be done, bearing in mind academic freedom and the international nature of research and practice?

   (b) Is infertility really a problem if viewed in the light of excess global population? It can be argued that global overpopulation should

outweigh the problem of infertility at the individual level among Canadians.

(c) If infertility is seen as a social problem, should over-production of children by some couples also be seen as a social problem?

(d) Are NRTs already changing our society's attitudes toward seeing babies as "commodities" rather than "blessings" or "gifts"? If so, can and should this be stopped?

(e) Does every person, individually, have a positive right to reproduce, or is it a privilege subject to the vagaries of the lottery of life?

(f) Should every woman (be she normally fertile or apparently infertile) who wishes to establish herself as a single-parent family have society's full support in fulfilling her wish? If not, why not?

(g) Should lesbian couples have the support of society and accessibility to NRTs if they wish to have children? If not, why not?

(h) Will *surrogate gestation* for direct payment lead to victimization of the poor? Does this possible societal burden outweigh any benefit? (Though surrogate gestation is not strictly speaking an NRT, it is a new societal problem involving a new way of looking at reproduction and so is included here.)

(i) Is infertility always an "illness"? Can an ethically valid distinction be made between pathogenic (due to a disease) and non-pathogenic (due to developmental or genetic aberration) forms of infertility?

(j) Does infertility justify methods other than those designed to restore fertility through normal sexual intercourse (i.e., preserving the intimate relationship of sexual intercourse to conception)?

(k) Is it a widely accepted Canadian value to place great emphasis on vertical transfer of one's own genes when apparently infertile rather than looking to adoption?

(l) Prenatal diagnosis of genetic abnormality carries a twofold burden — a drive toward abortion without considering the option of caring for a baby with a disability, and a drive in society to disparage the disabled in general. Does the benefit always outweigh these burdens?

(m) For couples or single women, does "freedom to choose" include the right to choose the sex of one's offspring?

2. The interests of **government**, in both legislation and administration:

(a) How should ethical decisions be made in a sophisticated pluralistic society, which no longer recognizes traditional

(religious or political) ethical authority? This question is not confined to NRTs, of course, but it is only possible to decide logically on NRTs in the "context of the values and opinions held by people in Canada, and with full participation."[21] But how are such values and opinions to be determined?

(b) As most NRTs involve something being done to a woman, how can the unique interests of women be safeguarded from subtle exploitation (usually by male planners) in the name of procreation?

(c) Is there a need for legislation and regulation concerning sperm banks, sperm donor screening, and the maintenance of sperm donor information for offspring (while strictly maintaining the anonymity of donors)?

(d) Should the judiciary have the benefit of legislation/regulation to help in defining judicial intervention during gestation (when mothers are accused of injuring their fetuses)? How does one rationalize overriding the autonomy of non-consenting mothers for protection of their fetuses?

(e) Should gametic and pre-embryo research in animals be regulated? It often leads directly to attempts to apply new findings to human problems.

(f) Will there not come a time when leaving important questions such as those raised by research in NRTs (and by all human experimentation) under the control of "guidelines" will be insufficient? How does one decide when the time has come to enact controlling legislation (with all the cumbersome properties of law) and its accompanying regulations? One way was to have an excellent body such as the Law Reform Commission of Canada; alas! it has now gone.

(g) In view of the difficulty of law-making concerning the ethical conduct of research, should legislation be enacted for the establishment, composition, and function of both IECs and REBs (as has been found necessary in the United States), and the regulation of research and ethical clinical problems left to them?

3. The interests of **religious groups**:

(a) Religion lays down rules on ethical matters to guide its believers. The Christian religion can claim the adherence and respect of at least 40% of Canadians. How are the views of this large minority to be respected in publicly financed practices, such as NRTs, other than through denominational hospitals and clinics?

(b) While recognizing that views of adherents of one denomination may not be imposed on others who do not share them, does this

mean that those who wish to make common cause on a particular issue, based on faith perspectives, must be denied recognition?

4. The interests of **children-to-be**, those who result from NRTs:

   (a) How can the assessing the suitability of would-be parent(s) for NRTs serve the interests of the child-to-be when such assessments of suitability are not applied to the normally fertile population?

   (b) What measures, if any, may be introduced to protect the rights and welfare of children-to-be who result from NRTs? How needed is this protection? Who imposes regulation of access in the guise of this perceived need for protection?

   (c) Should there be a confidential record kept of the identity of the sperm donors used for women receiving AID for purposes other than donor identification? If so, how can the rights of the sperm donor be protected?

5. The interests of **prospective or would-be parents, or a single mother**:

   Approaching the NRTs from this viewpoint, pertinent ethical questions are:

   (a) Does every person, individually, have a positive right to reproduce?

   (b) If all have a positive right to reproduce, what are the associated societal responsibilities, and how are they set? Are they different for those who need NRTs than for those who do not? If so, why?

   (c) Are those wishing to use NRTs sufficiently informed of all their choice options by the present "gatekeepers"? Is the relationship one of full participation in which clients can preserve their autonomy? Should counsellors other than health professionals also always be involved?

   (d) By what ethical authority might society deny (usually to a couple) the right to sex preselection (usually for a male child) by a method such as differential sperm sorting, if that is what is fervently wished by both parents? (The issue of sex selection is framed this way to distinguish it from the abortion issue.)

6. The interests of NRT **researchers and practitioners**:

   Contemporary medical science in other fields has repeatedly shown that good or bad outcomes at the level of human application could not have been foreseen when the research leading to them was in its basic stages. Basic scientists act on the presumption that all scientific knowledge is good (only its application may raise ethical problems).

However, with accelerating bioscience technology, many in society are apprehensive of the ultimate social cost of scientific applications when basic science is so unplanned. On the other hand, the historical record of authoritarian control over basic science research has been both lamentable and unethical. For the basic scientist this dilemma poses such questions as:

(a) what can justify prohibiting research at the level of human ovum and sperm, when such questions as sperm penetration and the triggering of blastula formation may ultimately give great insight to problems of infertility?

(b) Research on the early steps of the gene expression triggered by fertilization might lead to an understanding of the organ differentiation process, which knowledge might later lead to great benefit. What societal ethical authority should have power to inhibit such possible benefit to humankind?

Clinical researchers recognize that applied new knowledge creates ethical dilemmas, but would argue that, even if the early application of new knowledge seems crude and inadequate, in the end technology transfer from laboratory to clinic nearly always provides social benefit. One could cite examples from the history of medicine to support or refute this viewpoint, but because most of the examples pertain to new knowledge directed at changing the course of serious human disease, they do not raise such important social issues as do the NRTs. Clinical researchers would obviously dissociate themselves from the travesty of human eugenics research (1890-1944) and the research that led to weapons of mass destruction.

Clinical practitioners ask similar questions but framed in the more immediate language of direct benefit, such as:

(c) All agree that prevention of infertility (major cause: sexually transmitted diseases [STDs]) is more urgent and important than its management. But do those who have elected to serve the infertile ask themselves, as clinical practitioners, what obligations they have toward STD prevention?

(d) Even though the success rates for a given NRT practice may be low, this has been the pattern with all innovative therapies. The plea of the clinical practitioner would likely be: "Recognize it as research; fund it adequately, and anticipate that it will become increasingly efficient."

(e) Practitioners are very much aware of the dilemmas of live multi-fetal reduction in both IVF and GIFT and look for both social guidance and progress in research in trying to resolve them.

7. The role of the **judiciary**: There are legitimate questions about the role and function of the judicial system in many ethical issues

surrounding NRTs. These are also mentioned in the above section on government legislation. In the absence of legislation, judges must decide issues by making common law. Which is the better way to go for the type of issues raised by NRTs? It seems that a body equivalent to the Law Reform Commission of Canada is needed to react to this aspect of NRTs.

8. The implications for the **health care system**: These are substantial and raise a number of questions, among which are the following:

   (a) If would-be parent(s) meet certain standards of parental responsibility, should society fund the exercise of their positive rights to procreate, regardless of marital status, sexual orientation, or expense?

   (b) Who decides on access to NRTs? By what societal standards do such persons exercise their gatekeeper role?

   (c) Can there be justice in a system that funds simple measures to correct infertility (treatment of salpingitis, etc.), but fails to fund more costly methods such as AID or IVF?

Abbreviations

AID	artificial insemination — donor
AIH	artificial insemination — husband
CBS	Canadian Bioethics Society (Ottawa)
CEO	chief executive officer (generic)
CFPC	College of Family Physicians of Canada (Toronto)
CHA	Canadian Hospital Association (Ottawa)
CMA	Canadian Medical Association (Ottawa)
CNA	Canadian Nursing Association (Ottawa)
DH&W	Department of National Health & Welfare (Federal Govt., Ottawa)
DHHS	Department of Health & Human Services (Washington, United States)
GIFT	gamete intrafallopian transfer
HPB	Health Protection Branch (DH&W, Ottawa)
IEC	Institutional Ethics Committee (generic, United States & Canada)
IRB	Institutional Review Board (term for REB in United States)
IVF	*in vitro* fertilization
LRCC	Law Reform Commission (Canada — now abolished)
MAC	Medical Advisory Committee (generic)
MRC	Medical Research Council (Ottawa)
NCBHR	National Council on Bioethics in Human Research (Ottawa)
NHRDP	National Health Research and Development Program (Ottawa)
NIH	National Institutes of Health (Bethesda, MD, United States)
NPTC	New Program & Technologies Committee (generic)
NRTs	new reproductive technologies
OPRR	Office for Protection from Research Risks (DHHS, NIH, United States)

RCNRT	Royal Commission on New Reproductive Technologies
RCPSC	Royal College of Physicians and Surgeons of Canada (Ottawa)
RCTs	randomized controlled trials
REB	Research Ethics Board (generic, Canada)
STD	sexually transmitted disease

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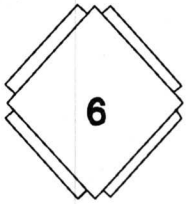

Economic, Ethical, and Population Aspects of New Reproductive Technologies in Developing Countries: Implications for Canada

Pran Manga

Executive Summary

This paper reviews the ethical, economic, and population aspects of new reproductive technologies (NRTs) in developing countries and discusses their implications for Canada. As a multicultural country, it is important for Canada to recognize the importance of the cultural values and dimensions of health and the need to develop culturally sensitive and responsive health care services.

The concern of governments of developing countries and of international funding agencies has been to curb fertility rates. A review of programs aimed at reducing population growth suggests a number of important shortcomings:

- the improper use of contraceptives with scant attention paid to the health needs of women;
- violations of ethical norms in clinical trials; and
- the use of coercion to participate in sterilization projects.

This paper was completed for the Royal Commission on New Reproductive Technologies in April 1992.

The paper suggests that while infertility has not been a priority for governments in the developing world, it does exist in those countries. The causes of infertility vary between developed countries and developing countries.

Biomedical technologies are easily transferable internationally, and even very poor countries have sufficient numbers of patients with the ability to pay and the human resources expertise to absorb these technologies. *In vitro* fertilization (IVF) clinics are largely offered by the private sector in those countries, and there is a potential for much greater investment in such technology.

The report also discusses sex selection, the commercialization of fetal tissue, and surrogate motherhood. The movement of human tissue across national boundaries may be largely unregulated. As a member of all the United Nations organizations concerned with health, and as signatory to international conventions, agreements, and covenants, Canada has the opportunity to raise concerns about the following:

- commercialization of reproductive tissue and material;
- efforts to liberalize international adoption policies and procedures;
- enforcement of and adherence to the human rights of women, children, and minorities; and
- influencing the policies and priorities of international organizations.

Canadian policies must be determined by and respond to Canadian experience and realities. There are, however, universally common themes that transcend national and political boundaries that can be observed while remaining sensitive to differences due to poverty, the status of women, and the lack of reproductive freedom in developing countries.

Canada should play a leading role in the development of ethical guidelines and regulations governing reproductive technologies and should continue to be a supporter of human rights and an opponent of discrimination against women in developing countries. Canada must first ensure that Canadian practices are beyond reproach under intense international scrutiny.

Introduction

This paper provides an overview of the ethical, economic, and population aspects of new reproductive technologies (NRTs) in developing countries and their implications for Canada.

Although infertility is a universal concern, its cultural and social significance is generally thought to be more serious in the societies of many developing countries than in those of advanced industrialized countries. In the case of the former, governments have been largely concerned with

reducing their fertility rates and, until now, have paid scant attention to the ethical, legal, social, and economic implications of infertility-related NRTs.

Population control has become an increasingly international responsibility because of the known or presumed economic, political, and ecological consequences of rapid population growth in developing countries. The United Nations Fund for Population Activities, and many other authorities, have called for a major increase in the financing of developing countries' fertility reduction efforts through bilateral and multilateral aid, including the research into and development of new contraceptives (Sadik 1989a, 1989b, 1991; Djerassi 1981; Mardlen et al. 1982; Easterlin and Crimmins 1985). In addition to these concerns about population growth, many of the concerns about NRTs are also likely to become global in scope and importance. There is increasing recognition of the need for international collaboration and action to respond to some of the current and emerging problems of reproductive health.

The first section of this report presents the relevance of the subject to the Royal Commission on New Reproductive Technologies. The next section offers a brief commentary on the need for a multicultural and cross-cultural perspective on biomedical ethics. Controlling the growth of population in developing countries is the subject of the next section, which is followed by an overview of NRTs in these countries. The difficult issues of discriminatory use of prenatal diagnosis (PND) and sex selection in developing countries are briefly presented. The next section offers an overview of the controversial issues surrounding the commercialization of gametes, embryos, fetuses, children, and women in developing countries. Finally, the implications of the above-noted developments and concerns for Canada are presented.

Relevance of the Subject to the Royal Commission on New Reproductive Technologies

Canada has a high ratio of immigrants to total population and is unquestionably one of the most multicultural countries in the world. Its official espousal of multiculturalism also distinguishes it from most other countries. There is increasing recognition of the importance of the cultural values and dimensions of health, and of the need to develop culturally sensitive and responsive health care services. This is very apparent and important in the area of reproductive health (Akhter 1990; Cebotarev 1988; Hartmann 1987; Mahadevan et al. 1986; Nichter 1989b).

Canada is a member of the major United Nations organizations concerned with health, such as the World Health Organization (WHO), United Nations Children's Fund, United Nations Fund for Population Activities, and the International Labour Organization. It is also an active member of the World Bank — one of the principal international

organizations promoting policies and related efforts to control population growth in developing countries.

In addition, Canada is a signatory to international conventions, agreements, and covenants relating to the human rights of women and children, adoption, international trade and commerce dealing with patents, and intellectual property and products. Thus, Canada has the opportunity to raise concerns about the commercialization of reproductive tissue and material; to renew efforts to liberalize international adoption policies and procedures; to seek better enforcement and adherence to the human rights of women, children, and minorities; and generally to influence the policies and priorities of international organizations.

Biomedical technologies — whether embodied in devices, equipment, pharmaceuticals, or biologicals; or manifested as procedures and technical skills — are easily transferable internationally: the health care systems of even very poor countries have sufficient numbers of patients with the ability to pay and the human resources expertise with which to absorb the newest medical technologies. The question of appropriate technology transfer from developed to developing countries, so prominent in agriculture and industry, is persistently and generally ignored in the area of health care (Banta 1986; Bonair et al. 1989; MacCormack 1989; Piachaud 1979; Melrose 1982; Manga 1991).

In addition, women's concerns about the ethical, social, and health implications of NRTs are no longer confined to local or parochial experiences or impacts. The improper use or abuse of contraceptives, violations of ethical norms in clinical trials, and involuntary sterilization in projects involving Canadian funds are issues that emphasize the globalization of reproductive technology, a trend matched by the internationalization and effective networking of the feminist movement (Estrada-Claudio 1990; Mies 1987, 1989; Raymond 1989a; Spallone 1988; Women's Health Interaction 1990; Tudiver 1986). A growing and increasingly organized international network of women's (or feminist) groups has sensitized medical and government authorities about the implications of NRTs in other countries, and this is certainly true of Canada as well (Women's Health Interaction 1990; McDonnell 1986; Tudiver 1986).

Finally, a comparison and monitoring of national and international policies and practices for biomedical research in reproductive health will enhance Canada's understanding of the extent of the diffusion of NRTs in the world's developing countries.

No doubt there are considerable differences in the ethical norms and codes governing clinical trials and biomedical research between industrialized and developing countries. There have been many allegations of unethical clinical trials, research, and use of reproductive technologies in developing countries. Canada has begun to respond to these concerns and will have to do more in the future (Medical Research Council of Canada 1988).

Biomedical Ethics: A Multicultural and Cross-Cultural Perspective

The ethical, economic, and population implications of NRTs in developing countries constitute an immensely complex and largely unresearched subject (Nichter 1989a). It should be understood that reference to the "Third World" or "less developed" or "developing" countries as a singularity is a gross generalization, as there is a bewildering heterogeneity in the experience and sociocultural realities pertinent to both fertility reduction and infertility-related technologies and policies in these regions of the world (Hartmann 1987; Kaur 1989; Nichter 1989c).

Biomedical ethics is generally more secular, pluralistic, and individualistic in Western societies than in developing countries, a broad generalization that is probably more applicable to contraceptive and assisted reproductive technologies than to other health care technologies. The medical profession in most of these countries appears less well informed about ethical precepts or principles by Canadian standards. This is reflected in their practice (Kaur 1991), in the relatively poorer articulation and enforcement of professional codes of ethics and health law, and in the lack of studies, colloquia, conferences, and courses on this topic in medical and nursing curricula (Lingam 1989). The application and relevance of the principles of biomedical ethics vis-à-vis NRTs in less industrial countries are also determined by the lack, if not the absence, of patients' rights, the generally much lower status accorded to women, and the myriad of sociocultural taboos and restrictions associated with women's sexual and reproductive health and autonomy.

As far as one can gauge from the literature and from observation of clinical practice and research, the principles of biomedical ethics that do matter in the "Third World" are not much different from those in Western societies. These principles include informed consent, autonomy or self-determination, justice, confidentiality, and beneficence (Angell 1988; Barry 1988). However, the interpretation, understanding, and importance attached to these principles vary. With regard to reproductive health, the principles of autonomy or self-determination and informed consent have become the most important in Western societies (Hamnett et al. 1984; Barry 1988; Walters 1987).

In most developing countries, paternalistic choices made by husbands, family, or doctors are much more common. Indeed, there is a widespread belief among physicians in countries like India that it is not possible to get "informed consent" because of the illiteracy and ignorance of their patients. Consent is often regarded as implicit in the fact that patients have sought the expertise of the physician (Kaur 1991; Nichter 1989b).

Are ethical standards relative? Should situation ethics dictate what principles are accepted and how they are applied? To what extent can Canadians insist that the principles and procedures governing clinical

research in Canada be applied to research to be conducted in developing countries? It would be inconsistent for an ostensibly pluralistic society to claim that there are universally absolute ethical principles: Western countries should be sensitive to and mindful of the charge of "ethical imperialism." However, this does not mean that there are no common principles on which we may rely. Fortunately there are several international agreements and declarations that are helpful in this respect, including the Nuremberg Code and the World Medical Association Declaration of Helsinki. Both these codes require "voluntary consent" (autonomy) and "informed consent." There are other international covenants and conventions that guide the design and execution of clinical research and the access to and use of medical services (Cook 1990; Cook and Haws 1986). These include the "Convention on the Elimination of All Forms of Discrimination Against Women," the "International Covenant on Economic, Social and Cultural Rights," and the "International Covenant on Civil and Political Rights." Beyond these, and quite pertinently, are the WHO guidelines on clinical trials and the codes of international professional bodies.

One reason for not entirely accepting the view that ethical values in clinical research or trials are relative is that it would justify certain research in developing countries that would not be permissible (in fact, would be deemed unethical) in Western countries. Obviously, the social, psychological, and cultural sensitivities of these societies have to be respected (Levine 1991). To this end, mutually acceptable ethical standards and research procedures must be developed, and this will require the collaboration of many interested national and international parties (Angell 1988; Fathalla 1988; Kunstadter 1980; Engelhardt and Rie 1988; Barry 1988; Medical Research Council of Canada 1988).

Controlling Population Growth

There is abundant empirical evidence that rapid, or a high rate of, population growth contributes to the worsening socioeconomic prospects for many developing countries, and impedes the development and improvement of the health, educational, nutritional, and social standards of large sections of these societies (Manga 1991). There are several theories about population and demographic transitions that attempt to explain how countries might best reduce their fertility rates. Developing countries exhibit striking successes and disappointing failures, and there is much to learn from a careful analysis and evaluation of the successful and failed attempts to reduce fertility rates over the past 40 years. A review of family planning policies and experience suggests the following principal criticisms of existing attempts at reducing fertility rates:

1. There is evidence of coercion in family planning programs in many developing countries, especially in promoting "terminal methods," that is, sterilization of women and men. Laparoscopic sterilization is sometimes carried out by inadequately trained physicians, leading to unnecessary deaths (Akhter 1987; Hartmann 1987). The use of economic incentives or disincentives and force is especially resented. While some might excuse coercion in a good cause, the impact of such coercion has been a setback to family planning efforts in countries like India (Kamal 1987; Parsons 1988; McDonnell 1986; Hartmann 1987).
2. The burden of family planning programs has fallen almost exclusively on women. Vasectomies are safer and cheaper than tubectomies, yet the majority of sterilizations are carried out on women (Hartmann 1987; Nichter 1989a). Contraceptive research and development (and use) overwhelmingly focus on women. This also means that it is mainly women who are subjects of clinical tests or trials.
3. An important related criticism concerns the unethical nature of many clinical trials. Such trials of contraceptives, such as Depo-Provera®, Norplant (both approved by the WHO), hormonal or estrogen-progesterone combination drugs, and intrauterine devices, have drawn the ire of many feminist groups (McDonnell 1986; Balasubrahmanyan 1986; Akhter 1987, 1988). Complaints about these include lack of information about risks to health, sometimes even outright lies; targeting the poor and illiterate (Walsh 1992); high-pressure tactics bordering on compulsion or force; collusion between local government officials and physicians, and multinational firms or international organizations; the use of food, clothing, or other economic incentives to elicit participation in the clinical trials; and compulsion to remain in the trial. Other criticisms include lack of confidentiality and poor monitoring of the health impacts of the drug or device being tested, in contrast to an obsessive and exclusive concern for its efficacy (Gomes dos Reis 1990; Marcelis and Shiva 1986; Duggan 1986).
4. A single-minded concern for curbing fertility rates may contribute to not meeting the health care needs of women. There is often little or no health care for many women using contraceptives (Patel 1989).
5. It is alleged that some contraceptives that are banned in the Western countries where they originate, for example, Depo-Provera®, are freely or illegally used in developing countries, and that others that are used with restrictions and precautions in Western societies have these restrictions waived or ignored in developing countries. Such differences in practice are often viewed not only as being inequitable, but also as *prima facie* discrimination against these countries (McDonnell 1986; Kaur 1989).
6. There are further criticisms of family planning programs in developing countries. The "social marketing" of contraceptives is criticized as

> being more concerned with the profitability and market share of pharmaceutical firms (mostly multinationals) than with meeting the real needs of men and women wishing to control the size of their families. Official family planning policies and programs have tended to discourage and denigrate traditional methods of family planning, sources of information, barrier contraceptives, child spacing strategies, and breast feeding (Hartmann 1987).

Abortion is now legal or more readily available in about two-thirds of developing countries, but remains strictly limited or unavailable in many Catholic and Islamic countries (Dixon-Mueller 1990). Even in countries where abortion is legal, access to services can be a serious problem (Tribe 1990). Millions of illegally induced abortions have taken a heavy toll on the lives and health of women.

It is arguable whether United Nations conventions and covenants about the human and reproductive rights of women also cover or include the right to abortion. The subject is notoriously difficult and intensely politicized in developing countries and the West (including the United States, which is the largest contributor to international organizations promoting a reduction in fertility rates in developing countries). While the abortion pill RU486 could make a significant contribution to the government's effort to reduce fertility rates, so far only a few countries (notably China) have opted to use it. There is a strong antipathy to RU486 in the United States and, to a lesser but unknown extent, in other Western countries. Beginning about the mid-1980s, the United States began to deny aid to any organization that performs abortion, counsels women on abortion, or lobbies for the liberalization of abortion laws and abortion rights even if these activities are also supported by non-U.S. funds (Horgan 1991). This policy has led to a denial or reduction in U.S. funds for family planning for many organizations, and an increase in support for anti-abortion and even anti-contraception groups. Consequently, it is feared that unintended pregnancies and illegal abortions are increasing:

> Abortion-related deaths are rising throughout Asia (China excepted) and Africa. Such deaths now account for 31 percent of all recorded maternal deaths in Bangladesh and 25 percent in Ethiopia. In six Latin American countries ... unsafe abortion is already the leading killer of women in their twenties and thirties and the second leading cause in another six. The World Health Organization has estimated that some 200 000 women die every year of complications from improper abortions. (Horgan 1991, 18)

What is clear is that there is much room for improvement in the design, delivery, and implementation of family planning programs. It is equally clear that while reproductive choice in most developing countries is problematic, significant improvements in reproductive freedom are possible even within the overall policy objective of reducing fertility rates.

The degree of coercion needed in family planning programs is a controversial matter and an endless source of argument over the ethics of controlling a population's rate of growth. Implicit in much of the literature critical of existing policies is the view that social and economic policies that set justifiable limits to procreative decisions could go far to reduce population growth without coercive interventions in individual reproductive choice. However, would coercion be justified if such policies failed to reduce population growth? It can be argued that reckless procreation itself can be coercive when the needs of children cannot be met by society through either increasing or reallocating resources, and that coercion to prevent such desperate and irreparable destitution is justified (O'Neill 1986).

New Reproductive Technologies in Developing Countries

While good epidemiological data and health statistics on infertility are not available for developing countries, there is an impression by some that the incidence and prevalence of infertility are increasing (Poston et al. 1983). Such data, though unsatisfactory, are more common in developed countries. It is therefore difficult to say whether infertility rates are greater in the developed or developing countries. As in many Western countries, there are different concepts and definitions of infertility, thus making comparisons and analyses of trends more difficult.

The causes of infertility and the risk factors associated with it are likely to vary between developing and Western countries, and also within developing countries themselves. Given the wide array of causes and risk factors, it may well be that the infertility rates of at least some developing countries are higher than those in Western countries.

In the West, some of the permanent childlessness may be voluntary. In developing countries, virtually all of the permanent childlessness is involuntary (Poston et al. 1983). The social and cultural pressure to bear children is intense and relentless and is widely thought to be considerably greater than in the West (Nichter 1989a). The infertile are frequently stigmatized, and separation, divorce, wife-beating, and husbands taking a second wife are not uncommon consequences of female infertility. Moreover, childlessness is commonly attributed to female infertility (Bumiller 1990). With the breakdown of the extended family, one traditional solution of "child donation," under which an infertile couple received a newborn infant from another couple in the family, is disappearing.

While there appears to be an abundance of unwanted infants and orphans, many societies in the developing world do not favour adoption. In India, for example, the rate of adoption is very small. Adoption of infants from developing countries by Western couples is costly and cumbersome,

and media accounts of illegal and unethical international adoptions have increased over recent years (Raymond 1989b; Serrill 1991).

The prevention of infertility is universally ignored in the developing world. It is hardly likely to be a priority of fiscally strapped governments trying to reduce their countries' fertility rates. While the prevention of infertility has not been accorded a high priority in Western countries, there is considerable public effort to reduce sexually transmitted diseases and occupational exposure to hazardous substances. There is considerable expenditure on sex education and information in schools and reduction of drug abuse. Sex education in developing countries is uncommon.

It would appear from the preceding discussion that there may be a large potential market for assisted human reproduction in developing countries. The cost of adoption in these countries is very small relative to the cost of *in vitro* fertilization (IVF), yet there is a relatively greater preference and demand for IVF, a demand that is largely limited by capacity constraints. In Western countries, the cost of adoption may more closely approximate the cost of a successful IVF, though both are considerably more expensive than artificial insemination by donor. Moreover, accessibility to IVF is unequal, with the better educated and more affluent strata of society more likely to avail themselves of such services. In developing countries, such services are largely offered by private sector infertility clinics or centres. However, IVF services are relatively less costly than in Western countries, due to lower professional fees. There is already foreign direct investment in IVF centres in some developing countries, for example, India and Malaysia (Raymond 1990), and growing foreign participation in privately owned hospitals. There is also speculation about the export potential of IVF centres, that is, centres in developing countries taking in foreign patients.

As in the Western countries, IVF in developing countries has had low overall success rates, which vary greatly among centres. In the developing world there is little public knowledge about the success rates, health risks, or costs of IVF. Media publicity in India, for example, differs little from the "miracle baby" promotional coverage in the early years of IVF in Western countries.

The diffusion of IVF technology through infertility centres and clinics in very poor and apparently overpopulated countries like India is often considered by many as an example of inappropriate technology transfer. Some have even proclaimed it irrational and wonder how these countries can justify such resource allocation decisions, when many tens of millions have to do without basic health care services such as immunizations, prenatal care, and deliveries without any birth attendants (let alone a nurse, midwife, or physician) (Manga 1991). The answer to these concerns is startlingly simple. In most developing countries, there is a sufficient absolute number of wealthy persons who can readily afford the cost of IVF and other reproductive technologies and procedures, and it is the absolute numbers who can afford to pay that matters, not the average level of

income or the widespread poverty. Further, virtually all investment in IVF centres is private. If necessary, the rich in poor countries avail themselves of such services in Western countries. Therefore, for social, political, and economic reasons, governments do not disallow such private investment or import of services.

Another justification for such centres is the much proclaimed "right" to bear children of one's own. Indeed, it is not at all uncommon to hear claims for public financing and support of such centres. Physicians and researchers often defend such clinics as providing "frontier research" in reproduction and genetics. They argue that there is a need to "keep up" with new discoveries and advances in these areas.

As for the concern about overpopulation, the advocates of NRTs offer two points in rebuttal: the first and most obvious is the fact that there are indeed very few IVF babies in the developing world — the population effect of IVF in these countries is negligible. The second may appear disingenuous to many critics of the developing world's health priorities. It is sometimes said that IVF technology will permit a greater acceptance of contraceptives and family planning. That is, should family planning result in infertility, the availability of IVF techniques is a safeguard or backstop to the aggrieved couple.

There is also a desire to be "first" in some technique or procedure. These justifications for the new technologies are often coupled with a demand for government financial support of IVF clinics.

The first IVF baby in India was born in Bombay in 1986. Within a year, such "successes" were noted in China, the Middle East, and Colombia. In Hong Kong IVF began in 1984, and the first IVF baby was born in December 1987. In 1987, Zimbabwe had its first IVF baby "under way." This country has a population growth rate of 3.2 percent and a cultural practice in which the "bride price" (dowry) is handed over only when the wife becomes pregnant. Apparently, Zimbabwe health authorities received requests for IVF treatment from infertile couples in Botswana and Zambia (Edwards 1989).

The commercial potential of IVF worldwide, according to one estimate, is about $6 billion (U.S.) (Raymond 1990, 1991). Australia's "export" of IVF services to the United States is used as an example to strengthen the argument by some doctors in developing countries for local provision of the services. There is alleged to be considerable interest in investing in IVF clinics in the developing world (Raymond 1991). Whether greater investment, and hence the capacity to provide much greater volume of IVF-related services, actually occurs remains to be seen. Such expansion of capacity with or without foreign investment is more likely to occur in the developing world should the success rates of IVF increase, the costs of IVF treatment decrease, and further specialist training in the use of these NRTs occur.

Use of Prenatal Diagnosis and Sex Selection in Developing Countries

It is the qualitative dimensions of human reproduction and not the quantity (of babies born) that will dominate the debate over NRTs in the near future. Indeed, this debate has already begun over the controversial issue of sex selection.

The notion of avoiding the birth of a disabled or incurably ill individual may be very appealing and quantitatively very significant in the developing world, where there are tens of millions of mentally or physically handicapped persons. For example, PND is not at all uncommon in urban areas of China where, while not mandated or compelled, it is readily accessible.

Abortion of defective fetuses is quite accepted in a country with a fairly strict one-child-per-couple policy. The improvement in the extent of sexual equality in China, compared to pre-revolutionary China, is remarkable and probably unmatched by any other society. Yet there are both female infanticide and abortion of female fetuses in the rural areas. Chen Muhua, head of the All-China Women's Federation, claims that millions of baby girls have been killed in the last decade. "Foreign experts estimated that, in a population of 1.13 billion, there were 30 million too few Chinese women" (Kersterton 1992, A18). Both practices are officially discouraged. China also discourages the mentally retarded from having children, and some of the provinces have such laws. There is a great interest in broadening PND services and improving the range of potential illnesses and disabilities screened or detectable by PND.

In the so-called "Comilla Declaration," feminist groups from many countries that have studied the development, use, and ethics of NRTs in their own countries and elsewhere declared that these technologies are sexist, racist, and eugenic in nature (Estrada-Claudio 1990). According to these groups, the technologies discriminate against and are coercive of women of colour, the poor, and minorities. It would seem that the potential of NRTs to be used in a discriminating way evokes as much or more fear and foreboding than their alleged violation or threat to women's autonomy or self-determination (Estrada-Claudio 1990; Bartels 1988; Arditti et al. 1984; Kanno 1987; Degener 1990; Ewing 1988; Kollek 1990; Laborie 1988; Zimmerman 1990).

Sex selection is of universal relevance according to a recent international survey of the practice and attitudes of physicians (Wertz and Fletcher 1989). While it has been practised for some time, it is only in the last decade that it has become increasingly controversial (Wertz and Fletcher 1989; Patel 1989; Lingam 1989; Warren 1985; Wichterich 1988), a controversy that may be related to the increase in the number and accuracy of sex selection techniques, falling female-to-male ratios in countries like India and China, and greater awareness of the practice by

feminist groups in the developing world. There are many protests and demands for laws and regulations prohibiting sex selection (Patel 1989). It is noteworthy that the World Medical Association (1987) declared "that physicians refrain from intervening in the reproductive process for the purpose of making a choice as to the fetus' sex, unless it is to avoid the transmission of a serious sex-linked disease."

The arguments for sex selection in countries like India include the following: sex selection, which in India means a preference for sons (Bumiller 1990), is an effective means of controlling the rate of population growth, as fewer girls mean a reduction in fertility. Therefore, satisfying a couple's desire for sons would result in smaller families. Many couples express an optimal family size in terms of the number of sons.

Another argument is that dowry, once restricted to the elite, is now practised by virtually all socioeconomic classes or castes, with the law banning it rarely enforced. The burden of dowry is often punitive, leading to financial ruin for millions of families (there are daily media accounts of dowry deaths or suicides) (Patel 1989). The cost of amniocentesis is in the range of R70 to R600 ($4 to $35). Access to such techniques is thus not limited to the rich. Even working-class people and the poor can avail themselves of amniocentesis. An abortion is R0 to R90 ($0 to $4.75) in Bombay. Compare such costs to the cost of dowry of more than R10 000 even for lower-caste marriages, and it is obvious that there is a powerful economic incentive for aborting a female fetus. Economics reinforces cultural and gender prejudices (Bumiller 1990; Roggencamp 1984).

Advocates of sex selection in developing countries (as in developed countries) consider sex selection to be implicit in the right to reproductive freedom and self-determination. They also suggest that a relative scarcity of women would tend to raise their value and social status much like the law of demand and supply is supposed to work for most commodities. Contrary arguments by feminists at least have an empirical basis. For example, in India, rape, abduction, forced polyandry, and lower status of women are more common in states with lower female-to-male ratios. In these states women also have lower levels of income and literacy and poorer access to basic health services (and hence higher maternal mortality) than in the state of Kerala, which has the highest female-to-male ratio in the country. Respect and status are determined more by social and cultural values, various institutional arrangements, and economic independence than by relative numbers.

It is not only paradoxical but counterintuitive to suggest that female feticide leads to a heightened value and respect for women. It is interesting that in China, despite 40 years of "socialist reconstruction" and a significant increase in the status of women, the coercion and compulsion surrounding its one-child policy have resulted in femicide gathering ground, although hard evidence is rare and difficult to establish.

Feminist groups from developing countries are largely against male or female feticide and implicitly argue that sexual preference is not a

legitimate ground for abortion. Feminists in the West are divided on the matter (Mies 1989). For many, reproductive freedom includes the right to abort a female or male fetus, and sex selection falls within the ambit of reproductive choice.

No doubt there will be changes in NRTs that will make sex selection cheaper, earlier, and perhaps more accurate. Sex selection or preselection at the IVF or embryo stages appears likely. Such advances may make sex selection more common than it already is, especially in those countries that put a high value on male offspring.

In India, there is a flourishing sex selection industry. In Maharastra, there were 10 clinics that did amniocentesis for purposes of sex selection in 1982. By 1987, there were between 500 and 600 such clinics using amniocentesis and chorionic villi biopsies. In 1990, the figure had risen to about a thousand. Gametric Inc. from the United States has set up clinics in India, Singapore, Taiwan, Egypt, Malaysia, Jordan, and Pakistan. An Australian firm, Pivet, has established clinics in Brazil, India, Malaysia, and Indonesia (Raymond 1990). Sex selection is by far the largest product line of the emerging international "reproindustry."

In response to intense pressure from feminist groups, Maharastra passed a law in 1988 that was meant to ban sex selection. Since the regulation of the clinics and the enforcement of the law have been weak and hopelessly ineffective, the passage of the law has not had a significant effect on the practice. However, since the law imposes a small financial penalty on doctors, a suspension of licence for two years, and a one-year jail sentence, it has led to an increase in the price of sex selection. It is interesting to note that while son preference is nationwide, the demand for the practice of sex selection is especially virulent in the north and is strong in both the poorest (and most backward) and wealthiest states. Indeed, the female-to-male population ratios in these regions are among the lowest in the nation (Women's Centre 1990).

From 1972 to 1982, about 80 000 female fetuses were aborted after sex determination tests in India. In 1984-85, one clinic in Bombay alone aborted almost 16 000 fetuses, virtually all of them female. Indians abroad, for example in the United Kingdom, often request information on the sex of their fetuses. However, they are by no means unique or distinctive in this respect.

According to a study by Wertz and Fletcher (1989), there may be an increasing tolerance of sex selection in Western countries. The study argues against sex selection on moral grounds and calls on the medical profession to "take a stand now against sex selection" (ibid., 27).

Sex selection violates the principle of equality between males and females, and perpetuates gender stereotyping, sexism, and a variety of social institutions that discriminate against women (e.g., dowry). There are serious consequences to this practice, especially in societies where the quality of life for girls — in terms of nutrition, health care, and education — is already markedly inferior to that for boys (Waldron 1987). The use of

PND for non-medical reasons (i.e., sex is not a disease) diverts scarce medical resources from other, more productive, uses and undermines the legitimacy and use of PND.

The implications of these developments for Canada are far from obvious. One view might be that Canada does not have a moral obligation to respond to these problems and developments in the developing world. An opposite view is that some action is warranted from a country that has frequently expressed concern about human rights domestically and internationally. This matter is discussed later in this paper.

In summary, in the author's view, sex selection is an unacceptable reason for abortion. In the view of many, it demeans and trivializes what is a serious and difficult decision for women and men. Acceptance of sex selection as a reason for abortion will probably make the struggle for the liberalization of abortion laws more difficult.

The Commercialization of Gametes, Embryos, Fetuses, Children, and Women

In addition to the concern about sex selection as a reason for abortion, another controversy surrounds the commercialization of fetuses. Payment for a fetus may be sufficient inducement to poor and destitute women to abort. In fact, there is alleged to be a growing number of cases of intentional pregnancies to produce fetuses for purposes of generating transplantable tissue (Raymond 1990; Kitzinger 1991).

Fetal organs and tissue may be valuable for the treatment of disease, in the manufacture of pharmaceuticals, and in biomedical research. While hard and reliable data are very difficult to obtain, what is alleged by some is that both the commercialization of and the "market" for fetuses are growing (Raymond 1989a). Further clinical uses of fetal tissue in the treatment of diseases, such as Parkinson's, Alzheimer's, diabetes, and others, may provide additional impetus for growth in the demand for fetal material. If so, it is feared that the "womb as a fetus farm" could become a reality, especially in the developing world (Roberts 1988; Women's Centre 1990; Kitzinger 1991; Raymond 1989a, 1991; Dixon-Mueller 1990).

This development is fraught with dilemma. It might engender yet further assaults on the right to abortion. To obtain better organs or fetal material, abortions might be performed later, thus heightening the risk to the pregnant woman. It would also complicate the yet unresolved and controversial issues of fetal rights and personhood. It is difficult to speculate about the consequences on notions of maternal duties and current feelings and attitudes about anatomical gifts. And, of course, there may yet be other effects.

One consequence is clear: commercialization of fetal tissue could result in greater international trade from the developing to the developed

countries. The human tissue industry is largely unregulated, and existing codes and regulations were not designed for the recent developments in medical technology. The size and extent of any current trade and market for fetuses are not known. However, because of the potential market for fetal tissue, there is an urgent need for humane and sensible regulations and conventions relating to the issues surrounding abortion and the use of fetal tissue.

Laws regarding commercialization of human biological material by donor or recipient (researcher and pharmaceutical companies) are still unclear. The question of proprietary rights and dispositional authority over one's own cells and tissues, once removed for treatment or research purposes, is still to be resolved. There is a fear of reducing one's body and its parts to the level of mere commodities subject to crass bartering.

The commercialization of sperm, eggs, and derivatives of conceptions (including embryos) is already a reality in many countries, with sperm and egg donors not in IVF treatment paid a fee. This practice is controversial because it poses risks to the health of women. It also raises the possibility of class bias and exploitation. Whether a commercial arrangement for gametes and embryos is necessary or desirable is debatable. However, the reasons given for commercialization, such as quality assurance, reduction of risks, and adequacy of supply, are hardly compelling arguments — in principle, such properties and objectives can be met by a non-commercial arrangement, much as in the case of transplantable organs.

It seems that commercialization of such products has occurred too quickly and without the benefit of a full public discussion and ethical analysis of the issues. The Council of Europe (1987), among others, recommended that the commercialization of fetal tissue and embryos for therapeutic, scientific, or commercial purposes be strictly prohibited. In every country official commissions of inquiry recommended separating a woman's decision to abort from any decision about the medical or scientific use of the fetus. They also recommended that physicians who are involved in therapeutic decisions over the termination of pregnancies be kept independent and separate from medical scientists who may use the fetal tissue and embryos for research purposes (Brody 1990).

Even more controversial is the commercialization of pregnancy — surrogate motherhood. This has also been termed "contract motherhood" (or "rented wombs"), "paid gestational services," and "commercialized childbearing" (Annas 1984; Elias and Annas 1986; Winkler 1988; Raymond 1989a; Holmes 1990; Ewing 1990). Preconception contracts are occurring on a small scale in developing countries, though it is feared surrogacy may materialize into a growth industry. Women in developing countries would likely contract for a much lower price to bear children for Western couples. Feminists' concerns about coercion may be exaggerated, but their fear about the exploitation of these women may well be valid.

A compelling case can be made for simplifying and liberalizing the rules of international adoption. Reproductive trafficking in women and

children is alleged to be occurring, though the magnitude is not known (Raymond 1989a, 1991). There are numerous shocking and distressing media accounts about illegal adoption networks and the theft and sale of children from hospitals, clinics, and streets in South American and Asian countries. In many South Asian countries, very young girls have been sold into prostitution. This is not a new phenomenon; the "baby trade" has been the subject of unsavoury and unpleasant news accounts for many years (Serrill 1991). In Thailand, Korea, and Sri Lanka, such trade is said to involve doctors, lawyers, and corrupt government officials (Raymond 1991). Some of the trafficking in infants and children involves private aid agencies. There are also allegations of children having been sold or kidnapped for purposes of obtaining organs for transplants, but such allegations have not been confirmed (Raymond 1989b).

The issue of contract motherhood is likely to remain controversial for a long time. Surrogacy brokers in the West, notably the United States, are increasingly using women from the developing world because they are cheaper and likely to be more passive and unquestioning (Raymond 1989a). In many countries, there are many women willing to serve as surrogate mothers or to sell their unborn children. In the view of some, procreative rights include the right to contract motherhood. But such rights may have untoward consequences for women in developing countries: will these rights indenture them to "incubatory servitude" as some feminists have suggested?

Implications for Canada

The literature on NRTs in developing countries is recent and sparse, and there is a need for further data, documentation, research, and analysis. Furthermore, what is known about developments in this area is worrisome and suggests that further research by both professional and international organizations is needed.

It is difficult to relate the extent to which international problems with NRTs must influence the policy, legal, and procedural norms about these technologies in Canada. Of course, Canadian policies on these technologies must be primarily determined by Canadian experience and realities. However, the debate and discussions about these technologies are not that different between developed and developing countries. Canada cannot simply tend to its own affairs in isolation, without consideration of its global neighbours. As the discussion in the previous section illustrates, there are universal themes and issues that transcend national and political boundaries. Indeed, the differences that exist are largely due to the widespread poverty, lower status of women, and relative lack of reproductive freedom in the developing world, and not to any technological advantages that devel-

oped nations have over others. The question in this section, then, is what can and should Canada do to meet these challenges.

In those situations where Canada is giving aid to a developing country, Canada may wish to consider placing even greater emphasis on its "women in development" strategy. Under this strategy, foreign aid is directed toward development projects that especially favour women. One of the conditions of aid is that the aided project must explicitly benefit women of the recipient country. Such a focus could be extended to other aid projects, particularly primary and secondary level education and, of course, health. That is, health and education projects must be seen to benefit women in particular. There is little doubt that women in most developing countries are especially disadvantaged in terms of their socioeconomic development.

In addition, through the Canadian International Development Agency, Canada could offer greater financial and logistical support to non-government organizations, both Canadian and foreign, that concentrate on women's health and human rights. It could also increase its support for bilateral family planning programs that are favourable and likely to prove beneficial to women — for example, support for safer and more effective contraceptives. Canada could promote the health of women from developing countries by supporting the WHO Programme of Research, Development and Research Training in Human Reproduction (Fathalla 1988). Under this program, which suffers from limited resources (ibid.), it would be possible to mobilize a global effort to develop and test reproductive technologies, especially where the existing technologies are not satisfactory or where research is lacking. The program is also instrumental in strengthening in-country resources through training, so that local expertise can deal with country-specific problems and employ the best available technologies.

Moreover, Canadian-sponsored clinical research (or research that involves Canadian researchers) should be used to develop mutually agreeable ethical guidelines that, at the same time, respect international conventions and agreements (the International Development Research Centre and the Medical Research Council may have considerable experience in this respect). There is a worldwide resurgence of interest in the field of biomedical ethics, especially research ethics. The Medical Research Council of Canada (1988) made a significant contribution in this respect by hosting and publishing the proceedings of a conference entitled "Towards an International Ethic for Research with Human Beings." More recently, the American Society of Law and Medicine published a special volume on "Research on Human Populations: National and International Ethical Guidelines" (Dickens et al. 1991). Both of these reports contain useful advice that the Government of Canada could profitably use in its deliberations and interventions in international organizations, and in designing its own ethical guidelines for research conducted in developing countries.

The banning of contract motherhood (payment of services to the gestational mother) and commercialization of fetal tissue and embryos is of

significance to women in the developing world. Issues of sex selection and the trafficking in children are also significant and demand a response. Pretending not to know of illegal or unethical adoption of foreign babies by Canadian couples is neither policy nor responsible conduct: a concerted effort to prohibit such adoptions is necessary.

Canada has just signed a landmark agreement with Romania (the first of its kind) that safeguards the best interests of the child by ensuring that child welfare authorities in both countries are directly involved in adoption cases (Hum 1992). Such bilateral agreements should be attempted with developing countries and the experience transferred to the appropriate international organizations and conventions. There is much scope for improving the policy and procedural regulations governing international adoptions.

At the international or multilateral level, Canada has recourse to various international declarations and covenants on human rights to which it is a party, including (but not limited to) the Convention on the Elimination of All Forms of Discrimination Against Women; the International Covenant on Economic, Social and Cultural Rights; the Convention on the Rights of the Child; and the International Covenant on Civil and Political Rights (Cook 1990; Cook and Haws 1986). Canada should place greater emphasis on reporting on the implementation of human rights and on demanding greater accuracy (i.e., ethical evaluation and scrutiny) in these reports. Such responsibilities could be carried out by the Committee on the Elimination of Discrimination Against Women (CEDAW), the international group of experts charged with pursuing appropriate progress under the Convention on the Elimination of All Forms of Discrimination Against Women. Discrimination is defined by this group as any distinction, exclusion, or restriction made on the basis of sex that has the effect of impairing or nullifying the recognition, enjoyment, or exercise by women of human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field. The scope of CEDAW is thus quite wide and, because it transcends many other human rights, it is seen as being "useful in illuminating important issues concerning compliance with the (international) conventions" (Cook and Haws 1986, 52).

However, there are few internationally enforceable legal mechanisms to compel non-compliant countries to meet the requirement of these conventions. Canada should encourage the international bodies mandated with the enforcement of human rights provisions (such as the United Nations and the International Court of Justice) to seek such remedies. In the interim, Canada might consider withholding foreign aid from nations in contravention of international conventions and covenants; however, there are grave doubts as to whether tying aid to a country's performance on human rights is practical. To do so would test Canada's consistency in applying such conditions. Also, "tied-aid" tends to victimize the victims — a double injury as it were — and puts at risk direct aid to a country's poor

people through non-government organizations. Rather than denying bilateral aid to recalcitrant countries with a poor human rights record, it would be better for Canada to quietly reward countries that are attempting (successfully) to improve their human rights record. Even this approach has its shortcomings, however.

There is also an apparent need to establish international conventions on the international exchange of, or transactions in, contract motherhood and fetal and reproductive tissue in general. The commercialization of gametes, embryos, fetal tissue, and contract motherhood raises many complex ethical, legal, and economic problems. While it is unwise for Canada to urge that certain policy or procedural packages on commercialization be adopted, it is important for Canada to raise these issues in the appropriate international fora. In the absence of international codes and agreements, there is a danger that markets for such reproductive tissue and services might develop, which may prove difficult to correct later on. As was suggested earlier in this report, existing conventions and codes are inadequate.

As a member of the many organizations concerned with family planning, Canada could attempt to influence the development of reproductive health programs, research priorities and policies on contraceptive technology, and family planning generally in the developing countries, so that it could better address the criticisms of current practices mentioned earlier in this paper. Canada should argue for more generous funding of family planning efforts by the relevant international organizations as a means of ensuring an appropriate level of access to health care services for all women, regardless of their marital or social status.

Finally, the professions in Canada, especially physicians and nurses through their codes of ethics, may also be able to influence their respective world bodies on matters of reproduction and family planning. These professions and Canadian governments would do well to learn more about the uses and impacts of NRTs in the developing world. A call for information-gathering by United Nations and health professional organizations would be an important basis for future initiatives and interventions.

In themselves, NRTs are not all bad. However, to appreciate their uses, it is important to understand their potential for abuse. *Abusus non tollit usum* is a Latin phrase cautioning that abuse does not take away use — that is, abuse cannot be an argument against proper use. Canada should play a role in the development of ethical guidelines and regulations governing reproductive technologies, and continue to be a strong proponent of human rights and a staunch opponent of discrimination against women in developing countries. However, before Canada serves important functions, it must ensure that Canadian practices themselves are beyond reproach under intense international scrutiny and are exemplary of both

the positive and negative types of human rights accorded as a minimum to its citizens.

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Mandate

(approved by Her Excellency the Governor General
on the 25th day of October, 1989)

The Committee of the Privy Council, on the recommendation of the Prime Minister, advise that a Commission do issue under Part I of the Inquiries Act and under the Great Seal of Canada appointing The Royal Commission on New Reproductive Technologies to inquire into and report on current and potential medical and scientific developments related to new reproductive technologies, considering in particular their social, ethical, health, research, legal and economic implications and the public interest, recommending what policies and safeguards should be applied, and examining in particular,

(a) implications of new reproductive technologies for women's reproductive health and well-being;

(b) the causes, treatment and prevention of male and female infertility;

(c) reversals of sterilization procedures, artificial insemination, *in vitro* fertilization, embryo transfers, prenatal screening and diagnostic techniques, genetic manipulation and therapeutic interventions to correct genetic anomalies, sex selection techniques, embryo experimentation and fetal tissue transplants;

(d) social and legal arrangements, such as surrogate childbearing, judicial interventions during gestation and birth, and "ownership" of ova, sperm, embryos and fetal tissue;

(e) the status and rights of people using or contributing to reproductive services, such as access to procedures, "rights" to parenthood, informed consent, status of gamete donors and confidentiality, and the impact of these services on all concerned parties, particularly the children; and

(f) the economic ramifications of these technologies, such as the commercial marketing of ova, sperm and embryos, the application of patent law, and the funding of research and procedures including infertility treatment.

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Assisted Reproductive Technologies: Informed Choice	F. Baylis
Medicalization and the New Reproductive Technologies	M. Burgess/A. Frank/ S. Sherwin
Prenatal Diagnosis and Society	D.C. Wertz
Roles for Ethics Committees in Relation to Guidelines for New Reproductive Technologies: A Research Position Paper	J.B. Dossetor/J.L. Storch
Economic, Ethical, and Population Aspects of New Reproductive Technologies in Developing Countries: Implications for Canada	P. Manga

Volume 2: Social Values and Attitudes Surrounding New Reproductive Technologies

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