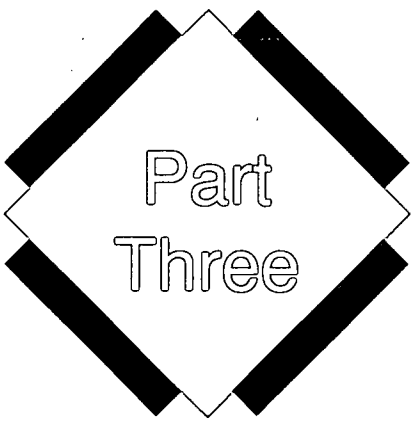
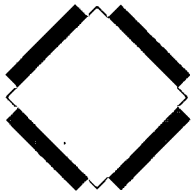


Overview of Recommendations



Overview of Recommendations

As a society we need to create a situation such that individual Canadians can make decisions about their involvement with new reproductive technologies in the knowledge that their ethical, legal, and social aspects and their safety and effectiveness have been given due consideration. Given this goal, we have made recommendations that set boundaries around the use of the technologies and that establish a National Reproductive Technologies Commission to license and regulate those activities in this field that are permissible. This would not be its only function, however; it would also play a facilitating and coordinating role, bringing together, learning from, and giving policy direction to provincial/territorial ministries of health and professionals working in this field.

In this third and concluding part of our report, we have grouped together the recommendations we made in Part Two, according to who would be responsible for implementing them. In the preceding 31 chapters, we discussed individual technologies in a detailed way and made recommendations flowing from our ethical and scientific analysis of the data we gathered. In this final part we give an overall picture of the way we propose that new reproductive technologies be managed in Canada and an overview of our recommendations. Simply providing a comprehensive list of recommendations would not highlight what we consider to be the most important recommendations, clarify how they are intended to work together, or identify who is responsible for implementing them or for their cost. It also would not highlight how our recommendations can contribute to preservation of our publicly supported health care system by their evidence-based approach.

Many of our recommendations are quite detailed or technical and require the context of our data and reasoning to render them meaningful to readers. Therefore, we believe it is more helpful to step back from our detailed recommendations and to concentrate instead on the overall

picture, focussing on the role of the essential partners we have identified and the responsibilities we envisage for them. At the same time, we provide numbered cross-references so that readers can easily refer back to Part Two for the context and details of our recommendations and summaries of licensing requirements.

As we have seen throughout our examination of the conditions, technologies, and practices encompassed by our mandate, both potential benefits and potential harms are associated with the use of new reproductive technologies. The Commission therefore concludes that it is essential, in a field where individuals may lack the knowledge necessary to protect their own interests, that these vulnerable interests be protected through rules and regulations established by society, which will also serve to protect the vulnerable interests of the wider community. As a society we all have an interest in the character and values of the community in which we live and responsibility to ensure that the community is one in which people are not treated as commodities and technologies are not used in ways that offend human dignity. It is the role of governments as guardians of the public interest to ensure that individuals and society as a whole are not harmed by inappropriate use of reproductive technologies.

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Given the potential harms to women and children and to important social values, to allow Canada's response to new reproductive technologies to be delayed or fragmented by the existing web of jurisdictional and administrative arrangements would be, in the Commissioners' view, a mistake of enormous proportions. We believe that the national regulatory framework we propose is essential, but by itself it is not sufficient. If we are to deal with new reproductive technologies appropriately in our society, strong leadership and cooperation will be required among governments, researchers, and professionals involved in new reproductive technologies, as well as many other sectors of society. Taking an evidence-based approach to the provision of permissible technologies is the only way to achieve the goals of effective treatment of people, avoidance of harm, and efficient use of resources. It is quite clear that no one group or organization can act effectively in isolation — partnership and cooperation between the federal government, provincial/territorial governments, professional organizations, patient groups, and other affected interests are critical.

All these partners have a necessary and interactive role: for example, provinces are essential partners with several ministries involved (provincial family law regimes must take into account the situations created by the use of new reproductive technologies; provincial ministries of education must grapple with the real and necessary role they will play in preventing

infertility; and so on); professional organizations must ensure that their members receive the necessary training in preventing, diagnosing, and treating infertility; researchers and organizations funding research have a responsibility to ensure that all research receives ethical and social evaluation before being funded and carried out; health and social service workers will have to take into account the unique needs of the new types of families created by the use of new reproductive technologies; and individuals have the responsibility to inform themselves as fully as possible before making any decisions.

It is clear, then, that many sectors of society beyond the health care sector and public institutions beyond the federal government will have crucial roles to play. Concerted action and cooperation by the provinces/territories, the professions, and other key participants in the context of the proposed national framework are the only way to ensure ethical and accountable use of new reproductive technologies in Canada — now and in the future. This cooperation will enable provinces/territories to harmonize and standardize the delivery of new reproductive technologies in their respective jurisdictions, allow more effective strategies aimed at preventing infertility, and let Canadians know that their interests are being protected in a comprehensive and open way.

We recognize that implementing our recommendations will take considerable public and political will. By grouping our recommendations according to who should have responsibility for implementing them, we hope not only to assist those who are responsible but also to assist advocacy groups, individuals, and others who will be monitoring development in this field and monitoring progress in implementing our recommendations.

Recommendations by Area of Responsibility

We outline the general structure of the approach we recommend by focussing on the various "actors" responsible for implementing our recommendations with regard to infertility and new reproductive technologies. These actors include the federal and provincial/territorial governments, the health professions, private sector interests, and various advocacy and public interest groups. The detailed recommendations in Part Two reflect our view about how these institutions and groups should act and interact in the sphere of new reproductive technologies.

By focussing here on the main responsibilities we envisage for the principal actors, we hope to clarify the overall structure of our recommendations and to identify clearly who is accountable for implementing them. However, numbered cross-references to specific recommendations are provided for readers who wish to look up the details of the recommendations or the data and reasoning that led to them.

Consistent with our mandate from the federal government, with the call we heard from Canadians for a national response, and with the constitutional obligation of the federal government to legislate for the peace, order, and good government of Canada, many of our recommendations are addressed to the federal government. We look first at the role we have recommended for the federal government, before considering the important roles of the provincial/territorial governments; the health care professions; private sector interests; and other interested groups.

Federal Government

The recommendations we address to the federal government fall into three general categories: first, recommendations regarding the need for criminal legislation to set boundaries around the use of new reproductive technologies in Canada; second, recommendations regarding the establishment and operation of a National Reproductive Technologies Commission to manage new reproductive technologies within those boundaries; and third, other recommendations addressed to existing federal departments and agencies. We look at each of these categories in turn.

Criminal Legislation

We have judged that certain activities conflict so sharply with the values espoused by Canadians and by this Commission, and are so potentially harmful to the interests of individuals and of society, that they must be prohibited by the federal government under threat of criminal sanction. These actions include human zygote/embryo research related to ectogenesis, cloning, animal/human hybrids, the transfer of zygotes to another species [184], or the maturation and fertilization of eggs from human fetuses; the sale of human eggs, sperm, zygotes, fetuses, and fetal tissues [192, 286, 287]; and advertising for or acting as an intermediary to bring about a preconception arrangement, receiving payment or any financial or commercial benefit for acting as an intermediary, and making payment for a preconception arrangement [199].

We also recommend that unwanted medical treatment and other interferences or threatened interferences with the physical autonomy of pregnant women be recognized explicitly under the *Criminal Code* as criminal assault. To ensure that medical treatment never be imposed upon a pregnant woman against her wishes, we also recommend that the criminal law, or any other law, never be used to confine or imprison a pregnant woman in the interests of her fetus, and that the conduct of a pregnant woman in relation to her fetus not be criminalized [273, 274].

Establishing the National Reproductive Technologies Commission

The legislative prohibitions we have recommended will protect against certain egregious threats to human dignity and to women's equality and freedom. However, criminal legislation is not flexible enough to regulate the day-to-day provision of new reproductive technologies. To ensure that new reproductive technologies are provided in a safe, ethical, and accountable way within these boundaries, we recommend that the federal government establish an independent National Reproductive Technologies Commission, charged with the primary responsibility of ensuring that new reproductive technologies are developed and applied in the national public interest [1]. In particular, we recommend that the National Commission be composed of 12 members appointed by the Governor in Council, at least 6 of whom, including the president, are appointed on a full-time basis. We recommend that National Commission members be appointed for an initial five-year term, with a possible one-, two-, or three-year renewal of their terms, to allow for the staggering of new appointments. We are of the view that these numbers and terms of appointments will permit the development of a high level of expertise while allowing for sufficiently diverse representation of interests and a close working relationship among National Commission members.

We believe that women should make up a substantial proportion of the National Commission's members, normally at least half. In addition, membership of the National Commission and its sub-committees should always include persons knowledgeable about the interests and perspectives of those with disabilities, those who are infertile, and those who are members of racial minority, Aboriginal, and economically disadvantaged communities. A range of expertise should also be represented, including reproductive medicine, ethics, law, and social sciences. In other words, Commissioners see the need for a broad mix of views in the membership of the National Commission and are confident that there are many Canadians, both women and men, who are fully qualified to take on these responsibilities and from among whom such appointments can be made.

Given the range and diversity of its mandate, we believe that the National Commission can best fulfil its responsibilities if it establishes six permanent sub-committees devoted to different aspects of new reproductive technologies. These six sub-committees would focus on infertility prevention; assisted conception; assisted insemination; prenatal diagnosis and genetics; human zygote/embryo research; and the provision of fetal tissue for use in research. We recommend that each of these sub-committees includes both National Commission and non-National Commission membership, and that outside members include people representing the views and interests of governments, relevant professional bodies, consumers, and other groups with particular interest in the area of the sub-committee activity in question. Like National Commission members

themselves, we recommend that at least half of sub-committee members normally be women, and that all members be chosen with a view to ensuring that they have a background and demonstrated experience in dealing with a multidisciplinary approach to issues, as well as an ability to work together to find solutions and recommend policies to address the difficult issues raised by new reproductive technologies in a way that meets the concerns of Canadian society as a whole. The sub-committees would therefore serve as important forums for public input and community representation. The functions of each sub-committee are summarized below.

Infertility Prevention Sub-Committee

We recommend the establishment of a permanent sub-committee of the National Reproductive Technologies Commission, with primary responsibility in the field of infertility prevention and reproductive health promotion [61]. It will serve to promote and coordinate public education and research in the area of reproductive health and infertility prevention both in Canada and internationally. Among the functions of the Infertility Prevention Sub-Committee would be the following:

- promoting and supporting consultation and cooperation among federal and provincial/territorial departments of health, labour, and the environment; among agencies such as the Canadian Centre for Occupational Health and Safety and the Canadian Centre on Substance Abuse; provincial workers' compensation boards; and other governmental bodies with responsibilities related to the field of reproductive health;
- consulting with the provinces/territories, directly or through the Conference of Deputy Ministers of Health, on matters related to infertility prevention and reproductive health;
- advising the federal and provincial/territorial governments on legislative and regulatory issues related to infertility prevention and reproductive health promotion, including in the areas of environmental protection and occupational health and safety;
- consulting with health care professionals, community and public health personnel, educators, family planning organizations, and others involved in public education efforts in the field of reproductive health;
- promoting, on behalf of the federal government, international co-operation in research, information gathering, and public health initiatives related to infertility prevention (see, for example, our recommendation with respect to a cooperative international effort to assess existing data on workplace and environmental exposures that may represent risks to reproductive health) [41]; and

- promoting public awareness and discussion about the causes, incidence, and preventability of infertility in Canada, in part through the National Commission's annual report.

Assisted Insemination Sub-Committee

We recommend that the National Commission establish an Assisted Insemination Sub-Committee with responsibility for licensing the collection, storage, distribution, and use of sperm in connection with assisted insemination; for setting the standards and guidelines to be adopted as conditions of licence; and for monitoring developments in the field of assisted insemination [84].

The compulsory licensing requirements would apply to any individual or facility either engaged in the collection, storage, distribution, and use of sperm in connection with the assisted insemination of a woman other than the social partner of the sperm donor or using sperm having had sex-selective treatment for insemination even if for the social partner. Sperm collection, sperm storage and distribution, and the provision of assisted insemination services would constitute three distinct licensing categories, although one facility could apply for a licence in more than one category [83, 85].

The Assisted Insemination Sub-Committee would develop, with input from relevant bodies, standards and guidelines to be adopted as conditions of licence [83-103]. The recommendations of the Royal Commission on New Reproductive Technologies should serve as a basis for these guidelines.

In particular, we recommend that the conditions of licence for facilities involved in sperm collection ensure [88]:

- screening of donors and testing of donor sperm for infectious diseases (including a six-month quarantine on donated sperm to allow for human immunodeficiency virus [HIV] testing of donors);
- informed consent of sperm donors (including standardized information and consent forms and counselling);
- compensation to donors is for inconvenience only, with no financial incentive;
- sperm is forwarded only to licensed sperm storage facilities; and
- proper record keeping, and that identifying and non-identifying information on the donor accompany sperm sent to a licensed storage facility.

For facilities involved in sperm storage, we recommend the following conditions of licence [94]:

- all sperm stored or distributed by a sperm storage and distribution facility must be obtained from a licensed sperm collection facility;

- applications for sperm should be accepted only from an individual or facility licensed to provide assisted insemination services or from an individual woman seeking sperm for self-insemination (without discrimination on the basis of factors such as sexual orientation, marital status, or economic status);
- informed consent of women receiving sperm for self-insemination is obtained (including a signed statement that the sperm is for her own use, that she has received, read, and understood information materials outlining the risks, responsibilities, and implications of donor insemination, and that she consents knowingly to using the sperm);
- non-identifying information about the sperm donor should accompany sperm distributed to qualified applicants;
- there must be proper record keeping enabling the necessary linking of donor, recipient, and the child(ren), to ensure that there are no more than 10 live births from a single sperm donor, and that the donor or the child(ren) can be contacted in the event of serious medical need (for example, discovery of a serious disease in either the child or donor that would have implications for the other); and
- identifying information regarding the donor should be kept confidential and forwarded to the National Reproductive Technologies Commission for secure storage. It should be released only in the event of serious medical need as determined by a court of law.

For facilities providing assisted insemination services, we recommend the following conditions of licence [99]:

- only frozen sperm from licensed storage and distribution facilities should be used;
- the importing of sperm is not permitted;
- a licence is required to perform insemination at any site other than the vagina even if the recipient is the social partner;
- access should be determined by legitimate medical criteria, not on the basis of social factors such as sexual orientation or marital or economic status;
- standard information, counselling, and consent forms should be completed and signed by all recipients before any treatment;
- at the time of the insemination, the recipient should be provided with donor information (identified only by the donor information code number); and
- there must be proper record keeping, which would involve the completion of a form by the recipient to be returned to the sperm storage and distribution facility in the event of a live birth.

We also recommend that licensed facilities providing assisted insemination not be permitted to use sex preselection techniques — that is, sperm treatment methods designed to separate X- and Y-bearing sperm — except for individuals who have a clear medical indication for this procedure (for example, X-linked disease) [93]. Patients with these indications should also be provided with objective information about the lack of reliability of any technique used, and data allowing estimation of success rates should be kept and forwarded annually to the National Reproductive Technologies Commission [100, 266].

All three types of licensed facilities should be required to report annually to the National Reproductive Technologies Commission [89, 96, 101], and all should operate on a non-profit basis [88(p), 94(m)].

Assisted Conception Sub-Committee

We recommend that the National Commission establish an Assisted Conception Sub-Committee with responsibility for setting the standards and guidelines to be adopted as conditions of licence and for monitoring developments in the field [105].

The compulsory licensing requirements for assisted conception services would apply to any physician, centre, or other individual or facility providing any of the following services or any other service related to assisted conception [104, 130]:

- *in vitro* fertilization (IVF)
- embryo transfer (either to the woman who was the source of the egg giving rise to the embryo or to another woman)
- gamete intrafallopian transfer (GIFT)
- zygote intrafallopian transfer (ZIFT)
- preimplantation diagnosis
- insemination at sites other than the vagina
- direct egg/sperm transfer (DOST) [130].

The Assisted Conception Sub-Committee would develop standards and guidelines to be adopted as conditions of licence, with input from relevant professional bodies and individuals and groups representing patients and other key sectors of the community [132].

The recommendations of the Royal Commission on New Reproductive Technologies should serve as a basis for these guidelines [130-159]. In particular, these guidelines should ensure the following:

- informed choice (including the provision of standard information materials and consent forms; non-directive counselling) [115-120, 146-151];

- standardized calculation of success rates, based on live births per 100 treatment cycles initiated [110, 112, 152, 153];
- consistent record keeping according to specified criteria (including the protection of patient confidentiality and the use of standard forms to allow record linkage) [155-157];
- annual reporting to the National Reproductive Technologies Commission (including success rates and side effects) [111, 113, 155, 156];
- the establishment of staff qualifications and expertise consistent with specified criteria [114];
- offering only drugs and procedures of proven effectiveness for the infertility condition in question as treatment; offering procedures whose effectiveness has not yet been clearly established only in the context of clinical trials [133-136];
- transferring a maximum of three zygotes to a woman's uterus in any IVF attempt [108, 143];
- basing access to IVF treatment on legitimate medical criteria, without discrimination on the basis of factors such as marital status, sexual orientation, or economic status [121, 141, 145];
- not operating assisted conception services on a for-profit basis [154]; and
- offering IVF only after infertility investigation of both the male and female partner, and only after less intrusive/costly options have been considered [137, 138, 142].

The guidelines developed by the Assisted Conception Sub-Committee should also prohibit the provision of assisted conception procedures in support of a preconception arrangement [202] and the use of prenatal diagnosis to determine fetal sex for non-medical reasons [265].

The Assisted Conception Sub-Committee would also develop standards and guidelines governing egg and embryo donation in licensed clinics [182]. We recommend that the guidelines ensure that

- no designated donation of eggs or zygotes occurs [167, 172];
- women who have experienced menopause at the usual age not be candidates to receive donated eggs or zygotes [162, 173];
- egg retrieval procedures solely for the purpose of donation not be performed [166, 174];
- informed consent is sought for both donors and recipients, including provision of standardized information materials and counselling [160, 164, 165];
- zygotes are disposed of in accordance with the wishes of the gamete donor(s), expressed in writing before the gamete retrieval [170, 175, 180, 181];

- zygotes are not stored for more than five years from the date they are frozen, and zygotes stored for a couple's own use only are stored up to the death of either partner [171, 180];
- record keeping is uniform and consistent with specified criteria (including identifying and non-identifying information on donor, and reporting to the National Reproductive Technologies Commission) [163, 176];
- donor anonymity is protected (access to information about the donor should be the same as for assisted insemination, discussed above) [176(b)];
- donors are screened and tested to prevent the transmission of infectious diseases (including a six-month quarantine on donor zygotes to allow for HIV testing of donors) [161, 177, 178]; and
- egg and zygote donors are not compensated in any way [168, 179].

In addition to its licensing functions, the Assisted Conception Sub-Committee would also

- facilitate and monitor randomized control trials of unproven drugs and procedures such as GIFT or IVF for endometriosis [63, 74, 107, 124-127, 135, 136];
- monitor the promotional activities of pharmaceutical companies in the marketing of fertility drugs [71];
- analyze the data reported to the National Reproductive Technologies Commission by the clinics; regulate access to coded information in this data base by qualified researchers; and issue an annual report based on the data [75, 76, 78, 81];
- consult annually with the Conference of Deputy Ministers of Health;
- monitor the assessment and introduction of new assisted conception technologies [109]; and
- develop guidelines for prescribing fertility drugs within licensed clinics, including the provision of standard information materials and consent forms [69, 72, 73] and standardized record keeping and reporting [75, 76, 78, 80].

Embryo Research Sub-Committee

We recommend that the National Reproductive Technologies Commission establish a permanent Embryo Research Sub-Committee, with responsibility for licensing facilities engaged in research using human zygotes, for developing standards and guidelines to be adopted as conditions of licence, and for monitoring developments in this area [197].

The licensing requirements for zygote/embryo research should apply to any physician, centre, or other individual or facility using human zygotes

in research. Both experimental and "innovative" therapies for human zygotes should fall under the rubric of research [193, 195].

The Embryo Research Sub-Committee would develop, with input from relevant bodies, standards and guidelines to be adopted as conditions of licence [197]. The recommendations of the Royal Commission on New Reproductive Technologies should serve as a basis for these guidelines [195-198].

In particular, we recommend that the following requirements be adopted as conditions of licence:

- all approved research must be restricted to the first 14 days of development of the human zygote [183, 198(a)];
- research involving genetic alteration of human zygotes or embryos is not permitted [185, 198(i), 269];
- informed consent of the persons who have donated the gametes used to create the zygote (including standard gamete donor information materials and consent forms) is essential [186, 187, 198(b), (d)];
- objectives of research on human zygotes should be achievable only through the use of human zygotes [198(h)];
- research must be directed at understanding human health and not be undertaken for commercial gain [198(g)];
- the creation of human zygotes specifically for research purposes is permissible, but invasive procedures specifically to retrieve eggs for purposes of creating zygotes for research is not [188, 198(c)];
- human zygotes that have been subject to manipulation of any kind for research purposes cannot be transferred to a woman's body without the specific approval of the National Reproductive Technologies Commission, and then only in the context of a clinical trial [189, 190, 194, 198(f)];
- any research project involving the use of human zygotes undertaken by a licensed researcher or facility must be approved by a local research ethics board, based on national guidelines developed by the Embryo Research Sub-Committee [198(j)];
- there must be proper record keeping (including confidentiality of information on donors) [198(e)]; and
- there must be annual reporting to the National Reproductive Technologies Commission [198(k)].

Prenatal Diagnosis and Genetics Sub-Committee

We recommend that the National Reproductive Technologies Commission establish a permanent Prenatal Diagnosis and Genetics Sub-Committee, with responsibility for licensing facilities providing prenatal

diagnosis services, for developing standards and guidelines to be adopted as conditions of licence, and for monitoring developments in this area [230].

The compulsory licensing requirements for prenatal diagnosis services should apply to any physician, centre, or other individual or facility providing the following prenatal diagnosis services [232, 233]:

- amniocentesis
- chorionic villus sampling (CVS)
- any other prenatal testing of pregnant women aimed at obtaining information on the health status of the fetus with regard to congenital anomalies and genetic disease, other than provincial maternal serum alpha-fetoprotein (MSAFP) screening programs or other provincial programs involving testing of pregnant women's blood and provincially licensed diagnostic ultrasound programs.

The Prenatal Diagnosis and Genetics Sub-Committee would develop, with input from relevant bodies, standards and guidelines to be adopted as conditions of licence [235]. The recommendations of the Royal Commission on New Reproductive Technologies should serve as a basis for these guidelines [233-254]. In particular, facilities seeking a licence would have to obtain prior accreditation by the Canadian College of Medical Geneticists [233, 248].

We recommend that the following requirements be adopted as conditions of licence:

- fully informed consent is obtained (including the provision of standard information materials and consent forms, and non-directive counselling) [214, 215, 244-250];
- prior willingness or unwillingness to terminate a pregnancy should never operate as a precondition for prenatal diagnosis [214, 247];
- counselling prior to and following termination of pregnancy, including grief counselling, should also be available, either on-site or by referral [212, 213, 250];
- no genetic alteration of a human zygote/embryo is permitted [241, 270];
- record keeping is according to specified criteria (including the protection of patient confidentiality) that would allow outcomes to be assessed [243, 251]; and
- there must be annual reporting to the National Reproductive Technologies Commission [252].

We also recommend that special safeguards be in place for the prenatal diagnosis of late-onset disorders [256]. Licensing guidelines should provide that

- special counselling be available for prenatal diagnostic testing for late-onset single-gene disorders [257]; and
- prenatal diagnosis should *not* be offered to detect so-called susceptibility genes [259].

We also wish to prevent the misuse of prenatal diagnosis for sex-selection purposes. The Prenatal Diagnosis and Genetics Sub-Committee guidelines should therefore also specify that

- prenatal diagnosis to determine fetal sex for non-medical reasons should not be offered [242, 261, 262]; and
- where prenatal diagnosis has been provided for a medical reason, patients should be informed prior to testing that the usual practice is to reveal information on the sex of the fetus only if it is medically relevant to the health of the fetus. Information on the sex of the fetus should be given to the woman or referring practitioner only on direct request [263].

In addition to its licensing functions, the Prenatal Diagnosis and Genetics Sub-Committee would also

- provide guidelines and monitor clinical trials of procedures that remain experimental in nature [237-239];
- determine which prenatal diagnosis procedures are of sufficiently proven safety and effectiveness to be offered as services, and help ensure that procedures whose safety or effectiveness has not yet been clearly established should be offered only in the context of clinical trials [236, 238, 240];
- consult annually with the Conference of Deputy Ministers of Health [231]; and
- monitor developments in deoxyribonucleic acid (DNA) testing as they relate to reproductive technologies [260].

The Prenatal Diagnosis and Genetics Sub-Committee would also be responsible for monitoring developments in gene therapy in the reproductive context. We therefore recommend that the Sub-Committee develop guidelines concerning the appropriate indications for fetal applications of somatic cell gene therapy as the field evolves, and that any proposal for somatic cell gene therapy research involving human fetuses be reviewed and approved by the Prenatal Diagnosis and Genetics Sub-Committee, following review and approval by the Medical Research Council national review committee for gene therapy [267, 268].

Fetal Tissue Sub-Committee

We recommend that the National Commission establish a permanent Fetal Tissue Sub-Committee to monitor the supply and use of fetal tissue,

to develop standards and guidelines to be adopted as conditions of licence, and to oversee the implementation of the licensing program [292].

Compulsory licensing would be required for the provision of human fetal tissue by any physician, centre, clinic, or other individual or facility providing human fetal tissue for research (including transplantation research) or for any purpose other than medical care of the woman, routine pathology testing, or disposal [277, 290].

The Fetal Tissue Sub-Committee would develop, with input from relevant bodies, standards and guidelines to be adopted as conditions of licence [292]. The recommendations of the Royal Commission on New Reproductive Technologies should serve as a basis for these guidelines [290-293].

In particular, we recommend that the following requirements be adopted as conditions of licence:

- full and informed consent of the woman, sought independently of and subsequent to the decision to abort, and including specific consent for use in transplantation, must be obtained in relation to any fetal tissue provided for use [281, 293(b)];
- fetal death must be determined before use of fetal tissue in research [278, 293(a)];
- donation of fetal tissue to designated recipients should not be permitted [284, 293(c)];
- there is no compensation to the physician supplying fetal tissue, except to cover costs of handling the tissue [288, 293(d)];
- the woman is informed that no commercial benefit or other financial benefit will accrue to her from use of fetal tissue [281(e)];
- the research is permitted only if it is directed to understanding human functioning or disease, or to diagnose or treat disease [280, 293(e)];
- fetal tissue is provided only for projects that meet ethical research guidelines developed by the Sub-Committee and that have received prior institutional research ethics committee approval, including scientific and ethical review [293(f)];
- records must be kept according to specified criteria [293(g)];
- no personally identifying information regarding the woman accompanies fetal tissue [282];
- physicians supplying fetal tissue do not receive co-authorship credit for this role in publications resulting from the research use of that fetal tissue or any direct or indirect financial benefit [285]; and
- there must be annual reporting to the National Reproductive Technologies Commission [293(h)].

Federal Departments and Agencies

In the Commissioners' view, the most urgent responsibility of the federal government is to set boundaries around the provision of new reproductive technologies, through the criminal prohibition of certain activities, and to establish the National Reproductive Technologies Commission to regulate new reproductive technologies within those boundaries. However, we also recommend that federal departments and agencies undertake several other important activities, in some cases in conjunction with other governments and non-governmental bodies.

In particular, we see an active role for the departments of Health, Human Resources and Labour, and the Environment, as well as the Medical Research Council of Canada. We look at each in turn.

Health Canada

We believe that Health Canada should take a leadership role in initiating and coordinating public health education campaigns for the prevention of infertility. This would include:

- conducting surveys of reproduction and of reproductive behaviour every five years, and ensuring that these surveys include a measurement of the prevalence of infertility, using a standardized definition so that infertility can be tracked over time [2];
- updating every five years the *Canadian Guidelines for the Prevention, Diagnosis, Management and Treatment of Sexually Transmitted Diseases in Neonates, Children, Adolescents and Adults* (1992), and ensuring that a free copy of the guidelines is available to all primary care physicians, obstetricians/gynaecologists, urologists, sexually transmitted disease (STD) clinics, provincial and territorial nurses, community care clinics, nurses in school settings, educators teaching STD management at nursing and medical schools, and nursing and medical students [18, 19];
- funding the Canadian Task Force on the Periodic Health Examination or a similar body to compile, update, and publish its findings in a practical guide for primary health care workers on useful preventive services and ensuring that the guide include STD prevention [20]; and
- if results of a current study show they have an effect, requiring manufacturers to include on all containers of alcoholic beverages health warnings about the risks of alcohol consumption, including risks to the fetus [50].

We also recommend several initiatives that involve consultation and coordination between Health Canada and provincial/territorial ministries of health and education. Working in conjunction with provincial/territorial governments, Health Canada should

- ensure that goals and objectives for health education incorporate information about the effects of severe dietary restrictions and severe weight control on health and fertility [45];
- review and evaluate existing programs to reduce alcohol consumption among young people and, where necessary, develop new or improved initiatives to accomplish this objective [49];
- develop school-based and public education programs for young people concerning drug use [54, 55]; and
- develop specific programs targeted at high-risk individuals such as drugs users, prostitutes, and street youth regarding drug use, and, in particular, ensure that counselling and treatment programs are made available to help women who become pregnant while abusing drugs to stop using them [56].

Other recommendations will require Health Canada to work not only with provincial/territorial governments, but also with a wide range of other sectors. This is particularly true of our recommendations regarding sexual health education and anti-smoking campaigns.

Health Canada is currently assessing the national Guidelines for Sexual Health Education, developed by a multidisciplinary advisory committee involving federal, provincial, professional, and community input. We endorse these guidelines, which call for a collaborative effort of a range of sectors: family, education, medicine, public health, social services, and all three levels of government. We therefore recommend to Health Canada, and to all parties involved, that sexual health education programs be based on the national Guidelines for Sexual Health Education [4, 5]. We recommend further that

- sexual health programs offer help and support for parents to play an active role in providing sexual health education to their children [3];
- sexual health education programs be designed and presented in recognition of the fact that individuals engage in a range of sexual behaviours (including abstinence, delay, sexual activity) and that they need accurate information pertinent to all these choices [8, 9];
- sexual health education programs convey the message that young people who are sexually active need to protect themselves in two ways, that is, against both pregnancy and sexually transmitted diseases [10];
- sexual health education programs be designed to help individuals identify and evaluate the sexual messages conveyed by the media, to understand what these messages mean for individual and societal sexual health [11];
- initial funding for sexual health education programs include funding for an evaluation component [6];

- national surveys and other research be undertaken regularly (at least every five years) to document the knowledge, attitudes, and experience of youth and adults regarding sexual health and sexual behaviour [14]; and
- agencies involved in public health education develop sexual health programs and services designed specifically to target hard-to-reach populations [15].

The federal government, including Health Canada, has been actively involved in anti-smoking campaigns through the Steering Committee of the National Strategy to Reduce Tobacco Use, whose membership includes federal, provincial, and territorial governments and eight national health organizations. We endorse the guidelines developed in support of the National Strategy to Reduce Tobacco Use [23], which emphasize the need for all levels of government and many non-governmental organizations to coordinate their activities. Hence we recommend to Health Canada, and to all the parties involved, that this strategy be supported. We recommend further that

- public education efforts endorsed by the Steering Committee of the National Strategy to Reduce Tobacco Use in Canada include informing women of the evidence regarding the effect of cigarette smoking on ability to conceive, in addition to the adverse effects on pregnancy and the health of the fetus [27];
- public education efforts include messages that encourage men to stop smoking to maximize the chances that their female partner will be able to conceive and have a healthy pregnancy and birth [28]; and
- prenatal classes include information and support with regard to the importance of smoking cessation [30].

We have also made recommendations directed to the Drugs Directorate, a unit of Health Canada, to improve its system of drug approval and post-marketing surveillance:

- Canadian specifications be required for the evaluation of drugs used in assisted conception [65];
- the Drugs Directorate consult with experts who have clinical and research experience with fertility drugs, to ensure that the benefits and risks of new drugs have been evaluated comprehensively [66];
- up-to-date criteria be developed appropriate for screening the safety and efficacy of new biotechnology products, including recombinant fertility drugs [67]; and
- any trial of a fertility drug be reviewed by the research ethics board of a major hospital or university [68].

Finally, we recommend that Health Canada develop national standards of fetal death, in conjunction with the provinces, relevant professionals, and ethicists [279]. We also recommend that they require pharmaceutical companies marketing fertility drugs to contribute funding for clinical trials to test unproven uses and for studies to follow up on post-marketing reports of adverse effects [64, 74]. Given that pharmaceutical companies benefit from fertility drug sales, they should be required to contribute to the appropriate evaluation of these drugs.

Department of Human Resources and Labour

We believe that the federal Department of Human Resources and Labour should also play an important role in the prevention of infertility, particularly in terms of delayed childbearing and occupational health and safety.

Some of our recommendations will require close cooperation between the federal Department of Human Resources and Labour and its provincial counterparts. In conjunction with provincial/territorial departments responsible for labour, the Department should

- inform employers about and encourage them to adopt work-related policies and programs that help employees balance work and family responsibilities [32];
- review legislation, policies, and programs to ensure that these provide adequate time for paid parental leave and that they protect employment opportunities, seniority, and work-related benefits for women who leave the workforce temporarily to have children [33];
- work toward establishing uniform standards in occupational health and safety across the country, in particular in relation to reproductive hazards [37];
- develop programs to monitor the exposure of workers in various occupations to known reproductive hazards, with the aim of developing appropriate control and prevention measures [42]; and
- introduce a comprehensive strategy for child care that addresses the need for licensed and affordable child care services [34].

Environment Canada

Environment Canada has a particular responsibility in the area of environmental threats to reproductive health. We therefore recommend that

- reproductive health experts be asked to examine existing and proposed regulations under the *Canadian Environmental Protection Act* and make appropriate recommendations to ensure that they take into account reproductive health risks [39];

- Environment Canada specifically include consideration of the issue of reproductive health in all actions undertaken to protect the environment [40]; and
- the federal government organize and provide funding to a working group of Canadian experts in the field of reproductive health and workplace and environmental exposures, to work with the World Health Organization to initiate a cooperative international effort to critically assess the existing data on occupational and environmental substances that may represent risks to reproductive health [41].

Medical Research Council

The federally funded Medical Research Council (MRC) provides some 30 percent of the funds for medical research conducted in Canada. Its funding decisions help determine which health problems are researched in Canada and which experimental treatments are tested. We believe that the area of reproductive health, particularly the prevention of infertility, should be a greater priority and receive a higher level of research funding.

We therefore recommend that the Medical Research Council

- consider making basic and applied research on sexual and reproductive health, including sexually transmitted diseases, a higher priority [21];
- consider targeting funding to the training of epidemiological researchers as part of an overall approach to assigning higher priority to applied research on sexual and reproductive health [22];
- support research studies on the impact of designated substances and families of chemicals that are suspected of causing adverse reproductive health effects [43]; and
- consider how to increase the pool of trained researchers qualified to conduct research in the area of occupational and environmental reproductive health effects [44].

We believe that research involving human zygotes and the use of fetal tissue is ethically acceptable, under certain conditions, and can provide important health benefits. We therefore recommend that

- research projects involving the use of human zygotes and carried out in licensed facilities be eligible for public funding [191]; and
- research projects using fetal tissue (including those related to transplantation in human beings) be eligible for public funding by the Medical Research Council of Canada and other agencies, provided they meet applicable ethical and scientific research standards and tissue is obtained in accordance with the recommendations of the Royal Commission on New Reproductive Technologies [289].

We believe, however, that research in humans involving the alteration of DNA for enhancement purposes would not be ethically acceptable, and that any proposal for such research should be refused by the Medical Research Council review committee on gene therapy [271].

Although the MRC is the largest source of federal funds for medical research, these recommendations should also apply to other federal research funding organizations, such as the National Health Research and Development Program of Health Canada.

Other Federal Action

Two final areas for federal action relate to patenting and to adoption.

We believe that patenting in this new and changing area is a topic that requires further study before specific policy can be recommended. We therefore recommend that Industry and Science Canada (Canadian Intellectual Property Office), in conjunction with the National Reproductive Technologies Commission, undertake further study of the issue of intellectual property protection in the area of new reproductive technologies with a view to making recommendations to the federal government for any necessary amendments to the *Patent Act* [206]. In our discussion of this issue, we outlined the principles and goals that we conclude should underlie such policies.

We believe that adoption is an important alternative to the use of new reproductive technologies. We therefore recommend that the federal government, in conjunction with provincial/territorial governments, undertake a joint review of adoption in Canada, with a view to addressing such issues as the relative merits of public and private adoption systems in promoting the best interests of the child and in meeting the needs of the other parties involved; access to adoption and barriers to access; cost; record keeping and disclosure; counselling and consent; the advantages and drawbacks of interprovincial/territorial harmonization of policies, services, and practices; and issues in relation to international adoptions [62].

National Council on Bioethics in Human Research

We recommend that the National Council on Bioethics in Human Research monitor evolving knowledge and potential developments in the field of non-therapeutic genetic alteration (that is, outside the field of reproduction itself) with a view to considering whether and what types of measures may need to be put in place in the future [272].

Provincial/Territorial Governments

Many of the recommendations we have made to the federal government can be achieved only through consultation and cooperation with the provincial/territorial governments. Provincial/territorial governments will be a vital partner in implementing our recommendations. For example, the federal government must work together with provincial/territorial governments on issues such as sexual health education and other public health education campaigns that relate to infertility prevention, occupational health and safety, and adoption policy. We are impressed by the cooperation shown in the development of the national Guidelines on Sexual Health Education, and in the work of the National Strategy to Reduce Tobacco Use. These examples show that the various levels of government can work together very effectively toward common goals when the health and well-being of Canadians are involved.

Provincial/territorial governments, because of their role in health care, are also essential partners in the six sub-committees of the National Reproductive Technologies Commission, and provincial/territorial input will be crucial in the formulation of standards and guidelines governing the provision and licensing of new reproductive technologies. Moreover, annual interactions between the National Reproductive Technologies Commission and the Conference of Deputy Ministers of Health are important in promoting information sharing and the development of common approaches in this area. This partnership with regard to reproductive health care will enable more effective, evidence-based management of this part of the health care system.

In addition to working together with the federal government in these and other ways, provinces/territories should take the initiative in several areas to protect and promote the best interests of Canadians. These areas include aspects of health education in schools, workers' compensation, family law, funding of the delivery of new reproductive technologies through the publicly supported health care system, support for clinical trials of unproven techniques, and reform of human tissue gift acts.

In the area of health education in schools, we recommend that provincial/territorial ministries of education

- mandate health education that includes smoking prevention for all young Canadians in elementary and high school grades [25];
- ensure that health curricula and school programs, in conjunction with community programs, focus on the benefits of a smoke-free life as a means of preventing and reducing smoking among young people [26]; and
- mandate the provision of comprehensive sexual health education sequentially from the beginning of elementary school through to the end of high school [7].

In the area of workers' safety, we recommend that

- workers' compensation boards establish their employer contribution rates using penalty assessments based on observed hazards or health and safety audits. This approach should be adapted to include specific provisions for reproductive hazards [36]; and
- occupational health and safety legislation be amended to provide more equal participation by employers and workers with a view to reducing workplace hazards [38].

In the area of family law, we recommend that provincial/territorial legislation be amended (by those provinces/territories that have not already done so) to reflect the reality of assisted conception. In the context of sperm donation, we recommend that legislation be passed to ensure that [82]

- the donor's rights and responsibilities of parenthood are severed by the act of sperm donation;
- the married or cohabiting male partner of a donor insemination recipient, if he has given his written consent at the time of insemination, is considered the legal father of the child;
- if the legal mother of the child has no male partner, the child has the legal status of "father unknown"; and
- if the female partner of a donor insemination child's mother acts as a parent toward the child, such a relationship be recognized by the courts in determining the best interests of the child for purposes of custody, access, and support, or in the event of the death of the child's mother.

Similarly, provincial/territorial legislation should clarify legal parenthood in the case of egg donation, with the woman gestating and giving birth being declared the legal mother of the resulting child [169].

In the matter of preconception agreements, as well as the criminal prohibitions we have recommended, provincial/territorial legislation should specify that:

- all preconception agreements, whether or not they involve payment, are unenforceable against the gestational woman [200];
- a woman who gives birth to a child is considered the legal mother of the child, regardless of the source of the egg [203];
- as in the case of adoption, the birth mother should be allowed to relinquish her maternal rights only after a minimum waiting period following the birth of the child [204]; and
- in any dispute over custody, the best interests of the child should prevail over the interests of the adults involved [205].

The funding decisions made by provincial/territorial ministries of health will play a vital role in determining how new procedures are disseminated, how accessible they are, and whether appropriate counselling and information are provided. It is important that provinces/territorial ministries make these decisions in accordance with the precepts of evidence-based medicine, equal access, and the importance of informed choice.

In terms of evidence-based medicine, we recommend to provincial/territorial ministries of health that

- *in vitro* fertilization for bilateral fallopian tube blockage be an insured service under provincial medicare programs, but not for other indications [128, 129];
- the program framework within which routine ultrasound scanning during pregnancy is offered be reviewed; facilities that offer ultrasound should be licensed in order to promote women's best interests and best medical practice [224];
- potential conflicts of interest be eliminated by ensuring that those ordering routine obstetrical ultrasounds do not usually provide them [225]; and
- physicians or laboratories should not be reimbursed for MSAFP screening conducted outside coordinated provincial MSAFP screening programs [229].

In terms of promoting informed choice and equal access to reproductive technologies offered through the publicly supported health care system, we recommend that adequate funds be provided by provincial/territorial ministries of health for the following purposes:

- making available appropriate educational materials on the technologies to women and the general public through physicians' offices, public health units, local hospitals with obstetrical units, community centres providing prenatal classes, and other appropriate means; centres with large immigrant populations should ensure that written materials and, in particular, consent forms are available in the relevant languages [208, 209];
- the establishment of outreach programs where necessary so that appropriate information and referrals are available to all women closer to home [219];
- in areas where obstetricians or family physicians are not available to provide referrals, a designated individual in the public health system, such as a public health nurse, should provide information and referrals, so that women contemplating technology use can obtain information closer to home and, if they wish, be referred to the appropriate centre [220];

- interprovincial barriers to access to assisted conception and prenatal diagnosis services should be removed to allow women to receive services at the most appropriate centre [221]; and
- standards for funding based on caseload be developed to ensure that adequate resources for counselling are available. This would allow more comparable care to be delivered across the country [210, 258].

Provinces/territories also have an important role in protecting the autonomy of pregnant women against the threat of judicial intervention and providing support to pregnant women whose fetuses may be at risk. We therefore recommend that

- child welfare or other legislation never be used to control a woman's behaviour during pregnancy or birth; and that civil liability never be imposed upon a woman for harm done to her fetus during pregnancy [273(d), (e)];
- information and education programs be directed to pregnant women so that they do not inadvertently put a fetus at risk [275(a)];
- outreach and culturally appropriate support services be provided for pregnant women and young women in potentially vulnerable groups [275(b)]; and
- counselling, rehabilitation, outreach, and support services be designed specifically to meet the needs of pregnant women with drug/alcohol addictions [275(c)].

Finally, we recommend two further provincial initiatives:

- existing legislative measures designed to discourage tobacco use among teenagers should be strengthened and rigorously enforced [24]; and
- human tissue gift acts should be amended specifically to prohibit the sale of fetal tissues and any payment to the woman from whom the tissue is obtained [286]. The prohibition on the commercial exchange of fetuses and fetal tissue extends to tissue imported from other countries [287].

Health Care Professions

Health care professionals are equally vital partners in the implementation of our recommendations. For example, professional bodies will be represented on the various sub-committees of the National Reproductive Technologies Commission, and their input will help the sub-committees formulate their standards and guidelines. In the case of the Prenatal Diagnosis and Genetics Sub-Committee, given the demonstrated experience

and record of the Canadian College of Medical Geneticists in evaluating centres, we have recommended that accreditation by the College be a precondition for licensing of genetics centres by the Prenatal Diagnosis and Genetics Sub-Committee [248].

In addition to their participation in the National Reproductive Technologies Commission, we have also made various recommendations regarding the education, training, and practices of health care professionals in Canada. We believe that many health care professionals are not well informed about issues relating to the prevention and treatment of infertility or to the uses and limits of prenatal diagnosis, and that some patients are therefore not receiving appropriate advice, referrals, or treatment.

To ensure that health care professionals practising outside licensed clinics are able to advise their patients properly regarding sexually transmitted diseases, we recommend that

- the Royal College of Physicians and Surgeons of Canada, the College of Family Physicians of Canada, and the Canadian Nurses Association propose standards for the content and duration of sexually transmitted diseases training provided by medical/nursing schools for various levels of clinical practice [16]; and
- continuing medical education courses be offered by faculties of medicine for obstetricians/gynaecologists, infectious disease specialists, and general practitioners, and by nursing faculties and community colleges for nurses, on the diagnosis, treatment, and counselling of individuals with sexually transmitted diseases [17].

To ensure that patients are not subjected to unnecessary or inappropriate infertility treatments, physicians and other health care workers should assess and counsel patients about their possible risk factors. In particular, we recommend that physicians and health care workers

- routinely evaluate women or couples seeking infertility treatment to determine whether smoking, eating habits, excessive exercise, alcohol consumption, or illicit drug use might be a contributing factor in their infertility. Patients should be informed about the effect of these factors on their fertility. If one or more of these factors is present, patients should be encouraged to modify their behaviour accordingly, and counselling and support to help them accomplish this goal should be available. This should be a first step before any form of infertility treatment is attempted [29, 31, 46, 47, 51, 52, 53, 57];
- ensure that women who have endometriosis know about the possible implications of the disease for their fertility so that they can take this information into account when making their childbearing plans [48];
- counsel couples considering surgical sterilization to ensure that they view the decision as permanent, and inform them of the likelihood of pregnancy after reversal of tubal ligation or vasectomy [58];

- counsel young women (and men) who are not in long-term monogamous relationships about the need for dual forms of protection against pregnancy and sexually transmitted diseases — in particular, that oral contraceptives should be used in conjunction with a barrier form of contraception to protect against not only pregnancy but also sexually transmitted diseases [59]; and
- inform women about the protection against sexually transmitted diseases provided by various forms of contraception and whether their use may be associated with a delayed return to fertility after contraceptive use is discontinued [60].

Once infertility has been properly diagnosed, it is important that the physician be able to provide treatment in a safe and effective manner or be able to provide an appropriate referral. If the treatment is provided within a licensed assisted conception clinic, standards of care will be determined by the guidelines established by the Assisted Conception Sub-Committee of the National Commission. If the treatment is provided outside a licensed clinic, however, there must be professional guidelines. We therefore recommend that

- the College of Family Practitioners of Canada and the Society of Obstetricians and Gynaecologists of Canada develop and disseminate guidelines for use by practitioners prescribing fertility drugs outside the context of licensed clinics. In particular, these guidelines should recommend against the prescribing of drugs where safe use requires specialized expertise and hormonal monitoring of women taking the drugs [70]; and
- a practical referral guide for general practitioners be developed by the College of Family Physicians of Canada and distributed widely [122, 123].

In the context of prenatal diagnosis, we believe that improvements can be made in the way patients are counselled, both within and outside centres. We recommend with regard to prenatal diagnosis that

- the College of Family Practitioners of Canada and the Society of Obstetricians and Gynaecologists of Canada encourage their members to pursue continuing medical education to increase their knowledge and understanding of the capabilities and limitations of prenatal diagnosis, the proper provision of accurate information, and the process of informed consent and choice. Specifically, increased efforts should be made in continuing education of referring physicians to emphasize the right of individual women and couples to reproductive autonomy, to decide for themselves whether to have prenatal testing, and, if a serious disorder is detected, to decide whether to terminate or continue the pregnancy [216, 217];

- the Canadian College of Medical Geneticists coordinate a collaborative effort by genetics centres, with the input of organizations representing patients, people with disabilities, and concerned women's groups, to develop accurate, understandable, and clear educational materials on prenatal diagnosis that fairly portray living with the disabilities diagnosed [207, 218];
- provincial colleges of physicians and surgeons and medical associations emphasize to their members that failure to discuss with patients the option of referral for a medically indicated prenatal diagnostic service is unethical and constitutes unacceptable medical practice. Information in this regard should be incorporated into medical school curricula and intern and residency training and examinations [222]; and
- relevant professional associations emphasize to their members that a woman having pregnancy termination because of a serious fetal disorder, together with her family, should receive support from medical and paramedical staff [211].

The licensing scheme we propose will help to ensure that prenatal diagnosis provided within genetics centres will not be misused for sex-selection purposes. It is also important to avoid such misuse outside the clinics, and to that end we recommend that the Society of Obstetricians and Gynaecologists of Canada, the Canadian Association of Radiologists, and the College of Family Physicians of Canada review their practice guidelines to ensure that practitioners using prenatal ultrasound do not perform ultrasound for the purpose of sex identification (except where medically indicated) and do not deliberately seek or offer information on fetal sex except for medical reasons prior to the third trimester of pregnancy [226, 255, 264].

Given that these tissues must be disposed of, we do not think the practice of selling placentas for use in the production of pharmaceutical and therapeutic products should be discontinued. However, we recommend that hospitals seek written consent from the mother for any use of the placenta other than disposal [276].

Finally, we believe that professional associations must ensure that their members are not facilitating preconception arrangements. We therefore recommend that all self-regulating professional bodies, such as provincial colleges of physicians and surgeons and provincial law societies, adopt strict codes of conduct, disciplinary measures, and severe penalties, including loss of licence to practise, against members knowingly involved in brokering or performing assisted insemination, *in vitro* fertilization, or zygote/embryo transfer to facilitate a preconception arrangement [201].

Patients and Other Affected Groups

Organizations representing individuals and groups affected by new reproductive technologies (such as women, people who are infertile, people at risk to have affected children, and people with disabilities) have important roles to play and perspectives to bring. In particular, we have recommended that such groups be represented on the relevant sub-committees of the National Reproductive Technologies Commission. For example, groups representing people with disabilities and patients at risk of genetic diseases should be included on the Prenatal Diagnosis and Genetics Sub-Committee. Moreover, the input of these groups will help the sub-committees formulate their standards and guidelines.

We have also recommended that organizations representing people with disabilities, people at risk, and women work with the Canadian College of Medical Geneticists in developing counselling protocols and information materials to ensure that disabilities and living with a disability are represented fairly and accurately [218].

We also believe that an important role for these groups is to pressure other bodies — particularly the federal and provincial/territorial governments and the health professions — to implement the recommendations we have made. Indeed, we hope that by summarizing our recommendations here by area of responsibility, we will help advocacy groups and the general public identify who they should look to, and hold accountable, for action on these recommendations.

Commercial Interests

We have already addressed the need to protect vulnerable interests of individuals and of society from commercial interests in some of the recommendations listed above. In some cases, commercial interests have been excluded entirely from activity in an area. For example, facilities involved in assisted insemination or assisted conception must operate on a non-profit basis, and commercial surrogacy agencies are prohibited [88(p), 94(m), 154, 199]. In other cases, we have recommended that the activities of commercial interests be tightly monitored. For example, we have made recommendations regarding the sale of products that may pose risks to fertility, including restrictions on the way tobacco is sold and required warning labels on alcohol products [24, 50], and we have recommended that those physicians ordering routine obstetrical ultrasound testing do not usually provide it [225]. The promotional activities of companies marketing fertility drugs in Canada will be monitored by the Assisted Conception Sub-Committee [71], and we have recommended mechanisms for ethical review of any clinical trials funded by

pharmaceutical companies even if these occur outside universities or university-affiliated hospitals [68]. We have made recommendations that will enable outcomes of drug treatment to be evaluated more effectively and to limit unproven use of drugs for infertility treatment [63-67].

We believe that pharmaceutical companies should be required to contribute to the cost of conducting the clinical trials needed to assess the safety and efficacy of fertility drugs even after these are on the market. We therefore recommend that the federal government require those pharmaceutical companies marketing fertility drugs to contribute funding for clinical trials for unproven uses, as well as for studies on them identified as necessary by Health Canada based on post-marketing reports of adverse effects. This funding should be administered at arm's length by national research funding agencies, but the studies should be facilitated and overseen by the National Reproductive Technologies Commission [64, 74, 79].

Employers

Some of our recommendations regarding workplace safety will affect employers whose workers may face reproductive hazards [see, for example, 36-38]. We also believe that the presence of workplace reproductive hazards should not be used to discriminate against women. We therefore recommend that control of workplace hazards not be sought through discriminatory personnel policies, and that reduction of hazards be sought through the use of engineering and workplace design controls wherever feasible [35].

School Boards

School boards have a pivotal role in the provision of sexual health education. They can help ensure that requirements for teachers delivering sexual health education in schools are in accordance with the criteria outlined in the Guidelines for Sexual Health Education [13], as we recommended earlier.

We recommend further that school boards consider the benefits of making contraception more accessible to young people who are sexually active — for example, through condom dispensers in high schools and referral to appropriate health services [12].

Conclusion

The recommendations summarized here are the product of three and a half years of research, analysis, consultation, and conscientious deliberation. Commissioners spent untold hours weighing evidence and considering the various positions and points of view presented to us by Canadians. We were conscious throughout that the recommendations we made would affect the day-to-day lives of many thousands of Canadians and that we could not take this responsibility lightly. Our goal was to seek a way that Canada, as a society, can obtain the benefits of technology for its members while also protecting them from potential harms through its abuse or misuse.

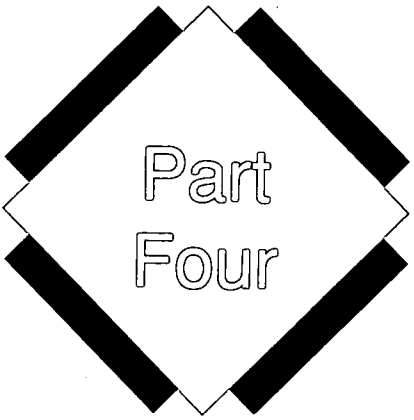
Each of the technologies, conditions, and practices in our mandate had potential harms and benefits that had to be considered. There were no easy solutions, no obvious yes-or-no answers, to many of the complex social, ethical, and legal issues they raised. Their complexity and differences in potential use meant that we could not take a simplistic all-or-nothing approach to their evaluation. We therefore listened to Canadians; we assessed new reproductive technologies in light of exhaustive evidence and data and analyzed their implications using explicit ethical principles, an understanding of Canadian social values and attitudes, and a belief that medical treatment should not be offered without evidence that it works. We reached three major conclusions. First, there is an urgent need for boundaries around the entire field of new reproductive technologies, and some technologies must remain outside the boundaries of the permissible. Second, within those boundaries, accountable regulation of permissible activities is needed to protect the interests of all involved. Third, we concluded that permanent mechanisms should be put in place to provide a flexible and continuing response to issues concerning new reproductive technologies as they evolve further.

First, there is an urgent need for boundaries around the entire field of new reproductive technologies, and some technologies must remain outside the boundaries of the permissible. Second, within those boundaries, accountable regulation of permissible activities is needed to protect the interests of all involved. Third, we concluded that permanent mechanisms should be put in place to provide a flexible and continuing response to issues concerning new reproductive technologies as they evolve further.

We have set out a blueprint for how Canada, with its unique institutions and make-up, can approach new reproductive technologies, regulate their use, and ensure that future development is in the public interest. Our blueprint is detailed and involves the participation and

commitment — financial, temporal, and moral — of many different sectors of society. The approach we propose is feasible and practical, and we have laid out a detailed plan for how it can be accomplished. In our view the reasons for taking such action are compelling: the potential for harm to individuals, and the need to protect vulnerable interests of individuals and of society. Implementing our recommendations will enable Canada to use scientific knowledge to better the lives of many Canadians: it will demonstrate that we care about each other's well-being and that we recognize collective values with respect to the importance people attach to having children. At the same time it will ensure only ethical and accountable use of technology is made with the awareness that there are potential harms that must be guarded against. Implementing our recommendations will enable Canadians to take pride in our collective ability as a society to demonstrate wisdom, compassion, and decency in the way we choose to use technology.

At the beginning of our mandate we made a commitment to keep Canadians apprised of what we were doing so that they could benefit from the information and discussion generated by our activities. In that spirit, in this concluding part of our report, we have outlined who should be responsible for taking action on our recommendations, so that it will be equally possible for Canadians to see whether and how well our recommendations are being implemented. We have done our job in as caring and conscientious a way as we know how. The next steps are not ours — they belong to governments, the professions, and individual Canadians.



Annex
Glossary
Appendices

Commissioner Suzanne Rozell Scorsone:

Six Dissenting Opinions

Preamble

The supplementary statements made here must be taken in the overall context of my agreement with the vast majority of the recommendations of the Royal Commission on New Reproductive Technologies. The areas of disagreement are few, indeed only six: educational strategies for STD prevention, access to new reproductive technologies, embryo research, termination as an appropriate response to the prenatal diagnosis of a disorder, the genetic link in donor insemination, and judicial intervention.

Under the Chairmanship of Patricia Baird, our discussion as Commissioners was free and wide-ranging, all concerns and perspectives brought to the table. The presence of these few supplementary differences of opinion as part of the unitary final report witnesses to the liberty given to the expression of viewpoints. That the areas of disagreement are serious should not be taken to reflect in any way on the rest of the report, since in other areas of similarly serious import we have been able to reach a mutual, collaborative view and common recommendations, if in a minority of instances out of different reasoning. These questions are matters of great debate in Canadian society at large; that there would be some degree of respectful difference of opinion on a Commission called together out of diverse backgrounds and expertise to examine these issues on behalf of Canadians is precisely what one would expect. The overall unanimity on all other recommendations witnesses to the fact that they arise out of genuinely achieved and viable agreement.

The presentation of these arguments is necessarily complex and lengthy, but it reflects only the great complexity of the long process of discussion and research in which we have engaged together. The volumes upon volumes recording the testimony we have heard and the research undertaken for the Commission are witness to the amount of evidence, analysis, and reasoning on which each conclusion and recommendation is based.

The Commission report is capable of a short-form presentation of reasoning because each point is a conclusion based on far more complex assumptions and analyses. Unfortunately, to argue persuasively toward different conclusions on these few subjects, more of that background has to be made explicit and examined.

The most essential points and recommendations are presented in this section, and the reasoning on which they are based is in the following section. Those readers with little time may wish to concentrate on the former, while the latter will be of interest to those others who wish to

examine in greater detail why and how these conclusions have been reached and to explore their implications.

It remains for Parliament and the people of Canada, along with the various levels of jurisdiction and the organizations and individuals concerned, to assess the persuasiveness of arguments and to decide upon the implementation of recommendations. Now that our deliberations have ended, and both our many common and our few differing conclusions reached, it is time for the next stage of the democratic process.

I. Educational Strategies for STD Prevention

I agree that education in sexual health should be available to all. There is, however, no national consensus on the value context of such education. The present freedoms and jurisdictional roles of the parents of minor children, provinces, school boards, hospitals, and social services, particularly those mandated and sponsored by religious or other value-based groups, in determining the approaches and value contexts of sexual education should therefore be preserved. However thorny and difficult the issues, Canada, by tradition and constitution, honours legitimate differences in values and approach.

The Guidelines for Sexual Health Education generated in response to a recommendation by the Expert Interdisciplinary Advisory Committee on Sexually Transmitted Diseases in Children and Youth (EIAC-STD) and the Federal/Provincial/Territorial Working Group on Adolescent Reproductive Health ought not to be adopted at the national level. These guidelines contain some elements that constitutionally protected separate, denominational, and dissentient schools could not implement without breaching their moral codes and mandates. The guidelines, moreover, discuss "sexual health" without mentioning such key concepts as commitment, childbearing, children and child-rearing, marriage, or love; the focus is the behaviour, knowledge, motivation, and choice of the individual which, important as they are, do not suffice. The ethic of care, the prism of the Royal Commission's understanding and clearly imbued with the concepts of relationship and commitment, is not inherent in the guidelines themselves. It would not follow them into national adoption were the Guidelines for Sexual Health Education not to be amended and revised from their foundations in accord with the ethical guidelines laid out by this Commission.

The requirements for those teaching sexual health education should not be based on those recommended in the Guidelines for Sexual Health Education. The mandating of the requirements for persons delivering sexual health education in schools should promote the enabling of every classroom teacher, not only of specialists. Properly resourced classroom teachers have an important role, following that of parents, in the provision

of family life education. Particularly in Grades 1-8, it is important that education and example in this intimate and relationship-based area be mediated primarily through people with whom a child has an ongoing and supportive relationship and who are in a position for follow-up and clarification.

The membership of the recommended Infertility Prevention Sub-Committee should be broadened to include parent groups, ethicists, representatives of religious and other groups engaged in the sponsorship of schools, and others. A full range of viewpoints representative of those in the Canadian population should be ensured. The principles for participation in the full National Reproductive Technologies Commission are broad and representative. As the list for this particular sub-committee now stands, however, containing as it does, beyond the necessary professionals, the advocacy groups of only one sort of overlapping network, only one possible viewpoint in a highly controverted field would be likely to have effective representation. In an influential national body, a narrow perspective would be inappropriate.

Finally, I would give key prominence to parents, particularly those of minor children. The Commission report rightly underscores the importance of their capacities, but nonetheless places agencies, government bodies, and other outside organizations in all explicitly mentioned primary decision-making roles, portraying parents as a promising but adjunct resource. It is instead the case that the legal rights and primary responsibility of parents for the medical and educational care of their minor children are both inherent in and essential to their role.

This includes their responsibility for notification and consent for medical treatment related to contraception. Schools should not be engaged in making unilateral referrals of minors for medical treatment, including contraception, without the consent of parents. This is an unjustified expropriation of the normal custodial role and jurisdiction of the responsible parent. The issue is not a simple one of the autonomy of minors, since the custodial role of parents is rooted in the empirically observable and normal incompleteness of minors' process of development of the capacity for fully competent and responsible autonomy, whether in their own best interests or those of others. Mechanisms exist for dealing with overtly dysfunctional or neglectful family or other social situations; the treatment of all families as though they were dysfunctional and hence targets for state intervention is highly inappropriate.

The generation of all programs of STD prevention directed at young people should also have primary involvement of parents and their representative groups from the earliest stages. It is parents who have the primary responsibility and right to determine the nature of the values education of their minor children, and parents who, on the ground, provide the most prevalent support systems for their children of any age in living

with and coping with the results, both positive and negative, of their sexual choices.

Legitimate diversity is essential to fundamental human freedoms.

II. Access to New Reproductive Technologies

The vast majority of the recommendations of this Commission maintain a fine and humane balance of the complex medical, ethical, social, and legal factors which form their context. On very few points do I feel obliged to object that this balance has not been maintained. This is one. On this issue a single perspective is being taken as normative, whereas a multiplicity of perspectives are not only present among Canadians but are, in my view, a matter of legitimate and necessary freedom.

Had the Commission report recommended simply that, in a pluralistic society, the provision of new reproductive technologies to persons living in a broad range of social situations is acceptable so long as the best interests of the child are maintained, this dissent would not have been written. Such a recommendation would have permitted diversity and freedom of both thought and action for all those involved. I cannot agree, however, with a recommendation which would impose on all health care institutions and personnel the use of a single and solely medical set of criteria, to the absolute exclusion, always and everywhere, of other factors.

While medical criteria are one key and essential component of determining access to *in vitro* fertilization (IVF), donor insemination (DI or AID) and other new reproductive technologies, there are also social and diverse ethical questions surrounding them which ought not to be dismissed. Health care institutions have latitude in setting their policies concerning access to new reproductive technologies, but there should be no absolute requirement of provision without regard to "factors such as marital status, sexual orientation or social and economic status." Such a requirement might appear to reduce the decision to solely objective criteria. It does not. To consider such factors relevant or irrelevant is, either way, a social/ethical opinion and choice. Those who consider them relevant, particularly but not only because of their impact on the best interests of a child and/or for reasons of conscience or religious belief, must not have the contrary view imposed upon them with no possibility of legitimate diversity.

Nor can I agree that the exclusion of all but medical indications should be a condition of the licensing of any assisted conception facility. Such a condition would discriminate against religious groups and board-electing communities which did not accept this perspective; health care facilities sponsored by such groups and communities would be denied the capacity to offer direct oocyte/sperm transfer (DOST), gamete intrafallopian transfer (GIFT), IVF, donor insemination, or any other of the licensable treatments.

It would also have the unintended effect of reducing access to assisted conception for the great majority of those seeking it, as the imposition of such a requirement would cause existing fertility clinics in health care facilities sponsored by some such groups and communities to close.

Licensing requirements have a legitimate purpose in the maintenance of high medical, record-keeping, and research standards. They should not be used as a mechanism of social engineering. Yet this is what the licensing and its inherent advocacy of the activity of those holding only one set of moral and ethical values and the exclusion of all others, particularly when their views reflect those of the majority of Canadians, would be. The Commission report agrees that religious institutions exist and should not be forced to contravene their religious beliefs, seeking to demonstrate this by saying that they have no intent to force any practitioner or clinic to provide new reproductive technologies if they do not wish to do so. Yet the erection of government licensing structures implementing a policy that one may believe as one wishes so long as one absents oneself or accepts being excluded from the public forum, from a public service, and from an activity would itself be a contravention of religious freedom or freedom of any other sort of conscientious opinion. It closes the field to all those who hold any but one set of ideas. This does constitute discrimination based on religion.

The imposition by government of a single view would have implications far beyond new reproductive technologies, since it would be a precedent of state override of diversity arising from religious belief and other values. This would have implications, not only in many fields of religiously sponsored health care and education, but in the social services, including adoption.

Policy with respect to access should be set by the boards and/or organizational owners (for instance charitable organizations, religious orders or religious bodies) of the respective health care facilities. Boards and/or organizational owners should set these policies in accord with their mandates and ethical policies, bearing in mind the guidelines of the relevant professional associations, within the guidelines, regulations and legislation of provincial government, and in dialogue with the values and concerns of the surrounding community of the ultimate providers, the taxpayers.

Conflicts over the applicability of a policy to individual cases should be resolved as such conflicts are resolved in other fields of medicine, of law, and of social service to children and families. It would be unreasonable and impracticable for each criterion "to be specified in law." Such prior legislative specification is not made in cases of child protection or home assessment for adoption or other aspects of child welfare, or, on another level, of legitimate variation in mandate, policy, and practice between and among secular and religiously sponsored institutions. The variability of human situations is too great, and the effect of any one factor may vary,

compensated for or rendered more serious depending upon the concomitant existence or severity of others. The blunt instrument of legislation centralizing inflexible criteria for assessments is unwarranted and would itself have negative consequences. Arguments in the Commission text appealing to the Charter are a matter of opinion expanding the interpretation of its application well beyond what has been or is likely to be established.

The principle of the best interests of the child, clearly recognized in law, should take precedence over any other interest; this is clearly justified in a free and democratic society. Similarly, the freedom of conscience of individual professionals, physicians, nurses and others must be upheld. The freedoms of health care institutions sponsored by religious bodies or communities must be preserved. They are and must remain free to set policies in accord with the moral codes inherent in their mandates as a matter of fundamental human rights.

III. Embryo Research

I accept and endorse, not only the great majority of the recommendations of the final report of the Royal Commission on New Reproductive Technologies on the subject of *in vitro* fertilization, but many of those dealing with embryo research and with directly associated aspects of IVF. I cannot, however, accept others; my dissent and my reasoning are laid out here.

Experimentation and other forms of non-therapeutic research on viable human zygotes or embryos should not be permitted at any point in development. Still less should human zygotes or embryos be deliberately brought into being for the purpose of research. Such experimentation instrumentalizes the human, and is incompatible with commonly accepted ethical norms for research on human subjects. It would set precedents which would have implications far beyond embryo research, implications which would be counterproductive for the sick, the disabled, the elderly, and for anyone else who may not be accepted by or convenient to some other individual or group.

Researchers should not be permitted to fertilize ova taken from ovaries removed from women having hysterectomies, nor (the Commission makes no recommendation on this latter point) from the ovaries of women who have died. This would make the instrumentalization of the human, woman and embryo, still more grave, first because of the impersonal objectification involved. Second, the numbers of ovaries potentially available from hysterectomies and/or cadavers, as well as the ease with which sperm can be procured, carry the risk of the creation of a vast industry (even if non-profit) utilizing such embryos, most likely for experimental research rather than for conceptions in the treatment of infertile women, to the

dehumanization of both the embryos and the adult individuals involved and of society as a whole. There are already so many supernumerary ova and embryos remaining from IVF that some are used for research; let these be used for donation to other infertile women if they appear to be healthy.

That research on viable zygotes/embryos would yield useful information is no doubt true, but the same could be said of many sorts of experimentation on human subjects which are deemed unacceptable. Human dignity, non-maleficence, respect for life, and the protection of the vulnerable are higher values.

Research into infertility treatments which do not generate supernumerary embryos and treatments which do not submit a woman to the stress and risk of hormonal ovarian stimulation and superovulation should be pursued as a matter of high priority in policy and funding. I fully endorse the recommendation in which the Commission report encourages such research; the only difference is the primary priority I would prefer to see it given. Treatments of this sort would not only be unambiguously in the health interest of the woman and the intended child. They would also free medical facilities from any suspicion that access to embryos for research would be a priority driving or structuring some modalities of infertility treatment. In accord with the principles enunciated many times by the Commission, the choice of any treatment modality must be unambiguously in the interest of the particular woman and the intended child.

Any viable embryos which have been generated *in vitro* and which are not transferred to the mother immediately should have the possibility of normal life and development, whether by being cryopreserved for subsequent implantation, or by immediate transfer to the uterus of another woman in what may be viewed as a sort of prenatal adoption.

If embryos have been cryopreserved and the male parent dies, it should be the choice of the woman whether or not to have the embryos transferred to her uterus. No external entity, whether a physician, a clinic, a regulatory body or the state, has the right to oblige her to be bereaved at once of her spouse and of their expected, already-conceived children.

Embryos cryopreserved for the time limit allowed by the National Commission, or of whom the female parent has died (given that the male parent cannot gestate them), or who are the subject of irresolvable dispute such as might exist where the male and female parents have died or have divorced, should not be destroyed; rather they should be offered for prenatal adoption to an infertile woman in a manner parallel to the adoption of born children who are wards of the Crown.

With respect to the patenting of cell lines derived from embryos or fetal tissues, the Commission report lays out very real dilemmas, recommending further study. While seeing the strength of the report's arguments from the need for investment, I view the patenting of cell lines derived from human

tissues, specifically those of embryos and fetuses, as unacceptable. If lacunae in the law with respect to patenting of "microbial life forms" now permit such patenting, they should be closed. Patenting of the inventive processes of cell line cultivation or distribution by pharmaceutical companies of the biochemical products (such as insulin or dopamine) derived from such cell lines would be acceptable, but the cell lines themselves are and remain human tissue, with the full, distinct, and individual human genome. Other modes of investment should be developed to ensure research and non-profit access.

The licensing and monitoring structure recommended by the Commission's final report presents a highly useful mode of avoiding abuse and commercialization, of ensuring that all treatments are in the primary interest of the specific woman and intended child, and of assuring high standards of research practice and record keeping. It should, however, permit only research which uses unfertilized gametes or non-viable embryos certainly incapable of human life or development, such as those with three or more pronuclei, or those which will clearly develop into a hydatidiform mole. Some researchers already do very useful work based on observation or manipulation of embryos known to be nonviable.

The approach of Germany, which prohibits all embryo research including research between sperm penetration and syngamy, is exceedingly careful to avoid even the possibility of exploitation of an intrinsically or potentially human subject. An empirically-based and quite reasonable argument can also be made for research on ova which have been penetrated by sperm but in which the separate chromosome-containing pronuclei of sperm and ovum have not yet fused at syngamy. This question deserves further careful examination.

The task of the recommended Sub-Committee structure is licensing and monitoring; the Commission has not recommended that it engage in the active promotion and expansion of embryo research. It is, however, a common tendency of human groups to become agents of facilitation for the activity with which they are concerned — indeed promotion is rightly part of the recommended mandates of other Sub-Committees, such as that on infertility prevention. That promotion is not part of its task should be made explicit in the mandate of the Sub-Committee on Embryo Research.

IV. Aspects of Prenatal Diagnosis

No part of the text of this report which would state or imply that termination is an appropriate response to a prenatal diagnosis finding of a disorder has my support or assent. The pain and great difficulty which the parents of a child with a severe early-onset disorder face should be met by society with greatly increased resources for social support, care, and research into treatment. The knowledge that a person bears a gene for a

disease of late onset says nothing about the value of the life of that person before — or after — that onset.

For each of us death will inevitably come, although most of us do not know when or how. Not knowing the time or the length and difficulty of the process of dying does not make one person's life more significant than the life of a person who does know or whose parents know. Termination, whether for disorders of early or late onset, seems to me to be a final discrimination against the disabled and the sick, a prenatal form of direct euthanasia.

It does not follow that prenatal diagnosis should be opposed as a matter of policy. That many do terminate pregnancies after the finding of some types of disorder does not invalidate the investigation itself. The decisions that people make upon receiving the information may be of greatly differing kinds.

Uncertainty, under circumstances of advanced maternal age or a family history or other likelihood of a disorder, would once have caused physicians routinely to recommend abortion or would have led fearful couples to abort; the availability of PND and the reassuring result most receive cause many to continue their pregnancies to term.

Prenatal diagnosis may prepare a family to receive a disabled child. It may increasingly permit treatment, at the time of or even before birth, of many disorders, such as spina bifida revealed by testing for MSAFP or even some single-gene disorders such as cystic fibrosis or ADA deficiency. Given recent explorations of the genesis of beta-amyloid protein with relation to both trisomy 21 (Down syndrome) and some chromosome 21-associated forms of Alzheimer disease, it may not even be too much to hope for a future treatment for Down syndrome. Recent statements by Dr. Teepu Siddique, head of a research team very recently reported as having identified the defect in a "free-radical" combatting enzyme associated with one form of amyotrophic lateral sclerosis, offer a similar, if still distant, hope for the late-onset disorder commonly known as Lou Gehrig disease.[1] Many other examples are possible. Such treatments would be eagerly desired by many parents.

The structures, norms of information and consent, medical standards and counselling requirements recommended by the Commission are highly constructive overall. Canada does not have a law limiting or regulating the criteria for abortion, although law and precedent do — and must continue to — recognize the freedom of physicians and health care institutions not to participate in it, and should further recognize that freedom as the right of nurses and others. The Commission report's recommendations concerning even-handed, objective presentation of all relevant information and options, including social supports, care, treatment, and the non-directive exploration of personal values in the making of decisions, if fully implemented, will do much to help people to understand clearly the

implications of the decisions they ultimately make, and to encourage at least some people to bear and care for their disabled children.

For these reasons, I give my general acceptance and support to the recommendations of this Commission on prenatal diagnosis.

V. The Genetic Link in Gamete Donation

The Commission has made a highly significant contribution to the question of gamete donation in the recommendations on medical and informed consent standards, record keeping, and the rejection of commercialization. While not all Canadians accept the deliberate and health-care-system-facilitated engendering of children without a personal knowledge and a committed bond between their genetic parents, the widespread existence of the practice and its acceptance by others necessitate its regulation in the best interests of all those involved, particularly the children born. The implementation of most of the recommendations would make great strides toward the care and protection of all parties.

I differ, however, with the recommendation that the children of ovum or sperm gamete donation be denied access to identifying information concerning their progenitor(s) except after a court process and under conditions of serious medical need. Even this would be great progress over the present situation, in which the lack of adequate — or any — record keeping denies the offspring any information, non-identifying or identifying, about his or her progenitor. The Commission report has recommended great progress in procedure and record keeping and it eloquently sketches the negative effects of secrecy, but it does not follow its insight through to completion. The recommendation of a continuing near-universal barrier fails to recognize the rights of the child at the age of majority to have access to his or her own personal information, information which is of great importance to the identity of many people and which is of great social and cultural significance to both individuals and groups in this country.

The donor's right to privacy if he or she does not wish to be known can be protected, and the donor's wish not to bear legal responsibility and obligations toward the child can be given formal and binding recognition without the erection of absolute barriers to identification and contact if both parties are willing.

The right and need of the nurturing parent(s), both social/genetic and solely social, to have full care of and legal custody of the child until adulthood can also be protected. Adoption, with the recognition of rights, needs, and viable protections now evolving in that field, is a very relevant exemplar of the same valid concerns.

If the activation of the disclosure process were to require the child's having reached adulthood, the possible disruption of the process of bonding

and rearing within the custodial family mentioned in the report would not arise. The gamete donor could be able to state intent at the time of donation but be further able to change that decision either way at any subsequent time. This is the model most commonly followed in adoption.

The assumption that the rights of an adult child of gamete donation to information on the specifics of his or her heritage can be negated rests upon definitions of the parent-child bond which would deny the importance of the perduring genetic link, that aspect of his or her identity which is genetically based. In this respect the Commission report has gone beyond affirming social definitions of relationships to absolutizing social definitions, making them the fundamental and sole criterion of ethical and legal recognition, irrespective of the existence of other salient and inherent realities. The determination of these social definitions has been set solely on the wishes of the engendering or receiving adults and, even more, on the fiat of the state; this nullification of the rights of the offspring appears to me to be unjustified on any social or empirical ground.

In any case, reaching conclusions on the nature, structure, and legal definition of the family and of the parent-child link as such is outside the mandate of this Commission. It has not been the subject of the sort of extensive exploration which has rightly been devoted to such mandated subjects as the circumvention of infertility. Such absolute conclusions based on such far-reaching assumptions are therefore unwarranted.

On one other question I also have practical concerns which have implications for the principles we have unanimously affirmed.

Even the general norm that outcome be reported by sperm recipients — unless that reporting is confirmed by confidentiality-maintaining health record data bank linkages — is likely to weaken record keeping to the point that many of the recommendations made in our report would be difficult or impossible to fulfil, given the known low rate of return on questionnaires of any sort. There is a further strong possibility that encouragement of self-insemination, particularly if sperm banks were to operate on a carry-out basis, would undercut the application of the principles at which we have arrived. Of greatest concern here would be questions of record keeping, of medical and other history, and even of commerce. Sperm for self-insemination should be therefore used in a comfortable and well-appointed room provided on the site of the clinic or sperm bank, and should not otherwise be taken out of the facility.

VI. Judicial Intervention in Pregnancy

I do not concur with the recommendation that judicial intervention in pregnancy not be permissible, nor do I concur with the associated legislative measures. Words like "never" are, in my view, far too absolute. Intervention is generally inadvisable, but should not be entirely precluded.

The existing possibility of recourse to the courts, a disinterested forum with accepted legitimacy for mediation and resolution of conflict in matters of human welfare, remains necessary in an area so fraught with ambivalence on the part of all parties in very specific and particular personal difficulties.

Nor would I support a departure from the normal protections of all individuals from medical or other intervention, whatever their sex. Application of the severe sanctions of the criminal law uniquely to interventions directed at pregnant women appears to me to be unjustified. Intervention in pregnancy is not fundamentally different from other forms of medical or social intervention, and women are not so different from men in their essence or before the law that the protections and sanctions governing them should be of different orders.

Such an absolutization could, moreover, have negative and discriminatory implications, calling into question the equality of men and women before the law.

There are many issues in which attention to the collective status of women and the autonomy of women as women would be of proportionately overriding importance; this is not one of them. The consequences for individual vulnerable human beings, both woman and child, are too severe and personal, and the variability of circumstances is too great to be resolved by an absolutized application of a general principle without the possibility of review of individual cases.

The resolution of the situations of individuals should be determined in the best interests of those individuals and of those whom they affect. Their cases should not be predetermined in service to the interests of some other or larger aggregate group, such as women, whose cause (or rather one available sociopolitical interpretation of whose cause) that individual has not explicitly embraced, since no one may be used as a means to an end, however worthy that end.

There may be instances in which judicial intervention would enable and defend a woman's best interests, her actual consent and autonomy against the coercion arising from some particular factor in her situation. One such example would be the case of a severely addicted woman who states clearly and explicitly that she wants her child to be healthy but whose withdrawal symptoms would demonstrably drive her to seek the drug she abuses were she not in mandatory treatment. Since only judicial review and possible intervention would allow the nature of her most fundamental consent and the actual expression of her choice and autonomy to be ascertained and enabled, even autonomy would in some instances require the continued existence of the possibility of judicial intervention in pregnancy. The Commission report itself, in what appears to me to be a contradiction of its own position, refers to the appointment of a legal guardian for a person found mentally incompetent. Such a finding and appointment requires court examination of the case and would

therefore in fact constitute judicial intervention. It is precisely the ineradicable need for the availability of objective assessment such as this in grave cases that is the point of this dissent.

Questions of the existence or non-existence of independent legal or constitutional rights of the fetus are irrelevant to the issue. The state has been declared by the Supreme Court of Canada to have an interest in the fetus, which means that this interest must have some possibility and venue of exercise. The principle of the requirement of consent to treatment, including treatment in the interests of another of any age or relationship, is accepted both in ethics and in law, which means that a woman is protected in general from non-consensual intervention. Positing that the fetus "has no legal existence" and that no third party can volunteer to defend the rights of such a being is therefore neither strictly accurate in law nor necessary to the ordinary protection of women.

I do fully concur with my fellow Commissioners, however, in recommendations which would maximize education, service, and care extended to all women, especially to those who are vulnerable or addicted, so that risk to both woman and fetus can be avoided.

Detailed Reasoning on the Dissenting Opinions

Educational Strategies for STD Prevention

I am in full agreement with my fellow Commissioners with respect to most recommendations on STD prevention, including the conviction that education in sexual health should be made available to all. There is, however, no national consensus on precisely what the content of such education should be. The essential biological facts about sexual function, reproduction, its control, and dysfunctions such as sexually transmitted diseases can be effectively rendered within a variety of value contexts. Value contexts are of crucial importance to those who hold them, but those contexts, while they overlap in some respects, will in some degree be mutually exclusive. There should be full freedom for the presentation of information within those differing value contexts.

Accordingly, I do not endorse the recommendation of adoption at the national level for sexual health education programs of the Guidelines for Sexual Health Education generated by a working group convened by the Sex Information and Education Council of Canada (SIECCAN) at the initiative and under the auspices of EIAC-STD and the Federal/Provincial/Territorial Working Group on Adolescent Reproductive Health. While the guidelines acknowledge differences in value systems, they nonetheless focus on certain components of sexual education as to be required. Many schools, notably the Catholic separate public schools — but also those sponsored by many Protestant, Jewish, Muslim or other religious groups — could not comply with certain aspects of those guidelines and remain true to their mandates. As just one example, such schools cannot, within their value mandates, "affirm individuals who make either choice" in their approach to "adolescents" who "may elect abstinence while other adolescents may not."[2]

The Royal Commission on New Reproductive Technologies, through its commitment to the ethic of care, does take a fundamental stance throughout that the treatment of all human beings should be viewed through a prism of connectedness, commitment, benevolence, and relationship. Were the Guidelines for Sexual Health Education to be adopted as they are at the national level, however, they would not be viewed or implemented through the prism of this Commission but entirely independently unless they were extensively revised from their foundations using the ethical principles of the Commission. The ethic of care, then, cannot be assumed as the prior context of implementation.

The Guidelines themselves, while endorsing choice among a range of behaviours which would be contrary to the belief systems of many parents and religious schools, are silent on such key aspects of the context of sexual health as commitment, childbearing, child-rearing, marriage, or even love. The approach focusses almost entirely on the autonomous individual;

relationships are presented only as something potentially positive about which the individual may wish to make decisions. Sexual expression seems to be the primary given, with relationships a secondary and optional adjunct.

There are many who, consistent with the ethic of care, would see a primary setting in relationships, particularly as a component of the education of children and adolescents, as absolutely essential to the formation of sexual and broader human responsibility. This is the context and the human reality of personal decision. The guideline makes clear that it does not adopt particular strategies, perhaps because it seeks to leave room for the information desired by virtually any age or value or behavioural group. Its very abstinence from any value stance, however, leaves little of practical substance said, and that little highly impersonal. The absence of a value stance is, after all, as much a statement of value judgement as the presence of one. It is a statement of indifferentism and moral relativism. Some people hold this view, as is their right, but it is not in any sense objective or value neutral. Its imposition at the national level would be the imposition of one available view upon all who hold other views.

The guidelines present parents, including the parents of minor children, as one resource among many, rather than as those with the primary responsibility and right with respect to the education and custody of their children in these deeply value-laden areas. In my view and in that of many Canadians, responsibility for the sexual and family life education of minor children is not primarily collective, as these guidelines present it as being. Rather, schools and other agencies of the state function as the delegates of parents. Yet these guidelines, in defining comprehensiveness, lump together in "shared responsibility" virtually anyone who may have some influence, "parents, peers, places of worship, schools, health care systems, governments, the media, and a variety of other such institutions and agencies."[3]

One wonders, moreover, what form of new constitutional social structure is envisioned under the categories of "Integrated" and "Co-ordinated."[4] It seems that in the recommended system "learning in formal settings such as schools, community health systems and social service agencies are [*sic*] complemented and reinforced by education acquired in informal settings through parents, families, friends, the media and other sources," and that "the various sources of sexual health education work collaboratively with each other and with the related health, clinical and social services to maximize the impact of such education."

In such a system, then, the schools, community health systems and social services would have the primary role, and be "reinforced" by parents, who are just one source among families, friends, the media and others. This negates the primary responsibility and jurisdiction of parents with respect to minor children. Yet, as the Commission report clearly and rightly acknowledges, it is they who provide the most effective sex education

when they are actively involved and who provide the most enduring and most deeply imprinted role models to their children. It is they who are most likely to be called upon, before or beyond any state-provided services, to support and help their children, both minor and adult, in whatever may develop out of their sexual relationships and behaviour.

If all these very diverse "sources" are to "work collaboratively," who, precisely, is to coordinate or direct them? Who is to ensure that formal and informal systems really do say the same thing, particularly when we know that many of them at this time (parents, peers, the framers of these guidelines, and various segments of the entertainment and other media) hold widely differing views on these subjects? Surely this model is not intended to be an elevation of statism to a level hitherto undreamt of in Canada. If it is not, then what is being suggested as integration and coordination is not realizable, and one wonders whether it constitutes more a notional ideal than a practical and implementable program of education in sexual health. One may, then, question its appropriateness as a set of coherent guidelines to be adopted at the national level.

The guideline approach also assumes a fully adult, rational, consequence-aware mode of decision making in all sexual matters. It makes reference to age level or cognitive development, but makes few practical distinctions in that light in its discussion of information to be transmitted or behaviour which is appropriate. Whether this is entirely applicable to youth is highly questionable.

The methodology of contraceptive protection, moreover, tends to call upon modes of perception which most young people are still developing and tend to exercise inconsistently. This suggests that other methodologies, such as the presentation of a value-consistent world view which includes the postponement of sexual activity until marriage, have an important role to play. This implies making, at some point, a set of value judgements, not an element of the guideline approach. Teenagers tend to have, as a normal aspect of their developmental stage, an incomplete sense of cause and effect, action and consequence. This is particularly so when the effect is separated from the cause by an indeterminate time, as sexual activity, STD infection, and later infertility inevitably are. Risk and probability are consequently also less than fully comprehensible to many teenagers, the population most at risk for STD-based infertility, since they tend to have an age-based sense of invulnerability and immortality.

Research has repeatedly shown that, however much young people report they know about contraceptive use and STD avoidance, many or most who are sexually active do not use the protections they know about, either consistently or at all. Yet effective STD prevention, condom-based contraception, or family planning of any sort all require precisely the systematic skills and perceptions of planning, cause and effect, and reality-recognition. One may question whether simply multiplying the information and contraceptive provision which is already being done — and of which virtually every teenager is well aware — is necessarily the most effective

approach. Others must not be precluded. Nor is a stress on communication, self-esteem, and assertiveness enough, as important as they are for the avoidance of exploitation, coercion, or simple misunderstanding. Getting their messages straight is not sufficient if what two teens communicate and agree about is nonetheless unsafe and uncommitted premature sexual activity.

Much sex education aimed at teenagers, including that suggested by the guidelines, seems to assume that most are at present or imminently to be sexually active, and that most parents take little or no primary responsibility in preparing their children for responsible sexual health. This is true of some. It is not true of the majority of parents or the majority of young people under the age of 18 years. It is simply not the case that, as the Commission report text claims: "most" 15-19 year olds are sexually active. The evidence is quite otherwise.

The terminology used suggests that the vast majority are engaged in present and frequent sexual activity. The studies available to date do not indicate that such an overgeneralization is appropriate. Distinctions have to be made on grounds of age cohort, of the presence of activity, of the degree of activity, and of other factors such as region and social group.

The *Canada Youth and AIDS Study* tabulates those who have had intercourse at least once in their lifetimes as being 31% of males and 21% of females in Grade 9. In Grade 11, the percentage of those who have had intercourse at least once in their lifetimes rises to 49% for males and 46% for females. These numbers are far higher than one would wish, certainly, but it is not a majority, let alone "most" of those in the population, and, since a single incident at any time in the past counts for tabulation purposes, the actual present activity of respondents is not conveyed. This study goes on to make that distinction; this is helpful because, while even one incident carries a risk, a young person who had sexual intercourse once or twice, at some indefinite time in the past, and who is not sexually active now presents quite a different risk profile altogether from that of a young person who is having sexual intercourse with multiple and shifting partners weekly. The educational and other approaches appropriate to reach the two young people effectively are just as different.

The study indicates that those Grade 9 males were comprised of 11% who had had intercourse once, 13% who had had it a few times, and only 7% who had it often, this last group being a closer representation of those who "are sexually active." For females, the percentages for Grade 9 were 6% once, 9% a few times, and 6% often. For Grade 11, the numbers rise, but still do not convey a majority activity phenomenon. Some 9% of males and 7% of females reported sexual intercourse once; 24% of males and 18% of females reported it as occurring a few times; while 16% of males and 21% of females reported it as occurring often. It is with dropouts (to whose behaviour school-based sexual education programs are irrelevant) that the numbers of those engaged in frequent sexual activity rise precipitately, to

52% of males and 47% of females. These numbers are even higher than those for university and college students, as high as those are.

Let us turn the numbers around, however. In Grade 9, 69% of males and 79% of females report themselves to be virgins. In Grade 11, 51% of males and 54% of females also report themselves never to have had sexual intercourse. Even among university and college students, legal adults who are no longer involved in school-based sexual education programs, 23% of males and 27% of females report themselves as not having yet had sexual intercourse in their lifetimes.[5]

This seems to vary, moreover, not only by study, but by region. A study of girls and young women under the age of 18 years, carried out by Insight Canada Research for Ortho-McNeil, Inc. and endorsed by the Society of Obstetricians and Gynaecologists of Canada, indicated that in 1992 a full 64% of 1 024 respondents had never had sexual intercourse. This rose to 70% among Toronto respondents and 68% among Vancouver respondents, while 55% of Montreal respondents said they had not yet had sexual intercourse.[6] One does not know what the figures for smaller cities and towns or for rural areas would be, nor do these figures cover the Maritime or Prairie provinces or the Territories. One might expect further variation. There is variation also by other characteristics which would be of particular relevance to those framing family life education in separate, denominational, or dissentient schools. The *Canada Youth and AIDS Study* cites church attendance and positive relationships with parents (these two factors themselves found to be linked) as associated with significantly reduced risk-taking behaviours of various kinds, not only sexual activity, but use of alcohol, cannabis, or tobacco, as well as low self-esteem or wishing to leave home.[7] This would tend to support arguments that the different approach of religiously based schools and homes has positive results, that not all populations have the same profile or the same needs, and that not every program need be — or ought to be — geared to the worst-case scenario.

The sexual activity of students under 18 years of age is therefore a minority phenomenon in no way comparable to that of legal adults aged 18 or 19, either in frequency or in its social or psychological meaning. They should not be lumped together. It is at those younger people that sexual education in the schools is directed. The behaviour of the majority should be reinforced, not taken as exceptional and non-normative at their age level. Moreover, mechanisms exist to deal with the hard cases of parental neglect or the information needs and behaviour of troubled minors. To frame all of sexual education in terms appropriate to the hard cases runs the risk of making them normative, of appearing to condone and hence of fostering, for some, the very mindset and activity which it intends to counter.

I do not endorse the recommendation that "requirements for teachers delivering sexual health education" be "in accordance with the criteria outlined in the Guidelines for Sexual Health Education." This would mean

that sex education could only be provided by specialists or the small minority of classroom teachers who have already received specialized training, rather than primarily by the properly resourced classroom teacher who knows the children and is available for follow-up and for an ongoing relationship with parents.

Curricula exist which give teachers and students the materials required for a consistent and well-informed program in sexual and relationship education. One such is *Fully Alive*,[8] a curriculum activating and resourcing parents, teachers, and students, written on the basis of wide grass-roots consultation and collaboration with teachers, students, and parents in every Ontario diocese under the sponsorship of the Ontario Conference of Catholic Bishops. This curriculum is enhanced by in-service workshop training, but does not require expert credentials to present it. The program already covers Grades 1-8; secondary school texts and resources are in preparation. Other such programs exist or could be written.

Family life/sex education is not so different from the other subjects in the curriculum that it requires a different and more elite structure for its presentation. Training of teachers is an excellent thing, and the availability of specialists to help classroom teachers is to be supported; sexual education components can be built into the programs preparing new teachers for the classroom. Neither funding nor personnel exists, however, for the training of the entire body of teachers. As of this writing, indeed, the continuing struggle with public debt has meant that new teachers are experiencing great difficulty in finding employment, and many school boards are facing the grim possibility of staff reductions. For the foreseeable future, requirements of specialized training not already in the background of existing personnel would necessarily mean the removal of responsibility for sex education from most classroom teachers and its lodging with existing specialists and outside speakers.

I would not wish to see sex education dominated by the certainly useful but too often isolated parachuting of an external "expert," such as a sex education consultant or a public health nurse, into the classroom or auditorium for a quick session largely divorced from a larger value or relationship context. Sex and family life education, by its nature, deals with intimacy and relationships rather than impersonal information (the standard "plumbing" lecture) and unfamiliar persons. It should therefore be done, insofar as possible, and particularly in Grades 1-8, by parents and by teachers who have an ongoing and supportive relationship with the child.

As valuable as qualifications are, there is a well-known professionalizing tendency, identified elsewhere in our report, of specialists to believe that they and their colleagues are the only and most appropriate providers of whatever their given activity might be. It is particularly ironic that professionalization should become a factor in something so universally human as the transmission of values in sexual and family life education.

If only specialists are capable of competent transmission in this area, the entire world has been in a very bad way for many thousands of years, and the existence of any healthy families or supportive and loving relationships, or the births of many billions of children themselves are all highly inexplicable.

This is not to speak of the interest involved in making the services, resources, and training which one particular viewpoint-group provide mandatory for a vast population of other educational professionals serving literally millions of clients (i.e., Canadian children). Education is an industry, if an industry of a particularly altruistic, non-profit, and highly regulated sort, and, as in any industry, the nature of regulations and credentialling requirements affects not only the interests of consumers (students and their parents) and of suppliers (teachers), but also of the suppliers of the suppliers (those who engage in the provision of credentialling courses and other resources). Umbrella groups comprising numbers of persons involved in sex education, credentialling, and resource production can be very fertile sources of expertise and insight. Qualifications required for classroom teaching of sex education, however, should be determined by school boards and provincial ministries of education.

I do not endorse the recommendations that schools provide information, condom machines, and referral of young people to clinical facilities for contraception. Children tend to pass through puberty between the ages of about nine and fifteen; all such individuals are minors. For schools to make unilateral provision or referrals without parental knowledge or consent would violate the rights and responsibilities and the religious freedoms of parents. The statement in the text that "in our view, laws related to the age of consent for medical treatment should not preclude teenagers from obtaining contraception on their own behalf" makes the intent to bypass parental knowledge and consent explicit, at least for minors aged thirteen to fifteen. I am not one of those referred to as being of this view.

Extending mechanisms of the override of parental responsibility, which may be appropriate in exceptional cases of neglect or dysfunction, to cover the entire population of families is to extend state intervention far beyond its rightful and constructive role. The schools and family planning clinics would not and could not be there to support the young people in coping with the results of sexual activity they would be being encouraged to make or at least condoned in making. That would be left to the parents whose responsibility and even awareness of the existence of risk had been circumvented and denied.

Decisions on questions of sexual education, moreover, rest with the parents and other taxpayers who elect trustees, even of secular, non-religiously mandated schools and school boards. What may be in accord with the views and values of one community may not be in accord with those of another. Community values should be manifest in the care and

education of the young. Parents and individual students who wish a particular approach are free to choose their school, bearing in mind the values that it promotes.

A requirement that schools provide non-judgemental information, availability of condoms, and referrals to health services with respect to students of any age, minors or older, would also violate the religious freedoms of denominational, separate, and dissentient schools. These are recognized and protected, both under long-held Canadian law and tradition and under Sections 15 and 29 of the *Canadian Charter of Rights and Freedoms*. The Commission report is more careful than the guidelines in its wording, recommending only that "school boards consider the benefits of making contraception readily accessible ..." This is not a new question for any school board given the three decades and more of the debate; it is certainly not a new question for the denominational, separate and dissentient schools. Boards are and must remain free to have policies consistent with their own value mandates and the wishes of the communities who elect their trustees.

I disagree with the linked statements in the report that approaches that promote or give information on only a single approach such as abstinence offer nothing to those who become sexually active, and that programs *should* reflect the "reality that society is characterized by a range of sexual attitudes and behaviours." There are two objections here, one of accuracy and one of constitutional rights and freedoms.

First, accuracy. No group of which I am aware teaches abstinence only, which sounds like a bleak requirement of universal and life-long involuntary celibacy. Many do teach the postponement of good and healthy and satisfying sexual activity until the commitment of mutually faithful marriage. As the Commission report insightfully acknowledges, there is no question that doing this will prevent sexually transmitted diseases, indeed more effectively than any other method. In any case, it is entirely possible to present information on contraceptive methods — what they are, how they work and also their drawbacks — in a context that informs but does not condone non-marital sexual activity. Those who are sexually active would have the information in the context of encouragement to cease that activity. Promotion of the maintenance of sexual expression within marriage is best done, not on a base of ignorance as this report seems to imply, but on a base of full awareness of its constructive appropriateness. Fertility awareness training, including discussion of natural means of family planning as compared with other means, given in many programs, does this. It may be argued that people need to know what a thing is in order to decide not to do it, particularly when it is as socially pervasive as the non-marital sex/birth control message is today. *Fully Alive* presents such information for Grade 8 in a clear fertility-awareness and marital-sexual-expression value matrix.

The need for an elaborate and expensive campaign to train educational personnel and teenagers in the specifics of birth control methods is

questionable in any case, even from the perspective of those who look upon them as important to reductions in STD and pregnancy rates. Any North American teenagers who are unaware of condoms or other methods of birth control must live in a most improbable isolation, not only from their parents and peers, but from television, billboards, pharmacy displays, and mass circulation magazines and other forms of media. Sexually active teens who are capable of decoding the operational instructions for complex audiovisual machinery can also read the instructions on a box of condoms. The semi-literate, who unfortunately are not few, can readily understand the pictorial instructions. The problem is not ignorance but attitude. What is needed is not information that teens already have, but perspective and motivation toward healthy relationships and behaviour. This will of necessity involve value perspectives; these do vary in sometimes mutually exclusive ways, meaning that one approach cannot be imposed upon all.

Beyond that problem of accuracy, however, is the far deeper problem of constitutional rights and freedoms. The requirements and recommendations under discussion are incompatible with the beliefs and the derived moral codes of particular religious groups. Any requirement that a particular essential religious or other mandated moral teaching should be replaced by an incompatible one would be a direct violation of religious freedoms. It would also be a violation of the freedoms and responsibilities of provinces, school boards (both separate and non-separate), private schools, and those social service agencies and health care institutions that serve adolescents out of a particular religious or other value mandate.

Catholic separate school boards, or other religiously mandated schools, or other providers of sex education, whether Protestant, Jewish, Muslim, or any other, are highly unlikely to consider it consistent with their mandates to be obliged by some outside body or guideline to present, as the report suggests, "the range of sexual attitudes and behaviours" that occur in our society as equally legitimate or condoned, or as part of a "variety of options for maintaining sexual health." Many would hold that they could not act consistently with their moral values by telling teenagers, for example, that "sexual activity in life-committed, monogamous marriage is an option, but if you choose such other options as 'delay' (time and criteria unspecified) or 'sexual activity' with a series of 'caring and respectful' partners here are some suggestions, such as 'dual protection,' to make them 'safer' as your 'path to sexual health.'" What of the rest of the possible "range of sexual behaviours and attitudes" not mentioned in the parenthetical examples, since surely those are not the only sexual attitudes and behaviours in society's range? Could such schools maintain the recommended public education norm of being "non-judgemental," suggesting condom use for those who choose promiscuous — or even commercial — encounters? The purpose of religiously mandated schools is to present education within a belief system and its associated value system. This necessarily entails value judgements.

There remains also the delicate question of homosexuality. The Roman Catholic Church which sponsors the Roman Catholic separate public schools teaches that persons who are of homosexual orientation must be welcomed with respect, compassion, and sensitivity, and that one must avoid any sign of unjust discrimination in their regard, but it does not give approbation to homosexual activity, believing that homosexual persons are called to chastity.[9] Many other religious groups — as well as many people whose opinions have a non-religious base — believe and teach from a similar perspective. The Guidelines for Sexual Health Education would oblige all schools explicitly to contradict that perspective.

The Commission report takes as an exemplar the third study by Orton and Rosenblatt. Let us leave aside for the moment the methodological weaknesses of that study. If their work is to be taken as representative of what religious groups may expect, it is enlightening to look at their fourth study, *Sexual Health for Youth: Creating a Three-Sector Network in Ontario.*[10] Since the Commission report does not cite it, the Commission has given no approbation to this aspect of its content. Its mention here, then, is useful rather because this study makes explicit the conflict over values and with religious freedom which has been hitherto under the surface of the debate.

In this publication, distributed by Planned Parenthood of Ontario, the authors target the Catholic Separate School System. They object explicitly not only to its existence, which would be problematical enough, but to certain of the specifics of the belief system of Catholicism — not only with respect to sex education but with respect to its sacramental theology and ecclesiology. While acknowledging that students in Roman Catholic separate schools have more consistent access to family life education than do students in public schools, they object explicitly to the religious values in its content. They represent Catholicism as incompatible with Canadian democracy, which would come as a disenfranchising surprise, both to the voters among the near-half of the Canadian population who are Catholic and to the many who have served or are now serving in public office. The democratic process initiated by the Ontario Bishops in the generation of *Fully Alive* is not mentioned. Even Catholicism's international character is the subject of opprobrium, since the Church is "centrally based in another country." They recommend that the State act in support of change in the belief system of the Church. The intolerant rhetoric is reminiscent of the "no Popery" diatribes of the last century. Since the writers are faced with the existence of a separate school system, they recommend that Catholic schools be permitted to teach according to their beliefs in religion class but be obliged to present Orton and Rosenblatt's agenda (essentially identical in its specifics to that of the Guidelines for Sexual Health Education) in health class. They also state that the same difficulties exist with respect to Catholic children's aid societies.

All of this is clearly incompatible with the freedoms and rights of separate, denominational, and dissentient schools, which exist as fully

integrated educational environments. The statements in the report with respect to the belief system of the Catholic Church would, if made governmental policy, constitute a severe invasion of the religious freedoms of both individuals and groups. In a publication purporting to propose a structure coordinating the educational, social service, and public health systems under provincial jurisdiction for sex education, this is of major concern. The authors have the freedom to hold any opinion they choose about values, personal religious beliefs, and the educational strategies they prefer. In a free and democratic society with constitutionally protected freedom of religion and of separate, denominational, and dissentient schools, one may question whether it is either appropriate or a matter of right for them to recommend that government deny that same freedom to others, in this case to Catholic persons and their institutions.

Fortunately, it is highly doubtful that such an intervention to violate religious rights and freedoms would be taken up as the policy of any level of government. Yet, since Orton and Rosenblatt's agenda and their recommended imposition of their methods on all schools and social service agencies are essentially similar to the agenda of the Guidelines for Sexual Health Education recommended by the Commission report, it is important to note that the Orton-Rosenblatt recommendations have only brought explicitly to the surface the conflict with religious belief systems which the imposition of those agendas would necessarily entail.

Those of that opinion would without doubt have much the same disagreements with the belief systems and educational policies of many religious groups drawn from among those of Protestant, Jewish, Muslim, or Hindu faith, as well as others. Many such groups have private schools that educate within provincial ministry guidelines. Some already receive public funding in some provinces; whether such schools will also receive funding parallel to that of the Catholic separate public schools is the subject of a court case ongoing in Ontario as of this writing. Whether religiously based schools are public or private, however, it is clear that, were such methods to be imposed on all schools and other institutions giving sexual health education, the freedom of religion would indeed become a major issue, of grave concern to many Canadians of many backgrounds and faiths.

There is indeed a role for educational strategies targeted directly to populations, such as drug users, street youth, and prostitutes, clearly engaged in high-risk activities. For this reason I entirely support the recommendations fostering programs to reach these groups. There is also a role for one-on-one counselling of individual students who have demonstrably and irrevocably chosen to take repeated sexual risks. Such strategies are not, however, appropriate for the classroom, the role of which is the development of a value-consistent view of sexuality, not damage control to deal with attitudes and behaviours which are already dysfunctional. Parents of minor children and adults on their own account

are free to choose to be served by institutions whose philosophy and approach are consistent with their own. They should remain so.

A case in point is the Baltimore pregnancy prevention program taken as another exemplar in the Commission report.[11] That program involved schools in a high-poverty inner city region of a city similar to no city existing anywhere in Canada in its industrial decline, unemployment, and associated urban problems. Pregnancy rates were elevated well above the national average, beginning in junior high school. Nine out of ten of the junior high school students and three out of four of the high school students in the study were from families of such low incomes and at such risk of malnutrition that they qualified for the government-provided free lunch.[12]

The control group of schools did not have other types of information, counselling, or service programs; they had no programs at all. It is not surprising that the program produced some considerable rate of positive results, since anything under such severe circumstances may more than reasonably be expected to be an improvement over nothing. On the other hand, the study and the methods of the program provide no valid comparison with other sorts of program, since no others were tested. It seems likely, indeed, that the class presentations and group discussions were far more important than individual counselling or clinic use in delaying first intercourse and in reducing pregnancies, since 72.7% of students were exposed to class presentations and 50.6% to group discussions, while only 19.7% had any individual counselling and 14.5% (most of them girls) made even a single medical visit.[13] Classroom presentations and group discussions are elements in virtually any sort of family life education programs.

One may question, at the same time, whether a model used in this near-crisis context, atypical even of communities in the United States, is necessarily an appropriate model for every school in every city, town, and village across this very different country.

That the Baltimore articles conclude that provision of and school-based referral to medical facilities for contraception is nonetheless a good thing is also unsurprising, not to say predictable. The authors are associated with the Johns Hopkins Department of Obstetrics and Gynaecology, which is deeply involved in research and information-dissemination publications on international provision of birth control. *Family Planning Perspectives*, in which the articles are published, is an organ of the Guttmacher Institute, which has a similar focus. The publication is at least in part funded by pharmaceutical companies through full-page advertisements of contraceptive drugs and devices. These sources represent only one segment, albeit an important one, of a far wider field of discussion and debate.

Conclusion

In sum, the appropriate jurisdictional bodies, institutions, and, in the case of adults and parents of minor children, individuals should remain free to choose the approach they will take to sound and full education in sexual health, both in general and with specific reference to the prevention of the sexually transmitted diseases which can damage or destroy fertility.

Some may assume the prior, inevitable and value-neutral existence of a broad range of sexual practices and seek to provide information, drugs, and devices to reduce the risk. Others see it as their role, their right, and their mandate to reduce the development of the more risk-bearing forms of sexual behaviour by educating young people in committed, respectful, life-giving, and stable relationship formation as a prerequisite for healthy sexual activity. This varies by community, by school, and by other factors. The freedom to choose an approach — and for parents to choose the approach suitable for their children — must remain. Insofar as separate, denominational or dissentient schools — and the parents and taxpayers who support and entrust these schools with their children — take the latter approach as a necessary component of their fulfilment of their mandates, their right and responsibility to do so are constitutionally protected.

No governmental body at any level should attempt to impose conformity with the former view in this highly controverted area.

Any governmental body, including the proposed Infertility Prevention Sub-Committee, with a mandate to foster STD prevention and education in sexual health should have among its members people with a broad range of representative viewpoints, rather than advocacy and service provision groups chosen only from among those with a narrow range of interests and perspectives. Essential among members should be representatives of religious and other value-mandated groups which sponsor educational institutions and other sources of sexual health education such as social services and health care facilities. The Sub-Committee should have a prominent, indeed primary, component of representatives of parents and their groups.

When and if future evidence indicates that one or another approach is vastly more effective and supportive of human flourishing than any other, it will be adopted voluntarily by most. Until that time and beyond, the full and legitimate diversity of views and methods must be preserved and fostered as a matter of fundamental human freedoms.

Access to New Reproductive Technologies[14]

One source of the difficulty arising around access to new reproductive technologies is that, in this field perhaps more than many others, medical, social, legal, and ethical considerations overlap. It is precisely for this reason that the Commission was called into being with its given mandate. In most fields of medicine, treatment is provided on medical grounds utterly

irrespective of the social context. There are certain situations in which aspects of the social context may impinge upon medical considerations, as for example the presence or absence of family caregivers, or the presence of a social network fostering substance abuse. Even in these cases, however, the primary concern and the only criterion of indications for treatment would almost invariably be medical and primarily focussed on the individual.

The social, particularly the social service, and the legal spheres are in many respects different in that regard, since human relationships and personal capacities and attributes are by definition an intrinsic factor in any assessment, therapeutic program, or legal relationship in the undertaking of social and legal roles. Where in medical practice the focus is the relatively isolated individual, in the social, social service, and legal spheres the focus is on relationships linking varying numbers of individuals, the characteristics of one necessarily having an impact on all the others and on the nature and functioning of their relationship. Social factors are a crucial element in whether or not a social or legal relationship is likely to be functional or enduring. If such relationships are set up without regard to those factors, harm, sometimes great harm, may ensue for all involved, and particularly for the most vulnerable. These separate spheres, then, have tended to have somewhat differing ethical approaches to criteria for access. Assessment of one or another among a broad range of criteria, such as marital status and stability, personality profile, or income and stability of employment, can under limited circumstances be considered not only acceptable but necessary in determining the appropriateness of access to many sorts of service or relationship, both personal and wholly contractual. Examples could include adoption, admission as a client to a specific sort of social service therapy group or program, employment as a Children's Aid Society foster parent, or, as with income and employment, the taking out of a mortgage.

New reproductive technologies are not focussed solely on the isolated individual patient, but necessarily affect others, principally the child who is to be born, over a lifetime. They also affect the human relationships which are the subject of much of the content of value systems held by individuals and groups, not only of patients, but of practitioners and health care institutions and the body politic comprising the taxpayers and their governmental institutions. In my view, given the broad interaction of social and legal factors in the medical practice of provision of new reproductive technologies, the reduction of the multifaceted ethics of the social, social service, and legal spheres to the single-factor ethics which appropriately characterize the medical sphere would not only be inappropriate in itself, but would also have negative consequences of many sorts. It is with these that this dissent is largely concerned.

It is one thing to say that people may do a thing if they consider it appropriate. It is another thing entirely to say, as the Commission report recommendation does, that they must do it whether or not it is in accord

with their moral and ethical convictions, on pain of being excluded from any capacity to provide that type of service to anyone.

The recommendations of this Commission report would not, indeed, overtly and actively force a physician or a religiously sponsored medical facility to provide new reproductive technologies against their consciences; it would simply face them with an invidious choice. They would be obliged to provide licensable technologies under circumstances that would conflict with their mandates and ethical codes, or they must withdraw from providing them altogether. This would, in effect, discriminate against such religious individuals and institutions, since it would bar them from the provision of new reproductive technologies to anyone. The fact that their views would be in accord with those of the majority of Canadians would not protect them from being excluded from the field of reproductive technologies. For example, a physician who would not give a prior commitment to provide assisted insemination to unmarried or lesbian women would be barred from receiving a licence to provide it to the majority of those seeking it, those already in stable and committed heterosexual relationships. The same would be true of physicians or clinics whose fertility practice consisted largely of licensable hormonal treatments of anovulatory or irregularly ovulating married women or of IVF or GIFT or DOST to women in stable heterosexual couples. That unmarried or lesbian women would be unlikely to seek such treatment would be irrelevant, were an explicit commitment to use only medical criteria and exclude any social factors nonetheless a condition of every licence issued by the National Commission. If he or she were already in practice, the choice for a physician would be between conscience and the abandonment of developed expertise and livelihood. A hospital which could not accept such a policy in principle would be barred from seeking to provide licensable reproductive technologies, and, if it were already providing fertility therapy, would be obliged to close its existing facilities.

The non-use of any but medical criteria should therefore not be made a condition of the licensing of fertility clinics/sperm banks. Such a condition would be discriminatory in that it would prohibit the provision of reproductive technologies by hospitals and clinics sponsored by religious groups or community-elected boards which hold another moral/ethical perspective. It would also be counterproductive with respect to overall access to provision of assisted conception. There are at this time in Canada a certain number of such health care facilities providing one or more of the licensable treatments, such as DOST, GIFT, IVF, and donor insemination. They may have a mandate and character arising from Salvation Army, Roman Catholic, or some other affiliation or community value base. Some health care facilities and sponsoring organizations would be certain to decide that they could not both comply with such a requirement of licensing and act consistently within their mandates. This licensing requirement would have the concrete effect, then, of causing health care institutions sponsored by some religious bodies or working in

board-electing communities viewing some non-medical factors as legitimate and essential to close down existing assisted conception facilities rather than act in contravention of their own consciences and mandated ethical perspectives. It is ironic that a requirement which seems directed toward increased access would have the actual effect of reducing it for the great majority of the population of those seeking assisted conception.

Licensing requirements can be exceedingly constructive in maintaining high standards of medical practice, record keeping, and research. It is on this base that I am in accord with their establishment. They should not, however, be used as a mechanism of social engineering. To use such licensing as a basis of enfranchising and conferring legitimacy upon only those practitioners and others who espouse one set of values, thus setting precedents for other areas and forms of practice and excluding those who hold other sets of values, does, in my view, constitute social engineering, whether or not those making the recommendation intend it to be so. If that were to become a feature of the purpose and function of licensing requirements, inseparable from their other, legitimate purposes, I would oppose them. Permitting diversity in practice is one thing. Forcing uniformity of practice in a conscientiously controverted and value-laden area, against the clearly stated values of the majority of Canadians, is quite another.

The exceedingly important principle of equality is cited in the Commission report with respect to access to new reproductive technologies, but it is implicitly equated with autonomy. This individual autonomy is an extension of the single-factor ethics of medical indication which the Commission report has taken into the social sphere on this issue, duplicating there its focus on the individual. People are considered equal only if they receive the same service if and as they autonomously choose. This is not, in my view, a valid equation. A person may be fully equal with all other persons, and have all the rights and obligations of citizenship, without having a right to demand the activation of every available service of society to facilitate each of his or her social choices.

We may look for parallels to other fields of social life. Marriage is a great good, and the freedom to marry is as fundamental a human right as the right to seek to bear or beget children, but a person cannot demand that the state provide him or her with a spouse if there are no volunteers. A person may wish to be employed in a high-income position, and must be free to seek such a position, but he or she cannot expect to be hired without certain social characteristics such as the relevant ability, training, and experience, and even then a given employer is not obliged to choose that individual if another, more qualified applicant is at hand. The government, for its part, is not called upon to provide or guarantee another such position. Yet the unmarried person is equal as a human being and as a citizen to any married person in the land, and the person who must seek another job is equal as a human being and a citizen to the other who was, in the event, hired for the specific position.

The absolutization of the principle of autonomy, which is what is chiefly at issue here, would risk or require the non-fulfilment or the contravention of other principles, such as those of the best interests of the child, the constitutional and other appropriate jurisdictions of the various levels of the health care system and social service systems, the freedom of individual health care providers not to be obliged to act against their consciences, and the freedom of religiously mandated health care institutions to follow the moral codes inherent in their nature.

The recognition by the Commission report that there may indeed be some circumstances in which provision of new reproductive technologies would not be appropriate is very much welcome. Yet reproduction is not so different from the other fields of medicine and, with respect to the best interests of a child, of family law and of the social services that the ordinary modes of resolution of conflict over the applicability of health care facility policy to particular individual cases should be replaced by the blunt instrument of prior specification in law of some list of criteria for discretion. Such a requirement would be unwieldy and unreasonable, given the great variability of human situations. What may be a factor of limited weight in one situation may, in combination with others, have quite a different significance.

The best interests of the child, a principle clearly recognized in law, should take precedence over any other interest, as all Commissioners agree. As will become clear, however, we disagree as to the probable effects of various non-medical factors on those interests. As with any other dispute surrounding the application of policy or the assessment of what would constitute appropriate action, appeal may be made, as for example to institutional boards of ethics, to boards of directors, or to the courts. To substitute for this a list of criteria emanating from the federal or provincial legislature would constitute a major shift of the locus of decision making with respect to individual indications for treatment and service from the local institution and jurisdiction where the treatment or service takes place to the legislative functions and offices of the upper reaches of government. This would be contrary to the principle of subsidiarity, that decisions should be made as close to the level of application as reasonably possible, authority being accorded to each successively higher level of jurisdiction only as necessary for the effective functioning of society and for the mutual respect, protection and service, both of those directly concerned and of all.

A centralized, governmental, legislative specification, at either the federal or the provincial level, of a list of such criteria would be insensitive to the complexities of human situations. It is quite true that individual physicians or social workers or other such front-line personnel may err in their assessment of such a situation; it is for this reason that appeals may be made. It does not follow that they always err, or that they err in any but a minority of instances. The entire system of child protection, for example, is predicated on the assumption that in a majority of instances social service personnel, properly trained and supervised, will only intervene when

there is sufficient reason, and that it is better to risk intervening unnecessarily in some cases than to risk the results of failing to act upon an assessment indicating serious cause. It is also true that only such front-line, trained persons are in any realistic position to perceive and analyze what may be very complex and difficult human situations. Even where appeals occur, they are usually accompanied by yet more analyses of often ambiguous and always complex human situations through the perceptions of other front-line persons with specialized expertise.

To replace the best judgement of a physician, associated social service personnel, and the whole process of boards and appeals with a legislated list is tempting because it may appear to cut the Gordian knot. By ancient legend he who untied the convoluted knot tied by King Gordius of Phrygia would rule all Asia. Alexander the Conqueror did indeed take direct and apparently simplifying action, slicing the knot in two with his sword. He did not, however, untie it; he merely left its severed strands in a heap on the ground. He did defeat the armies of diverse societies until he crossed the Indus River in what is now Pakistan, but he had little inclination to create or foster administrative structures which, to be effective in dealing with human complexity, diversity and ambiguity, are necessarily somewhat tedious. He promptly died, and his brief empire quickly came to resemble what his over-simple and control-taking action had made of the knot.

It appears to me likely that replacing front-line perception, decision, and due appeal to established structures with a blunt, legislated list of permissible criteria could do less good and more damage by its insensitivity to individual situations and to legitimate variation than would ever have been done by the modalities and entities it seeks to replace.

Even from the perspective of the adults seeking service, access to reproductive technologies is not a simple question of autonomy rights. Reproduction is not entirely a private act, even under the usual circumstances. It affects the community, and the community is called upon to exercise energy and resources supporting the adults and children involved. For this reason we publicly license, witness and register marriages, register births, assess and register adoptions, pay to educate children, and bring to bear all the provisions of family law where necessary. The act of conception and the choices around reproduction, however, are so very personal that they are essentially private except insofar as they necessarily call upon the resources and activity of the public sphere. Ordinarily they do not. When, however, a person or two persons seek the help of new reproductive technologies, the acts have taken on a more explicitly public character. Instead of proceeding on their own, without interference or help from society, individuals or couples are seeking to mobilize the health care system, its institutions, its personnel, and public funding to bring about a conception. The choice is no longer primarily private, but in some large, even predominant degree, public. At this point, others are being asked to act to enable an action. They, too, have choices.

Reproductive rights are negative rights; that is, no one may interfere to prevent individuals from making the reproductive decisions they choose to make, whether or not the actions may be deemed wise, moral, or functional, so long as no publicly demonstrable harm is done to others and all actions are consensual. Reproductive rights are not, however, positive rights, or entitlements.

First of all, as this Commission has underscored, a child is a person, not an object to which another person has a right. The child is an end in himself or herself. This is an issue, not just in the relatively new field of new reproductive technologies, but in the established field of adoption, in which social criteria are very much part of the home study assessment in the best interests of the child. Again, people have a negative right to seek to have children, not a positive right to demand that government and its agencies act to provide access to another person. It is the child who is the end, to be cared for by the adults who derive their satisfaction and fulfilment from enabling the child, not by using the child for their own rights-fulfilment.

It is entirely appropriate to apply human rights theory and law on non-discrimination to access to goods, services, and equal opportunity in the educational and occupational life of an individual. That individual, however, cannot demand that the same characteristics which must be ignored in giving him or her access to things also be ignored when he or she seeks access to persons, particularly when one or more of those characteristics would in some way limit the best interests of or jeopardize the other person or persons.

As just one obvious example, age is a prohibited ground of discrimination under human rights law, but the adoption of a child by a person or couple over the age of, say, 50 would make the orphaning of that child before the age of majority a distinct possibility, not to speak of the natural, progressive diminution of the sheer physical energy required to care for a young child or adolescent. There are instances of post-menopausal women seeking egg donation by IVF so that they can bear a child; it is not only for medical but also for social reasons that this is unwise, in the best interests of the child. The unanimous recommendation of this Commission that post-menopausal women not be candidates to be recipients of egg donation is therefore, in my view, wise and justified, not only on the cited biological and medical grounds, but on social, psychological, and other grounds as well. This is just one among the illustrations possible of a situation in which the social context ought to be an important factor in the formation of policy and/or in the right of a physician to refuse treatment. This would clearly not be consistent with the recommended rarity of instances of refusal on non-medical grounds. Similarly, the presence or absence of significant marital conflict if a person is in a partnership is irrelevant to and should not be a factor in job applications or advancement unless it demonstrably affects job performance; it is highly relevant to the environment in which a child will

be raised, to the point that it becomes a factor in what is, in effect, the capacity of an individual or couple to fulfil the parental role. This is recognized under child welfare legislation and jurisprudence, as the presence of grave marital conflict can become one element in cases of child protection.

As a further example, Sweden, a very liberal culture with its acceptance of a high out-of-wedlock birth rate and its strong emphasis on individual human rights, is only one of many countries which require that both *in vitro* fertilization and donor insemination be provided only to stable heterosexual couples. It requires, moreover, that insemination must be performed in a public hospital. Sweden goes further in specifying that only the gametes of such partners (rather than donated gametes) be part of IVF therapy, and in requiring that only those willing to make a commitment to disclosure of their identity when the child reaches adulthood be permitted to donate sperm.[15, 16] That some social criteria have a legitimate component role in access to reproductive technologies has ample precedent, then, not only in practice and health care institution policy in this country, but in both practice and law in various other countries.

Both age and marital stability or conflict are part of the overall question of the ability to parent. On one level, some social criteria as related to parenting are parallel to job qualifications and ability, assessment of which is not deemed discriminatory. On a far deeper level, however, it is a question of whose welfare and interests are the focus of decision making; family law reflects the broader principle that it must be primarily those of the child.

Second, those providing even a highly valuable but nonetheless not medically necessary service have a right to choose whether or not they can in conscience perform any act. Childbearing is a very deep part of our humanity, and infertility is a physical and therefore a medically definable condition. It is a great good to give the medical help necessary to enable a wanted conception. Yet an infertile person is not in personal, physical danger. A person who is fully fertile but who wishes access to new reproductive technologies to bring about a pregnancy for the essentially social reason that there is no partner of the opposite sex is still less at any discernible medical risk. I do not think there is an absolute requirement to provide a medical service to a person who is not, effectively, in physical danger, although providing it may be a good thing. There is no positive requirement at all, in my view, to provide that service if the person has no medical indication as such. Nor, from the testimony I have heard and the material I have read, am I alone in this view. A difference of opinion clearly exists on whether or not the ethical principle of an obligation to rescue is operative here. Differences of opinion and therefore, when it comes to the point of action, differences of conscience may therefore exist on either entirely secular or religious grounds.

A person or a pair of persons, while they may request facilitation of their wishes, do not have the right to oblige others to facilitate or act to

bring about what they wish, even against the will, conscience or better judgement of those others. Government funding, and hence taxpayer funding, of new reproductive technologies is a prudential choice, in my view not only a good but a wise one, since among other things it brings them under a regulatory and record-keeping framework and avoids both commercialization and a two-tier system of health care. It is for this reason that I fully support related recommendations of this report. Such funding is not, however, a matter of strict entitlement.

Society cannot interfere, then, in most personal reproductive activities even in circumstances under which those activities may be thought to be dysfunctional, ill-considered, or contrary to the moral views of some or even most individual members of the body politic. Society is not, however, obliged to enable and fund all such reproductive activities. That is a choice, like many other questions of social policy, which society must make. This should usually be on a local institutional basis and ordinarily with responsiveness to the community being called upon to fund the policies and activities being undertaken. This is in accord with the principle of subsidiarity. The freedom of conscience of individual professionals, both physicians and nurses, and the freedoms of religiously mandated and sponsored health care institutions must also be preserved as a matter of fundamental human rights.

Social considerations become concerns, indeed they become moral questions, not solely but largely because they have a practical impact on the welfare of human beings. Let us take the instance of marital status. There are legitimate and well-documented concerns about the difficulties faced by the children of single-parent families. Certainly, love and stability are even more important than family structure. A loving and stable single-parent family is a better environment for a child than a two-parent home filled with severe and irresolvable conflict or even abuse. Single mothers often labour heroically and successfully to raise their children healthily and well.

Their task, however, is more difficult than that of a two-parent family, for both economic and psychological reasons. Children in single-parent families are, much as we wish it were otherwise, more at risk than are children in stable two-parent families for lower school achievement, a higher rate of psychological difficulties requiring treatment, and dysfunctional behaviour, including involvement with the justice system. This is, be it noted, only an increased risk, not an absolute prediction for every individual case, but the increased risk has been repeatedly demonstrated statistically. It is real.[17]

As a society, and as the relatives, friends and neighbours of single parents, we are called upon to be as supportive as possible to those who find themselves raising children alone, and to recognize and value their achievements. Nonetheless, whether we are required to act, or to fund the health care system to act, deliberately to set up this higher-risk situation from the outset is a question which may legitimately be asked.

Income is another question. Concerns, valid concerns, have been raised in the report about the tendency of those couples recorded as having received infertility treatments to be of the upper income brackets. Insofar as this is due to the cost of treatment, it is a compelling argument for government funding of the procedures. It is likely, of course, that some of the skewing by income status has to do with the known tendency of those with higher education to be aware of and to seek out and trust technological solutions to this as to many other setbacks or challenges they experience.

Nonetheless, beyond the immediate question of treatment funding, there is the question of the resources available for the child's ongoing security and upbringing. A child of a non-affluent but nonetheless financially secure, solid, loving family is as well off on the human level as the child of a similarly stable but affluent family. Discrimination against the non-affluent would be contrary to justice, and our recommendations seek to counter it. In the probably rare case in which the income of a woman or couple seeking new reproductive technology assistance is exceedingly low, however, or were the income to be dependent upon social assistance (welfare), one may question whether either the best interests of the child or fiscal responsibility would be consistent with *requiring* a practitioner to provide infertility treatment or donor insemination. Again, absolutizing even a good principle is frequently imprudent, excluding the fulfilment of other principles.

There are many reservations expressed by Canadians about the appropriateness of provision of new reproductive technologies in cases which do not concern a committed marital partnership or in which there are doubts about the capacity of an individual adequately to care for a child. The Commission report cites a survey of clinics, reporting that a number of non-medical criteria are often used in determining access at many facilities. These may range from such factors as the ability of a mother to stay home with the child to psychological immaturity, or doubtful ability to parent, with lack of a partner, low income, sexual orientation, and country of residence among them.

First, the questions raised in the survey of clinics are very different in their import. In a society in which the majority of mothers of young children do work outside the home, at least in part because the costs of raising children now often require a double income, it would seem inconsistent for a health care facility policy to exclude women who are in the workforce. New reproductive technologies, we must remember, if successful, aid in the birth of newborn children. This is quite distinct from the situation of adoptions of children who are older than newborns; the disruption they have experienced may make the full-time, consistent availability of an adoptive parent at home a therapeutic necessity as it would not be for a newborn whose sense of trust and bonding is still in healthy formation and has not been traumatized. Country of residence or low income may have quite a different practical import, whether for the

child or for the publicly funded health and social service systems. Sexual orientation and marital status touch both upon social values and upon differing views of the best interests of the child.

Second, the Decima survey entitled *Social Values and Attitudes of Canadians Toward New Reproductive Technologies*, carried out for this Commission, demonstrates that Canadians do share some of these concerns. While 74% supported new reproductive technology use by a couple unable to "conceive unless the egg and sperm are brought together outside the body and placed in her womb," with only 6% opposed and 15% neither supporting nor opposing, a very substantially lower 30% supported the proposed scenario of a "single woman who is inseminated with an anonymous donor's sperm so she can have a child," with 46% opposed and 23% neither supporting nor opposing. The proposed scenario of "a lesbian couple who have one of them inseminated with an anonymous donor's sperm so she can bear a child" was supported by 11% and opposed by 71%, while 13% neither supported nor opposed it. They were not asked directly about their views on the ability to parent.[18] It seems, then, that the Canadian population does not equate all situations of family formation. It would seem clear that many Canadians do consider at least some social criteria to be relevant and applicable to the use of new reproductive technologies.

Taking the issue from a different angle, more indirectly related to the use of reproductive technologies, the survey found a similar variation. When asked their attitudes toward various groups having or adopting children, 39% were supportive of a single woman deciding to have children outside of a marriage or common-law relationship, while 35% were opposed or strongly opposed and 25% were neither. Some 33% were supportive of a single man doing so, with 43% opposed or strongly opposed and 23% neither. A homosexual co-residential couple having or adopting children was supported or strongly supported by 16%, opposed or strongly opposed by 65%, with 18% neither supporting nor opposing. Only 15% supported or strongly supported having or adopting children on the part of a married couple on welfare, while 63% were opposed or strongly opposed and 22% were neither.[19]

This would clearly indicate, again, that many Canadians consider some social characteristics to be relevant to family formation. It would seem that this constitutes a considerably more widespread and more definite and analytical societal view than is suggested by the report phrasing that "some Canadians are uneasy about family forms that might be facilitated by such access to AI." It is not a vague emotion of unease; it is an opinion and a fairly consistent set of social values. It is unlikely that respondents as a representative sample of voters and taxpayers would wish to fund services, or would wish their government and publicly supported health care institutions to be required across the board to provide services which would deliberately bring about situations which they do not support or which they oppose.

The argument against the applicability of the opinion of the Canadian public as framed in the Commission report is interesting. It affirms that "society's approach to new reproductive technologies should be governed by the social values of Canadians." It goes on, however, to make a distinction between "social values" and "individual opinions," which appears to mean that the opinions of even a majority of Canadians are not their real social values. The report states that "the social values held by Canadians are reflected in the *Canadian Charter of Rights and Freedoms*, and the prohibitions on discrimination it contains must be our guide in this matter."[20] There are various levels on which the implications asserted to be covered by this statement can — indeed must — be examined and questioned.

First, the stated view of the nature of non-discrimination is only one among many possible interpretations of the Charter on this question. Up to the present, no court has ruled that the Charter is in fact to be interpreted in such a way that the prohibited grounds would take precedence over the best interests of a child or of the freedom of conscience and religion in matters of doctrinal and the derived moral import.

Nor is it readily apparent that all the grounds mentioned in the Commission report are in fact subsumed under the grounds prohibited under the Charter. Even marital status, sexual orientation, and income are given only as examples of an unspecified range of non-medical criteria to which the Commission report refers. Of yet more fundamental importance, the Charter does not disallow the use of criteria which affect the capacity to fulfil a function or a job description.

I do not see how the views of an overwhelming majority of Canadians can be construed as not being an authentic representation of the social values of the country. The survey done for this Commission of Canadians on their attitudes toward new reproductive technologies delineates the problem clearly. Half again as many respondents opposed single women's use of reproductive technologies as supported it. Nearly three-quarters were opposed or strongly opposed to the use of reproductive technologies by homosexual couples, a tiny minority supporting it. Nearly two-thirds opposed a couple on welfare having or adopting children. Respondents were not asked their opinion of new reproductive technology use by such a couple, but, on the clear pattern emerging on the other questions, one would expect greater opposition to action by the public health care system to bring about a situation that respondents do not support. The responses cited here have specifically to do with marital status, sexual orientation, and income, the three examples of an unspecified range of non-medical criteria which the Commission recommends not be used as criteria of access. If this survey validly reflects a cross section of the views of the population, and every indication seems to confirm that it does, how can their stated opinions on appropriate family structure and on inappropriate uses of health-care-system-provided new reproductive technologies be said not to reflect or constitute the "social values of Canadians"?

One interpretation among the diverse existing interpretations of the Charter is taken in the Commission report to be the real and only reflection of the social values of Canadians. Do not the views of a strikingly large proportion of its citizens have a role to play in defining what the social values of a country are, and in the intimately related interpretation of what, under the Charter, is "justifiable in a free and democratic society"? Do the views of the people, the *demos*, not have an essential role in defining the values and therefore the shape of a democratic society? Quite an interesting — and probably rather heated — discussion of the nature of democracy, representation and responsible government could be focussed on this question.

It is, moreover, the right of health care professionals to follow their consciences in matters of health care provision. As of the present time, that right is recognized for doctors; it should also be clearly recognized for nurses and others who are closely involved. Social considerations in the provision of therapy which is not a matter of entitlement even if it is publicly funded may also be questions of conscience. That some of those social considerations are indeed matters of conscience is clear enough from their being the subject of ethical and moral codes in virtually every society of the world.

Questions such as whether those codes ought to be altered in some way, or whether the services should be provided within such a code under one circumstance or another, and the salience of the effect of that choice on others, including the child, are part of a moral and ethical argument, not a medical one, no matter what the opinion of a particular speaker one way or another may be. This is even more the case with donor insemination than it is with IVF, since the provision of donor insemination to a woman not in a committed marital or common-law relationship with a man is an instance of medically delivered circumvention of a social problem. On the medical level the woman herself is probably fertile, which means that the procedure is not, in essence, a medical treatment at all. If recent developments in the technological capacity to fertilize a woman's ovum with the single sperm of her husband become widely successful, donor insemination or IVF using donor sperm within marriage could become almost completely obsolete, used only in cases of total azoospermia, or lack of sperm, on the part of the husband. The field of donor insemination, then, including the formal structures recommended by this Commission, would be almost entirely concerned with provision of sperm to fertile women with no male partner.

Let us leave aside the surrounding prudential judgements about the financing of DI services and structures if demand from married couples (the majority of present cases) were to be greatly reduced. Let us rather focus directly on the existence of a significant social component in the question. Access to new reproductive technologies, particularly DI, then, is now and, in a probably increasing degree will be, a medically mediated circumvention of a social, not a physical, problem.

In a pluralistic society, the available provision of such a circumvention is acceptable, so long as the best interests of the child are of primary concern. The framing of an absolutized national requirement that no social/moral questions can be brought to bear on the provision of a primarily socially conditioned service is not acceptable. It could not help but be an interference with the consciences of those health care providers who object, either in general principle or under specific circumstances, to doing so.

The incompatibility of such a recommendation with the essential freedom of religiously mandated health care institutions is also quite clear. Hospitals and other health care institutions run under the auspices of religious groups, whether they be Catholic, Jewish, Salvation Army, or any other, are protected (as collective expressions of individual religious freedoms) under the religious freedom provisions of the Charter. These freedoms have their foundation, not only in fundamental human rights, but in Canadian law and jurisprudence since the *Quebec Act* of 1773 and the *British North America Act* of 1867. Religiously sponsored health care and other institutions are and must remain free to set their policies in accord with the moral codes inherent in their mandates. This means that they must continue to be free to expect, not only that their co-religionists among the staff will be personally free, but that the institution as a whole will, through the decisions of its board of directors, remain free to set policy to be followed by all staff in accord with the principles, religious laws and values of the sponsoring religious group. No national commission or agency has the right or jurisdiction to deny that freedom.

This is of utterly essential importance far beyond the field of new reproductive technologies. If once the policy of a national or any other secular body were to be given effective jurisdiction to overrule religious principle and were to be made binding on a religiously based institution, this would have the effect of denying the freedom of religious health care, social service, and other institutions. The precedent would be as applicable in hospices for the terminally ill or in chronic-care facilities for the frail elderly, emergency wards, and intensive care units, or in the adoption services of social service agencies as in departments of obstetrics and gynaecology.

This is not alarmism, but the consequence of the application of a certain controversial school of thought about the nature of the definition of equality under the Charter. This school of thought would seek to erase religion — among other value systems — as a foundation of legitimate diversity of practice in public institutions. There is discussion in some circles, for example, of viewing as discriminatory the placement of a child for adoption in accord with the religion designated by the mother and in accord with the mandate of religiously sponsored adoption agencies. This would mean that a Christian or Jewish or other religious organization sponsoring an adoption agency could not place children according to the religion of the mother who had approached them on her child's behalf, and

that a mother could not designate the religion in which her child would be raised should she approach a secular agency. This, in my view, would violate the freedom of religion of the mother and the legitimate mandates and policies of the agencies concerned. The imposition of this and other, similar policies in adoption would also, I am certain, cause still more young mothers to avoid situations of adoption placement in which they would have their newly-won role in the choice of adoptive setting for their children taken away from them again.

I am fully in accord with the Commission recommendation that there be a review of adoption in Canada. It is clear from the text, however, that this is one of the issues which would be examined under the heading of "equality or non-discrimination in access." This illustrates the fact that the ruling out by government of any social factors, including religious belief, with respect to provision of new reproductive technologies would set a precedent with application in a far wider range of fields than would be at first apparent.

The fields of application are broad. A precedent would have been set by which Christian moral and ethical principles, or Jewish moral and ethical principles and rabbinic decisions on the application of Halakha to health care — or any other moral system basic to a religiously-sponsored facility — would no longer be matters of right in religiously-based institutions. They would have been preempted by governmental fiat at the federal or provincial level. If they operated at all they would do so only at the pleasure of government. In these days of reductions in available funding and of discussion of triage, treatment priorities, and even euthanasia, it is essential that religiously based institutions remain free to interpret their ethical policies according to their mandates.

I gravely doubt that the removal of the freedoms of religiously-sponsored institutions with respect to new reproductive technologies, or the setting of the associated precedents for other institutions would be in accord with the intent or the policy of the federal government or of most decision makers within provincial governments; I also gravely doubt that it would survive a court challenge. It would certainly be a question of crucial import to the religious communities. This set of recommendations should not, therefore, be supported.

In our pluralistic society there is a clear diversity of perspectives on how best to apply even universally-held human values, as well as the well-known respectful disagreements on what the approach to other values should be. Religiously sponsored institutions, whether in health care, education or the social services, pioneered the foundation of these services in Canada. They carried the bulk of the responsibility during much of the history of our country until changes in scale, demographics, and technology made the transfer of funding responsibility and some — but not all — other functions to the secular government necessary and appropriate.

Religiously-based service institutions have a great and constructive contribution to make, both in today's complex society and in the developing

future. They must continue to be free to present their vision and to be available to those who seek their services, amid the evolution, and/or the waxing and waning, of opinion, philosophical theory, and political approach in other wings of those sectors.

Those who hold that only medical criteria should impinge on access to new reproductive technologies are working as much out of a philosophical, ethical, political, and moral position as are those who see consideration of some social factors as appropriate, whether they hold that contrary view for secular or religious reasons or both. There is no purely or minimalistically "scientific" or "objective" approach to these questions; all approaches entail value judgements based upon a set of ethics arising out of a world view, whether the person holding them has reflected systematically on them or not. Even agnosticism and atheism are theologies; on the secular level even the avoidance of ethical/social evaluation entails an ethical/social evaluation. A public forum that excludes the ethical values and the contribution of religious communities, comprising as they do large sectors of the citizenry of this country, and that excludes the service institutions they sponsor, has not opted for the removal of value judgements from the process. It has merely imposed one set of value judgements, those absolutizing autonomy whatever its characteristics or impact, on everyone and removed other voices from the service of the people.

Nor is it clear to me that even health care institutions not sponsored by religious groups need necessarily exclude social characteristics or criteria entirely from their consideration of policies on access to new reproductive technologies. They are certainly free to exclude some, most, or all social characteristics as factors. Some already do, on a general policy basis or in response to individual circumstances on the basis of physician discretion. They are, however, in some degree responsible to the communities who pay the taxes supporting their services. Some communities might be in full overall agreement with the exclusion of social criteria from the question. Other communities might exclude some but consider others relevant. As has been pointed out, the data from the general cross-section survey of Canadian opinion found considerable variation in the importance given to one social factor and another by respondents.

The boards of such particular hospitals should not only consult with a broad range of persons of expertise, such as ethicists, social scientists and the members of community groups, but maintain an open dialogue with their surrounding communities; the setting of policies with respect to access to new reproductive technologies should then rest with those boards. Again, this should be a local institutional decision, bearing in mind the appropriate professional association guidelines and within the guidelines, regulations and legislation of the appropriate provincial bodies.

Conclusion

It might not seem that so apparently small and inclusive-sounding a thing as recommending a requirement that access to new reproductive technologies be confined to medical rather than any social criteria would raise such broad and fundamental questions. Nor would the brief discussion of the reasons given in the report for it seem to bear so many unexamined presuppositions and implications. The reality, rather, however unintended it may be, is a radical exclusion. Its purpose and mode of operation are specifically to exclude health care personnel or institutions — and the communities of citizens who host and fund and are therefore the ultimate providers of infertility treatment — from the exercise of their choices based on differing ethical priorities and/or their religious freedoms. It is to oblige them to act in ways in which they have a right to choose not to act.

In a free and democratic society, one would expect recommendations which would permit variation of practice in accord with legitimately differing value systems. Instead, the recommendations impose one ethical view upon all, excluding those, the majority, who hold any different and legitimate ethical view from the process and from practice. The Commission report clearly would not have any intent whatever to jeopardize the best interests of children, but there is ample evidence to support arguments that the giving of near-absolute primacy to the autonomy rights of adults in this sphere would jeopardize those interests nonetheless.

The question of access to new reproductive technologies therefore cannot fail to raise just such fundamental questions of human rights and hence of the Constitution of this country.

Embryo Research

To place so serious a concern before the Government and people of Canada, I must also place before them my reasoning with respect to the ethics of experimentation on human subjects, with respect to the clear difference between this question and the issue of abortion, and with respect to what an embryo (sometimes termed in its earlier stages a zygote) is. I shall then lay out the justifications we as a Commission have heard for the use of human embryos for experimentation, and the reasons why I find these justifications both unpersuasive and deeply disturbing as carrying implications which range far beyond our actions toward human embryos.

In my view the only experimentation on a human embryo which should be permitted is that which would be of therapeutic benefit to that specific embryo in order to avoid or treat a severe disorder. Since, at the present stage of animal embryo research, it does not seem that such therapy could be done on human embryos with a reasonable expectation of success, even this should not be attempted, now or in the immediately foreseeable future.

The norms for research on human subjects accept only research which is for the benefit of, or at the least non-harmful to, the research subject. No human subject is subjected to substantial risk in experimentation for the benefit of others, however possibly enlightening that research might be. Embryo research is the only form of present-day research on human subjects in which those norms are disregarded. Up to the present, therapy on human embryos is not, as far as I am aware, being attempted; all research on embryos now done is for other purposes. Experimentation on embryos which will necessarily die from the intervention or be destroyed thereafter is clearly not for their benefit; the risks to them are absolute.

The question of experimentation on embryos is not related to, nor an extension of, the question of abortion. Experimentation on embryos involves no removal of a conflict between the embryo and the desires, aspirations, welfare, or health of a woman. There is no question of the balance of conflicting rights between an unborn and an adult human being. Those, including myself, who view humans at any stage of development to be full (though perhaps unrecognized) persons would of course hold experimentation on embryos to be a lethal offence against human rights. There are many others, however, who do not share this view of the unborn who would nonetheless oppose experimentation on embryos. Where conflict with the woman is absent they would hold the embryo and the fetus to be of great human significance and value. Indeed many of the public opponents of embryo research are pro-choice feminists. Each one of us begins life as an embryo. There are many with diverse opinions on abortion who agree in viewing experimentation on embryos with deep misgiving or outright opposition, seeing in it the instrumentalization of the human.

The question of acceptance or prohibition of experimentation on embryos presupposes a clear understanding of the point at which an embryo comes into existence. Gametes do not, by themselves, have the amplitude of the human genome, which requires the union of both sperm and ovum; gametes are not on their own capable of human development. There is not, therefore, what the Commission report posits as being an undifferentiated continuum of human life from gamete to embryo to fetus to born child. The continuum begins with fertilization. Only with the joining of two gametes does the full genome of a human individual come into being; without that joining no human life, no human development and no human individual can be possible. Experimentation, observation and the future development of preconception diagnosis using gametes would therefore, with due safeguards and respect, be legitimate, as the Commission report states if for other reasons. The absence of an ethical problem with research on gametes does not relativize or diminish the ethical problem once two gametes have joined and an embryo has come into existence. Key to the point at which ethical problems arise, then, is the point at which two gametes fuse to become a single human embryo.

Much popular or even political or bioethical discussion on the subject assumes that the genetic materials of the sperm and of the ovum fuse at the point of penetration of the ovum by the sperm. Much literature speaks of a "single cell." It appears, however, that the single cell of the fertilized ovum contains the two pronuclei, the still-separate envelopes of maternal and paternal chromosomes. They do not fuse until the chromosomes have replicated and segregated, migrating along the spindle and separating into the two cells of the first cleavage.[21] In the mouse, expression of paternal gene-derived proteins is first found at the two-cell phase,[22] suggesting that, if the process in humans is similar in this respect to that in the mouse, the genes of the embryo as an entity become operational after syngamy. The joining of the two gametes, or syngamy, then, is a process which may take a range of estimated time spans, perhaps 24 hours.

Whether sperm penetration of the ovum or full syngamy is the point of existence of an embryo is a question which still requires careful scientific, philosophical, and ethical examination. At penetration, the single cell contains the full genetic complement received from sperm and ovum, but they only fuse and interact together at syngamy. So is the penetrated ovum a zygote? Or is it still an ovum through which the envelope containing the genetic complement of the sperm, still a separate entity, is travelling toward the envelope containing the genetic complement of the ovum, the zygote only coming into existence at syngamy?

If syngamy is the point at which the zygote (the early embryo) comes into existence, it is possible that some of the forms of observation or intervention (such as prenatal — or preconceptional — diagnosis using the third polar body, or the so-called "hamster test" for sperm function) are legitimate so long as they are ended before syngamy takes place. The hamster test does involve, and the finding of a severe abnormality by polar body analysis presumably would involve, termination of the penetrated ovum before syngamy. However these questions are resolved, after syngamy an embryo certainly exists, with all the ethical issues which surround it.

If an embryo is dead, these questions do not arise. If there are such severe abnormalities that development is impossible, and the zygote is non-viable, as in the case of three pronuclei or an entity which will certainly become a hydatidiform mole, it could be argued that what exists is not truly a human embryo. An entity with three pronuclei or a hydatidiform mole has no inherent capacity to be or to become a human being or individual.

The ethical issues surrounding the treatment of embryos do not appear to me to be raised in these cases either. I do not, therefore, object to those research projects which involve non-viable embryos or tissues which are certainly developing into a mole. They may yield much information about fertilization and early development and metabolism which may be both medically and scientifically useful, yet without the exploitation of viable human subjects. It is, however, precisely the living and normal embryo, with its full inherent being and its capacity for

development, upon which the report of the Commission would allow experimentation.

This Commission has adopted certain ethical principles within an overarching ethic of care, among which are non-maleficence, protection of the vulnerable, informed consent, and respect for life. I do not see how these principles can be consistent with experimentation on embryos ending in their death. Human embryos are alive, they are certainly vulnerable, and they cannot consent to being the subjects of non-therapeutic research.

Surely non-maleficence is incompatible with a course of experimentation and destruction; this, for its subjects, is harm.

Surely respect for life has to do with its preservation, not with its use and termination with some sort of due solemnity.

Nor can the protection of vulnerable human embryos be accomplished by their use and resultant destruction.

If it is others who are to benefit from the non-maleficence, protection, and respect, then we are using one human directly and deliberately for the benefit of another. The other who will benefit is not only someone other than the research subject; it is not even the woman who is receiving the fertility therapy which allows the retrieval of the ova. The research would benefit the scientists who gain information from the research, and perhaps at some future time it may (or may not) yield application to infertility treatment. The research is not, however, to be of any direct therapeutic benefit to either of the subjects concerned.

This use is, in my view, far more problematical than the use of fetal tissue from elective abortions for therapeutic transplantation to victims of such disorders as Parkinson disease. Those transplants, as thus far performed in Canada and as recommended by this Commission, would be separated by elaborate systems of decision and personnel from the elective abortions on which they thus far depend. It is our recommendation that no fetal tissue be taken unless the fetus is already dead.

The results of the survey of the attitudes of Canadians done for this Commission indicate that, even among those who were opposed to the termination of an unplanned pregnancy, only 18% considered it wrong to use fetal tissue in medical procedures. A somewhat larger proportion, 26%, approved of the use of fetal tissue, and 56% were uncertain.[23] It seems, therefore, that opposition to termination does not necessarily carry with it opposition to the use of fetal tissue in medical procedures if there is no link to the abortion decision.

Moreover, in my view other alternatives can be and ought as a high priority to be developed which would avoid these ethical problems and the current systemic dependency upon ongoing elective abortion. This, too, accords with the response of Canadians to the Decima poll. Some 31% overall would support the research if the fetus would be aborted anyway, but 48% said they would support research if the fetus were "miscarried." Again, 18% opposed it under any circumstances.[24] This strongly suggests that 66% of Canadians would prefer alternatives which would involve no

ongoing dependence on terminations of pregnancy. Such alternatives could include autologous grafts of treated tissues from some other part of the patient's body, retrieval and storage of tissue from ectopic pregnancies, cultivated cell lines, or animal tissue which is rendered immunologically mute, as well as further research in drug therapy. Use of fetal tissue for transplant has been and can be further divorced from both individual and systemic complicity in the death which produces the tissue, at least until the day when it can be fully replaced by other effective treatments which raise no such ethical difficulties.

By contrast, while the parental decision to donate embryos could be separated from the experimental activities of staff performing the experiments, the acts which bring about the embryos' demise cannot. The doctor/researcher who does the one does the other. The experimentation and the termination are parts of a single action, or the termination follows the experimentation. In either case, the experimentation is the inseparable reason for the termination. In the case of creation of embryos from sperm and ova, not as supernumerary results of *in vitro* fertilization but for the express purpose of experimentation, the decisions and acts of use and destruction would be deliberate from the very outset. I cannot see experimentation on embryos as anything but a lethal exploitation in varying degrees of premeditated severity.

Various arguments have been used to justify the use of embryos; I shall outline here why I do not find them persuasive. I do not in the least doubt the sincerity and good will of those who use these arguments. My fellow Commissioners and I are fully agreed on the centrality of an ethic of care; many others who use these arguments are also of good intent. The disagreement has to do with how and to whom the ethic of care is to be applied in a situation in which the interests of all cannot be gathered into a single solution.

Some say that knowledge concerning biological processes and potential therapeutic applications can be gained. This argument presupposes that the end justifies the means. That great knowledge could be gained would be true of any number of experiments on human subjects which could be — or have been — performed and which are now universally agreed to be unethical.

Whether or not *in vitro* fertilization has shown sufficient empirical promise of success that the sacrifice of embryos would yield any significant improvement is still uncertain. Whether any practical benefit is particularly likely to result is only one criterion of the ethical evaluation of any sort of scientific enquiry. That benefit might result does not *by itself* justify any action; other conditions must also be satisfied which I do not see as having been satisfied here.

Some follow the utility argument further, saying that, since we have supernumerary embryos, we might as well use them rather than allowing them to go to waste. This reasoning does not by itself justify any action either. It has been used for activity ranging from the entirely legitimate and

constructive use for transplant of organs taken from people who have died in traffic accidents to the atrocity of using the bodies of the victims of genocide as resources for hair cloth and soap. The use of any part of a human body is only legitimate and ethical if the means of gaining access to it involve consent, and no exploitation or complicity in the death.

It seems to me that we neither need generate spare embryos nor, if we have generated them, need we put them to such use. Other alternatives for infertility treatment are available or should be pursued, such as fertilization of the single ovum of a natural cycle, in the form of IVF or, better still, combined with fertilization within the body of the woman, as in GIFT or DOST. All of these allow infertility treatment without leaving supernumerary embryos. Such techniques would remove the ethical ambiguity of supernumerary embryos. In the case of natural cycle IVF or DOST, in which the single ovum of a natural cycle is retrieved and transferred in the same cycle, the absence of hormonal intervention would entail lesser stress and risk for the woman and very likely would also raise the likelihood of successful implantation in a normally developed endometrium.

Once cryopreservation of ova has become feasible, there will be no justification for the fertilization of more than the number of embryos, normally three, appropriate for a single transfer. Supernumerary ova for subsequent transfer, research, or disposal, or ova retrieved from a stimulated cycle for transfer in an unstimulated cycle, would replace supernumerary or stored embryos, and would present few of their ethical dilemmas.

Were such techniques to be developed to a point of effectiveness equal to or superior to that of hormonally stimulated *in vitro* fertilization, there would be no further reason for the production of supernumerary embryos outside the body.

If supernumerary embryos already do exist *in vitro*, the alternatives of cryopreservation for implantation in the mother, or of adoption for gestation by a second woman, while presenting associated difficulties of their own, offer at least a chance of normal life and do not involve the exploitation and destruction which are inherent in experimentation. This should be the alternative if a couple choose not to have more than a certain number transferred, or if they have not chosen to have cryopreserved embryos transferred during the time limit (the Commission report suggests five years) specified at the outset by the fertility clinic. The Commission report has recommended that only ova, not embryos, be used in pregnancy-generating infertility treatment of non-ovulating women unless there is a medical problem in both spouses. Yet, since the purpose of generating embryos through IVF is to bring them to birth, not to provide a resource for research, ruling that supernumerary embryos are, for that sole reason, to be consigned only to use as research subjects and/or disposal appears contradictory. In my view the adoption of embryos is, in terms of relationship, parallel to the adoption of a born child, and is hence acceptable.

A widowed man cannot himself gestate the embryos he and his wife have conceived and caused to be cryopreserved. He should therefore also offer them for prenatal adoption, as difficult as giving them up might be, since the only mode by which he could cause them to be gestated to birth and parent them himself would be some form of gestational contract arrangement, commonly called gestational surrogacy, or to marry another woman and cause her to gestate the embryos of the first wife; neither of these scenarios would be ethically acceptable because of their implications for the woman.

This difference depending upon the gender of the surviving spouse is not, as the Commission report suggests, discriminatory; it is derived from the physical realities of sexual dimorphism. This Commission has recommended a prohibition on a single man's contracting the ovum-producing and gestational services of a woman to generate his own genetic child (preconception contracts, or "surrogacy"), while recommending that single women be permitted contractual access to the sperm of a man to generate her own genetic child. It therefore seems that, in principle, this Commission holds that, where the physical realities of gender would give rise to differing social consequences of apparently parallel actions, a difference in policy is legitimate and non-discriminatory. Permitting a widowed woman to gestate the embryos she and her husband had already conceived while not permitting the surrogacy option to a widowed man is a precisely similar application of the principle. Universal deprivation is not a necessary or appropriate response to sexual difference.

Nor is it the case that the limit "does not deprive people of an option that most people have." That would be true of posthumous insemination, which, as we shall see, has its own legal and social ambiguities. It is not true of embryo gestation. The embryo exists. "Most people," if what is meant by this is those who do not require or have not already made use of new reproductive technologies, would indeed not have access to insemination by their husband if he had died. If, however, there existed already-conceived embryos, "most" women would be pregnant and would be free to carry the pregnancy through to term. It would be surprising, indeed, if they did not wish to do so. We do not oblige a pregnant widow to abort, however early the stage of pregnancy, even though the birth will take place after her husband's death. Some women would view an external intervention to prevent them from gestating their own embryos after the death of their husbands in much the same light.

It seems contradictory to permit donor insemination of single women, an entirely *de novo*, technologically established single parenthood, while seeking to prohibit the completion of the birth of existing embryos already initiated with the wish of both parents. The mother would be a single parent and the birth would no longer take place within a couple which did previously exist; if the first sort of single parenthood is acceptable to this Commission, it is strange that the second would not be.

It seems doubly ironic that the Commission recommendation would prevent a woman from gestating embryos she and her much-loved and committed husband had already conceived, while the same widow could, under the Commission's recommendations, approach a sperm bank/ infertility clinic and gain access to a stranger's sperm and IVF for her ova as infertility treatment with no social or marital status questions asked.

If embryos have been cryopreserved and the male parent dies, it should be the choice of the female parent whether or not to have the embryos transferred to her uterus. No external entity, whether a physician, a clinic, a regulatory body, or the state, has the right to oblige her to be bereaved at once of her spouse and of their expected children. It seems inconsistent that the report recommends, on the one hand, that "embryos should be disposed of in accordance with the wishes of the gamete donors," while, on the other hand, recommending that embryos not be stored beyond the death of one "gamete donor," irrespective of the wishes of the other, or of both.

Yet such embryos were conceived by a couple, whatever the technological help they may have received, in order that they might have the hope of bringing to birth a wanted child or children. In the absence of evidence to the contrary, it should be assumed that the survival of the embryos would also be in accord with the wishes of the man who has since died. This may well be the only hope the woman has of ever having a child.

Some are of the view that the completion of the gestation of such embryos would be harmful to existing siblings. This is unpersuasive, for at least three reasons. First, most couples who seek the help of an infertility clinic do so because they have no children already born. There are likely to be no siblings to disrupt; in fact, this may be the woman's only chance of having any children at all. Second, if there were children already born, it could equally be argued that the knowledge that the state or a clinic had intervened to destroy their embryonic siblings when their father died would be as or even more disruptive for them on the psychological level.

Third, Canada's social structure is not inheritance bound. In a society with a lingering tradition of hereditary social status, of impartible or entailed estates passed down a single lineage, perhaps by primogeniture, and of agriculture based on inherited ownership or tenure, the number and birth order of siblings might well be salient, whether or not it was just. Such considerations contributed to a parallel recommendation in the Warnock Report, coming as it did out of the history and society of the United Kingdom. Inheritance is not this sort of economic or social factor in Canadian society, structured as it is around social mobility, achieved status, education, or other forms of skill, and independent employment or entrepreneurship, largely in occupations not bound in any way to the land or to hereditary tenure of any form. It is unlikely that any unfairness or undue dislocation to siblings already born would result from the birth of another. If "legal reform to ensure clear succession and inheritance rights"

is necessary to expedite the settling of estates and to protect the "interests of already existing children" (in the unlikely event that there are any), so be it. This Commission has recommended the passing of much clarifying and regulatory legislation; this is merely one addition to what is desirable.

It may be doubted whether the courts would uphold such a stricture on embryo transfer to a widowed woman after the death of her husband in any case. A California case has been reported concerning the right of a man to have the authority in his will to determine what may be done with his cryopreserved sperm after his death. The woman who is designated in the will as able to choose whether or not to be impregnated had been his lover rather than his wife; there exist two adult children from a previous marriage who have sought to have the vials of sperm destroyed. The California Supreme Court, upholding a lower court decision, ruled that the Court did not have the authority to make a value judgement as to whether or not it is better for such a potential child to be born. Nor did the state have an interest sufficient to justify interference with an individual's decision about the use of his own sperm, although the child, if born, would be unlikely to have rights in the existing estate. Any further challenge to the will proceeds on other grounds.[25, 26] No parallel case has reached the courts in Canada as yet as far as I am aware. What the effect of the precedent would be in this different jurisdiction remains to be seen. Nonetheless, in this one instance even the posthumous use of sperm by a woman who is not a marital partner has been ruled as a matter of the choice of the man from whom it came and the woman who would be inseminated, even over the objections of adults who would become the child's half-siblings. The implications for the upholding of the far less problematical choice of an established couple in the transfer of embryos already conceived by mutual act, where there are no pre-existent siblings or without objection from existing siblings, seem clear enough.

Whether or not this decision will be repeated in other jurisdictions is not yet known. A reasonable countervailing argument could be made that the initiation of hitherto non-existent offspring after the death of one parent goes beyond the usual social meaning and mutuality of reproduction. We shall see whether rights in one's gametes will in the end be established as a question of absolute autonomy. Even were the Canadian courts not to take reproductive autonomy quite so far, however, it is unlikely that they would uphold strictures on the right of a woman to complete the gestation of her and her husband's own embryos. The conception has already occurred by the act of both persons, and the embryos do exist; what remains is to complete a process already mutually begun, not to begin a process *de novo*. The woman has already begun her part of the action, and the only aspect of it which the man was capable of contributing has already been completed. One would expect a court to uphold her right to complete that part of the reproductive action which would have been solely hers even if her partner were still living.

In the absence of evidence to the contrary, the husband's wish for the embryos to reach birth and to be raised would be assumed from the very fact of his having joined with his wife in conceiving them and causing them to be cryopreserved. The reproductive decisions of a couple, and indeed of an individual, are personal and a matter of fundamental human rights. In this sort of case the decision is not only shared throughout its joint history by the couple and held by the woman; its realization is already in process in the existence of the conceived embryos. Whether a court would uphold an interventive policy or act of any external individual or body contravening and halting the progress of such an initially shared and now individual decision is at least highly dubious.

Death is grievous, but it is a natural part of life. Its sundering does not contaminate. We should not, in our modern fear of death, invent new taboos surrounding it which would prohibit a woman from making a decision about her own embryos and her own relationships which would under other circumstances be viewed as belonging in her hands as a matter of right.

One person might, as I have heard it argued, view as morbid a choice to gestate the embryos conceived with a husband who has since died. Another might view it as a transcendence of one aspect of death and a triumph of the couple's love through bringing forth, loving, nurturing, and educating to adulthood a child they had both wanted and conceived before death intervened unlooked for. The child would be an end in himself or herself, not a mere means of coping with mourning or a replacement for the lost spouse. The point, however, is that a woman may choose to keep the death that thwarted her in her marriage from thwarting also her (their) desire for parenthood and a familial future.

It is for the woman, not for others, to choose. If after a reasonable period, perhaps 18 months or two years allowing for mourning and the making of decisions, she has decided not to have them transferred to her own uterus, they should be offered for transfer to a woman who is infertile, again in a form of prenatal adoption. Such embryos need not be destroyed or used for research.

There is something of a potential for conflict of interest in the collaboration of infertility clinics with embryo research projects, a conflict which perhaps the establishment of a licensing body may help to reduce but cannot eliminate. A clinic which cooperates with or incorporates experimentation on embryos may indeed be using the research to aid in the understanding of both fertility and infertility. Simultaneously, however, it may experience a disincentive to developing modes of treatment, such as natural cycle IVF or DOST, which, although they may cause less hormonal stress on the woman and involve less surgical intervention, will also produce no embryos to supply the other research arm of the facility. It is a principle of this Commission that a woman's treatment should be in her primary interest and in the interest of her future child; in such a case the

setting of research priorities may not allow for the development of treatments which could potentially be most in the interest of the subjects involved.

The very reverse of the development of infertility treatments which do not expose embryos to use in research, or which cannot be used as sources for the deliberate creation of embryos for research, would be the utilization of ova taken from the ovaries of women having hysterectomies for reasons entirely removed from infertility treatment, or from the ovaries of women recently dead. Given the well-established use of other types of cadaveric organ donations, the latter question requires the attention, not only of the relevant National Commission sub-committee, should Government establish it, but of other concerned professional bodies, ethicists, and Canadian society as a whole.

Neither of these sources of ova for embryo conception should be permitted, in my view, as they would take the instrumentalization of the human to an even greater extreme. Such use is quite distinct from the legitimate transplantation of the healthy organ of a cadaveric donor or the blood or bone marrow of a living donor to save the life of someone at risk. Instead of the personal gift of the part of one recently dead person being used and maintained in saving the life of a specific (even if unknown) other person, an entire embryonic human entity would be raw material for use and disposal for some more remote, putative, and impersonal benefit. From the perspective of the woman, living or now dead, what is being used is not her body part but what will be, after fertilization, her offspring, removed from her in a procedure entirely unconnected to her own procreation. The embryos created under such circumstances would come into existence with no human relationship, no generative relationship at all; this essential aspect of our humanness and human reproduction would be deliberately absent.

Given the numbers of hysterectomies (and accidental deaths of women of childbearing age), the supply of such ovaries could be vast. Sperm are readily procurable. This Commission has taken a strong stand against the commercialization of any aspect of reproduction. Yet the instrumentalization of the human remains instrumentalization, whether or not it reaps a commercial profit. Indeed, not all industries are commercial; some, such as most medicine, publicly sponsored education, or the services of government itself, comprise a substantial proportion of the activity of a nation's economy with the incentives taking a non-profit form throughout. Were researchers to be permitted to utilize such ova, a similarly vast resource industry could be created, at first for (non-profit) research purposes and perhaps subsequently for the production of substances found through the research. That a source of supply for research is a principal purpose of the expansion of ovum retrieval to include ovaries removed during hysterectomies is made explicit in the Commission report chapter on embryo research, in the discussion of the *in vitro* creation of zygotes.

The result of permitted and expanded experimentation on human embryos would be the dehumanization, not only of the embryos, but of the adult human beings, the researchers, and the women and men asked to donate their gametes, who act to bring this about. A society which permits it suffers a great loss of its humanity. We would all become less by consenting to our society's permitting human embryos to be treated, not as the gift of human life or as individual entities with intrinsic human significance, but as a large, aggregate-volume resource.

Research on embryos has, of course, many sub-fields. One of these is the development of cell lines. With respect to the patenting of cell lines derived from embryos, or, for the same reasons, from fetal tissues, the Commission report lays out the very real dilemmas, recommending further study. In my view, the patenting of cell lines, whether derived from embryos, fetuses or other, including adult, human tissues, is a means which is not justified by its end. The Commission report has dealt overall with questions of commercial interests in a highly insightful, balanced, fair, and ethically acute fashion; it is only on this one point, on which the report leaves a specific question open for further examination, that I wish to differ by stating a firm and decided position.

While seeing the pragmatic strength of the arguments from the need for investment, I view the patenting of cell lines derived from any human tissues, including those of embryos and fetuses, as unacceptable. If lacunae in the law with respect to patenting of "microbial life forms," clearly intended to refer to lower life forms such as viruses or bacteria, now permit such patenting of the cells, not only of higher life forms, but of human beings, they should be closed. Patenting of the inventive processes of cultivation or distribution by pharmaceutical companies of the biochemical products (such as insulin or dopamine) derived from such cell lines would be acceptable, but the cell lines themselves are and remain human tissue, with the full, distinct and individual human genome.

Non-profit, university, and hospital-based modalities of cultivation, with appropriate cost recovery and salary remuneration, should suffice to ensure access. Even if pharmaceutical corporations were to become involved, perhaps in collaboration with research-ethics-board-monitored, university-related hospitals, in developing the patentable inventive processes and in distributing the derived biochemical products, the cell lines themselves are human tissue like all other similar human tissue and should not be patentable.

It is unquestionably true that cell lines may prove therapeutically very useful and that commercial interests might be more inclined to propagate them if there were expanded patent protection for their profits. This is also true of all the other uses of technology for which we have recommended a prohibition of commercial interest or for which commercial interest has already been prohibited in law. It is precisely because they would otherwise be attractive to commerce that commercialization is prohibited with respect to certain things considered too closely allied to our fundamental humanity.

Returning to the general question, it may be that by refusing to experiment on human embryos we will forego certain sorts of knowledge and some derived treatments. The same is true of our refusal to do any other sort of experimentation deemed unethical. Most of the objectives of embryo research enumerated in the Commission report can be largely realized through the use of animal embryos, or even the aforementioned human cell lines. Some specific applications of that general information, however, would doubtless be available only through the utilization of human embryos. There are many types of information for purposes of medicine and human biology (or social science or psychology) which we will never have, whatever their potential utility, because we cannot, for example, do the same sorts of controlled experiments which are possible with non-human subjects. We do not permit laboratory drug trials in which human subjects are chosen, confined, controlled, and ultimately "sacrificed" for observation of the drug effects. Such trials using animals are unquestionably more scientifically precise than anything which is done with free human beings, but the knowledge which might be gained from the use of human subjects in such controlled experiments is, as all agree, clearly less important than the dignity, welfare, and freedom of human subjects.

The Commission report has argued that the implantation of therapeutically treated individual embryos without prior testing of the techniques on populations of sacrificed human embryos would have an unacceptable level of risk. Beyond the risk that the offspring could have some disorder or that the pregnancy might not survive, the nature of the risk is unclear; risk to the mother is mentioned, but what that might be beyond psychological stress and the risks of any pregnancy has not been specified.

I would argue in return that any application of an innovative drug or other medical treatment to human subjects after animal trials involves a certain level of uncertainty and risk. We do not use that risk and uncertainty to justify the treatment of some intermediate human population as we would laboratory animals. Rather we accept the known level of uncertainty and hedge it round with ethical safeguards and limitations, such as, for example, the testing of somatic gene therapy first on those who had no other viable hope. The known uncertainties involved in transfer of any therapy from animal to human subjects does not justify the treatment of the initial human subjects like laboratory animals; this is as true for human embryos as for fetuses, born children, or adults. Since, however, there is no indication that successful therapy on embryos (of any species) will be possible in the near or foreseeable future, arguments on the question are necessarily hypothetical. If, moreover, the uncertainties around a procedure are unreasonably great and cannot be elucidated without exploitation, it ought not to be done. This might mean that some couples would not be able to have children genetically their own. This

would be grievous, but not so grievous as using unethical means to attempt to deal with their difficulty. Nor would society be harmed.

Human knowledge is exceedingly valuable and useful, but it is not of absolute value. Human dignity, non-maleficence, the respect for life and the protection of the vulnerable are higher values. If they and the search for knowledge cannot together be accommodated, human dignity, life, avoidance of harm and protection take precedence.

Some argue that the human embryo is not yet a human being or a person, and therefore the respect for life and protection of the vulnerable due to human beings are not due to it. This is usually framed around one or more of four justifications, that individuation is not observed to be complete, that it is not implanted in the mother's endometrium, that there is a considerable rate of embryonic wastage, and that an embryo becomes the focus of care and nurturance to and beyond birth because someone, usually the physician guiding the choice of the mother, decides to confer that status — all other embryos are deemed not to have this social role and therefore not to be due those forms of care.

As I have said, both those who are pro-life and many who are pro-choice object to experimentation on embryos. The flaws I see in these four justifications would also be, I think, of common concern to many who may differ with one another on the issue of abortion, because of the implications of the locus of decision for the fundamental determination of the human rights of anyone, not only for embryos. There will be many people who, whatever they may or may not consider the moral status, the nature, value or rights of the human embryo to be, will find broader implications for human rights of these four rationales deeply disturbing.

The key difficulty with all these arguments is that, in one way or another, they rest on defining inclusion among those having humanity, rights, and value in terms of the perception or desires of others, not in terms of what the one under definition is in himself or herself. The application is to the human embryo, but there is no reason given or implied which would limit these principles to the embryo.

It is indeed the case that science must work from empirical observation; it would be, however, a serious mistake to confuse what we can know or observe of another with what is. Each thing or person in the universe has a reality in itself, himself, or herself. We observe, we perceive, we form a portrait (or, in science, many overlapping portraits) of that reality, but those portraits are necessarily incomplete and may shift over time with changing information and with the perspective of the observer. The portrait is not the reality. The portrait is only a more or less accurate representation of the reality. The reality has an existence in itself, herself, or himself which is prior to any perception by others, any social relationship, or any role.

It is also true, on the social level, that our relationships are a vital, indeed essential, part of our humanity; it would be deeply unjust, however, to define human beings solely by those relationships and roles. Would any

one of us wish to have our validity as human beings contingent upon our being known or accepted by someone else? Has not each of us had the experience of being negated or refused acceptance by another or an entire group of others? Our freedom and human dignity are contingent upon the fact (and it is to be hoped also our awareness) that we are valid and real and endowed with human worth and dignity in ourselves, prior to and irrespective of the presence or absence of relationships with — or acceptance by — others. Only upon that foundation of intrinsic human validity and dignity can we then build effective human relationships. Acceptance by one or more others may be a criterion of our entry into various sorts of structured groups. It is not the criterion of our reality and dignity as human beings.

We cannot negate or create one another, conferring or denying existence and reality by some exterior acknowledgement or dismissal.

In the case of human embryos, we as external examiners cannot yet in our present state of knowledge *observe* individuation until the primitive streak appears or until we are certain that twinning will not occur; it may well be, however, that the processes which determine individuation have been established long before we can observe them. Indeed they must have been, in order for the cells to be sorted into the differentiated placement which the subsequently visible primitive streak embodies. In any case, to say that two human individuals may exist in the future, as in the case of identical twins, is not to say that what is present now is not a human individual. Before twinning, the embryo is nonetheless a human entity, someone. The embryo is not a nothing before the rare event of twinning is no longer possible. The embryo is human, and has his or her full individual genome (including gender) from the beginning, long before someone else, with the amazing but nonetheless limited and extrinsic capacities of science for observation, can see the primitive streak. That an embryo is a human reality is not made true by what we can perceive or say of it, but by what it — he or she — is.

Arguing from implantation is considerably further yet from the definition of the embryo by what it is in itself. Implantation, which begins at approximately the seventh day and is complete by the eleventh or twelfth,[27] is the commencement, not of an identity of the embryo, but of one aspect of the relationship of physical contact with the mother. In other words, arguments from implantation argue from relationship, not from identity — from one form of direct encounter with the mother, not from the reality of the embryo itself. The choice of implantation as the beginning of that relationship is so arbitrary as to seem perhaps at least in part political.

Even the aspect of physical contact is not consistently followed through in these arguments, since implantation begins around the seventh day. Cutoff dates for experimentation at the fourteenth day utilize the later point of completion of implantation around day 11 or 12, plus an extra 2, not the actual establishment on day 7 of the process of physical envelopment in the lining of the maternal uterus. (I have not seen

reasoning that would justify the extension of the 12 days to 14, and can only wonder whether it may conveniently round the calendar workweeks for decision-making bodies and researchers.) The existence of the embryo has been within the mother, receiving the sustaining environment from her from the outset; more than half of its genetic identity (given the maternal transmission of the mitochondria) comes directly from her. Hormonal signals between the embryo and the mother have been mediating subtle physical interactions. The physical relationship of the embryo with the mother has been a reality since the outset, and does not begin at day 7, let alone at day 14. To define an embryo as being the focus of care once fully implanted, then, is to define her or him by relation to another, not in herself or himself, and in terms of only one, relatively later-occurring aspect of the relationship at that.

Those who argue from the rate of embryonic and fetal wastage appear to me to pursue a perspective of trivialization which is difficult, upon examination, to support. This is so even when it is argued that embryos fertilized *in vitro* should be suitable subjects for research because they have an higher rate of wastage than those fertilized *in utero* and hence a lower likelihood that any given individual embryo would have the capacity to live and develop fully. To say the probability that many embryos would not live justifies termination of some who are now alive seems to imply that those with a high probability of death are *for that reason* legitimate subjects for use and termination.

Given other differences in gene expression between superovulated and normally ovulated ova,[28] the relatively high rate of lethal chromosomal abnormalities observed in embryos fertilized *in vitro* very likely does not reflect natural rates so much as side effects of the forced ripening of ova by superovulatory drugs. Since human embryos naturally fertilized are ordinarily unavailable for examination, it is difficult to be certain what the natural rate of embryonic death would be; estimates tend to vary widely and the assumptions upon which extrapolations are based tend not to be made explicit by the writers who make them. Some rate of natural embryonic death does nonetheless occur, difficult as it may be to measure.

Except in the presence of observable malformations, however, it is impossible to know which embryos under observation *in vitro* would live and which would, if transferred to the woman's uterus, nonetheless undergo a natural death. Whether the probable embryo death rate would have been a third or a half or nine-tenths or any other given estimate, the other proportion, the two-thirds, the half, the tenth or whatever it might be, *would* have lived had they been in the nurturing maternal environment. Arguments seeking to justify experimentation on embryos which show all observable signs of being alive and normal on the grounds of their *possible* death seem to be saying "they might die anyway, so it is all right to kill them."

Again, the rationale specifies no reason why it could be applied only to embryos. Infant mortality rates in some countries today — and in our

own only a century and more ago — may run as high as some estimates of embryonic and fetal death. Some infants are born with diseases which make their early deaths probable or certain. The same can be said of adults under circumstances of epidemic, war, or specific diagnosis of disease, and at any age. That he or she may die, whether by the strength of probabilities or by the certainty of diagnosis, does not make anyone less worthy of care, or less human in himself, or in herself. For that matter, for each of us the mortality rate over the long term is 100 percent. On a historical or geological or astronomical scale, our lives are many and brief. Most of us will be forgotten in a generation by all but our immediate families, and few indeed will be remembered by anyone three generations hence.

Yet each of us is of infinite dignity and worth. That our existence on earth is ephemeral does not diminish our worth by one iota, since it is not derived from lifespan or impact but from our intrinsic human dignity. The most vulnerable and the weakest of us may also have an unlooked-for effect on others: even an embryo, like a poor child, or a sick adult, or a frail elderly person, by his or her very existence obliges others to make decisions, to act, to be or to refuse to be, toward another in ways which affect who they themselves become. Those who have a faith believe they know from Whom this dignity comes and to Whom we go, but many others who do not believe in a God nonetheless see and hold fast to the dignity of all human beings and the justice and care that are due them in this short life.

That human individuals, embryo or young adult or octogenarian, are likely to die, then, does not mean that *this* specific individual before us will die soon or what would happen if we provided care. Still less does it mean that we are justified in doing anything which will bring that death about. Human dignity perdures in the face of even the certainty of our death; the possibility or the fact of coming death diminishes it not at all. Rates of embryo or fetal death are not relevant to the question of experimentation on them as human subjects.

The fourth argument for the legitimacy of use of embryos as human subjects is that, until a doctor designates an embryo as healthy and a woman chooses to have the embryo transferred to her uterus, the embryo is not yet the focus of the parent-child relationship and care which derive from that choosing. This is an extension of the same exclusively relationship-based, recognition-based definitional reasoning implied in taking implantation as a benchmark, and has the same flaws. The choice or designation argument only makes the ground of the definition that much more explicit. The embryo is ascribed a status based on the perception and the choice of others, not on anything intrinsic to itself. Indeed, it is acknowledged by those of this view that fully healthy embryos may not be so designated and may therefore be used as experimental research subjects — or even be brought into being expressly for that purpose; the key point

is the extrinsic choice of someone else, not the intrinsic reality of the one chosen or refused.

This calls to mind the ancient Greek and Roman practice of presenting the newborn to the *paterfamilias*. If he explicitly recognized the child as part of the family, the child lived and was cared for; if not, the child had no status within the group, was what we might today call an unperson, and was exposed to die on a hillside if not found and fostered by someone else. In terms of social structure, the principle of an inclusion contingent upon the desire of another is the same; only the persons making the decision and its point in time are different.

It is for all these reasons that I dissent on the question of the use of viable human embryos for experimentation or arbitrary disposal. The use itself is, in my view, an exploitation of human subjects. The justifications commonly used for it I find unpersuasive because they rest on assumptions which have broad, negative, and thus far largely unexamined implications for society, for law, and for ethics.

"You're nobody 'till somebody loves you."[29] A subjectively emotive line in an old torch song this may be. It is a highly dubious principle in law, in philosophical anthropology, or in social or medical ethics. Our individual reality, our human validity is not contingent upon the will or the recognition of other human beings; when it is made so, as has happened all too often to many individuals and groups in human history, the result is injustice.

Conclusion

I have no doubt that those, and certainly my fellow Commissioners, who advocate experimentation on or a policy of destruction of viable human embryos wish to do what is constructive and to avoid harm. My purpose here is not to question their intent.

For all the reasons I have laid out, however, I am of the view that the establishment of non-therapeutic research on viable human embryos would have two overarching wrongful results. First, it would be a lethal exploitation of human entities. Second, it would set precedents for hitherto unaccepted principles of medical ethics and of experimentation on human subjects. The associated definition of who is of human significance and who is therefore worthy of protection and care would have implications far beyond embryo research. These implications would be counterproductive for the human rights of the disabled, of the terminally ill, and of any individual or group whom another individual or group does not wish to recognize. A dehumanization not only of embryos and the adults who participated in such research but of all society would be among the consequences, however unintended.

The recommended National Commission structure for licensing and approval of research, then, appears to me to be appropriate and potentially effective for the maintenance of standards and protection of all parties from

unmonitored or commercial exploitation. Without the establishment of such a body, the absence of regulation and monitoring, particularly outside institutions which have ethics review boards, would leave the field open to the possibility of shoddy research, inadequate record keeping, commercialization, and other forms of abuse.

This structure, however, should permit research only on gametes and non-viable embryos with abnormalities, such as having three pronuclei, intrinsically incompatible with human life or development. A strong and reasonable argument can also be made for allowing research on ova after the penetration of sperm but before syngamy, although the careful, because experienced, approach of Germany, which prohibits experimentation even at the pronuclear stage, is more certain of avoiding any possibility of exploitation of human subjects.

All viable embryos resulting from fertility treatment should be given an opportunity to develop normally, whether by implantation in the mother, by cryopreservation for future implantation in the mother, or by adoption by another woman to whom they are transferred.

The creation of embryos for the express purpose of utilizing them for research, whether by means of the deliberate fertilization of supernumerary embryos in fertility treatment or the creation of embryos from stored sperm and ova retrieved from cadavers or during hysterectomies, should be expressly prohibited. I am in full accord with the Commission recommendation that the use of ova from fetuses be prohibited.

The Genetic Link in Gamete Donation

Rights, Choice, Identity, and Disclosure

I fully endorse the recommendations in this Commission report having to do with non-commercialization, standards of medical practice, and informed consent, and record maintenance in cases of ovum or sperm gamete donation, as well as the recommendations having to do with the giving of non-identifying social, physical and medical information to the gamete recipient, with the hope that this will be transmitted to the child.

I differ with the report's recommended limitation of identifying information to cases of serious medical necessity. The searches of some adult adoptees for birth parents have been met with increasing legal recognition and the formation of registries facilitating contact between them if both parties agree. The similar searches increasingly undertaken by children of donor insemination indicate that there is a common need. It appears to me that there is no valid justification for refusing to meet it with the same recognition.[30]

Medical history, of course, is important; it has received the bulk of research attention until recently because most geneticists are physicians or work with physicians in the tracing and treatment of disorders. It is, however, a backward tracing of the role of genes from the sketching of

dysfunction, rather than an understanding of the normally functioning genome. Just as the physical and social meaning of the genetic link is far broader than the transmission of disease, people may clearly have legitimate reasons other than a documentable fear of a disorder for wishing to know the identity of their progenitor(s).

Beyond the compelling nature of specific medical or other reasons for seeking information, this is, in my view, a human right. Individuals should not have to approach some external tribunal or authority to plead their case for fundamental information about themselves which is theirs by right. A child, at least once having reached the age of majority, has a right to know the identity of his or her progenitor(s) if the progenitor(s) agree. Not all children of gamete donation and certainly not all gamete donors will, when the moment of the majority of the child comes, wish to know the identity of or be in contact with one another. The parallel to adoption would no doubt be apparent in this also. Both parties have rights to privacy which should not be violated. If, however, both wish to be known to one another, externally imposed prohibitions on that identification seem gravely arbitrary at best. There is a strong argument that such prohibitions constitute a violation of the rights of the individual to his or her own records and to his or her own personal information, information which is only one but nonetheless a fundamental component of his or her identity.

Concern is expressed in the Commission report that attention to the identity of a progenitor would belittle or disrupt the bonds of the child with the family of rearing. These are parallel to the objections once raised in cases of adoption to the identification of progenitors even once the child had reached adulthood. Yet the bonds of social rearing are exceedingly strong and deeply imprinting. They exist in their own right. Knowledge of the identity of a genetic progenitor cannot replace those bonds; it cannot disrupt them if they are founded in consistent love, commitment, support, and the bonding which arises from a long history of shared life. The identification of a progenitor could not bring about a fundamental disruption, although it may become an element in the expression of a disruption if one existed in some serious form already.

Many adoptive children who have found their progenitors simultaneously find their ties to their adoptive families affirmed as the realities they are even as the ambiguities and unknowns are replaced with clarity and knowledge. There is no reason to expect that the experience of the adult children of gamete donation would greatly differ, all the more since one parent is genetically linked.

Progenitors' choice with respect to identification would, of course, necessitate some offspring having access to that information and others not having it. This does not constitute discrimination as the Commission report alleges. It is one of the normal consequences of the operation of human freedom. Adoptive children and their progenitors have to deal with the reality of similar freedom to permit or refuse identification and contact on the part of the other. So do all people who wish to pursue any sort of

human relationship. This does not justify a merely apparent equalization by the utter denial of identification and/or contact to all, including those who mutually wish it. State-sanctioned, uniform deprivation is not a solution to differences in access which arise from personal, individual human choices.

I disagree with the Commission report's view that the gamete donation family is so fundamentally different from the adoptive family that the child should lack rights that the child of an adoptive family would have. That one parent is genetically related does not negate the fact that there remains another genetic link which is not part of the social family. Indeed, the case of adoption of the genetic children of one partner by a subsequent spouse not genetically related to them does not entail a legally defined or enforced denial or obscuring of the identity of the former spouse or partner who co-engendered the child. Some adoptive families, then, are precisely parallel in their structure to some families formed by gamete donation, yet function with identification of the genetic parent without any denial of the child's right to know the identity of the progenitor, custodial and jurisdictional questions being clearly resolved under the law.

That the parentage of some children in the general population is not accurately reported is unfortunate, but it is a result of private actions and decisions which the state cannot investigate and in which the state cannot intervene. The state remains passive in tolerating a private deception or a private refusal of identification. This is not parallel to and does not justify the overt action of the legislative and recording function of the state and the public health care system and its personnel to obscure information of fundamental importance to the person whom it most concerns, the adult offspring of gamete donation.

It is also probable that the courts would find as valid the right of the adult child of gamete donation to information concerning the perduring link itself, the field of adoption being one — but not the only one — providing ample precedent in Canada and other jurisdictions. There are also such precedents as a California ruling that a gestational surrogate was a "genetic stranger" to a child conceived from the ovum and sperm of the contracting couple.[31] Surrogacy of any sort is exploitative and unacceptable, as the Commission report elsewhere makes clear with full unanimity. What is relevant here, however, is that, when the court was faced with an already-existing case of gestational surrogacy, the genetic link was recognized and given primacy when the best interests of the child did not involve a social bond with the surrogate which the child had not yet had time to form. No case directly seeking a ruling on the nature and force of the genetic link as distinct from the social link has yet come before the Canadian courts. If, however, an adult offspring of gamete donation were to seek mutually consensual identifying information on a perduring genetic link, it is probable that the existence of such a right would not be denied.

Sweden has taken a very strong stand, in my view the ideal one, in allowing to donate their gametes only those who are willing to be identified,

should the child wish it upon reaching "a mature age." The approach acknowledges the reality of the genetic link from the perspective of both donor and child, while preserving the family of rearing from undesired legal or social/psychological complication during the child's upbringing. In the consultative framing of the legislation, the Prime Minister at the time, Olaf Palme, was determined that the law should not be "founded on a lie." He placed emphasis on the results of many international studies which demonstrated that children want to know their biological parents. The new law, passed in 1985, was framed to meet the need of children to know their biological background. This has reportedly greatly reduced the number of students donating sperm; after an initial drop the sperm supply subsequently returned almost to the previous level, estimates being 80-90 percent. The donor profile, however, changed to one of married men with children, donating out of a knowledge of what engendering children means and a conviction of social solidarity.[32, 33]

It is argued by those concerned with provision that this lessens the overall supply. No doubt it does, in some degree. On the other hand, this approach does require that people know clearly what they are doing and deal truthfully with all aspects of it, including that of all their relationships, without evasion. The rights of all are protected. Nothing is imposed upon the unknowing or the unwilling, since all provisions are known before the choice is freely made to enter upon the action.

Gamete supply is not, in my view, the most important priority. Nor is the engendering of children irrespective of the associated costs in personal conflict and denial of rights and identity, not to speak of the denial or obliteration of what is, in fact, true. The end, however important to those seeking it, does not by itself justify the means. If people may not wish to do a thing when all of its realities are known, one may question whether the solution is to ask the state and its health care system to act to hide the realities so that people will be more inclined to do it.

In our investigations and hearing of testimony, as the report eloquently relates, we learned that ambiguity and deception have their costs. It is quite true that donor insemination is a frequently-used procedure. I am not, however, aware of the existence of any large, random-sample controlled study of the long-term results of gamete donation which would tell us what the rates of various sorts of psychological and sociodynamic outcome tend to be. The studies brought before us, and the testimonies of those addressing us, were powerful but they were qualitative and anecdotal; we cannot yet know how representative they were. Many supported gamete donation. Nonetheless, they give rise to concern.

A frequent theme was conflict, even marriage breakdown, after, and reportedly in some degree because of, donor insemination. This conflict can occur, not only within the emotions and relationships of the offspring and of those receiving the donation, but within the psyche and subsequent relationships of the donor, when the fact of having "children out there somewhere" begins to acquire emotional significance for the donor or, a

little-noted complication, for the donor's subsequent partner. The secrecy which protects the "reputation" for fertility of a man or woman may be, in its own way, a time bomb, not only for the child who may learn of his or her origins later, but for the relationship of the man and woman who rear the child. The fact of having made use of donor insemination may not be a matter of secrecy for a single heterosexual or lesbian woman who visibly has no existing male partner; the erasure of the identity of the progenitor will not, however, keep a child from knowing of the existence of the fathers of other children, that he or she must have had one on at least the physical level, and wondering who he was and what he was like. The presence of a male partner and the identity of the progenitor can be blocked, but the void left cannot. It seems that many people — often with the instruction or encouragement of their physicians — who engage in gamete donation deal with the resultant questions by an avoidance which results, not in simplification, but in ambiguity and consequent interior and interpersonal conflict.

The main difficulty of the Swedish approach lies in the permanence of the commitment to disclosure, the fact that the adult offspring may or may not choose to act upon it notwithstanding. The permanence of the donor's commitment is not a valid objection — indeed it is in my view the ideal — in principle, once granted the fact of gamete donation. Our family-related commitments are public and remain permanently so, even when relationships break down and contact ceases. Divorce does not expunge the fact and the identities of a marriage from the public record; nor does relationship breakdown between parents and an adult child erase a birth certificate. Even such relatively less momentous acts as purchasing property or building an addition on a private house leave public records which remain after the property is transferred to another owner and the individuals have left. For an adult donor to make a commitment to something of such significance as the deliberate, health-care-system-facilitated generation of a child is at least as serious and public an act as many others which remain in the permanent public record as a matter of course.

In this respect gamete donation should be still more open to disclosure than adoption, which is based on the resolution of previously existent, difficult and often unintended human situations, even tragedies, as donation is not. If donors know what engendering children means and know before they make that commitment that it will be permanent, it is entirely reasonable to expect them to regard it as such, particularly when no legal requirements of nurture or financial support go with it. Even when identification is made, contact is no more obligatory than is any other voluntary human contact. If the life situation and relationships of the donor at the time are not favourable to contact — or, as in the Swedish case, to continued relationship after an initial contact — there need be none. That is a choice. All the commitment to disclosure does is remove

the mask, causing all those involved to deal directly and truthfully with the realities of the persons and the action.

In Canada, however, at this point it would be a major accomplishment even to allow mutual identification with full protection for the ability to change the statement of intent for or against disclosure at any time. Such a system would also allow the mutual identification of those very few existing donors and their adult offspring whose medical records have been sufficiently complete to permit it. Given that even the adequate record keeping recommended in our report will constitute a considerable change in gamete donation practice, a process parallel to that of adoption disclosure registries would be a major breakthrough for the adult children of gamete donation, and for their progenitors.

Gamete Donation and the Nature of the Genetic Parent-Child Link

The genetic and social aspects of the link between parent and child ordinarily exist and function together. The physical father and mother not only engender but nurture and rear the child to independent adulthood. Under serious circumstances, in the best interests of the child, these two aspects of the parent-child link can be separated, as in adoption, the genetic aspect of parenthood being overridden and all legal and social functions of parenthood being exercised by a person or persons who are not genetically linked to the child.

An essential genetic link, however, does perdure. Approximately half of the genes of any given individual come from each genetic parent. As is becoming increasingly clear, the genetic heritage of a person has, while not a determining role, nonetheless a crucially important role in that person's functioning and in his or her identity. This affects not only physical features and physical health, but aspects of function which are related to personality, perceptions and other important components of the self.

It is, moreover, only in very recent times, and chiefly in North America, that a segment of a culture has appeared which places little emphasis on ancestral ties and histories. In part this is an effect of the relativization of descent and inheritance as sources of social status and occupation. Adoption within a recognized legal framework has a relatively short history in Canada, the first province legislating its establishment in 1873 and other provinces following suit over several decades well into this century. Before that the genetic tie was the only mode of descent, as well as the primary mode of inheritance.

Observed from an anthropological perspective, adoption was made possible in part by the industrial revolution and wage or salaried employment or entrepreneurship based on education, skills and a mobile labour market. Now that hereditary status and land tenure are no longer vital to a prospective heir's livelihood in Canada, ascribed filiation, that is legal relationships of descent which are based on decision rather than on claims to genetic relationships, have become matters of preference which

radically threaten no one. They therefore are legally unchallenged (and unchallengeable) by those collateral relatives who would have inherited from a childless couple or by those siblings who would have had a larger share of an estate had a child not been adopted.

The perception of adoption has greatly evolved over this century (more or less, by province) of experience, and questions of "real" ties become matters of social bonding rather than validity of claims to property. As the adoptive bond emerged as psychologically, legally and socially enduring in itself, and genetically-based disputes over property faded to utter obsolescence, even the social reasons to deny the desire for mutual identification became uncompelling. Now, in effect, both those involved in adoptive relationships and the state which authorizes them can afford to recognize the genetic link because it does not threaten the psychological, social, or legal attributes of the adoptive link in any effective way. There is no longer any need to deny or block the genetic link.

In the case of donor insemination, as in adoption in earlier stages of its history, defining social parenting as being the only "real" bond has been an attempt, not only to affirm the social bond, but to deny, or at least block, any continuing salience or existence of what was commonly called the "blood tie." There is also, however, a movement among some groups in society to elevate the socially ascribed definition of social roles to the position of sole determiner of social structure and legal rights. The objective is to allow their preferred redefinitions of some of the more fundamental terms of social structure, including — or perhaps principally — those defining marriage and the family. On the conceptual level, from that theoretical perspective, if a social role can be "deconstructed" to negate any objective reality value of any of its definitions, components, relationships, or attributes, then it can be viewed as being no more and no less than what someone says it is. At that point it can be redefined as being virtually anything that a particular group or ideology would have it, without reference to any inherent physical characteristic or any appeal to the "nature" of any relationship.

That much about social structure is culturally defined is indisputable; some societies are matrilineal while others are patrilineal and still others are both (ambilineal); some assign status entirely by descent and inheritance while others assign it primarily by occupation or education. The role of relative income in status varies greatly by society and by subsegment in any larger society.

It does seem, however, when we look at the cross-cultural ethnographic record, that every culture has a form of marriage and of descent of some sort, and that the basis of that form is an agreed-upon type of relationship between male-female couples and the children they engender. The social and genetic aspects of the parent-child bond may under certain circumstances be distinguished in varying ways in various societies, and the relationships of male and female may be formalized in similarly varying ways. Families may function as co-residential

multigenerational units or as scattered extended families with widely varying degrees of cohesiveness. In the vast majority of circumstances, however, societies are comprised of structures based on enduring male-female pairs and their children. Even those traditional societies giving formal recognition to same-sex relationships, societies which, though not numerous, do exist, give them a status which is distinct from that of marriage.

This would seem to be related to, among other things, the recognition that any conception requires the action of a male and a female. Even the circumventing technologies which we are considering, however the ova and sperm may be redistributed, nonetheless require a male and a female whose gametes join and who have a physical genetic relationship with the resulting child. The anonymization inherent in sperm banking and the medicalization of donor insemination (or of ovum donation, although it requires surgery to bring it about) is in a very real sense a modality of masking the human relationships which exist even as they are being bypassed. A physician and/or a sperm bank intervenes so that a specific woman and a specific man do not have to "know" or acknowledge one another, in either the relational or the physical sense.

There is that about the capacity to engender children which is so primordial and inherent in the male-female and parent-child interactions, bonds, and relationships that this bond cannot be solely socially defined, or redefined, without reference to those realities. It is problematical and contradictory enough to attempt to separate the adult personal male and female components in generation even when two persons may not meet one another. It is impossible to separate the child from the genetic link with either parent, since he or she carries those genes, with all their effects, for life — in all likelihood passing them on to children of the next generation in turn.

Even on this continent, there is no consensus that the parent-child link can be restructured at will. Indeed the reverse has been universally taken as axiomatic until very recently. While social and economic mobility have made the inheritance of property and occupation of little practical importance, the sense of rootedness and personal connectedness in genetic ancestry tends to remain. The solely social definition of the parent-child link is actually supported by a fairly small segment of the population.

While the opinion surveys done by this Commission did not directly explore the definition of the genetic link after gamete donation, the genetic link is clearly held to be important by many Canadians of all ethnic backgrounds. It is held to be all the more so by Canadians of cultural and/or religious backgrounds which strongly emphasize lineage. Examples such as the genetic link being required for the fulfilling of the Jewish mitzvah of engendering male and female children capable themselves of engendering children, and the Chinese reverence for ancestors, are only two of many which could be brought forward. For that matter, the very fact that many of those who use donor insemination seek to do so in secrecy is

itself a paradoxical reflection of the value which genetic ties are held to have in the population as a whole. We should be leery of redefinition of precedent-setting social and legal roles based on premises which intrinsically deny or relativize values and self-definitions held by many, or even most, Canadians.

There is an important and insufficiently explored role of the genetic parent-child link in the development of the self-definition, the identity, of many people. The Commission report, indeed, insightfully acknowledges it. That this is true where the genetic and social parent-child links remain intact is patently obvious. What family — and what individual — does not make reference to the relatives who share, not only eye shape or hair colour, but also aspects of personal interest and temperament?

Studies of separated twins indicate that these commonalities are not only matters of nurture, the environment, and education of the child, but have a genetic component. That genetic commonalities are unpredictably assorted does not lessen the fact, and perhaps even more importantly the perception among both parents and children, that they exist and are a component of a reflective self-understanding. In the old nature versus nurture debate, it is increasingly clear that both are of essential importance — along with the large part of every individual which is utterly unique. The same questions that arise among individuals in intact families necessarily also occur to those whose genetic and social links have been severed, however appropriate that severing may have been at the time.[34]

One may question whether it is wise to frame social definitions and the derived legal definitions and applications of the parent-child link solely on conceptualizations which recognize only one ascribed aspect of that link, ignoring empirically observable inherent genetic continuities (which are also perceived and given a social value by most in this society). It is one thing to frame the law in a way which balances the acknowledged rights of individual parties who may differ in their wishes. It is another to frame the law in terms of monofactorial principles of social structure which are not held by consensus and which may be an imposition of one social view on those Canadians who hold another view, whether as individuals or as groups.

Self-Insemination Within the Health Care Facility Setting

It is possible that widespread encouragement of self-insemination (SI), if sperm banks were to operate on the recommended carry-out basis, would undercut the application of some of the principles at which we have arrived. Of greatest concern here would be questions of record keeping and of medical and other history, and even of the possibility of commerce. It seems somewhat contradictory to set up an elaborate formal structure for standard setting and record keeping in donor insemination, while simultaneously stating that "where possible, both heterosexual couples and women without a male partner should be encouraged to avoid the costly

and medicalized aspects of clinical DI programs by choosing SI," the recipient(s) being instructed in thawing and administering the sperm elsewhere. This would encompass the vast majority of donor insemination recipients. It refers to all but those who would require specialized interventions such as intrauterine insemination or sperm washing and concentration, techniques which are usually used for insemination by husband in any case. In my view, the intent that comprehensive record keeping and certain other standards not be compromised is, on the practical level, unrealizable with SI.

Once a private citizen has taken sperm out of a sperm bank, moreover, there is no certainty whatever that it was used by the person herself, or that it was not passed on, even for unrecorded for-profit payment, to someone else whose identity, medical history, etc., are unknown to — and perhaps would even have been of grave concern to — the sperm bank or fertility clinic. Given the large number of inseminations which are sometimes necessary for a conception, plus the possibility of seeking subsequent children by the same means, a private individual could distribute a considerable quantity of sperm to an indeterminate number of people over time without the awareness of the sperm bank or clinic, or of the national registry. Return of information on live births and other aspects of outcome, of course, would not be accurate or, as is far more likely, would not occur at all. If, however, the report recommendation that this information be routinely returned on a form by the parents of DI children were also to become practice, the non-return of information from these individuals would not arouse suspicion either.

The return of information on a form forwarded solely by the receiving parties, including by those who use it as intended, is a problem in any case, given the known low return rates on voluntary forms of any kind. This is particularly so in the case of forms which must be kept and remembered for a considerable period of time before being filled out and returned. The information gathered would also be skewed toward the optimistic, as those who experienced miscarriage or the birth of a child with a disorder would be still less likely to fill in and mail the forms. Viable follow-up would have to be made possible by confidentiality-maintaining data base linkages to other medical records. If, then, sperm is widely distributed on an informal, carry-out basis, there is no certainty that it has been used by those who present themselves as having used it or that the ethical standards and accurate record keeping which have been recommended would be maintained. In some significant proportion of instances they may not be.

Even when, as in the probable majority of SI cases, the sperm is used by those who undertake to use it, even as prescription drugs are used by patients outside a medical office, record keeping would be compromised. That many of those who receive prescription drugs do not use them correctly or completely, or do not use them at all, is well known. Drug trials routinely require formal follow-up to be able to ascertain both the

successful administration of the drug and the outcome. If one objective of record keeping is to know the success and risks of donor insemination, shifting the majority of donor inseminations to a largely informal self-insemination model will be unlikely to accomplish that objective. The birth, the records and the identity of a child are arguably also of even greater importance than the prescription of a drug, since the individual who does not comply with the physician's prescription instructions risks only himself or herself, while in the case of SI a child is also involved.

One can understand the desire that conception take place in the known surroundings of the home. Once the public health care system is being approached for donor insemination, however, some level of intimacy has already been sacrificed. Allowing SI outside the clinic setting would undercut the associated recommendations in this report and the principles they embody for the welfare of the child and all others concerned. The requirement that insemination occur only in hospital facilities has ample precedent, not only in Canada but in other countries, Sweden being only one.[35]

Sperm for self-insemination should be therefore used in a private, comfortable, and well-appointed room provided on the site of the clinic or sperm bank, and should not otherwise be taken out of the facility.

Conclusion

While the existence of gamete donation is accepted by many Canadians, other Canadians are not in accord with the practice. Asking that public regulation be given to it does not presuppose universal condoning or national consensus. Individuals, health care personnel and health care institutions are — and should remain — free to choose whether or not to participate in or to provide it. Some may argue, with considerable persuasiveness, that they would prefer that their tax monies not be devoted to a practice which they oppose. Others will argue, however, as we of this Commission have done, that bringing what is already a permitted practice under the umbrella of the governmental health care system allows it to be supervised and regulated. Only in this way can abuses such as commercialization, grossly multiple donation or use of medically dangerous fresh sperm, which, as this Commission has found, exist not only in other countries but in Canada, be avoided and standards and records be maintained in the best interests of all parties, the child foremost.

Judicial Intervention in Pregnancy

The role of law is largely to protect the rights of individuals, and, in cases of conflict, to balance those rights. Where there is a question of legal intervention, then, there are two related questions. What is the evil which the law is to remedy, and does any given remedy create more problems than did the original evil itself? The possible evils we must consider exist

at a minimum of two levels. The more obvious is the individual level, as between the life-long harm to a fetus and the limitation of a woman's autonomy. The second is the societal, as between the potential effects of judicial intervention in pregnancy on the collective status and autonomy of women and, by contradistinction, the potential effects on both equality and the nature of the rule of law arising from the absolute preclusion of such intervention.

Judicial intervention in pregnancy is a question which only arises because of situations which are tragic in the conflicts which they embody. In this I am in full accord with my fellow Commissioners. No matter what the disposition of an individual case, there will be results which one wishes had not occurred. To intervene means to save the child at the cost of coercing an unwilling woman into surgery or close supervision or imprisonment to control her harmful behaviour. Not to intervene means to leave the woman free to act in any way whatever at the cost of accepting preventable but almost certain harm, handicap, or death for her child. One cannot regard any resolution of the question without ambivalence.

The questions which must be resolved are many and complex. I do not believe that there has been sufficient reflection on them, by Canadian society as a whole or by the relevant expert disciplines, to warrant any categorical statements by this Commission on the most humane and constitutionally consistent approach. The arguments adduced here will have to suffice for the present, as the Decima survey done for this Commission did not ask the Canadian public their views on this question, confining itself to new reproductive technologies per se. Given the importance of its broad implications, this is a question on which the views of Canadians should be actively and representatively sought before any legislative change is even contemplated.

My task here is not to resolve the issue but to raise questions as to whether there are not other, still greater evils which arise if we hold that a woman must not or cannot ever, in principle, have her autonomy limited in these ways. Unless we are certain — and I am one among many who are not — we should not take premature action to alter the existing legislative and other protective structures.

The Dilemma

As presented to us, judicial intervention in pregnancy seems chiefly to arise under two sets of circumstances, those of harmful lifestyle at any point in pregnancy or those of medical emergency, usually at the point of birth. Intervention in the first set of circumstances, in the rare instances in which it occurs, takes the form of measures to alter the substance abuse or other harmful behaviour, whether by mandatory supervision, treatment or incarceration. Intervention in the second set would chiefly take the form of court-ordered Caesarian sections. There has been discussion of court-enforced surgery to correct a disorder in the fetus *in utero*, but this seems

to be a hypothetical concern rather than a concrete situation. A related question is that of whether a woman would be liable for civil damages or would be subject to criminal charges for damage done to the fetus after the child is born.

I am in full agreement with my colleague Commissioners that the question of judicial intervention in pregnancy arises when the ethic of care has broken down, and that our primary concern must be to provide such social, educational, economic and medical supports to pregnant women that such conflicts may be avoided. Most pregnancies are models of the ethic of care in action, first on the part of women, and with their partners, relatives, friends, and societal institutions providing all possible support.

A lapse in this manifesting of care does, however, sometimes occur. Our task, then, is to find a way to deal with something that everyone wishes had not happened. The ethic of care has broken down and we are faced, unavoidably, with a conflict of rights which an appeal to mutual and universal care will not resolve.

The fetus is vulnerable, and is certainly in no position to help herself or himself. One question, then, is whether the woman should be obliged to give the help, obliged, that is, to follow the principles of care for the vulnerable and respect for life, or whether her autonomy is of such prior importance as to be sacrosanct, even in a case in which most people would choose otherwise and would wish that she, too, would choose otherwise. A second question is what the broader implications of either conclusion would be.

The Courts and the Defence of Actual Consent and Autonomy

The recommendation that judicial intervention in pregnancy not be permissible assumes that the courts would necessarily be oppressive and coercive in overriding a woman's consent. Yet we must consider the possibility that in some cases the courts, in mandating treatment, could be acting in defence of a woman's best interests, actual intent and consent, and thus her authentic autonomy, against the coercion she experiences from some other factor in her life, such as severe drug addiction.

The only practical mode of determining whether this is or is not so is to carry out the examination of the particular case. It follows, then, that judicial review and possible intervention would have to remain a possibility in order to determine what the exercise of her best interests, intent, consent, and hence actual autonomy would be and to mandate measures which would enable it. Precluding judicial intervention in pregnancy, then, could in some cases militate against the very autonomy which the Commission report wishes to protect.

I agree that in general a woman's refusal to consent to treatment should not be overridden; this is not because she is a woman but because she is a human being. Since the one patient is inside the other, he or she can only be reached by intervention in the body or the behaviour of the

non-consenting other. We do not force a person to undergo invasive treatment for the sole benefit of another (as in living donation of a kidney), even when the other would die without the intervention. Nor do we force those of sound mind to accept medical treatment for themselves, even if we consider their judgement to be in error, or when non-treatment is likely to result in their death.

The principle of the requirement of consent would seem to mean that in general a pregnant woman ought not to be coerced into treatment against her will. The Commission report, however, appears to assume exceptionless, perpetual and unambivalent, unambiguous, consistent and rational choice on the part of the woman. In some cases as they actually occur in practice there may be doubt as to the competence and hence the nature of the consent of an individual woman. This may be so if she is drug-impaired or in a state of drug withdrawal which would cause her to say or do anything to get a fresh supply, whatever her deeper intent for her fetus might be. Perhaps a clinician is faced with a woman whose statements of intent are shifting because of some emotional state or panic, or because of some form of lack of capacity to understand that treatment is the only mode of bringing about the outcome she has explicitly said she wants, the birth of a healthy baby.

There may, therefore, be a question as to what her most fundamental choice actually is. Is she acting as a rational, choosing adult, having decided that drug ingestion is more important to her than the welfare of her fetus? It seems that the Commission report predicates its interpretation of autonomy only on this assumption. Or does she in fact intend good for her fetus but is being coerced at one irrational moment by the urgency and desperation of her drug withdrawal to say and do things which in another, rational moment, she would not wish to say or do? In such cases it may be that some form of objective assessment of her intent is necessary, not only in the child's interests but in her own. Would a court be coercing her, or would it be protecting her from coercion?

The weighing of consent or refusal of consent on the part of a woman under conditions of medical emergency and distress is not as straightforward as it might be were she deciding calmly over a period of weeks on whether or not to donate a kidney. The consent or refusal of a woman chronically under the influence of alcohol or drugs is similarly difficult to determine. If we as a society are ambivalent about such situations, it is highly likely that any given woman in that position would be far more so.

Society recognizes that diminished competence diminishes the capacity for informed consent. Our own Commission concludes that informed consent must go beyond mere acceptance to informed choice, which seems to me to presuppose not only full information, and awareness of alternatives and implications, but also sufficient rational capacity to choose. At what point does some state of impairment or incoherence or

panic or incapacity so diminish competence that a disinterested party must become involved?

Our society accepts the principle that, while the mentally ill should in general be hospitalized only with their consent, well-founded fear that a person will harm himself or herself or someone else can warrant committal. Because of the human consequences of either a narrow or a broad interpretation of that harm, the point at which this principle would apply is the subject of ongoing debate, or indeed struggle. The principle itself, however, is accepted and there is clear recognition that the dilemma is real. The question must arise whether severe drug addiction resulting in incoherence or uncontrollable compulsion is sufficiently parallel to or cognate with severe mental illness in some respects that similar approaches are appropriate.

The Commission report asserts that "the use of mental health legislation to commit or treat a pregnant woman against her will, even where the language of the statute appears to be applicable, would clearly offend Charter principles," but it does not give any reason why this should be so. One would assume, rather, that mental health legislation is applicable to both sexes, and is not suspensible solely because a person is female or because she is pregnant. If a woman is not mentally competent to determine the nature of her own consistent choice or her own best interest, even prior to consideration of the welfare of another, help may be needed as in many other instances of grave impairment.

The Commission report seems, indeed, to contradict itself on this point. It states that the "legal consequence of being found mentally incompetent is the appointment of a legal guardian to make decisions on one's behalf." Precisely. This requires judicial intervention, whether a person is pregnant or not, and even if the best interest of the woman were considered the primary or even the sole consideration. It may well be that treatment or behaviour which would protect the fetus would also be in her best interest with respect to her own health, were she found, under the principles of mental health legislation, likely to do herself severe and irretrievable harm. It would certainly be in her best interest with respect to her future life of responsibility for the care and custody of a child who could, were there to be the action of a guardian or some other modality of treatment, be born without handicaps burdensome, not only to the child, but to the woman.

It is in the face of these dilemmas that the application of ethical principles, social analysis, medical diagnosis and therapy, and the role of the courts come to overlap.

The courts are a disinterested forum with accepted legitimacy in our society for the resolution of what will necessarily be grave doubts, ambiguities, and conflicts. Any other body, such as an ethics committee, or another individual, such as an ombudsman or even a mediating social worker, designated to take responsibility for these conflicts will rapidly find themselves exercising what amount to quasi-judicial functions. Yet the

mandates of such bodies and persons are not, in fact, judicial; ambiguities may remain and time-limited emergency conditions may compound the urgency of finding a resolution. The final forum in our society is, and must be, the courts.

Women as an Aggregate

Arguments opposing judicial review in individual cases on grounds of a posited effect on the collective status of women or on the autonomy of all individual women seem to me to have serious internal contradictions, and to leave insufficient room for sensitivity to these specific individual women's interests and situations.

The assumption appears to be that no claim should exist which might limit the autonomy of any woman. This has many political, constitutional, and other implications.

The individuals, women and children, who are caught in these tragic situations are not being treated in these arguments as ends in themselves but more a secondary means to a separate and arguably unrelated political end, an end concerning which the individual women in these conflicts may have no — or some other — personal awareness or commitment. It is they, the individual women, however, who will be left with the care of the handicapped child, or with the bereavement, which follows non-intervention.

Judicial intervention in rare instances of grave circumstances does not in any way reinforce "the notion that a pregnant woman's role is *only* [emphasis mine] to carry and deliver a healthy child" or for that reason deny "her existence as an autonomous individual with legal and constitutional rights," hence being "dangerous to the rights and autonomy of all women." Every person has a multiplicity of often overlapping roles. To define any person in terms of only one of them — or to posit, as the Commission report does, that unspecified other people define and may be further encouraged to define all members of a group in terms of only one of them — is reductionist. Indeed I know of no group anywhere on any contemporary political or philosophical spectrum which claims that the delivering of a healthy child is a woman's — or a pregnant woman's — only role. When the subject is raised, the notion is universally condemned. It is hence a red herring, however politically potent the slogan.

Women and men both, as adult human beings, have formal and informal rights and responsibilities arising from each of the roles they undertake. This may be, to take just a few of the more commonly experienced examples, as employer, employee, spouse, friend, contractor, contractee, parent, child, and, yes, gestating woman. Gestation toward the goal of delivering of a healthy child is not the only role a pregnant woman has, as any woman who has been pregnant and any other person who has lived or worked with a pregnant woman knows. It is, nonetheless, one of the roles she does have, and the responsibilities which go with it exist as the responsibilities which arise from any other of her roles exist.

It is certainly true, as the Commission report points out, that a caring and nurturing relationship cannot be legislated. Society does, however, quite routinely legislate the minimum fulfilment of the formal responsibilities and obligations of various social roles, including those, such as the parent-child or the marital role, which are best generated and supported by the informal and strong bonds of affect, caring, and commitment. This is because it is often upon the fulfilment of social roles that the essential welfare of others depends.

If, as must be the case, women are to be deemed equal, women must be deemed to have the full responsibilities which accompany full rights. We expect every adult to act responsibly with respect to the roles they freely undertake, and with respect to the persons to whom they have undertaken both the rights and the obligations which characterize those roles. To expect that pregnant women act as responsibly as we expect every other adult to act is to uphold and defend the rights of women as competent, free and full participants in society. It is the negation or the waiving of those responsibilities which, in my view, would be "dangerous to the rights and autonomy of all women."

Those who argue against judicial intervention in pregnancy in order to protect or advance a gender-based, aggregate, absolute autonomy may be viewed, particularly if they are themselves women, as being in a conflict of interest. Whatever resolution is reached by society with respect to these situations, it should be primarily for the welfare of the principals, the specific woman and the specific child. It should not be in aid of positions on any other issue, or in aid of the separate and different interests of the members of any larger group.

Many of those who subscribe to the collective status argument would never intend to use individuals as means to an end; this nonetheless seems to me to be the other side of the collective status coin. The issue of judicial intervention in pregnancy should not be caught in, or be treated as a strategic element in, a larger and distinct political struggle, however important and worthy some of the issues in that struggle may be.

Such arguments may, moreover, by placing women either or both above or beneath the law, be ultimately counterproductive to furthering the equality of men and women within our common humanity. This, as I shall suggest, would be a far greater evil than would a continued wrestling with these agonizing conflicts on a case-by-case basis.

Responsibility, Equality, and the Constitution

We must deal with the question of a woman's accountability for her actions. The case of judicial intervention in pregnancy is different from that of abortion, in that the child is to be born and, if surviving, he or she will have to live with whatever the consequences of the conflict turn out to be. Fetal alcohol syndrome, brain damage from oxygen deprivation at the time

of birth, and the results of being born with cocaine or heroin addiction are among the more common of such consequences.

Again, we must deal with this question not only in pragmatic terms but in principle. There can be no doubt that the inconvenience or loss of mobility or other effects experienced by a woman of mandatory but temporary care or treatment would be far less severe than the effects of an entire lifetime of mental and/or physical handicap on the child who is to be born. This is a very important question of proportion. On the practical level, however, were women to be systematically threatened with lawsuits or criminal penalties when their addictions or choices had damaged their children, some pregnant women might well, as the Commission report rightly points out, avoid medical care for themselves and for their children, or perhaps abort out of fear of sanctions. This would obviously be counterproductive from the perspective of the good of the fetus along with that of the mother.

The concerns expressed in the Commission report that "the potential for curtailing women's choices and behaviour becomes staggering" and that many women's pregnancies could become "subject to challenge and scrutiny" nonetheless seem to me to be alarmist. It would be not only repugnant and totalitarian but simply impossible to set up some sort of science-fictional infrastructure to enforce the compliance of every woman who did not seek adequate prenatal care or who did not follow her doctor's advice. Equally repugnant and bureaucratically impossible would be the assessment of every newborn for possibly matrigenic (parallel to iatrogenic) damage, and the resultant laying of charges. A significant segment of the literature on the subject paints just such bizarre scenarios representing judicial intervention in pregnancy as the harbinger of some total and coercive (male) medico-governmental dictatorship over women.

The painting of such extremes, however, or rather the setting up of such straw men, tends to obscure the rather more prosaic but far more probable scenarios in the instances one finds on the ground. Specific children are born severely damaged in ways which were entirely preventable and which were entirely within the responsibility of the mother. Once the children are born there is no question that they are legal persons. Laws exist which allow them to sue for damage done — or to inherit — through events which occurred before they were born, so long as they are subsequently born alive. It would probably be imprudent, counter-productive and impracticable to sue women for the developmental and other handicaps children may suffer because of what their mothers did while they were *en ventre sa mère*. Yet we may ask whether women are not responsible in principle, and therefore what the implications of the question itself are for the status of women before the law.

The Commission report says that pregnant women "are no different from any other responsible individual; to treat pregnant women differently from other women and men, or to impose a different standard of behaviour on them, is neither morally nor legally defensible." It should be clear by

this point that I agree. Where we disagree is on the application. Autonomy is a necessary good, but it is not an absolute. All of us have, as the report says, the right to make our own choices, but rights necessarily entail responsibilities; where our choices may or do harm others, our choices are, in fact, limited, and we are held accountable, whatever our gender. It is the suspension of that accountability with respect to pregnant women which would constitute the setting of a different (and lower) standard of behaviour.

An employer who chooses to employ people in his or her factory or office is responsible before the law to provide them with a safe environment. If one of them is injured in some way for which the employer is responsible, the injured person can sue or the employer may be charged with offences related to negligence, up to and including negligent homicide.

A woman, unless she has been raped, has in some measure willed her pregnancy, at least to the degree that she consensually participated in the sexual union which initiated it. If family planning was not used, she participated in that choice also. Is she not to be deemed responsible for the environment she provides the one who is there at her initiative, even as the employer is responsible for the environment he or she provides for the employee who is there at his or her initiative? A householder who is liable for injury suffered by a person on his or her hazardously maintained property provides yet another parallel.

To some it may appear that a woman should not be held responsible in a manner parallel to the responsibility of an employer or a householder. Yet let us look at the questions raised by such an exemption. It seems to me that the rationale would have to be that a woman is either above or beneath the law on grounds of gender and pregnancy, assertions which one may question.

If the argument is that a woman must not be held responsible because she is a woman and it is her choice, this seems to me to imply that a woman is above the ordinary application of the law because she is a woman. I have not yet seen a clear, let alone persuasive, argument as to why this should be true.

Be it granted, only a woman can become pregnant, as only a man can produce sperm. Neither fact is discriminatory; they are simply an empirically observable given, a function of the highly adaptive, population-variability-maintaining sexual dimorphism that human beings share with most organisms above the evolutionary level of the worm. Granted, too, given the unique human capacity for awareness and, with that, the development of the philosophy and ethics of social and legal responsibility, that there may therefore be modes of exercise of responsibility which are possible only for a woman, as there are other modes of exercise of responsibility which are possible only for a man.

The standard of behaviour, however, is the same. While one *ought* to act in accord with the principles of benevolence and care, that is in ways which are supportive of and helpful to others, at a minimum one is free to

act as one wills so long as one acts in ways which do not harm others. As only a woman can, by her own drug abuse or other actions, severely handicap someone for life, only a man can rape. That only one gender can do one or the other form of harm does not make accountability for either discriminatory. The single standard of behaviour pertains to both. The difference in culpability has to do with the probable social circumstances of such a woman and the physiological and psychological burden of addiction, as compared with the improbability of any credible mitigating factors in rape. The difference, however, has to do with an independent assessment of the capacity of the individual to choose not to do harm, and hence an assessment of competence; it has nothing to do with gender discrimination.

If the argument is that any woman in this sort of situation is vulnerable, has arrived in her unfortunate situation for reasons utterly beyond her control and ought not to be burdened with the ordinary application of the law, this seems to imply that she is beneath the law because she is incapable of the responsible, rational choice which underpins all adult participation in the society as framed by the law, again because she is a woman. It appears to me that a blanket application of this to all cases involving all women would be to return women to the patronizing and disenfranchising protections once offered to "women, children and the insane."

That all persons are to be assumed mentally and morally competent and capable in the absence of evidence to the contrary is essential to their full, adult participation in a democracy. Placing this in doubt with respect to women as a group rather than with respect to particular individual women appears to me to be highly counterproductive.

The argument from aggregate seems to suppose that if any woman is judged incompetent, all women are by extension judged incompetent. Conversely, it seems to suppose that if all women are to be viewed as full legal and moral persons, every woman must be assumed under any and all circumstances to be wise, objective, and rational (and right "for her") in everything she does.

I would not make the assumption that if women are not deemed universally competent, they are condemned to being deemed universally incompetent as a class or group. They are individuals. Most would fall into the rational, decision-competent, responsible category, at least most of the time, not because they are women but because they are adult human beings. Some individual women, like some individual men, however, do have diminished responsibility which is due to temporarily, chronically, or permanently impaired judgement. If this is so in individual cases, then the question of the protections and treatments — and the controls — which ordinarily apply to those of seriously impaired capacity must arise. Otherwise, freedom requires that women, adults indistinguishable from men on that ground, are assumed to be competent, and hence both responsible and accountable.

We must, as women, beware of overusing arguments claiming protections and privileges on grounds that we will otherwise be victims. Victims are victims because they are weaker than those seen as victimizing them. The unspoken correlate of such arguments is that women are, in fact, the weaker vessel, and that we cannot stand on our own taking full responsibility for our actions. It is *because* I see women and men as equal that I cannot accept arguments from collective victimization. Some individual women are victims as some individual men are victims, and protections must be constructed accordingly. Arguments for protections and exemptions from responsibility on grounds of what amounts to a collective victim status, however, negate and undermine the collective and individual equality of women.

State Interest in the Fetus

The question of the personhood of the fetus is irrelevant to that of judicial intervention in pregnancy. By extension so, too, is the question of the treatment of the fetus as a separate patient, although in my view it is no more than a recognition of reality, whatever rights that patient may or may not be deemed under the law to have.

Even were the fetus to be recognized as a full person before the law, the ordinary protections of one person, the woman, against medical intervention or confinement for the sole benefit of another would still exist. If they apply with respect to aid to those already born and physically independent of the prospective donor, they will certainly apply with respect to aid to those located physically within another.

The Commission report raises the fact that the fetus has not been recognized to have the independent legal or constitutional rights of a person under the law. The woman is seen from this perspective by the report as having no legal obligation to undergo intervention since there is, in effect, no rights-endowed legal person whom she has an obligation not to harm. The report goes on to say that no third party can "volunteer to defend the 'rights' of a being that has no legal existence."

Many questions are raised by this approach.

The Supreme Court of Canada, in the Morgentaler decision, recognized a state interest in the fetus. The decision of the Court and the opinions of all but one Justice made no distinction between levels of advancement. Instances of judicial intervention in pregnancy have in any case for the most part arisen in later pregnancy.

Since such a state interest in the fetus does exist, one wonders what meaning it would have were that interest not to be of any force or effect even when a child is about to be born or is viable and the removal of the mother's access to drugs or alcohol or so very routine a medical procedure as a Caesarian section would be sufficient to save his or her life and health. If an interest exists it must have application in some set of circumstances. If that interest were not applicable in these extreme circumstances it would

be applicable in no conceivable circumstances which involved a conflict with the woman carrying the child.

Since the Morgentaler case focussed on abortion, which does indeed involve a conflict between the mother and the child *en ventre sa mère*, it is precisely in the welfare of the fetus in the event of some measure of conflict with the mother herself that the Court saw the state to have an interest, rather than in some conflict with another party, such as some individual committing assault on the mother or some corporate entity polluting the available drinking water with teratogenic effects on the fetus.

To argue, then, that a woman in principle has the unlimited right to endanger her fetus in any way she wishes at any stage before birth and that no third party, which would include the state, can defend the fetus is to argue that the Court, in finding a state interest in the fetus, had enunciated an absurdity, which I doubt.

The Question of Criminalization

I do not see sufficient reason for the recommendation that unwanted medical treatment and other interferences or threatened interferences with the physical autonomy of pregnant women be recognized explicitly under the *Criminal Code* as criminal assault. Making an action an offence under the *Criminal Code* implies that the action is unequivocally and clearly repugnant to the Canadian body politic, so much so that other remedies are neither sufficient to control it nor capable of a sufficient degree of symbolic censure. One must ask, then, whether all intervention in pregnancy fulfils those conditions.

First, as I have argued above, intervention in pregnancy under some very limited circumstances is not unequivocally repugnant to all members of Canadian society on either the symbolic or the practical level. Second, it appears to me that intervention in pregnancy can be and now is effectively controlled by more moderate and gender-neutral means. Third, there are internal difficulties with the recommendation itself.

One would assume that what is being suggested is that intervention without benefit of judicial warrant be criminalized. Judicial intervention itself could not, of course, be criminalized, since a judge cannot be charged or penalized for decisions he or she makes on the bench. To seek sanctions against judges for reaching particular decisions would strike at the roots of the independence of the judiciary and hence of the rule of law.

That a person has the right to refuse invasive treatment or detention by a physician or other professional is accepted both in ethics and in law. Protections already exist. The Commission has been told that the main remedy in the case of non-consensual medical intervention is in the form of *tort* law, claims of civil damages when suit is brought by the claimant. Malpractice is a parallel instance. One may ask whether the criminal sanctions with respect to assault would also already apply. They may; if so, their focus is the protection of persons, not of women as a separate group.

It is unclear to me why intervention in pregnancy would be more heinous than any other sort of medical or social/psychological intervention without consent. If it is at the same level of seriousness, then I do not see why it should be singled out so that a different and more severe set of sanctions should apply. Non-consensual intervention in a situation which is by definition confined to women is not more invasive than intervention in others which could occur in both men and women, such as kidney failure or removal of bone marrow for transplantation. An argument that confinement of or surgery on women is more serious than confinement or surgery which pertains to both sexes would be discriminatory; such an argument would privilege women on grounds of their sex and hence deny equality. I therefore cannot see justification for making the offence and the sanctions different in kind from those pertaining to all medical procedures or other interventions.

Even the criminalization of intervention in pregnancy would not remove the possibility of judicial intervention. In judicial intervention, it is the judge, not the physician or other professional, who is the prime actor, mandating the actions of others. A judge can authorize police to search premises or to seize property — or remove children — for sufficient cause. A judge can also authorize detention for certain grave reasons. These activities, without such authorization, would be criminal. Criminalization of medical and other forms of intervention would therefore affect only the activities of doctors or other professionals acting on their own, not judicial review and intervention itself. If the present sanctions are adequate deterrents to professionals' acting on their own, and if judicial intervention can take place whatever the sanctions, I can see no practical effect of a new measure of criminalization.

Nor does the number of instances of judicially mandated intervention in pregnancy seem to present sufficient concrete cause for concern. The small handful of cases which have come to appeal in Canada, and the fact that they have often been overturned, would seem to suggest that the present system is functioning to discourage judicial intervention in pregnancy. If the present system seems to be producing the outcomes desired by the Commission report, and if there is no evidence of an epidemic of such interventions, let alone of interventions for less than grave cause, I do not see any practical reason for an escalation of sanctions or for altering the judicial modes by which decisions are reached.

I grant that the workings of the Canadian judicial system may be imperfect, as the workings of any system are imperfect. If, however, we were to assume that all courts would make oppressive, biased or erroneous decisions, and that women require protection from them by removing from the courts the capacity to review and decide such questions, we cast into doubt the entire system our society has created for the resolution of disputes and harm-causing ambiguity with no viable replacement.

Nor is the argument from the claim that medical or judicial judgements may err, citing one selected case, convincing. To take the

possibility of error as an argument for never acting upon expert advice under any circumstances whatever is an extreme which would paralyze all social action. Our own report in another place has made the point that all of medicine carries some level of risk. Physicians offer expertise, not omniscience. The same is true of judges. In this they are like all human beings; beyond this they bear the same heavy responsibility as all those in positions of particular social trust.

On these questions as in all others within the body politic, within medicine and within the social services, evidence must be examined, prudence and caution exercised, but some degree of uncertainty is simply a reality of the human condition. It does not absolve us as a society, or the judges who act as the arbiters for our society under grave circumstances, of the responsibility to weigh what can be known of fact, expert advice and concern, to take care that any intervention will avoid doing serious or disproportionate harm to any party, and then to make decisions. Argument that those delegated by society should absent themselves entirely from doing so because of the possibility of error would be, were this accepted in principle and universally applied, to abdicate all active and governmental or custodial forms of human social responsibility. If it would be absurd to apply it universally, one may question the applicability of the argument to this one field.

It appears to me to be more reasonable to accept that judicial review may, in very rare and serious cases and with all due caution and attention to interests and evidence, take place at the time the question arises, before the decision on whether or not to take action is made. It should, however, be very clear that the ordinary protections against non-consensual intervention apply in cases of pregnancy as in all others.

Social Context

A woman's social context can certainly dispose toward the sorts of conflict we are considering, so it is largely through the social context that we as a society can seek to prevent them.

It seems that the majority of cases in which these conflicts arise are associated with poverty. It has been alleged by some (and is implied as a distinct possibility in the text of the Commission report) that the high proportion of cases of judicial intervention in pregnancy which involve the poor and members of visible minorities is due to racism and class discrimination in the medical and judicial systems. This is easy enough to assert, and carries a potent political impact. We as a Commission have not, however, been given a fully documented social analysis of such cases, including adequate evidence corroborating bias. We have not seen, for instance, a retrospective random or universal sample study of judicial decisions rendered to middle-class/working-class as compared with poor women, or white and visible minority women. I would not, as a social scientist, say that such bias has been demonstrated. There may well be

individual judges whose outlook is biased; this must be dealt with on that individual level. The remedy, however, is neither a restructuring of the jurisdiction of the courts nor an attribution of bias to the entire judicial system.

Applying Occam's razor, looking for the simplest explanation for the available data, it is more probable that it is poverty which is the root cause. Poverty is associated with the low levels of education and consequent low awareness of the importance of prenatal care, the low recourse to the health care system, the fear of complex, high-tech procedures and the alienation and addictions which tend to foster these conflicts. While in Canada the majority of poor women are not members of visible minorities, minority women are over-represented among the poor for their proportion in the general population, an inequity which must be remedied on its own terms. It is not necessary to assume — or to imply — that all doctors and judges who have mandated supervision or treatment for poor women are biased.

There is, moreover, no evidence that any causal relationship should even be suggested between the "religious convictions ... cultural beliefs ... or other deeply held values or personal beliefs" of Aboriginal women and women of colour on the one hand and cases of judicial intervention in pregnancy related to the "refusal to accept surgical or other medical treatment or to follow medical advice" on the other.

First, there are no grounds on which to make such a collective connection. Aboriginal women and women of colour come from highly diverse social, ethnic, religious and other traditions, since their ancestors were born in lands spanning not only the wide expanse of Canada but the globe itself. If there are groups who do hold refusal of medical treatment and advice as a value, we have not had evidence of it brought before us. Even if a specific group or groups did hold such a view, however, it could not be generalized to all Aboriginal women or women of colour. Each group and individual should be able to speak for themselves in this regard.

Second, we have had no concrete instances brought before us of judicial review or intervention in a case of refusal on principle or on grounds of culture, deeply held personal values or belief. It is certainly hypothetically possible that instances of such refusal might arise, parallel to the refusal of Jehovah's Witnesses to accept blood transfusions or of Christian Scientists to seek various sorts of medical technology. There may also be some women who wish to give birth within a "women's circle," with a group-chosen "wise woman" or unlicensed midwife rather than a medically credentialled practitioner. It may be that the defence of such latter groups against feared requirements of professional medical supervision is related to some significant segment of the feminist concerns which dominate discussion of this issue. No cases of judicial intervention on grounds of culture-based values or principle, however, whatever the ethnic or other context of the woman, appeared in the evidence with which we have been presented.

Third, as the report acknowledges, cases of judicial intervention in pregnancy usually involve abuse of drugs, alcohol or both. Still others involve often-related activities such as prostitution. Both substance abuse and prostitution carry a serious risk of violence and disease (such as AIDS, the toxic effects of cocaine, or the effects of alcohol on the brain) which damage and can kill both mother and child. Alcohol and drug addiction or prostitution are not part of the "cultural values" or "religious beliefs" of any Aboriginal or other visible minority groups, whatever the enmeshment of those dysfunctional behaviours with social conditions.

The testimony we as a Commission heard from Native groups emphasized the great and positive cosmic value placed on women and on their bearing and bringing forth of life as part of the work of the Creator. Many other groups hold equally positive views of the importance of a woman's nurturance of her child, including before birth. Many Aboriginal and other ethnocultural groups are engaged in movements to revitalize aspects of their traditional cultures, bringing them to bear on their contemporary lives by integrating today's realities with a strong sense of identity, dignity and values arising from centuries of experience understood through elements of their own tradition. One of the many purposes of this revitalization is to heal individuals affected by precisely those same sorts of behaviour which give rise to judicial review. Women, whatever their culture or ethnic background, do not "choose a particular course of action," refusing treatment or refusing to follow medical advice which would divert them from engaging in the substance abuse and prostitution which have in actual cases drawn the scrutiny of the courts, on grounds of their "deeply held values or personal beliefs."

The ethnic or cultural origin of a woman is therefore not a root factor in her behaviour in any case of judicial intervention in pregnancy of which I am aware. The courts have not scrutinized cases where rejection was based on principle, and those cases in which the courts have intervened have concerned dysfunctional behaviour unrelated to and indeed antithetical to the cultural, religious and other beliefs of all women, including Aboriginal women and women of colour. If some Aboriginal or visible minority women have been among the tiny handful of Canadian cases of judicial intervention in pregnancy, it is due to disproportionate rates of marginalization and poverty, not to the cultural or religious beliefs or values of the groups from which these specific women come.

I would agree with the Commission report that judicial intervention does not change the circumstances that bring about the attempts to intervene, or at least it does not change them directly. That the Commission report would object to judicial intervention in pregnancy on those grounds seems to me to be somewhat inconsistent, however. That an approach may not cure a problem, only circumventing it and changing its practical outcome, seems elsewhere to be presented in this report as acceptable and constructive. Circumvention and outcome alteration are, after all, precisely the modality of several of the approaches to infertility

which this Commission accepts, with due safeguards. The social context is, of course, very different, but the logical structure of the approach is the same.

I would disagree, moreover, with the report's view that intervention provides no solution. Any solution of such cases will probably be imperfect — indeed, non-intervention is itself concerned with avoidance of engagement, not with offering a solution of any sort. The very point, however, of those rare instances in which intervention is appropriate is to "create the social conditions and support that help to ensure a successful pregnancy and health outcome for both the woman and the child."

For example, a woman required to reside for a period of time in a treatment centre, well-fed, with access to counselling, peer support and referral to services to upgrade her education and prospects of employment, and free of the ready availability of the substances to which she is addicted (and which may elsewhere be pressed upon her by her companions) has precisely those social conditions and supports conducive to a "healthy outcome," if this is taken to mean the withdrawal of the woman from drug dependency, her reception of other forms of prenatal and perinatal care, and the absence of mental and/or other permanent disabilities in the child. The supports would indeed be temporary; the woman could later return to a dysfunctional pattern of life if she chose to. Yet there would be concrete benefits, not only to the child but to the woman. The child would not have been harmed; that particular systemically devastating source of harm would have been avoided and, for that child at least, could not recur. The woman herself would have been given the opportunity, the supports and the access to resources to choose to make a definitive and permanent change in her mode of life toward social and economic independence; she would also herself benefit from the fact that the child for whom she would have maternal responsibility and care would be unimpaired by the multiple severe disabilities which are the reason for the concern which gives rise to judicial intervention.

Middle-class and working-class women of all races and cultures in this country tend to have had knowledge of and relatively ready access to prenatal care, and to have been sufficiently aware of the need to avoid substance abuse and other harmful behaviour, particularly during pregnancy, that they would have been unlikely to have come to a judge's attention in the first place. If poverty is associated with the root conditions for much of the tragedy and conflict in society, the fact that the poor are those whose consequence-ridden turmoil comes before judges is precisely what one would expect.

The effective remedy to the problem, then, would lie in combatting poverty, not in removing the capacity of judges to review and adjudicate the conflicts of the poor.

Prevention

If, then, we seek to avoid these conflicts, the place to start is in outreach to women in low-income and any other vulnerable groups. There are many possible strategies, many or all of which could be used in concert. They dovetail with the concerns which have emerged over and over again in our work as a Commission.

Family life education is the first point of prevention, transmitting a strong awareness of responsibility, of pregnancy and of prenatal care and birth long before a girl or woman becomes pregnant.

Outreach to women (and men) with substance addictions is already a priority, but more is needed. In a sense, any social and economic and job training program which gives people hope and a means of building a constructive life is, directly or indirectly, contributing to primary prevention of addictions and to rehabilitation of those who have been addicted.

If many poor women do not receive adequate prenatal care, even in this society in which care is universally offered, perhaps innovative strategies to reach them should be attempted. Public health departments are already engaged in much work of this kind. Public health consultations should be encouraged with a random sample of poor women from all groups at risk, with public health personnel, with anthropologists and sociologists, and with community groups; such consultations could perhaps give rise to new or improved ways of bringing mobile prenatal care, combined where appropriate with addiction treatment, in their own settings, cultures, and languages, to women who do not spontaneously seek out care in large hospital institutions or in stationary private medical offices.

Programs of this type would be helpful, not only to those who would be at risk of conflicts which could come to the point of judicial examination, but to all women at reproductive risk of any kind. They complement efforts to prevent or control STDs, to avoid adverse outcomes of pregnancy from any cause, and to further maternal and child care.

It is probable that no program can eliminate all situations of conflict. The principles we have discussed will, in rare instances, have to be brought into play. Judicial interventions in pregnancy and birth are nonetheless already very few; if, in our overall support for women, we can answer most needs before they reach the point of conflict, judicial review and intervention in pregnancy can in large degree be avoided.

Conclusion

The judiciary provides the final forum with the broadest scope and accepted legitimacy for the assessment and resolution of otherwise irresolvable dilemmas. For the hard cases which we are discussing, there is no superior mode of seeking, with the full range of testimony and expert advice, the real intent, consent and interests of the individual woman, even

if these are placed prior to the recognized, affirmed and supported interests of the child within her. Some nightmarishly vast system of supervision of every pregnant woman would obviously be both repugnant and operationally impossible. It does not follow that rare cases cannot exist in which judicial intervention would be feasible, appropriate, and reasonable.

The unvaried assumption that a woman, because she is one of the class of women, must always be deemed to be fully and unambivalently certain at each given moment of what she intends and of its full implications, isolated from the context of her other expressions of intent, could well leave many individual women with the consequences having been allowed by default to abandon a positive intent under conditions of impairment or some other transitory state. So too would an assumption that, for broader reasons of the collective interests of women, even if a woman is not fully competent she must be treated as though she is. The same would be true of the opposite assumption that a woman, because she is a woman, should be taken solely at her word in such a moment, because she is so constrained by victimization, circumstance, and addiction that she is not responsible for the results of her actions and that those consequences, therefore, do not matter.

The women in such cases would then be left, not only with sorrow and guilt, but with a handicapped child. It is these women, not their doctors, not the members of hospital bioethics committees, nor yet the members of this Commission, who would have the burden of caring for their damaged children for what could be a lifetime, a burden which would be only partly alleviated by services provided by the state or by turning the children over for full-time state institutional care. The children would be left with those handicaps, not just as a burden, but as an overriding reality of life.

No system can guarantee that this would never occur. Only the availability of the objectivity of judicial assessment in cases of manifest ambivalence or impairment, however, will allow flexibility and sensitivity to individual women and their situations. If the wellbeing of a woman and the wellbeing, health and very life of a child depend upon that sensitivity, the absolutization of an approach which would preclude it would seem to me to be a deeply inadequate response.

Moreover, many of the arguments or recommendations against judicial intervention in pregnancy or for the imposition of criminal sanctions distinct from the ordinary, non-gender-related sanctions against non-consensual intervention are premised on assumptions which are, in my view, at odds with the fundamental principles of human equality and of full participation, irrespective of gender, in a free and democratic society. To accept them would ultimately be counterproductive for women and for children, and also for men. By identifying rights, protections and interests with membership in a group, such as the aggregate of women, rather than with universal human identity, responsibilities and protections, it would raise questions about the constitutional structures which underlie our polity itself, with implications which have yet to be examined.

For all these reasons, I see grave difficulties with, and would generally wish to discourage, overriding a woman's refusal of consent to surgical or behavioural intervention in pregnancy. Like my fellow Commissioners, I see every effort at prevention before these tragic situations arise as being the most constructive mode of approach. For both ethical and constitutional reasons, however, I see neither the absolute preclusion of judicial intervention in pregnancy nor the imposition of new sanctions distinguishing the protections of women from those of men as being justified.

Respect, Debate, and the Political Process

On most issues on which diverse opinions exist in society, the flourishing of human freedom, including the freedom to act according to those ideas, must be defended. This is fundamental to human dignity and welfare. There is a point, however, at which the life, welfare, and human dignity of human beings is at such serious risk that society is obliged to act in a universal fashion. It is on this principle, indeed, that we as a Commission have recommended prohibitions of such practices as preconception contracts or uses of technology which bear unacceptably high medical risks.

The majority of my expressions of dissent from our common report, therefore, have to do with the avoidance of absolutized single-perspective resolutions to complex dilemmas and the preservation of the legitimate freedoms of individuals and groups. The case of research on viable embryos, by contradistinction, appears to me to have such far-reaching and negative consequences, both for them and for society at large, that prohibition is the justified response.

In all of these cases, however, a common thread exists. When some, be they embryos, religious groups sponsoring education, women whose complex compulsions and ambivalences about their pregnancies may require judicial elucidation, or anyone else, are made objects subordinated to the collective or individual interests or opinions of others, there is ground for grave injustice, even when the intentions are good. It is better not to drive ahead in ways which, for some, place freedoms and welfare at serious risk or which obliterate those freedoms or that welfare altogether, even when benefit to some others might result or when those who hold a particular view might have the satisfaction of seeing their convictions implemented as universal practice. To do so would be, at its root, both a negation of human rights and, at worst, exploitation. The imposed narrowing of permissible opinion and practice, moreover, would reduce the variability out of which creative insights, adaptations and innovations come.

In a pluralistic society, there are many different views on all of these issues held by highly conscientious people of integrity. This is true among those who have intervened before our Commission; it is true within the

Commission itself. Those of my colleague Commissioners who take a different view from that expressed here would never, I am utterly certain, wish to see any form of negation of human rights or exploitation. On most subjects we are in overall agreement. Where we differ, we do so, not on our ethical principles, but on the conditions and relative priority of the application of them to specific situations, and on the probable results. We differ while sharing a complete and mutual personal warmth and respect.

It is important that this be explicitly stated, because so often the debate on issues of this importance and political controversy tends to slide from substantive toward *ad hominem* arguments, serving neither fairness to persons nor elucidation of the questions. It is one of the achievements of this Commission that questions of such substance have been investigated and debated to the point of final public presentation in an atmosphere of the quest for sound evidence and regard for both the views and the humanity of all. "In needful things, unity; in doubtful things, liberty; in all things, charity." This saying emerging from the Middle Ages is today no less wise.

It is for the Parliament and people of Canada, for the various jurisdictional levels concerned, and for the courts to read the arguments, assessing the persuasiveness of each in deciding the actions it is best for society to take.

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Glossary*

A

AFP: alpha-fetoprotein. See **MSAFP**.

AI: See **assisted insemination**.

AID: An abbreviation for **assisted insemination** by donor. To avoid confusion with **AIDS**, the term **donor insemination (DI)** is used.

AIDS: Acquired immunodeficiency syndrome. A disease defined by a set of signs and symptoms, caused by the **human immunodeficiency virus (HIV)**, transmitted through body fluids (e.g., **semen**, blood) and characterized by compromised immune response.

AIH: Assisted insemination homologous. Term for **assisted insemination** when **sperm** from the woman's husband or partner is used. Also known as *assisted insemination by husband.*

Adhesions: Rubbery bands of scar tissue resulting from the body's attempt to repair damage caused by **endometriosis**, by surgery, or by previous infections. Such bands, if in the **fallopian tubes** and **ovaries**, can obstruct the tubes and prevent **fertilization**. Adhesions may be removed by a minor surgical procedure, but major surgery is necessary to eliminate dense and fibrous adhesions.

Alpha-fetoprotein: See **MSAFP**.

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* Boldface terms used in these definitions are also defined in this glossary.

Alzheimer disease: A progressive, abnormal cognitive impairment, manifested as a loss of memory, language, and other intellectual capabilities, accompanied by a general diminishment of competence and resulting ultimately in death.

Amenorrhea: The absence of menstruation (which usually occurs from puberty until menopause) in a woman of menstrual age. In primary amenorrhea, the woman has never had a menstrual period by this age. In secondary amenorrhea, menstruation stops after having started. When menstruation is irregular or scanty, rather than absent, the term **oligomenorrhea** is used. There are many causes of amenorrhea and oligomenorrhea, some of which may be associated with **infertility**.

Amniocentesis: A procedure in which a needle is used to withdraw a small amount of the amniotic fluid that surrounds the fetus in the **uterus**. **Ultrasound** monitoring is used to guide the needle through the woman's abdomen into the amniotic sac. The fluid can be tested for **alpha-fetoprotein**. In addition, since the amniotic fluid contains fetal cells, these cells can be grown in cell culture and analyzed for a variety of genetic disorders. This takes two to four weeks. Amplification of the genetic material can shorten the time needed to obtain results. The test is usually done at 15 to 16 weeks' **gestation** but can be done as early as 12 weeks.

Amnion: The membrane that forms a fluid-filled sac surrounding and protecting the **embryo** or **fetus**.

Anencephaly: A **neural tube defect** resulting in severe lethal deformity of the brain, caused when the neural tube fails to close.

Aneuploidy: Any deviation from the usual number of **chromosomes** (46 in human beings). For specific examples, see **Down syndrome**; **Turner syndrome**.

Anorexia nervosa: An abnormal aversion to food. Individuals with the condition have an eating pattern that leads to dangerous weight loss. When a female's body weight falls below a critical level, **ovulation** and menstruation may fail to start or they may cease. **Fertility** may be affected.

Anovulation: Absence of **ovulation**.

Antibody: A protein produced by white blood cells in response to the presence of a specific foreign substance (antigen) in the body, with which it interacts. See **antisperm antibodies**.

Antisperm antibodies: Antibodies to **sperm** found in either member of an infertile couple, which may interfere with sperm movement or ability to interact with the egg. They may be present in the reproductive tract fluids of the female, or the serum or seminal fluid of the male.

Assisted insemination: See **AIH**; **donor insemination**; **IVF**; **intrauterine insemination**.

Assisted reproduction: See **DOST**; **donor insemination**; **embryo transfer**; **GIFT**; **IVF**; **ZIFT**.

Autosome: A **chromosome** other than a sex chromosome. Human beings have 44 autosomes (22 pairs).

Azoospermia: Absence of living **sperm** in the **semen**; may be caused by congenital abnormality or by an infection-related blockage of the duct that carries sperm, or by environment- or occupation-related impairment in sperm production. See also **oligospermia**.

B

Blastocyst: A fluid-filled sphere of cells — a stage of development of the **zygote**. A small cluster of cells in the centre of the sphere gives rise to the **embryo**, and the outer wall of the sphere gives rise to the **placenta** and supporting membranes.

Bromocriptine: A synthetic compound that interferes with the **pituitary** gland's ability to secrete **prolactin**, a **hormone** that effects **ovulation**. It may be prescribed for an infertile woman whose pituitary makes too much prolactin.

C

CVS: See **chorionic villus sampling**.

Caesarian section: (also Cesarean) Surgical delivery of a baby through an abdominal and uterine incision. Also called *C-section.*

Cervical mucus: Mucus produced by the **cervix** that undergoes complex changes in its physical properties in response to changing **hormone** levels during the **menstrual cycle**. The cervical mucus guards the upper reproductive tract against the entry of bacteria and against **sperm**, except for the days around **ovulation**. Around ovulation, the mucus becomes clear and watery and the number of antisperm white blood cells in the mucus drops. These changes aid the sperm in surviving and in moving up the female reproductive tract toward the egg. Vaginal infections may adversely affect the cervical mucus, creating an unfriendly environment for the sperm. For testing with respect to **infertility**, see **sperm-mucus cross test**.

Cervix: The lower portion of the **uterus** that opens into the **vagina**.

Chimera: An individual whose cells derive from different **zygotes**. They may arise naturally, as where blood-forming cells are exchanged *in utero* between dizygotic (produced by two separate eggs and sperm) twins, or they may be deliberately engineered in animals. A chimera differs from a **mosaic**, in which the two genetically different cell lines arise by a change in the genetic material of a cell within an individual, or in culture.

Chlamydia: The bacteria *Chlamydia trachomatis* causes a common **sexually transmitted disease**. In women, infection may cause **pelvic inflammatory disease (PID)** of the upper genital tract, leading to **infertility**. It is difficult to cure and as well as causing infertility it may cause an increased risk of **ectopic pregnancy**, stillbirth, premature birth, and eye infection and pneumonia in a resulting infant. In males, chlamydia may cause inflammation of the **urethra**, which, if untreated, can reach the epididymis, where **sperm** are stored.

Chorionic villus sampling (CVS) or chorionic biopsy: A procedure for obtaining fetal tissue. A small amount of chorion (outer membrane surrounding the **embryo** and **fetus**) tissue is removed through the pregnant woman's abdominal wall or **cervix**, using a catheter (small tube) under **ultrasound** guidance. Like **amniocentesis**, CVS can be used to detect biochemical, **DNA**, and chromosomal problems, and for sex determination, but it cannot detect **neural tube defects**. CVS can be done as early as the eighth or ninth week of pregnancy, and the results are usually known within a week (although confirmation after cell culture is advisable).

Chromosomal disorder: A disorder resulting from an addition or deletion of an entire chromosome (**aneuploidy**) or part of one. For examples of aneuploidy, see **Down syndrome**; **Turner syndrome**.

Chromosome: Thread-like structure in the nucleus of a cell, containing **DNA**, the hereditary material (i.e., **genes**). The normal number of chromosomes in humans is 46: 22 pairs of **autosomes** and two **sex chromosomes**.

Clinical trial: An evaluation of a new intervention, treatment (e.g., a drug), or procedure (e.g., a surgical approach) to see how well it works, as compared to known treatments or procedures or to no treatment. Ideally, patients would be assigned at random to one group or the other (randomized trial), but this sometimes may raise difficult logistical or ethical problems. A clinical practice is said to be *non-validated* where its safety and efficacy have not been established.

Clomiphene citrate: A fertility drug used primarily in women with menstrual irregularity. It is like **estrogen** and binds to estrogen receptors in the brain, thereby fooling the **pituitary** into releasing the

hormones necessary for **ovulation**. Its possible adverse effects include dry **cervical mucus**, an increased risk of **multiple pregnancy**, ovarian enlargement, and, sometimes, **infertility** by affecting the woman's **menstrual cycle**. It is also used in ***in vitro*** **fertilization** as an **ovulatory stimulant**.

Cloning: The process of producing a group of cells (clones), all genetically identical to the original ancestral cell. This may be achieved by asexual reproduction (without union of egg and **sperm**), as in plant cuttings. Another type of cloning is achieved by nucleus substitution (also called *nuclear transplantation*). The nucleus is removed from an unfertilized egg cell and replaced with a new nucleus taken from a donor embryonic cell. A third method, also used in agriculture, is by embryo division. In **gene** technology, cloning is the process of producing multiple copies of a single gene or segment of **DNA**. See also **genetic engineering**.

Conceptus: A fertilized egg and, later, the **embryo**, **fetus**, **placenta**, and membranes. After the egg has been fertilized, the cells begin to divide. Some of these cells will become the embryo. Other cells will become part of the membranes and placenta that nourish the developing embryo.

Congenital anomaly: An anomaly that is present at birth. It may be caused by: genetic factors (chromosomal or gene defects); injury by infectious disease during pregnancy (e.g., rubella); other environmental factors, such as drugs (e.g., thalidomide), chemicals (e.g., mercury), or radiation; or combinations of hereditary and environmental factors. The majority of congenital anomalies are of unknown cause.

Conjugated estriol: A mixture of the sodium salts of the sulphate esters of estrogenic substances, principally estrone and equilin, that are of the type excreted by pregnant mares, occurring as a buff-coloured, amorphous powder; the actions and uses are those of **estrogens** administered orally.

Contraception: A means of preventing conception (**fertilization** of an egg by a **sperm**). For possible effects on **fertility**, see **IUD**; **oral contraceptive**. See also **sterility**, surgical.

Corpus luteum: Literally, *yellow body*. **Follicle** cells left behind in the **ovary** when the egg is released. Its maintenance and function depend on stimulation by **luteinizing hormone**, and it produces **hormones** itself, the most important of which is **progesterone**. Progesterone prepares the uterine lining for implantation of the egg. If pregnancy does not occur, the corpus luteum regresses and menstruation occurs.

Cryopreservation: Preservation of tissues such as **sperm** or **zygotes** by freezing them at extremely low temperatures in liquid nitrogen. For

example, in ***in vitro* fertilization**, more eggs may be fertilized than can be implanted. These "extra" zygotes may be placed in serum and a cryoprotectant (a substance that helps to protect tissues when frozen for storage). The tissue may be used later, after thawing.

Cystic fibrosis: An autosomal **recessive** disorder with variable expressivity, which is most common in Caucasians. The secretory glands do not function normally, and abnormal mucus builds up in the lungs and digestive system, which can lead to death in early adulthood. The **gene** has been mapped and the missing protein identified. It can be detected prenatally in the majority of cases.

Cytomegalovirus: A virus that may be transmitted sexually. The effects are host-specific (i.e., depending on the age and the immune status of the infected person, the virus can cause a variety of clinical symptoms). A pregnant woman who is infected may infect her **fetus**, causing stillbirth or growth retardation and nervous system defects in the resulting child.

D

DES: Diethylstilbestrol. A synthetic **estrogen**, given to pregnant women, mostly in the 1960s, to prevent **miscarriage**. It was not proven effective in preventing miscarriage and has been found to cause cancer and genital tract and uterine anomalies, and thus decreased **fertility**, in some individuals exposed *in utero*.

DI: See **Donor insemination**.

DNA: Deoxyribonucleic acid. The genetic material contained in the **chromosomes** and mitochondria, which codes for hereditary characteristics. It consists of a double spiral, in which the two strands are held together by substances called *nucleotides*. There are four nucleotides, and each can pair with only one other; therefore, the sequence on one strand is complementary to that on the other.

DNA probes: See **gene probe**.

DOST: Direct ovum and sperm transfer. A technique of **assisted reproduction** in which retrieved eggs and **sperm** prepared by washing are transferred through the **cervix** into a woman's **uterus** using a catheter (small tube).

Danazol: A synthetic derivative of the male hormone **testosterone** used in treatment of **endometriosis** in women. It often has masculinizing effects.

Deoxyribonucleic acid: See **DNA**.

Diabetes mellitus: A disturbance in body metabolism that causes abnormal elevation of blood sugar levels and other destructive effects. In men, diabetes may cause retrograde ejaculation (see **ejaculate**). See also **fetal tissue transplantation** for experimental treatment of the juvenile type.

Diethylstilbestrol: See **DES**.

Dilation and curettage (D&C): An operation that involves stretching the cervical opening (dilation) to scrape out the lining of the **uterus** (curettage). It may be done, for example, after a **miscarriage** or to terminate a pregnancy. It may increase the risk of **infertility** through infection or scarring.

Direct ovum and sperm transfer: See **DOST**.

Dominant: Each body cell has two copies of the **gene** at any specific locus, one inherited from the mother and the other inherited from the father. A dominant gene is one that is expressed, regardless of the nature of its companion gene. A person with a dominant condition will have inherited it from one of the parents unless the person has a new **mutation**. Each child of a person with a dominant condition will get either the normal or the abnormal gene and so has one chance in two of being affected. Compare with **recessive**.

Donor insemination: Introduction of **sperm** into a woman's **vagina** for the purpose of conception (**fertilization** of an egg). If it is put into the **cervix** it is called intracervical insemination. The insemination is timed to fall just before or on the expected day of **ovulation** (egg release) to maximize the chance of fertilization. Intravaginal insemination is technically simple and can be done without medical aid (sometimes called **self-insemination**). However, there may be a risk of infectious disease. See **donor screening**. For a more complex method of insemination, see **intrauterine insemination**.

Donor screening, microbial: Screening of **sperm** or egg donors by direct culture of the **semen** or **cervix**, or by a blood test of the donor, depending on the infectious disease being screened, in order to protect the recipient and the resulting child. These infectious diseases or disease-causing organisms include **chlamydia**, **cytomegalovirus**, **gonorrhoea**, hepatitis, **herpes**, **HIV**, **mycoplasma**, and **syphilis**. For HIV, this screening will not detect newly infected donors. To do this, the sperm or fertilized eggs must be frozen and the donor retested for HIV in six months.

Down syndrome (trisomy 21): A chromosomal disorder caused by the presence of an extra **chromosome** 21. The frequency of the disorder increases with greater maternal age, beginning to rise more sharply at around age 35.

Duchenne muscular dystrophy: A severe disorder that begins during early childhood and leads to progressive wasting of the leg and pelvic muscles, heart disease, and death by early adulthood.

E

Ectopic pregnancy: A pregnancy that occurs when a fertilized egg implants and begins development outside the **uterus**, usually in a **fallopian tube**. Frequency is increased in ***in vitro* fertilization** pregnancies. Ectopic pregnancies are more likely to occur in women with tubal damage and in women who have had certain **sexually transmitted diseases**. Ectopic pregnancies end in **miscarriage** because tissues other than the uterus cannot support a **fetus**. If the ectopic pregnancy ruptures, this may result in a medical emergency and permanent tubal damage.

Egg donor: A woman who donates eggs to another woman. This may be a healthy volunteer or one undergoing sterilization, **hysterectomy**, or **egg retrieval** for her own reproduction. Such an individual is the genetic mother of any offspring resulting from **fertilization** of the egg.

Egg recipient: This might be a woman with no accessible eggs or one who is a carrier for an autosomal **dominant** or **X-linked** condition but who is capable of gestating. The donated eggs could be fertilized with **sperm** from the egg recipient's partner before implantation into her **uterus**.

Egg retrieval: Removal of one or more mature eggs from the **ovary** after administration of an **ovulatory stimulant** for ***in vitro* fertilization**, using **ultrasound** guidance, or for **gamete intrafallopian transfer**, using **laparoscopy**.

Ejaculate: The seminal fluid expelled by ejaculation and normally containing **sperm**. Ejaculation involves a two-part spinal reflex: first the emission phase, when the semen moves into the **urethra**, and then the ejaculation proper, when it is propelled out of the urethra at the time of orgasm. Ejaculation is said to be *retrograde* when **semen** flows into the bladder rather than through the penis. When a man has a spinal cord injury, electrical stimulation of the nerve that controls ejaculation may be used to obtain semen for **assisted insemination**.

Embryo: In humans, the term used to describe the organism during the stages of growth from about the second through the eighth week after **fertilization**. During this period, the brain, eyes, heart, upper and lower limbs, and other organs are formed. From fertilization up to this

point (14 days after fertilization) the organism is referred to as the **zygote**. From eight weeks to birth it is termed a **fetus**.

Embryo donation: Transfer of a **zygote** to a woman or couple for **implantation**. This may occur where more zygotes are created ***in vitro*** than can be used in a treatment cycle or where frozen zygotes are no longer needed by those who created them.

Embryo flushing: See **uterine lavage**.

Embryo freezing: See **cryopreservation**.

Embryo transfer or replacement: The procedure by which one or more **zygotes** obtained from ***in vitro*** **fertilization** or by **uterine lavage** are placed, or replaced, into the **uterus** of a woman, using a catheter (small tube) passed through her **cervix**. For specific techniques, see **GIFT**; **ZIFT**.

Endocrine system: Network of organs, including the adrenals, pancreas, **pituitary**, **ovaries**, **testes**, and parathyroid glands, which produce and secrete **hormones** directly into the bloodstream for transport to specific target organs, where they exert their effects.

Endometrial biopsy: Removal (for subsequent microscopic examination) of a sample of cells from the endometrium (lining of the **uterus**), usually just before menstruation, to evaluate ovulatory function. The procedure is done without an anaesthetic, using an instrument placed through the **cervix**. If the cells show the characteristics of normal cells at this point in the **menstrual cycle**, **progesterone** production is considered adequate.

Endometriosis: Presence of endometrial tissue (the normal uterine lining) in abnormal locations, such as the **fallopian tubes**, **ovaries**, or peritoneal (abdominal) cavity. Endometriosis can interfere with nearly every phase of the reproductive cycle. It may cause intercourse to be painful, may result in **adhesions**, and is associated with **infertility** in severe cases.

Endometritis: Inflammation of the lining of the **uterus**.

Epidemiology: Study of the frequency and distribution of disease in human populations.

Estriol: A reduction product of estradiol and estrone, having relatively weak estrogenic activity. It is detectable in high concentrations in the urine, especially human pregnancy urine. The official preparation, rarely used clinically, is a white, microcrystalline powder, to be administered orally.

Estrogen: A class of steroid **hormones**, produced mainly by the **ovaries**, having a variety of functions. The estrogen estradiol is necessary for complete maturation of eggs during a woman's **menstrual cycle**. Synthetic estrogens, produced in laboratories, are similar in chemical

structure to naturally occurring estrogens. They are used to alter or interfere with the production of menstrual cycle hormones.

F

Fallopian tubes: A pair of tubes that conduct the egg from the **ovary** to the **uterus**. **Fertilization** normally occurs within the tubes. Blocked or scarred fallopian tubes are a major cause of **infertility** in women. See **adhesions**; **endometriosis**; **pelvic inflammatory disease**; **salpingitis**. In some cases, surgical excision of the diseased area and reconnection of the tubes (salpingotomy) may restore fertility. Investigative tests include **hysterosalpingogram** and **laparoscopy**.

Fecundity: The capacity (degree of ability) to conceive or impregnate, whether or not this capacity has been fulfilled. Contrast **fertility**.

Fertility: The ability to produce offspring. In demographic terms, it is a statement of the actual number of births. Contrast **fecundity**. See also **infertility.**

Fertilization: Union of an egg and a **sperm** to produce a **zygote**, which may then develop further to the **embryo** stage.

Fetal therapy: A term that includes the established procedure of intrauterine blood exchange for Rh incompatibility, and experimental drug or vitamin treatment of an inborn error of metabolism (a genetically determined biochemical imbalance in which a specific enzyme defect produces a metabolic abnormality).

Fetal tissue research: Use of fetal cadaver tissue to study, for example, **congenital anomalies**, carcinogenesis, and infectious disease. Potential sources are **ectopic pregnancy**, **miscarriage**, stillbirth, and pregnancy termination. The latter renders the most usable source of tissue. See also **fetal tissue transplantation**.

Fetal tissue transplantation: Use of fetal cadaver tissue, for example, to treat infants in need of organ replacement, children with juvenile **diabetes mellitus**, and adults with **Parkinson disease**. Use of these tissues, such as liver, thymus, neural, and pancreatic tissue, is still experimental, with the exception of thymus transplant for infants with DiGeorge syndrome (absent thymus). Fetal tissue has major advantages for this purpose, over adult tissue.

Fetus: The developing entity from eight weeks after **fertilization** until birth. The two prior stages are **zygote** and **embryo**.

Follicle: A fluid-filled structure within the **ovary** that contains the developing egg. At **ovulation**, the follicle breaks through the surface of the ovary and the egg is released.

Follicle-stimulating hormone (FSH): A **pituitary hormone**, which, along with other **hormones**, stimulates maturation of the **follicle** in the **ovary** in women and formation of the **sperm** in the **testes** in men.

G

GIFT: Gamete intrafallopian transfer. A technique of **assisted reproduction** in which a woman's mature eggs are removed by **laparoscopy** or by a catheter (small tube) under **ultrasound** guidance and then reintroduced with **sperm** into the **fallopian tubes**.

Gn-RH: Gonadotropin-releasing hormone. Also known as **luteinizing hormone releasing hormone (LH-RH)**. The **hormone** released from the **hypothalamus** that causes secretion of gonadotropins from the **pituitary** gland. It can be pulse-injected to stimulate ovarian function in women with **infertility** caused by deficient gonadotropins. However, there is a risk of **hyperstimulation** of the **ovaries**.

Gamete: The mature male or female reproductive cell, which contains one set of 23 **chromosomes** rather than the two sets found in **somatic** (body) **cells**. In a man, the gametes are **sperm**; in a woman, they are eggs.

Gamete intrafallopian transfer: See **GIFT**.

Gene: The physical and functional unit of heredity; an ordered sequence of nucleotides (substances that make up the **DNA**) situated in a particular position on a particular **chromosome** and having a particular function.

Gene probe: A segment of single-stranded **DNA** or **RNA** containing the DNA sequence for part of a particular **gene**, labelled with a radioactive or chemical marker and used to identify a specific region of the **genome** by binding to the complementary sequence for that gene.

Gene therapy: Therapy aimed at curing a disease due to a defective **gene**, either by insertion of a normal gene or by correction of the abnormal one. It is called *somatic gene therapy* if it applies to the cells of the body other than the **germ cells** (eggs or **sperm**), and *germ line gene therapy* if it applies to the germ cells. See **genetic alteration, directed**; **genetic engineering**.

Genetic alteration, directed: Changing the structure of a particular **gene** in a controlled way. It includes **gene therapy** but also applies to hypothesized alteration of the **DNA** for non-therapeutic purposes, as in enhancement of supposedly superior traits. See **genetic engineering** for the kinds of techniques involved in gene therapy.

Genetic engineering: Isolating **genes**, replicating them outside their own cells, and altering their structures and their relationships to the rest of the genetic material in a directed way. The means include **cloning** (isolation of specific genes [e.g., for insulin] and replicating them in bacteria or other vectors), directed **mutation**, and transfection (transfer of a particular gene from its own cell line to another — either within or between species). These techniques have led to an understanding of how genes act and are regulated, and to introduction of economically valuable traits into domestic animals and plants. They are now being used to introduce genes that produce a therapeutic product (e.g., that kills cancer cells, or produces a compound lacking in a genetic disorder) into cells that will transport the product to genetically defective tissues lacking the product.

Genetic marker: A genetically determined difference, which is useful for gene mapping and for **genetic testing** by linkage analysis. Where there are two or more forms of such a trait, none of which is rare, the trait is termed a *polymorphism*. Genetic markers may result from changes within a **gene** or in the **DNA** between the genes. The latter is more appropriately termed a *DNA marker*.

Genetic screening: Use of tests in population groups to acquire genetic information about individuals who are at increased risk for having an inherited trait or disease. Contrast with **genetic testing**, which applies to individuals rather than groups.

Genetic testing: Identifying an abnormal **gene** (e.g., **phenylketonuria**), abnormal protein (e.g., **sickle-cell anaemia**), chromosomal change (e.g., **Down syndrome**), or a **genetic DNA marker** near or within the gene (e.g., **Huntington disease**).

Genetics: Study of the structure, regulation, expression, transmission, and frequency of **genes**.

Genome: The total genetic material contained in the **chromosomes** of an individual's cells. The human genome contains about 100 000 **genes**.

Genotype: The genetic make-up of an organism with respect to a particular **gene** locus or the entire complement of genes, as contrasted to the outward appearance.

Germ cell or line: The cell or cell line that produces **gametes** (**sperm** or egg) for reproduction. Any changes to the germ line (**mutation**) may be passed on to the next generation.

Gestation: The period of fetal development in the **uterus** from conception to birth, usually considered to be 40 weeks in humans.

Gonadotropins: **Hormones** that stimulate the **testes** or **ovaries**. Examples are **follicle-stimulating hormone**, **human chorionic gonadotropin**, **human menopausal gonadotropin**, and **luteinizing**

hormone. These can be administered to women with ovulatory dysfunction to stimulate the ovary. See **ovulatory stimulants**.

Gonadotropin-releasing hormone: See **Gn-RH**.

Gonorrhoea: A sexually transmitted bacterial disease. If not treated, in women it can spread to the **uterus** and the **fallopian tubes**, causing **pelvic inflammatory disease**; in men, it can cause inflammation of the **testes** and can affect **semen** quality.

H

hCG: Human chorionic gonadotropin. The **hormone** produced early in pregnancy (detected in one of the pregnancy tests) that keeps the **corpus luteum** producing **progesterone**, which prevents menstruation from occurring. It can be extracted from the urine of pregnant women and used in conjunction with other substances as a treatment for **infertility** by triggering **ovulation**. See **ovulatory stimulants**.

HIV: Human immunodeficiency virus. The **virus** that causes **AIDS**. It produces a defect in the body's immune system by invading and then multiplying within white blood cells.

hMG: Human menopausal gonadotropin. A **hormone** preparation that can be extracted from the urine of newly menopausal women and injected to stimulate **ovaries** and **testes**. It contains two hormones: **follicle-stimulating hormone** and **luteinizing hormone**.

Herpes, genital: An infection caused by the herpes simplex virus transmitted by vaginal, anal, or oral sex and sometimes through linens and towels. Men may have sores on their penis, scrotum, perineum, buttock, anus, and thighs and women on their **vagina** and **cervix**. The outbreaks recur and there is no medical cure.

Hormone: A chemical substance, synthesized in one organ of the body, that stimulates functional activity in cells of other tissues and organs. See **endocrine system**.

Human chorionic gonadotropin: See **hCG**.

Human immunodeficiency virus: See **HIV**.

Human menopausal gonadotropin: See **hMG**.

Huntington disease: A disorder of movement, intellectual deterioration, and personality change, which usually manifests itself between the ages of 30 and 50 and which leads to death. The disorder is inherited as an autosomal **dominant** and, thus, a person with the **gene** has a 50 percent chance of passing it on to each of his or her offspring. As a result of the late onset, affected individuals may have children before they know they are carrying the gene. The gene is situated near the

end of chromosome 4, and the condition is detectable by family studies of linkage to a **DNA genetic marker** in most cases. The gene has now been identified.

Hydatidiform mole: An abnormal "pregnancy" or development of a growth resulting from a pathologic egg.

Hyperstimulation: A syndrome that may include ovarian enlargement, gastrointestinal symptoms (nausea, vomiting, diarrhea), abdominal distension, and weight gain. Severe cases may be further complicated with cardiovascular, pulmonary, and electrolyte disturbances, requiring hospitalization. See **ovulatory stimulants**.

Hypothalamus: A structure at the base of the brain that controls (among other things) the action of the **pituitary** hormones. By secreting and releasing **hormones**, the hypothalamus orchestrates the body's reproductive function in both men and women.

Hysterectomy: Surgical removal of the **uterus**, which results in inability to implant an **embryo**.

Hysterosalpingogram (HSG): An X-ray of the female reproductive tract after injecting a dye into the **uterus** that travels into the **fallopian tubes**. Since the dye is dense to X-rays, the outline of the uterine cavity and the degree of openness of the fallopian tubes can be seen.

Hysteroscopy: Direct visualization of the interior of the **uterus** to evaluate the presence of abnormalities. It is done by inserting a hysteroscope (a long, narrow, illuminated tube) through the **cervix** into the uterus. The uterus is inflated by injecting either a gas (carbon dioxide) or a solution of sugar in water through the **vagina**. This test, which is performed under a local anaesthetic, may reveal a septate uterus (a uterus divided into compartments), polyps, fibroids (benign tumours), or **adhesions**. Minor surgery, such as removal of fine adhesions, can be done using tiny forceps placed through special "channels" in the hysteroscope.

I

IUD: Intrauterine device. Contraceptive device, usually a loop made of plastic or metal that is inserted through the **cervix** into the uterine cavity in order to prevent pregnancy. It works by preventing the **zygote** from implanting. Use of IUDs has been associated with infections leading to **pelvic inflammatory disease** and to **infertility**.

IUI: See **Intrauterine insemination**.

IVF: ***In vitro* fertilization.** A technique used in **assisted reproduction**. Mature eggs are removed from a woman's **ovary**, usually after

administration of an **ovulatory stimulant**, and fertilized with **sperm** in the laboratory. After **fertilization** and incubation, the fertilized egg is placed in the woman's **uterus**; it may also be transferred to another woman (see **embryo donation**). For a variation of IVF, see **ZIFT**.

Iatrogenic: Refers to conditions caused by medical intervention, including surgical, drug, or other procedures (e.g., **infertility** caused by **adhesion** following post-surgical infection, or **miscarriage** following a **prenatal diagnosis** procedure).

Idiopathic infertility: Infertility for which no organic problem has been identified in either partner.

Implantation: The process by which the **zygote** becomes embedded in the wall of the **uterus**, usually starting by the sixth and ending by the fourteenth day after **fertilization**.

Impotence: Inability to achieve or maintain sufficiently a penile erection.

Incidence: Proportion of instances of illness commencing, or of persons falling ill, during a given period in a specific population. More generally, the proportion of new events (e.g., new cases of a disease in a defined population) within a specified period.

Infertility: Diminished ability to bring about a live birth in spite of repeated attempts. It may include infecundity as well as pregnancy loss after conception (**miscarriage** and stillbirth). Infertility is said to be *primary* where a woman has never carried a pregnancy to live birth or a man has never caused conception, and *secondary* where the individual has had one or more biological children. The latter is sometimes called *one-child sterility*.

Informed choice: A decision about a particular course of action made after receipt of sufficient information about the non-medical and medical options. For example, in counselling of people who are infertile, the options might include adoption or remaining childless, as well as the medical means of overcoming **infertility**.

Informed consent: An agreement to proceed with a particular medical treatment, given after receipt of information about the risks and benefits of that procedure. In Canada, to avoid a negligence action, physicians are required to divulge a "material" risk or a "special risk with serious consequences" according to the needs of the particular patient. Whether a patient with this information would have consented is, however, evaluated from the objective of what a "reasonable patient" would have decided.

Insemination: Placement of **semen** within the **vagina** or **cervix**. See **donor insemination**.

Intracytoplasmic sperm injection: The **sperm** is washed and is put into a glass needle and injected into the **ovum**.

Intrauterine device: See **IUD**.

Intrauterine insemination: A form of **donor insemination** in which **sperm** are deposited directly into the uterine cavity. It may be used to overcome barriers to natural **insemination**, such as incompatibility between the sperm and **cervical mucus**, **impotence**, or **vaginismus**. See **sperm preparation**.

In vitro*:** Literally, *in glass*; pertaining to manipulations carried out on biological systems outside the body, usually in a culture dish or other laboratory vessel. Contrast ***in vivo.

***In vitro* fertilization:** See **IVF**.

In vivo*:** Literally, *in life*. A term used to describe biological processes in their natural environment within the living organism. Contrast ***in vitro.

***In vivo* fertilization:** **Fertilization** of the egg in the woman's body. This may occur by natural means or by **assisted insemination**. See **DOST**; **donor insemination**; **GIFT**.

J, K, L

Kallman syndrome: A congenital abnormality where a dysfunction of the **hypothalamus** causes problems, including failure to reach puberty.

Laparoscope: A narrow, light-transmitting instrument used to visualize organs within the abdominal cavity through a small incision in the abdominal wall.

Laparoscopy: A procedure, requiring a general anaesthetic, in which the reproductive (or other) organs are viewed through a **laparoscope** inserted near the navel after the abdomen has been inflated with carbon dioxide. It is used in investigation of **adhesions**, **endometriosis**, and **pelvic inflammatory disease**. A dye may be run through the **fallopian tubes** to show whether they are blocked. Surgical procedures such as removal of small cysts, adhesions, or endometrial tissue may also be performed with the instrument. It is used in **gamete intrafallopian transfer**, but its use in ***in vitro* fertilization** has been replaced by transvaginal **ultrasound** techniques.

Lavage: See **uterine lavage**.

Luteal phase defect (LPD): Failure of the endometrial lining of the **uterus** to develop properly after **ovulation** because of inadequate production of **progesterone** by the **corpus luteum** (cells left in the **follicle** after the egg leaves). This may prevent a fertilized egg from implanting in the uterus or may lead to early pregnancy loss. LPD is detectable by

graphing morning body temperature, by measuring the blood level of **progesterone**, or by **endometrial biopsy**.

Luteinizing hormone (LH): The **pituitary** hormone that causes the **testes** in men and **ovaries** in women to make sex **hormones**. In women, when the egg is ripe, the pituitary releases a large amount of LH. As a result, within 24 to 36 hours, the egg finishes maturing and leaves the ovary. The remaining cells in the follicle (**corpus luteum**) start producing the sex hormone, **progesterone**. In men, the two pituitary hormones, LH and **FSH** (**follicle-stimulating hormone**), are released together. LH, called *interstitial cell stimulating hormone*, stimulates **testosterone** production in the testes.

Luteinizing hormone releasing hormone (LH-RH): See **Gn-RH**.

M

MSAFP: Maternal serum alpha-fetoprotein. A test for the protein produced by the fetal liver that can be measured in a blood sample of a pregnant woman or in the amniotic fluid, which surrounds the **fetus**. The test on maternal blood — MSAFP — can be carried out around 16 weeks of pregnancy. An increased level of MSAFP may indicate that the fetus has a **neural tube defect** or certain other fetal anomalies, while a decreased level in the pregnant woman's blood may indicate a fetal chromosomal abnormality.

Medicalization: The process by which behaviours or conditions are defined in terms of health and illness.

Mendelian trait or disorder: A disorder controlled by a single **gene**, and therefore showing a simple pattern of inheritance (autosomal **dominant**, autosomal **recessive**, or **X-linked**).

Menopause: Cessation of the **menstrual cycle** when the **ovaries** are virtually depleted of eggs.

Menstrual cycle: A cycle of approximately one month in the female, during which the egg is released from an **ovary**, the lining of the **uterus** (endometrium) is prepared to receive the fertilized egg, and blood and endometrial tissue are lost via the **vagina** if pregnancy does not occur.

Meta-analysis: Pooling the results from studies with similar methodologies when each study on its own may not include sufficiently large sample sizes to provide reliable results.

Micromanipulation: Performance of surgery, injections, dissections with attachments to a microscope, which allows magnified visualization.

Microsurgery: Delicate surgery performed with the aid of a microscope or other magnifying apparatus. In cases of **infertility**, it is used to repair the **fallopian tubes** in women and blockage of the **vas deferens** in men.

Miscarriage (spontaneous abortion): The spontaneous shedding of the **fetus** or **embryo** from the **uterus** at any stage before viability, usually before the twentieth week after conception. The terms *habitual* or *repeated miscarriage* are applied where this occurs in three or more pregnancies. Causes include **chromosomal disorders** in one of the couple, uterine malformation, hormonal imbalance (see **luteal phase defect**), infection (see **mycoplasma**), and rejection of the **fetus** as a foreign tissue.

Morphology: The form and structure of living things, such as the shape of **sperm** during **semen analysis**. Abnormal morphology of sperm may affect movement (see **sperm motility**) and, thus, ability of the sperm to fertilize the egg.

Morula: A fertilized egg after a few days' growth, when the collection of cells resembles a mulberry in shape (Latin, *morula*) and is smaller than the period at the end of this sentence. This is the stage before the **blastocyst**.

Mosaic: An individual or tissue with two or more genetically different cell lines arising from a single cell line. Contrast **chimera**.

Multifactorial disorder: A disorder that is attributable to a complex interaction of environmental and genetic factors. See **polygenic**.

Multiple pregnancy: A pregnancy in which there is more than one **embryo** or **fetus**. The probability of occurrence is increased with use of **ovulatory stimulants**. In ***in vitro* fertilization**, more than one **zygote** may be deliberately transferred, to increase the chance that at least one will survive.

Mutation: A permanent change in the genetic material. When mutation occurs in a **germ cell** or its precursor, it can be passed on to subsequent generations. A **gene** altered by a mutation, and an individual bearing such a gene, is called *mutant*. A substance capable of inducing a mutation is called a *mutagen*.

Mycoplasma: A sexually transmitted micro-organism, which may be transmitted alone or with **chlamydia**. Women are often asymptomatic; men often have painful urination and discharge. This organism has been implicated in some studies as a cause of female **infertility**, **ectopic pregnancy**, **miscarriage**, and premature birth.

N

Neural tube defects: The neural tube gives rise to the central nervous system at about five weeks in the human **fetus**. Neural tube defects, which occur when the neural tube fails to close, include **anencephaly** and **spina bifida**. There is a higher frequency in some population groups. See **MSAFP** for prenatal detection.

O

Oligomenorrhea: See **amenorrhea**.

Oligospermia: Scarcity of **sperm** in the **semen**. If severe, it may result in **infertility**.

Oocyte: An egg cell produced in the **ovaries**. Its process of formation is termed *oogenesis*.

Oral contraceptive: A pill containing a combination of progestin (**progesterone**-like **hormone**) and **estrogen**. It stops **ovulation** by suppressing the **pituitary**, which then does not send out the usual signals to ripen and release an egg. After use of the pill is discontinued, normal ovulatory cycles and menstruation generally resume within three to six months. However, menstruation may not resume if the contraceptives were taken before the reproductive system matured or if they were repeatedly started and stopped. This may result in **infertility**.

Ovaries: Paired female sex glands in which egg cells are developed and stored and the **hormones estrogen** and **progesterone** are produced.

Ovulation: Release of an egg from a woman's **ovary**, generally around the midpoint of the **menstrual cycle**. Methods of timing ovulation include systematic measuring of morning body temperature, observing changes in the quantity and quality of **cervical mucus**, analysis of **luteinizing hormone** in the blood or urine, and high-resolution **ultrasound** scans of the ovarian **follicles**.

Ovulation induction: Treatment of ovulatory dysfunction using drugs that induce **ovulation** (see **ovulatory stimulants**) and as a part of **donor insemination**, **GIFT**, **IVF**, and their variants.

Ovulatory stimulants: These so-called fertility drugs include **bromocriptine**, **clomiphene citrate**, **gonadotropins**, and **gonadotropin-releasing hormone**, used in treatment of an ovulatory disorder; in ***in vitro* fertilization**, to produce eggs for retrieval (superovulation); and sometimes in **donor insemination**, to regulate timing of **ovulation**.

As a **fertility** treatment, ovulatory stimulants increase the risk of **multiple pregnancy** and may cause a serious condition — **hyperstimulation** syndrome.

Ovum (pl. *ova*): The female egg or **oocyte**, formed in an **ovary**.

P, Q

PID: Pelvic inflammatory disease. An inflammation of the upper reproductive tract involving the **uterus**, **fallopian tubes**, and **ovaries**, generally caused by **sexually transmitted diseases** or other infections. Organisms that cause **gonorrhoea**, **chlamydia**, or other infections can ascend from the lower genital tract through the lining of the uterus (causing **endometritis**), to the peritoneal (abdominal) cavity (causing peritonitis and **adhesions**), to the fallopian tubes (causing **salpingitis**), and possibly to the ovaries (causing their inflammation). The organisms may be transmitted by intercourse, by an abortion or childbirth, or by insertion of an **IUD**.

PKU: Phenylketonuria. An autosomal **recessive** inborn error of metabolism (a genetically determined biochemical imbalance in which a specific enzyme defect produces a metabolic abnormality), in which the enzyme phenylalanine hydroxylase is deficient. This results in a buildup of products that cause mental impairment. The condition is diagnosable at birth by a simple blood test and can be treated with a special diet during infancy and childhood to prevent mental impairment. If females with the disorder become pregnant, dietary treatment must be reinstated in order to prevent mental impairment and congenital defects in their heterozygous (having two different forms of a gene at a particular locus) offspring (i.e., the maternal disease acts as a **teratogen**). The **gene** has been mapped and can be detected prenatally.

PND: Prenatal diagnosis. Testing before birth with the aim of determining whether a **fetus** has a specific trait, usually a malformation or disorder for which the fetus is known to be at increased risk because of maternal age or family history; sex of fetus can also be detected.

PROST: Pronuclear oocyte salpingo transfer: See **ZIFT**.

Parkinson disease: A gradual loss of motor function with akinesia, rigidity, trembling, gait disturbance, and loss of postural reflexes.

Parthenogenesis: Development of the egg into a complete organism without **fertilization** with a **sperm**. It occurs naturally in some less complex species, but not in human beings.

Pelvic inflammatory disease: See **PID**.

Perinatal: Occurring near the end of pregnancy, during delivery, or soon after birth.

Phenylketonuria: See **PKU**.

Pituitary: The small organ at the base of the brain that produces **gonadotropins**, **luteinizing hormone** (**LH**), and **follicle-stimulating hormone** (**FSH**), which stimulate the gonads (**ovaries** and **testes**) to produce **gametes** and **hormones**.

Placenta: A tissue formed after the **zygote** becomes implanted in the **uterus**, through which the blood of the developing **embryo** proper and later the **fetus** and the gestating woman circulate in separate but closely apposed vessels; and through which the developing fetus receives nourishment. A part of the placenta, the trophoblast, lines the chorion (outer membrane surrounding the embryo and fetus) and secretes **human chorionic gonadotropin**.

Polar body: A small cell that buds off from the egg during meiosis and that contains one set of 23 **chromosomes**. Meiosis is a special type of cell division that occurs only in the germ cells (egg and **sperm**) during their formation. As a result, the number of chromosome sets is reduced from two to one. See **preimplantation diagnosis**.

Polycystic ovary disease (POD): Also called *Stein-Leventhal syndrome* or *sclerocystic ovarian disease.* A disease of the **ovaries** caused by malfunction of the hormonal system. Excess male **hormone** is converted into **estrogen** in fatty tissue. The high estrogen levels cause the **pituitary** to send a "confused" signal to the ovaries. This causes the eggs to start to ripen, but they never mature. The trapped **follicles** build up, the ovaries become cystic, and **ovulation** and menstruation fail to occur. Women with this condition tend to be obese and have a male pattern of hair growth. Surgical removal of a portion of the polycystic ovary may result in ovulation.

Polygenic: A trait that is determined by many **genes**, each with a small effect, acting in concert. When environmental factors are involved as well, the trait is said to be **multifactorial**. Some multifactorial disorders are relatively common (e.g., **neural tube defects**).

Preconception arrangement or contract: An agreement, commonly known as *surrogacy*, by which a woman agrees to gestate a child and then give up her parental rights to the commissioning party or parties. The woman may be artificially inseminated with **sperm** from the commissioning male or have a **zygote**, to which she did not contribute the egg, transplanted into her **uterus**. If the contract is for profit, it may be termed a *commercial contract.*

Predictive testing: Identifying an abnormal **gene**, protein, chromosomal change, or **DNA marker**. See **genetic testing.**

Pre-eclampsia: See **toxaemia**.

Pre-embryo: See **embryo**; **zygote**.

Preimplantation diagnosis: Diagnosis of genetic disorders or sex before **fertilization** or before the **zygote** is transferred to the **uterus**. One type involves analysis of the **polar body** of an egg that is heterozygous (having two different forms of a **gene** at a particular gene locus) for a known genetic disorder. If the polar body has the normal form of the gene, it may be inferred that the egg has the abnormal form and vice versa. Another type involves analysis of the **DNA** of one of a few cells of a zygote (e.g., following **IVF**). The **zygote** may continue to develop and, if the disorder is absent, can be placed or replaced in a woman's **uterus**.

Prenatal diagnosis: See **PND**.

Prevalence: Frequency of a condition in a population. Prevalence may be greater or less than **incidence**, depending on how long individuals with the condition live.

Progesterone: A steroid **hormone** produced by the **ovary** after **ovulation**, and by the **placenta**. It promotes development of the endometrium (uterine lining) essential for implantation of the **embryo** and continuation of the pregnancy. Progesterone may be used to treat a **luteal phase defect**. Its effectiveness in preventing **miscarriage** in such cases has not been adequately proven.

Prolactin: A **hormone** secreted by the **pituitary** that stimulates breast milk production in nursing mothers and supports gonadal function. Women with abnormally elevated levels of prolactin (hyperprolactinaemia) may not ovulate and may have either irregular or absent menstrual periods. Hyperprolactinaemia can be treated with **bromocriptine**.

Pronuclear oocyte salpingo transfer (PROST): See **ZIFT**.

Pronucleus: The precursor of a nucleus. The fully mature **ovum** loses its nuclear envelope and liberates its **chromosomes** to meet with those similarly derived from the male pronucleus. Together they comprise the genetic make-up of the **zygote**.

Prostate gland: A chestnut-size gland in males that surrounds the **urethra**, near the bladder, and produces a portion of the fluid that transports **sperm** into the **ejaculate**.

R

RU-486 pill: A pill available in France, but not yet in North America, containing a **progesterone** antagonist. When taken early in

pregnancy, it reduces the progesterone level necessary to maintain a pregnancy, resulting in termination without surgical intervention.

Recessive: Refers to a form of a **gene** that will be expressed only if it is present in two copies (i.e., on both **chromosomes**). Compare with **dominant**: a person with a recessive condition will have inherited one abnormal form of the gene from each parent. When the parent has only one copy, he or she will not show the condition and is said to be a *carrier*. Two such parents have one chance in four of having a child affected with the condition.

S

SHIFT: Synchronized hysteroscopic insemination of the fallopian tubes. Passage of a catheter (small tube) through the **cervix** into the **fallopian tubes** under the guidance of a small scope. **Sperm** is injected via the catheter into the fallopian tubes.

STD: Sexually transmitted disease. Also called *venereal disease*. Infectious disease transmitted primarily by sexual contact, including **chlamydia**, **gonorrhoea**, **herpes**, **HIV**, **mycoplasma**, and **syphilis**. STDs are linked to **infertility**. See **PID**.

Salpingitis: Inflammation of the **fallopian tubes**, sometimes caused by **sexually transmitted disease** or other infections. In salpingitis isthmica nodosa, the end of the fallopian tube near the **uterus** is thickened with irregularly shaped nodules, which can block the fallopian tubes, causing **infertility**.

Self-insemination: Term for **donor insemination** when it is performed, without medical assistance, by the woman, her partner, or other non-medical support. Also known as *alternative insemination*. See **DI**.

Semen: Fluid secretion containing **sperm** that is emitted during ejaculation. Also called the *seminal fluid*, more than half of which is produced in the seminal vesicles, the paired glands at the base of the bladder.

Semen analysis: A diagnostic tool in evaluating male **infertility** that includes evaluation of the physical characteristics and presence of **antisperm antibodies** and micro-organisms in the semen, the shape and concentration of **sperm**, and **sperm motility**.

Sex chromosome: The X- and the Y-chromosome, which are responsible for sex determination. XY individuals are male; XX individuals are female.

Sex selection: Methods used to enhance the likelihood that **sperm** are X- or Y-bearing (sex-selective insemination); to produce a pregnancy of

the desired sex by transferring only **zygotes** of one sex (sex-selective zygote transfer); or to eliminate **fetuses** of the undesired sex (sex-selective abortion). See also **preimplantation diagnosis**.

Sexually transmitted disease: See **STD**.

Sickle-cell anaemia: An often-fatal autosomal **recessive** haemoglobinopathy (hereditary anaemia involving disorders of haemoglobin, the oxygen carrier in blood), which occurs most often in blacks. The **gene** defect renders the haemoglobin liable to crystallize and the red blood cells to form a sickle shape, to lodge in the small blood vessels, and to cause serious health problems. People who are "heterozygotes" have the abnormal gene on only one of the two chromosomes, are usually healthy, and are said to have the sickle-cell trait. The condition can be detected by biochemical technology, and the gene by molecular technology.

Somatic cell: Any cell in the body that does not become a **germ cell** (egg or **sperm**).

Sperm: The free-swimming male reproductive cell produced by the **testes** that interacts with the egg, resulting in **fertilization**.

Sperm bank: A place in which **sperm** are stored by **cryopreservation** for future use in **assisted insemination**.

Sperm count: The number of **sperm** in the **ejaculate**. The total effective sperm count is the estimated number of sperm in an ejaculate capable of **fertilization**, calculated from the proportion of sperm with forward progressive **motility** and normal **morphology**. When expressed as the number of sperm per millilitre, it is called the *sperm concentration* or *density*.

Sperm motility: Movement of **sperm**, the measurement of which is used as one indication of **fertility** in men. Forward progression is the quality of movement demonstrated by the majority of motile sperm.

Sperm-mucus cross test: A test to determine whether it is the **sperm** or the **cervical mucus** that is affecting sperm movement. The male partner's sperm is tested against the female partner's mucus and that of a woman known to be fertile, and the female partner's mucus is tested against the male partner's sperm and that of a male known to be fertile.

Sperm preparation: Methods of preparing **sperm** to increase the success rate of **assisted insemination**. These include: chemical or drug treatment with caffeine, the amino acid arginine, or the protein kinin to improve **sperm motility** or with antibiotics to eliminate bacterial infection; concentration, by high-speed spinning; swim-up, in which a layer of protein is placed over the **semen** through which the most motile sperm will swim up, leaving behind most of the abnormal and non-motile sperm; and washing, in which a semen sample is diluted

with compounds to separate viable sperm from the other components of semen, such as prostaglandins (**hormone**-like substances), **antibodies**, and micro-organisms.

Spermatogenesis: The process of formation of spermatozoa (**sperm**).

Spina bifida: A defect caused when the neural tube fails to close, resulting in protuberance of some spinal cord tissue. See **neural tube defects**.

Sterility: Inability to reproduce. Surgical sterility results from a sterilizing operation, whether for contraceptive reasons or not (in men **vasectomy** and in women **hysterectomy**, oophorectomy [removal of one or both of the **ovaries**], and **tubal ligation**). In the latter, since the woman's eggs are left intact, they could be fertilized *in vitro*. Non-surgical sterility results from causes other than a sterilizing operation (e.g., accident, birth defect, illness).

Sterilization reversal: Surgery, called **reanastomosis**, to restore **fertility** by reconnecting tubes that have been severed in a **tubal ligation** (severing of the **fallopian tubes** or **vas deferens** for contraceptive purpose). The former is also called *salpingostomy* and the latter *vasectomy reversal.*

Streptococcal infection: Infections of the genital tract, which are not usually sexually transmitted. However, they sometimes travel through the lymphatic or blood vessels, causing **adhesions** to form around the outside of the **fallopian tubes**, thereby affecting **fertility**. The source can be an induced abortion, **miscarriage**, childbirth, or biopsy.

Syngamy: The process through which the 23 **chromosomes** of an egg cell and the 23 chromosomes of a **sperm** cell combine so that the new cell has 46 chromosomes.

Syphilis: A bacterial disease caused by a spiral-shaped bacterium, a spirochete. In infectious stages, it is transmitted through sex or intimate contact and may affect **fertility**. An infected pregnant woman can pass it on to the **fetus**, possibly resulting in stillbirth or congenital problems in an infant so affected.

T

TEST: Tubal embryo stage transfer. See **ZIFT**.

Tay-Sachs disease: A severe and fatal disorder that occurs predominantly in Ashkenazi Jewish populations. The affected baby appears normal at birth, but by six months of age has begun to lag developmentally. Progressive neurological deterioration occurs, with loss of muscle function throughout the body. Swallowing difficulties require eventual tube feeding; loss of respiratory muscles causes repeated pneumonias.

These children usually die within two to four years. An effective carrier test can be done on a small blood sample in Ashkenazi Jewish couples who wish to avoid the birth of an affected child.

Teratogen: An agent that causes a **congenital anomaly** by adversely affecting development of the **embryo**. The process by which this occurs is called *teratogenesis*. Contrast **mutation**.

Testes: The paired male sex glands in which **sperm** and the steroid hormone **testosterone** are produced.

Testicular biopsy: The excision of a small sample of testicular tissue through a small incision in the scrotum for microscopic pathologic evaluation to determine whether **sperm** are being produced.

Testosterone: A steroid produced in the **testes** that affects **sperm** production and male sex characteristics.

Thalassaemia: Chronic anaemia caused by a genetically determined reduction in the synthesis of globin (the protein of haemoglobin), which in some types is severe enough to lead to death. One type has a high frequency in persons of Mediterranean and African origin and another in persons of Far Eastern origin.

Thyroid gland: A gland, situated in the neck, that secretes the **hormone** thyroxin and controls many bodily functions. A low thyroid level, hypothyroidism, may affect **fertility** by raising the levels of **prolactin**, which, in turn, affects **ovulation** in women and decreases **sperm** number and **motility** in men. See **prolactin**.

Toxaemia: Often referred to as **pre-eclampsia,** an abnormal condition of late pregnancy characterized by swelling, high blood pressure, and protein in the urine. The condition can lead to convulsions.

Toxoplasma: A protozoan (unicellular animal organism) that may infect women during pregnancy and may cause **miscarriage** or nervous system damage to a surviving **fetus**.

Tubal ligation: Sterilization of a woman by surgical excision of a small section of each **fallopian tube**.

Turner syndrome: A natural process results in most of the immature eggs with which the female is born slowly degenerating during her childhood and reproductive years. Turner syndrome is a condition in which this process is accelerated, resulting in **infertility**. In this condition, women have one instead of two sex **chromosomes**. Those with the syndrome are usually infertile, since the gonads become streaks containing no eggs, and they lack normal ovarian **hormones**, do not go through puberty, and do not develop secondary sex characteristics unless hormonally treated.

U

Ultrasound: High-frequency sound waves focussed on the body and reflected to provide a video image of internal tissues, organs, and structures. Ultrasound scanning is particularly useful for *in utero* examinations of a developing **fetus**, for guidance of the needle in **amniocentesis** and **chorionic villus sampling**, for evaluation of the development of ovarian **follicles**, and for guided retrieval of eggs for ***in vitro* fertilization** and its variants.

Urethra: The canal that carries the urine from the bladder and, in the male, serves also as a genital duct that delivers **sperm**.

Uterine lavage: A flushing of the **uterus** to recover an egg or **zygote**. Not the method of choice because of risks to the woman, and not recommended.

Uterus: The womb; the female reproductive organ that holds and allows nourishment of the **fetus** until birth.

V, W

Vagina: The female organ between the **cervix** and vulva; the organ of sexual intercourse; the birth canal.

Vaginismus: Involuntary contraction of the muscles around the outer third of the **vagina**, which prohibits penile entry.

Vas deferens: The convoluted duct that carries **sperm** from the **testis** to the ejaculatory duct of the penis.

Vasectomy: Sterilization of a man by interrupting the **vas deferens**, usually by surgical excision.

Virus: A microscopic infectious organism without a nucleus or cell wall that reproduces inside living cells.

X, Y, Z

X-linked: Refers to any **gene** on the X-**chromosome** or traits determined by such genes.

ZIFT: A form of **assisted reproduction** in which a **zygote** obtained by ***in vitro* fertilization** is transferred to the **fallopian tube** usually by a catheter (small tube) through the **uterus** under **ultrasound** guidance.

This technique has also been called **PROST** (**pronuclear oocyte salpingo transfer**); and **TEST** (**tubal embryo stage transfer**).

Zona cutting or drilling: An experimental procedure in ***in vitro*** **fertilization**, whereby the **zona pellucida** is opened to make it easier for the **sperm** to fertilize the egg. There is a risk that the egg may be fertilized by more than one sperm (polyspermia).

Zona pellucida: Outer layer of the egg that interacts with the **sperm** at **fertilization**.

Zygote: The fertilized egg until approximately 14 days of development; from two weeks to eight weeks of development the developing entity is termed an **embryo**; from eight weeks to birth it is termed a **fetus**.

Zygote intrafallopian transfer: See **ZIFT**.