Royal Commission on
New Reproductive Technologies

Commission royale sur les
nouvelles techniques de reproduction

Executive Summary

"Proceed with Care"

Final Report of the Royal Commission on New Reproductive Technologies

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Executive Summary

The mandate of the Royal Commission was to examine how new reproductive technologies should be handled in Canada. Having children and healthy families are important goals to most Canadians, but some people cannot reach those goals without help. If there are technologies that can be used to help, a caring society should provide these. But there are misuses and harms, as well as benefits, that may come from use of the technologies — harms to both individuals and society.

We undertook our task by consulting very widely. As well as public hearings and submitted briefs, we had toll-free telephone lines, public surveys, and other avenues for Canadians to have input. In all, more than 40 000 people were involved in our work. We carried out a canvassing and examination of the issues that was extensive in both width and depth, with research projects and analyses in many disciplines, among them the social sciences, ethics, law, and medicine. More than 300 researchers at institutions across the country conducted projects for us.

We came to our conclusions in light of this widely based input and evidence, with three considerations in mind: a set of explicit ethical principles, the values of Canadians, and a conviction that offering any medical procedure as a service must be based on evidence that it works.

In spite of the existence of standards and guidelines recommended by various professional associations, we found that a varied patchwork of practices exists. Some practices are dangerous, such as donor insemination using sperm from donors who have not been tested for HIV. Some are harmful to the interests of the children born through the use of various technologies, such as the lack of records kept on their origins. Some are not respectful of women's choices, such as the finding that a woman's chance of being referred for prenatal testing varied more than fourfold across the country, despite the fact that women's attitudes toward testing varied relatively little. We found insufficient emphasis on the

prevention of infertility. We found some discriminatory practices in access to services, some clinics preparing to carry out procedures to allow surrogacy, and some commercial clinics existing to treat sperm to allow sex selection. Procedures are being offered as treatments without good evidence that they are effective, when they should be offered only in research trials. There are technologies on the horizon, such as embryo splitting and use of eggs from female fetuses for implantation. Our ethical analyses showed that some technologies and some uses of technology that are now possible or will be possible in the near future would contravene Canadian values.

It is clear that the situation with regard to the use of new reproductive technologies needs to be addressed; the issues will not go away — in fact, the field is growing, and potential uses are expanding. As this report went to press, the media were reporting the cloning of a human zygote. This vividly underscores the need to have in place a structure to deal with this evolving field in a way that takes into account the values and input of Canadians.

We conclude that government, as the guardian of the public interest, must act to put boundaries around the use of new reproductive technologies, and must put in place a system to manage them within those boundaries, not just for now, but, equally important, in an ongoing way. We therefore have two recommendations. First, we recommend legislation to prohibit, with criminal sanctions, several aspects of new reproductive technologies, such as using embryos in research related to cloning, animal/human hybrids, the fertilization of eggs from female fetuses for implantation, the sale of eggs, sperm, zygotes, or fetal tissues, and advertising for, paying for, or acting as an intermediary for preconception (surrogacy) arrangements.

Second, we recommend that the federal government establish a regulatory and licensing body — a National Reproductive Technologies Commission (NRTC) — with licensing required for the provision of new reproductive technologies to people. Only the federal government can set up such a system, and it is important that the government fulfil its responsibility to protect citizens and society by doing so.

Several requirements are common to all the technologies: the need for reliable information to guide policy and practice; the need for standards and guidelines for the organization and provision of services; the need for effective means to ensure compliance; and the need for accountability. The approach we propose builds on the best standards and practices of the medical specialties involved, which are already in use in some Canadian clinics. These standards should be expanded and should be embodied in a licensing system.

We recommend the NRTC be composed of 12 members, representing a broad range of experiences and perspectives. Consultation activities should be undertaken to further enhance public input and involvement.

Women should make up a substantial proportion — normally at least half — of the Commission's membership.

To ensure wide public input into the working of the system and to deal with setting policy as new issues evolve, we recommend that membership in the proposed NRTC should include persons with a broad range of experiences and perspectives, including the perspectives of those with disabilities, those who are infertile, and those who are members of racial minorities. A range of expertise should be represented, including reproductive medicine, ethics, law, and social sciences.

We recommend the NRTC have five areas of regulatory responsibility, in which the provision of services would be subject to compulsory licensing through five sub-committees established for that purpose. These areas are:

- sperm collection, storage, and distribution, and the provision of assisted insemination services;
- assisted conception services, including egg retrieval and use;
- prenatal diagnosis;
- research involving human zygotes (embryo research); and
- the provision of human fetal tissue for research or other specified purposes.

Licence hearings should be public, and a licence would be conditional on compliance with certain standards and stipulations of license. The major functions in these five areas of regulatory authority would be to:

- license, set standards, and monitor practice;
- collect, evaluate, store, and disseminate information;
- consult, help coordinate, and facilitate intergovernmental cooperation in the field; and
- monitor future technologies and practices and set policies for them.

In addition, we recommend the establishment of a sixth sub-committee, with primary responsibility in the field of infertility prevention. Its responsibilities would include the compilation and evaluation of data pertaining to the causes of infertility, the promotion of cooperative research efforts in Canada and internationally, and regulatory, public education, or other options for preventing or reducing the incidence of infertility.

With full implementation of these recommendations, a consistent country-wide system for the regulation of reproductive technologies and the provision of related services would emerge, with the following attributes:

- Assisted insemination, *in vitro* fertilization, and related infertility treatments would be provided only by licensed facilities, with national standards of service (related to matters such as counselling, informed disclosure and consent, standardized calculation of success rates, and

consistent record keeping) as conditions for obtaining and keeping a licence to provide these services.

- A national sperm collection and distribution system would be in place to ensure the availability of safe sperm, quarantined until donors are tested for infectious diseases, for use in assisted insemination in a medical setting or in self-insemination. The system would include comprehensive confidential record keeping on donors and recipients, with non-identifying information on the donor available to the recipient and child, and personal identification kept secure and available only in court-ordered cases.
- Prenatal diagnostic services would be provided only by licensed facilities, with national standards established and monitored through the licensing system. Prenatal ultrasound and testing of pregnant women's blood for congenital anomalies or genetic disease in the fetus would be provided only through provincially licensed or mandated programs. The structure would assure Canadians that genetic knowledge is applied in human reproduction in an accountable way and within acceptable limits — for example, not used for purposes of sex selection.
- A mechanism would be in place to facilitate multicentre trials and other research needed to assess the safety and effectiveness of reproductive technologies. It would promote interprovincial co-operation to mount the large-scale research projects needed to provide information on which to base health care service provision and resource allocation decisions.
- Once their risks and effectiveness had been assessed, infertility treatment and prenatal diagnostic services would be provided solely through provincial health care systems. Other treatments or procedures would be provided only in the context of research, with fully informed participation by volunteer research subjects and with rigorous protections for them. To preclude the development of commercial services, licensing conditions would include a stipulation that services not be offered on a for-profit basis.
- Annual reporting to the National Commission by licensed facilities would provide data that would allow evaluation of any long-term effects of treatments on the health of women or on their children.
- Any provision of fetal tissue for research would be licensed, so that it is used only in an accountable and ethical way according to guidelines, with permission for tissue use obtained separately from and subsequent to the decision to terminate a pregnancy.
- Any embryo research would be conducted only in licensed facilities, so that such research is carried out in an accountable and ethical way and in accordance with guidelines, including limitations on the

purposes for which research can be undertaken, and permitted only during the 14 days immediately following fertilization.

- A focal point for national action would be in place to support and encourage infertility prevention initiatives, to foster consultation and co-ordination of efforts among the many sectors involved, and to promote public education and research in Canada and internationally on the risk factors for and prevention of infertility.
- Canada would have a visible and continuing forum to monitor developments, promote public discussion, and develop public policy advice on the use of assisted reproductive technologies, prenatal diagnostic technologies, embryo research, research involving the use of fetal tissue, and other rapidly evolving or emerging technologies.

Getting There from Here

Commissioners are strongly of the view that the establishment of a National Reproductive Technologies Commission of the type we recommend must be an immediate federal priority. We believe that a National Commission presents the only feasible response to the clearly demonstrated need and justified public demand for coherent, effective, and appropriate national regulation of new reproductive technologies. The field is developing too rapidly, the consequences of inaction are too great, and the potential for harm to individuals and to society is too serious to allow Canada's response to be delayed, fragmented, or tentative.

A central goal of our recommendations is to enable individual Canadians to make personal decisions about their involvement with the technologies, confident in the knowledge that mechanisms are in place to assess their safety and effectiveness and to consider their ethical, legal, and social implications. Individuals have a responsibility to inform themselves as fully as possible before making such decisions, but government, on behalf of citizens, has a responsibility to ensure that inappropriate and unethical use of technology is prohibited and that the procedures and supports necessary for informed decision making are in place.

The regulatory framework we propose is essential to provide this assurance, but by itself it is not sufficient. Strong leadership and co-operation will be required among governments and professionals involved in the development and delivery of reproductive technologies, as well as among many other sectors of society. No group or institution can act effectively in isolation — partnership and cooperation among federal and provincial/territorial governments, professional organizations, patient groups, and other interested groups are critical.

Establishing such a system will take some time — although we should note that other countries have succeeded in putting their systems in place

within a relatively short period after their own inquiries. Nevertheless, some time will be required to appoint members of the Commission, establish and appoint its sub-committees, and carry out detailed implementation of the licensing system. Time will be needed to hold an initial round of licensing hearings, design secure record-keeping systems, and identify specific data collection methods and reporting forms.

The need for comprehensive action at the national level does not preclude the need for provincial and professional responses. Nor do provinces or the professions need to wait for a federal response before taking action themselves.

Provinces can take immediate steps to control the provision and proliferation of reproductive technologies in the health care system through the evidence-based approach we recommend. Practitioners now offering services can respond to the concerns Canadians raised before the Royal Commission and to the issues we have identified in the report. Professional associations can ensure that all their members are aware of the existing guidelines for practice and can promote more complete adherence to these standards among their members. Technology users and groups representing them can use the report of the Royal Commission to press for government and professional action. In the meantime, individual Canadians contemplating the use of reproductive technologies can use the information we have provided, ask questions, and request information from providers about the effectiveness, consequences, and potential risks of the technology use they are considering. Indeed, an informed public is the most effective bulwark against misuse or abuse of technology.

But all of these are only stop-gap measures. Government should act as the guardian of the public interest to set limits and to regulate the use of new reproductive technologies. No other body is sufficiently broadly based or has the mandate to do this. It is important that we put in place now the structures and an open, broad process to enable Canadians to deal with these growing dilemmas, dilemmas that affect individual lives and what kind of a society we are. How we use reproductive technology is not at root a medical matter, but a social matter that reaches into law, prevention, education, commerce, science, and research policy. Matters so important to women and children, in terms not only of their health but of their legal status and how they are viewed, cannot differ from province to province. The field is growing rapidly and Canadians want the government to act. There is clearly precedent — radio and television broadcasting is regulated and monitored through a licensing agency for the Canadian public interest. The area of reproductive technology use is at least as important to us as individuals and as a society.

Conclusion

Commissioners have set out a blueprint for how Canada, with its unique institutions and social make-up, can deal with new reproductive technologies, regulate their use, and ensure that future developments or use are in the public interest. Our blueprint requires action and leadership from the federal government, but also involves the participation and commitment of provincial governments, the professions, and many 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.

The reasons for such action are compelling: the potential for harm to individuals and the need to protect the vulnerable interests of individuals and society. Adopting our recommendations will enable this protection, but will also allow scientific knowledge to be used to better the lives of many Canadians. Implementing the blueprint will demonstrate that we care about each other's well-being and recognize collective values with respect to the importance people attach to having children. At the same time, it will ensure that only ethical and accountable use of technology is made, and demonstrate that Canadians have wisdom, humanity, and compassion in the way they choose to use technology.

The Commission has done its work and indicated the path it believes should be taken. The next steps belong to the government and people of Canada.

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PROCEED WITH CARE:

Final Report of the Royal Commission on New Reproductive Technologies

MAIN TOPICS

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Introduction

Having children and ensuring they are healthy are fundamentally important goals to most Canadians, but some people cannot reach these goals without help. As a caring society, Canada should respond to these deeply held aspirations, but the technology used to help can also be misused, and have harmful consequences both for individuals and for society. National action is needed to ensure new reproductive technologies are not misused, but used with care. It is the responsibility of the federal government, on behalf of society, to set boundaries around the technologies prohibiting those that contravene Canadian ethical and social values, and to put in place regulation to ensure that only legitimate, beneficial uses occur. Only the federal government has the power to put in place a system to manage the technologies. In the interest of protecting Canadian citizens, the federal government has the responsibility to do so.

Internationally, no other inquiry into new reproductive technologies had such a broad and far-reaching mandate, and no other looked at these issues from a uniquely Canadian viewpoint. The Commission examined the issues within the context of Canada's unique values and attitudes, social make-up, geography, institutions, and health and social systems. The scope of our recommendations and the breadth of our Final Report will set an international precedent, will complement other international efforts in this area, and will urge the Canadian government to take the lead internationally to protect society from unethical and unsafe uses of new reproductive technologies.

Within the clearly specified boundaries of what is ethically acceptable, the technologies must be offered only in a safe, fair and accountable way. For example, it is unethical to offer as services unproven procedures or treatments, and it is irresponsible to devote public resources for health care to them. Few existing treatments have been conclusively proven beneficial, and many need to be evaluated in research. Canada needs a regulatory and monitoring system to protect Canadians and ensure that only safe and effective treatments are offered as service, that appropriate record-keeping and informed consent mechanisms are in place, and that useful and beneficial research is conducted.

Strong provincial and professional participation and leadership is also required within the proposed national system for it to serve the interests of Canadians. There is a need for a rational approach to health care management with coordinated decisions about resource allocation and what services will be offered, in the light of an evidence-based approach to medical practice. Only this approach will allow us to keep and maintain our system of universal access.

New reproductive technologies are evolving. Canada's response to emerging and future issues must reflect inclusive, informed, broad-based input, and must be consistent with the values of Canadians. The structure we have recommended will ensure public input and accountability, and ensure future technologies are used only in a beneficial and ethical way.

How the Commission Went About Its Work

In completing the task of coming to recommendations about how new reproductive technologies should be handled in this country, the Commission consulted with and listened to Canadians from all sectors of society and carried out research and critical analysis of information and evidence on the technologies. The work was organized into two major streams — consultations and communications with Canadians, and research and evaluation of the technologies and the issues surrounding them.

Consultations and Communications

The Commission listened to Canadians across the country, and helped inform the public about the issues contained in our mandate. The following activities were undertaken as part of the consultations and communications programs:

- public hearings in 17 centres across Canada (2 000 participated);
- Toll-free telephone lines (6 000 individuals left their views);
- Information meetings with national groups interested in the technologies;
- National surveys exploring Canadians' values and attitudes (15 000 participated);
- The release of 14 research studies on varied topics to inform and educate Canadians, and to stimulate public interest and debate around the issues;
- Distribution of more than 50 000 copies of our newsletter, Update.
- Distribution of over 250 000 pieces of information, such as information kits, brochures, and information for use by journals, newspapers, and television networks.

Research and Evaluation

Research and analysis efforts involved more than 300 scholars and academics representing 70 disciplines, 21 Canadian universities and 27 hospitals and other institutions. The program culminated in 130 research projects available in 15 published volumes. They include:

- Analysis and inquiry into the prevalence, risk factors and prevention of infertility, methods of assisted reproduction, prenatal diagnosis and genetics, research involving human zygotes, the use of fetal tissue, and their social, ethical and other implications.
- Analysis of the experiences of other countries dealing with the technologies.
- Understanding the current context within which the technologies exist, including the values of Canadians and the societal systems that interact with reproductive issues such as the health, education, and legal systems and other institutions.
- An evaluation of relevant areas of law and ethics.

Through these two streams of work, the Commission was able to provide, for the first time, a picture of infertility and new reproductive technology use in this country, and substantive social, ethical, and legal analysis of the implications of using or not using the technologies. Our recommendations were reached relying on three considerations: explicit ethical principles, Canadian values as expressed to us in our consultations and through our surveys, and a conviction that decisions about offering medical procedures should be evidence based. In the next pages we give the most important points about the main topics we addressed — what we found, what we concluded, and what we recommend relevant to each.

Responsible Regulation: The National Reproductive Technologies Commission

In light of the evidence collected, and assessed according to an ethical framework, the Commission concluded that some reproductive technologies and some uses of the technologies are unethical and contrary to the values of Canadians — they should be prohibited. Others are potentially beneficial, if they are used ethically and responsibly. This means a system is needed to oversee, licence, monitor activities in this field.

The Commission recommends the federal government establish a regulatory and licensing body, the NRTC, to oversee research, technologies and practices. There is a need for urgent action in a rapidly evolving technological field, for comprehensiveness and similarity of approach across the country, and for public accountability in managing the technologies. It is the only way to ensure that the appropriate mix of resources, skills and experience is brought to the technologies in all their dimensions: ethical, social, legal, scientific and medical. Only the federal government can set up such as system, and it is important that the government fulfil its responsibility to protect citizens and society by doing so.

Several requirements are common to all the technologies: the need for reliable information to guide policy and practice; the need for standards and guidelines for the organization and provision of services; the need for effective means to ensure compliance; and the need for accountability. The approach we propose builds on the best standards and practices of the medical specialties involved which already are in use in some Canadian clinics. These standards should be expanded, and should be embodied in a licensing system.

We recommend the NRTC be composed of 12 members representing a broad range of experiences and perspectives. Consultation activities should be undertaken to further enhance public input and involvement. Women should make up a substantial proportion of the Commission's membership, normally at least half.

To ensure wide public input into the working of the system and to deal with setting policy as new issues evolve, we recommend membership in the proposed NRTC 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 minorities. A range of expertise should be represented, including reproductive medicine, ethics, law, and social sciences.

We recommend the NRTC have five areas of regulatory responsibility in which the provision of services would be subject to compulsory licensing through five sub-committees established for that purpose. They are:

- sperm collection, storage and distribution, and the provision of assisted insemination services.
- assisted conception services, including egg retrieval and use.
- prenatal diagnosis.
- research involving human zygotes (embryos).
- the provision of human fetal tissue for research or other specified purposes.

Licence hearings would be public, a licence would be conditional on compliance with certain standards and conditions of licence. The major functions in these five areas of regulatory authority are as follows:

- to licence, set standards, and monitor practice in the area.
- to collect, evaluate, disseminate and store information.
- to consult, help coordinate, and facilitate intergovernmental cooperation in the area.
- to monitor future technologies and practices and set policies.

In addition, we recommend a sixth subcommittee with primary responsibility in the field of infertility prevention. Its responsibilities would include the compilation and evaluation of data pertaining to the causes of infertility, the promotion of cooperative research efforts in Canada and internationally, and the regulatory, public education or other options for preventing or reducing the incidence of infertility.

National action is necessary, but not sufficient. Strong provincial and professional leadership and participation is also needed. Cooperation from all parties will ensure that the system serves the interests of Canadians.

New Reproductive Technologies and the Health Care System

The health care system is a source of national pride for Canadians. It is a tangible way in which our society expresses mutual support and caring for its members. It is important to manage the system responsibly and not overburden it with functions or responsibilities that should lie elsewhere.

Having children is important to most Canadians, and if effective, safe techniques exist to achieve that goal, it is appropriate that they are offered as part of the health care system in a non-discriminatory way; for example, prenatal diagnosis for serious disorders, IVF for blocked fallopian tubes, and donor insemination if there is no fertile male partner. However, it is unethical to offer as services unproven procedures or treatments, and it is irresponsible to devote public resources to them. Procedures without good evidence of effectiveness should be considered research, and regulated as such. Health care resources are limited, and the continued provision of unproven, ineffective, expensive technical procedures undermines the system by using resources without evidence of benefit. In fact, an evidence-based approach taken throughout the health care system would allow society could better use existing health care resources and manage the system better.

Decisions about resource allocation, access, and practice should be made in light of outcomes — that is, practice should be evidence based. The Commission's recommended NRTC will play a valuable role in establishing, administering, and exemplifying this approach by requiring data on outcomes that will be used to shape practice at licensed centres.

Ethical Framework and Guiding Principles

A broad ethical orientation was used in Commission deliberations — an ethic of care — which gives priority to the mutual care and connectedness between people and communities, and attempts to prevent conflict instead of resolving conflicts that have already occurred. Within that orientation, a set of guiding principles were used to assess how a technology's use should be viewed, and what conclusions should be made. They were:

Individual Autonomy: People should be free to choose how to lead their lives, particularly with respect to their bodies and fundamental commitments such as health, family, sexuality and work. This freedom must be limited if others are harmed, forced or coerced, or if social stability is undermined.

Equality: Every member of the community is entitled to equal concern and respect. This precludes any practice that reflects or perpetuates the idea that some lives are worth less than others.

Respect for Human Life and Dignity: All forms of human life and tissues should be treated with sensitivity and respect. Although the law does not treat embryos as persons, they are connected to the community by their origins and potential.

Protection of the Vulnerable: In the case of power imbalance where one party is open to exploitation, this should be given special consideration. This can arise from socioeconomic status, membership in a minority group, or disability, and society has a responsibility safeguard individuals who are vulnerable.

Non-commercialization of Reproduction: Human beings, their reproductive capacities or tissues should not be treated as commodities to be traded for money or other goods.

Appropriate Use of Resources: There are many needs yet finite resources, so we need to use resources wisely. Public resources should not be used on ineffective treatments, and evaluation of technology is needed to manage resources.

Accountability: Those who hold power, whether personally or because of their role in government or other fields, are responsible for the way they use it.

Balancing Individual and Collective Interests: Neither individual or collective interests take automatic precedence, each must be taken into consideration in any decisions made about new reproductive technologies. The Commission endorses a strategy that encompasses both individual and collective interests and maintains a necessary awareness of both, remembering that the Charter of Rights and Freedoms expresses the Canadian stance on the relationship between the individual and the collective.

The Prevalence of Infertility

The Commission conducted the first Canadian survey to determine the prevalence infertility in this country in couples in which the woman was aged 18-44. It found that 8.5% or 300 000 couples who have been married or living together for at least one year at the time of the survey were infertile. Seven percent or 250 000 couples married or living together for at least two years were infertile.

This estimate is useful for the following reasons:

- for public policy decisions regarding planning of infertility prevention programs and infertility treatment programs;
- for use as a baseline figure for future studies to determine if the rate of infertility is rising or declining in Canada;
- for comparison with other countries and communities.

Sexually Transmitted Diseases and Infertility

Preventing STDs, specifically chlamydia and gonorrhoea, must become a greater priority in Canada if we are to reduce the prevalence of infertility in the future. STDs cause pelvic inflammatory disease (PID), and an estimated 20 percent of all infertility among couples can be traced to damage to the woman's fallopian tubes that has resulted after PID.

STD prevention should be focussed on school health programs to educate young people about risks to their fertility and how to protect against these risks. Other programs should be targeted to reach sexually active young people at high risk who are not in school. More attention should also be given to the role of physicians and other health care workers in STD prevention.

Research on the incidence of STDs and on the evaluation of prevention strategies is very important. The proposed NRTC Subcommittee's role is to facilitate and promote a focus on policies that will be effective in prevention of infertility.

Smoking and Infertility

There is mounting evidence that heavy smoking reduces fertility as well as increasing risks to the developing fetus during pregnancy. The evidence on fertility reduction, while not conclusive, is enough to justify counselling couples to quit smoking before trying to conceive. Success rates of assisted conception techniques may be lower in smokers, so individuals considering using these should be counselled to stop smoking and receive support to do so.

Preventing smoking is as important as helping smokers to quit. Because the majority of smokers began in their teens, prevention efforts should be targeted at young people, and public "no smoking" policies and restrictions on tobacco advertising should be in place.

Age and Infertility

Women's fertility declines with age because of two factors; cumulative exposure to risk factors affecting fertility, and the natural aging of the reproductive system. On average, a woman in her mid to late 30s will take longer to conceive than a woman in her twenties.

From a biological perspective the ideal time for a woman to have children is in her twenties. This may not be practical or desirable for many women for many reasons. Steps must be taken to reduce the impediments to earlier childbearing, including lessening the financial and opportunity costs of interrupting a career to raise children by introducing family-friendly workplace strategies such as flex-time, paid leave, job sharing, and permanent part-time employment to allow women to continue in the workforce. Strategies to encourage men to assume more responsibility for child and home care are needed.

Women should have information on the biological realities of aging so they may factor this into decisions about when to have children. Information incorporated into school programs and information provided by health care workers can help them become aware of this.

Exposure to Harmful Agents in the Workplace and the Environment and Infertility

This field is characterized by a lack of information. Data clearly show that in a sufficient dose a number of agents in the workplace and environment can delay conception or reduce fertility (by affecting the menstrual cycle, sperm production or quality, reducing interest in sexual activity, or causing spontaneous abortion), but evidence about the effect of more common levels of exposure does not exist. A rational and effective prevention strategy must be based on knowledge, so research should be a priority. The task is one facing all nations, and Canada should take a lead role to organize cooperative and coordinated international efforts in the research and data analysis needed. We recommend the NRTC Infertility Prevention Subcommittee work toward facilitating and developing such an initiative.

Past and current prevention strategies have been fragmented, and have concentrated on removing at-risk workers (usually women) from positions where they are exposed to agents that could be harmful. A single approach is not sufficient; an integrated approach using exposure standards, regulatory measures, education of workers, and improved health and safety legislation is likely to be more effective in preventing reproductive harm. The focus should be to develop a knowledge base that provides a solid foundation for further definitive preventive action.

Environmental health hazards are emerging as a focus in public policy and legislation, but aspects related to reproductive health are often ignored. We recommend that reproductive health experts be involved as advisors to any environmental protection legislation, particularly existing and proposed regulations under the *Canadian Environmental Protection Act*, to ensure protection of human reproductive health is included in planning.

Preventing Infertility

Canada needs a national infertility prevention strategy so that aspects of current programs can be integrated for a greater focus on protecting fertility. Such a strategy should be aimed at reducing and preventing STDs and smoking, and at increasing awareness of the effects of delaying childbearing, and workplace and environmental risks to fertility.

Cooperation between federal, provincial/territorial and private bodies currently administering health, education, counselling and outreach programs is crucial. A central body such as the proposed NRTC Infertility Prevention Subcommittee is needed to stimulate and coordinate such cooperation, provide useful information and educational materials, and encourage legislative changes where needed. Research into what programs or initiatives are effective in infertility prevention should be a priority.

Adoption

Our review showed that the number of children available for adoption has dropped markedly, so that adoption is no longer a feasible alternative for most couples and even less likely for single people or those in non-traditional relationships. In 1990 there were eight people waiting to adopt for every infant in Canada. The current system is not structured in the best interests of children, and should be reviewed with attention to the following: meeting the best interests of the child, meeting the needs of other parties involved (such as adoptive parents and birth mothers), access to adoption, cost, record keeping and disclosure, counselling and consent.

How international adoptions are handled is an important aspect for review. International adoptions are problematic from an ethical standpoint if protections and policies are not in place, as they may contribute to commodification of human beings and possible coercion and exploitation of women in other countries. Regulations governing these adoptions should be reviewed. A priority for all levels of government should be a harmonizing provincial regulations and practices.

The current status of private adoptions in Canada raises concerns about non-commercialization and non-commodification of children, equality and non-discrimination in access. It should be reviewed and changes made.

Fertility Drugs

Drugs to induce ovulation are very commonly used in treating infertility. It is therefore important to collect information on short-term and long-term effects of their use. Their widespread prescription by physicians outside clinics makes it difficult to collect information on outcomes. Fertility drugs are not alone in this regard — there are problems with existing mechanisms governing all drugs, and serious deficits in evaluation of outcomes in an ongoing way after a drug has been approved for use in Canada. The Commission has made recommendations that will help assure Canadians that citizens are protected from unethical, unproven, or unsafe drug use at licensed centres, and that will help the profession more generally to follow better prescribing practices for these drugs.

The Commission found questionable treatment practices, such as drugs used for unapproved uses or at unapproved dosages, that put patients at risk yet are not in the context of research trials. There is a need to protect patients from experimental or unproven drug therapies by putting in place regulations and guidelines to ensure that only drugs meeting standards of effectiveness and safety are used in practice at licensed clinics. Licensed centres should offer others only in the context of multicentre clinical trials where standards of ethical research are adhered to. Use of some drugs should be discontinued altogether. Full information for patients is a crucial component.

Most fertility drugs, apart from clomiphene citrate used in approved dosages, should only be prescribed where monitoring and appropriate clinical and laboratory expertise for following the patient is available. This means it is inappropriate to provide them outside infertility treatment clinics.

Assisted Insemination

The Commission's investigation found that AI is the most commonly used method for women without a fertile male partner to form families. Far more children are born from this each year than are adopted in Canada, and children born this way are five to ten times more common than IVF children. This means AI is worthy of much more scrutiny, assessment, and policy attention than it has been afforded in the past.

We found insemination is being offered under widely varying clinical conditions, sometimes in a dangerous fashion; technical variations of the procedures are being performed with no evidence of their benefit; some practitioners are not adhering to the standards physicians have set for themselves as a profession; access criteria differ from clinic to clinic, with single women and lesbians being excluded in some.

Forming a family is of great importance to people. Provided standards are adhered to, DI is a safe and very effective way to have a child. Therefore, the Commission recommends DI be available through the publicly supported health care system. Unless there is evidence that the well being of resulting children will be harmed, DI should be equally available to all women. The available evidence does not show different outcomes in children born to or raised by lesbians or single women when compared to children born to heterosexual women and couples, in similar circumstances. Thus the best interests of the child cannot be used as a reason to deny access. If a service is available, women should be treated equally, unless there is good evidence that the best interest of the child will suffer.

The experiences of adoptees and their families have indicated the importance of information about biological origins, and access to medical and social information about genetic parents. Inadequate or absent record keeping by DI practitioners has made it impossible to meet the current and future needs of existing AI children and their families. We have recommended an integrated, reliable record-keeping system to ensure their needs are met.

Regulation and licensing is needed to standardize practices and safeguard the health of citizens. Neglecting to enforce regulation and adequate monitoring of the practice of AI endangers the health of AI recipients, their partners and children.

Family law has not kept pace with the realities created by DI. As a result, DI families and sperm donors could be vulnerable to challenges to custody, access, inheritance and support for DI children. This vulnerability encourages secrecy around DI, which is not in the best interests of DI children or families. We recommend changes to family law to reflect DI realities.

Commissioners are strongly opposed to commercializing human reproduction, as are Canadians generally. No profit should be made from the selling of any reproductive material, including sperm, because of ultimately dehumanizing effects. Current commercial practices in storage and distribution of donor sperm contravene these values, and we recommend a licensed, non profit system.

In Vitro Fertilization

IVF is currently offered in a way that is unacceptable. In about half of cases in Canada it is used for indications for which there is not good evidence it is effective, yet it is offered in these cases as a treatment, not as research. As well, there are marked differences in how services are offered, often without clear and understandable information for patients. Record keeping is unsatisfactory and insufficient to be able to assess outcomes — even such critical aspects as the number of children born. Voluntary guidelines developed by practitioners for practice are not routinely adhered to. The situation of voluntary regulation in the treatment community has led to practice ranging from excellent to completely unacceptable.

Medical procedures should move from the realm of research to that of treatment only if they can be demonstrated to be effective and beneficial, and only if information on their risks and effects is available. To date, IVF has been proven effective for only one category of infertility disorders — those involving complete blockage of the fallopian tubes. Only for this category of cases is it a treatment proven to be of benefit and therefore a candidate for provincial health-insurance coverage. For all other uses, there is a pressing need to find out for what indications IVF is effective. Until that information is available, IVF for indications other than tubal blockage should be offered only in the context of well designed clinical trials.

Some uses of IVF technology contravene Canadian values, and are unethical, thus they should be banned. These include IVF in support of preconception arrangements and IVF for post-menopausal women, IVF as a profit-making venture, and experimental uses of IVF offered as treatment.

A nationally administered, regulated, standardized system is needed to ensure adherence to rigorous standards of practice and care, useful and standardized record-keeping, access to adequate information and counselling for patients, analysis of any long-term effects, and ongoing monitoring and policy-making.

There is a good opportunity to put in place a well regulated system to provide assisted conception services in Canada. There is a history of voluntary cooperation in the field, and only a relatively small and clearly identifiable number of such facilities and concerned professional organizations.

Handling of Eggs and Embryos

Egg and embryo donation can be beneficial for some infertile individuals and couples, but it is also possible to misuse the technology. Some uses would violate Canadian values and are unethical when viewed through the Commission's ethical framework. These include designated donation of eggs and zygotes, which raises the issue of potential coercion, egg retrieval solely for the purpose of donation, which puts women at risk without benefit, donation to women who have experienced menopause at the usual age, storage of embryos for more than five years or after the death of either partner, and the implantation of eggs from female fetuses.

The autonomy of donor women and couples must be respected by having detailed standardized information and consent to fertilization, donation or disposition. Guidelines and standards as conditions of licence will ensure this consent is given before eggs are retrieved, and that eggs and embryos will only be used and disposed of in accordance with the wishes of the donor.

As in DI, the health of women recipients and the children that result should be protected by testing donors for infectious diseases that could be transmitted to recipients. Families need non-identifying social and medical information about donors, so standardized records need to be kept to allow this. Coded, recorded information will allow research on outcomes. NRTC licensing requirements for facilities will ensure these standards are met.

Embryo Research

Some knowledge about human reproduction particularly relevant to the treatment of infertility, can be gained only through research using human embryos or zygotes. Such research is an essential part of ensuring safety and quality of medical treatment in this field. However it is also essential to ensure that zygotes be treated with respect because of their connections to the human community.

Research on human zygotes in Canada to date has been conduced without clear legal and public policy direction. It is important to put in place boundaries, and to regulate within these boundaries to ensure that only ethically acceptable, accountable use of human zygotes in research is made. In view of our ethical principles, research on human zygotes is acceptable only if it occurs within certain boundaries, and to ensure this, any facility doing such research will be required to be licensed.

Conditions of license will include: the goal of the research is knowledge about human health and treatment of disease; there is no other way of gaining the knowledge than using human zygotes; it occurs prior to 14 days after fertilization. Strict and standardized protocols of informed consent are required when zygotes are donated for research, and retrieving eggs solely for fertilization and use in research is not permissible.

Preconception Arrangements

A preconception agreement is where a woman agrees to conceive and carry a pregnancy in order to hand over the child to a commissioning person to raise. Our review of the evidence shows that the potential benefits to a few individuals are far outweighed by the harms to others and to society. Commissioners believe strongly that preconception arrangements are unacceptable and should not be encouraged. Preconception arrangements commodify reproduction and children, they have the potential to exploit women's vulnerability because of race, poverty, or powerlessness and leave women open to coercion. Thus they contravene the Commission's ethical principles.

The most appropriate ways to discourage commercial preconception arrangements are by criminally prosecuting those who act as intermediaries, and by making payments for preconception arrangements illegal.

To be effective, prohibitions against preconception agreements must be national in scope and equally enforced in all areas of the country, so federal regulation is necessary. We also recommend that Canada take a lead in discouraging such practices internationally.

We recommend the interests of children born through non-commercial preconception arrangements should be protected by establishing that a child's legal mother is the woman who gives birth to the child. We recommend that the best interests of the child predominate in any dispute over custody.

Commercial Interests

New reproductive technologies may bring benefits but they also have potential harms to individuals and society if misused. This means the development and dissemination of new reproductive technologies cannot be left to market forces or corporate goals. A regulatory framework that ensures the profit motive is not the deciding factor in the development or provision of the technologies is essential, and the government, as guardian of the public interest, must put legislation in place to set this up. If commercial interests continue unregulated, they could lead to inappropriate, unethical or unsafe use of technology. However, within a regulated context commercial interests have a useful role — for example, in the development of drugs.

The technologies should not be used in a way that commodifies human beings, commercializes reproduction, or otherwise offends Canadian values and our ethical principles. Among the activities that are ethically unacceptable and that we recommend not be permitted are: the buying and selling of gametes, zygotes, embryos and fetuses, for-profit provision of assisted insemination and conception services, the use of financial incentives in preconception or adoption arrangements, and the patenting of medical treatments or of human gametes, zygotes, embryos or fetuses.

In the open market it is assumed that consumers can protect their own interests — in the field of health care they cannot, and they are vulnerable. We recommend specific policies to limit commercial interests so that vulnerable interests are protected including: licensing only non-profit service provision with required standards of quality control and provision of objective information to prospective patients; monitoring the promotional activities of pharmaceutical firms; strengthening the procedures governing the testing of new products and services and approving them for use; and ensuring ethical review of industry-funded research.

Prenatal Diagnosis for Congenital Anomalies and Genetic Disease

Some people are at increased risk of having congenital anomalies or a genetic disease in their children. A large majority of Canadians think PND should be available to such individuals. PND provides choices for at-risk couples, and allows them to have healthy children, and, if used for serious disorders with fully informed choice, is beneficial. Nevertheless there are risks if PND is misused, and a regulatory system is needed to ensure adherence to rigorous standards of practice and care, and to ensure that practice continues to evolve in line with Canadian values.

We found a major difference in the likelihood a woman would have access to testing by being referred to a genetics centre — a more than four-fold difference between provinces, although women's attitudes to PND varied little regionally. It is imperative that the choice to use PND be made by the woman, not by the physician.

Not enough attention has been given to how patients view the PND experience and how the public perceives genetics. There is a great deal of misinformation about PND, and there is a need for accurate, unbiased, accessible information in this field. It is important that all eligible women be informed of the service and that their wishes to use or not use the technology be respected.

A regulated licensing system for facilities providing prenatal diagnosis is recommended to ensure continued adherence to standards of practice, record keeping, adequate information and counselling for patients. The structure we have recommended for this system will ensure that a wide representation of views is included in policy-setting as the field continues to evolve. It will also report publicly on current and future developments so Canadians will be reassured that all activities are open and accountable.

Prenatal Diagnosis for Late-Onset Single-Gene Disorders and Prenatal Diagnosis for Susceptibility Genes

Presymptomatic prenatal diagnosis for late-onset disorders raises issues in addition to those raised by PND for congenital or early onset problems. If a couple does not consider termination an option, the benefits of prenatal testing are outweighed by potential harm to the child. Women and couples, when given complete and accurate information, are capable of making enlightened and appropriate decisions for themselves and their children. Appropriate counselling should be available to ensure parents are aware of negative and positive aspects of such prenatal testing and possible outcomes.

There has been no demand for the development and provision of prenatal testing for genes that increase susceptibility to common multifactorial disorders. Such testing at this time is unable to provide any useful or reliable information about the likelihood of a person becoming ill. This means prenatal testing for such disorders would not be an effective or responsible investment of scarce health care resources.

We recommend continued and ongoing monitoring of developments in this field, and a mechanism, in the form of the NRTC Prenatal Diagnosis Subcommittee, to ensure policy responses take into account public input to ensure future technologies are used in a beneficial and ethical way.

Sex Selection for Non-Medical Reasons

The practice of PND and sex-selective abortion, simply because one sex is preferred over the other, is contrary to the Commission's guiding principles and incompatible with Canadian values. It violates the principles of respect for human life and dignity, protection of the vulnerable, and appropriate use of resources.

For the same reasons, sex-selective zygote transfer is also inappropriate if used simply because of a preference. Licensing of IVF practitioners will ensure that pre-implantation diagnosis for non-medical reasons will not be done in licensed centres.

Sperm treatments and sex-selective insemination does not violate the principle of respect for human life. Although evidence suggests that the great majority of Canadians do not have a gender bias with respect to the sex of their children and would consider using this technique only with the aim of having at least one child of each sex, additional factors must be taken into consideration:

- it reinforces the idea that the sex of a child is important, and encourages the view that families with all boys or all girls are less than ideal.
- it could make existing children in the family feel that their own sex was lacking in some way.
- it would involve an inappropriate use of resources.
- the technique is unproven and research to determine its effectiveness and safety is not of sufficient value to devote scarce research resources to it.

These considerations led us to conclude that sex-selective insemination services should not be available in Canada for reasons of sex preference. We recommend such services be provided only where there is a medical indication such as an X-linked disorder, and only in licensed settings with requirements for informed consent, data collection, and reporting.

Gene Therapy and Genetic Alteration

Several applications of DNA technology, such as gene therapy and genetic alteration, are relevant to human reproduction and all are highly experimental.

Somatic cell gene therapy involves the insertion of genetic material into the non-reproductive cells of an individual for the purpose of correcting a genetic disease. Technical limitations mean that only a small fraction of single-gene disorders are presently amenable to gene therapy. Use of this therapy in children or even adults may be appropriate if it is the only treatment available for severely affected individuals. In the prenatal context, use of gene therapy poses risks to both the woman and the developing zygote or fetus. A two part mechanism for review of any proposed gene therapy research involving prenatal treatment is recommended. The Medical Research Council and the NRTC would both assess any such project before approval to proceed could be given.

Germ-line genetic alteration refers to the introduction of corrective genetic material into germ cells (gametes or zygotes) so that the resulting genetic change is passed onto offspring in subsequent generations. There is no situation where this is the only way to avoid having affected offspring, and the risks are significant. Therefore we recommend such research should not be conducted in Canada. The practice is inconsistent with the Commission's guiding principles and there are many potential harms, without clear benefit to any individual.

Non-therapeutic genetic alteration involves the insertion of a gene into an already healthy structure in order to improve or enhance a known characteristic, such as intelligence, height, or longevity. Genetic enhancement carries social and medical risks disproportionate to any benefit, and involves opportunity costs by diverting scarce financial and professional resources away from real medical problems. No research into this area should be permitted or funded in Canada.

Judicial Intervention

Judicial intervention into pregnancy and birth has increased in part because of technological and medical advancements allowing the fetus to be seen as a separate entity from the pregnant woman. This has positive consequences — increased awareness of risks to the fetus with avoidance of harmful exposures and treatment of disease in utero. It also has the potential to establish an adversary relationship in which a pregnant woman's autonomy is compromised. This has serious, negative implications for all women who become pregnant.

Society has an interest in promoting the health and well-being of the fetus, but not at the expense of the basic components of the woman's human rights — the right to bodily integrity, and the right to equality and human dignity. To coerce and compel by judicial intervention is also unlikely to be effective in protecting the fetus. The instruments available to the courts are blunt and unsuited to the goal of promoting anyone's well-being.

A better alternative to judicial intervention in reaching the goal of fetal well being is care and assistance to the pregnant woman: this respects the life and dignity of both the woman and fetus. The woman's consent and cooperation are needed to ensure a positive outcome for the fetus. Judicial intervention should not be permissible, instead steps should be taken to maximize the health of the woman and fetus through information, education, culturally appropriate outreach, counselling and support.

Uses of Fetal Tissue

On the basis of the evidence reviewed by the Commission, there is a real possibility that research involving the use of fetal tissue could result in considerable alleviation of human suffering. At present, elective abortion provides the only practical source of fetal tissue. Research carried out under the controlled conditions we have specified may benefit human health and is respectful of human dignity.

The controlled conditions for obtaining and using fetal tissue include safeguards against coercion, commercialization and unethical use of fetal tissue. We recommend: prohibition of giving or receiving payment for fetal tissue; consent to use of tissue obtained separately from and subsequent to the decision to have an abortion; standards of information disclosure; and the method of abortion to be chosen for the woman's safety and health only. We recommend licensing by the NRTC of any provider of fetal tissue, with conditions of license to ensure that fetal tissue is obtained in accordance with the above licensing requirements and is only provided for use in research directed to understanding biologic mechanisms with potential relevance to treating disease.

Commission research found that placentas are being sold to a firm that uses them to make pharmaceutical products used in the diagnosis and treatment of disease. This material is a byproduct of birth and would be incinerated otherwise, so we do not view this as unethical. However, the consent of the woman is not currently being obtained. We recommend that this be done and that she may chose disposal if she does not wish the placenta to be used in this way.

Conclusion

As we have shown, having children and healthy families are centrally important life goals for most Canadians. Commissioners therefore believe that a caring society should help people attain these goals, but always in the context of guarding against larger harms, whether to individuals or to society. As guardian of the public interest and on behalf of individual citizens, the federal government has a responsibility to prevent harms. This means clear limits and boundaries must be placed around the use of reproductive technologies, and that only ethical and accountable use of permissable technologies be allowed within these boundaries. The approach we propose will do this, will allow input from a wide range of interests in society, and will allow a continuing response to evolving issues.

Commissioners have set out a blueprint for how Canada, with its unique institutions and social make-up, can deal with new reproductive technologies, regulate their use, and ensure that future developments or use are in the public interest. Our blueprint involves the leadership of the federal government but needs the participation and commitment of provincial governments and many 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.

The reasons for such action are compelling: the potential for harm to individuals and the need to protect the vulnerable interests of individuals and society. Adopting our recommendations will enable this protection, but will also allow scientific knowledge to be used to better the lives of many Canadians. Implementing the blueprint will demonstrate that we care about each other's well-being and recognize collective values with respect to the importance people attach to having children. At the same time, it will ensure that only ethical and accountable use of technology is made, and demonstrate that Canadians have wisdom, humanity, and compassion in the way they choose to use technology.

The Commission has done its work, and indicated the path we believe should be taken. It is now up to the Government and the people of Canada to decide if they will take it.

Budget of the RCNRT

Original budget, October 1989- October 1991:	$24.7 million
October 1991- November 1993:	$3.5 million
Total:	$28.2 million

Mandate

. . . inquire into and report on current and potential medical and scientific developments related to new reproductive technologies, considering in particular their social, ethical, health, research, legal and economic implications and the public interest, recommending what policies and safeguards should be applied.

The Commission will examine in particular:

a) implications of new reproductive technologies for women's reproductive health and well-being;
b) the causes, treatment, and prevention of male and female infertility;
c) reversals of sterilization procedures, artificial insemination, *in vitro* fertilization, embryo transfer, prenatal screening and diagnostic techniques, genetic manipulation and therapeutic interventions to correct genetic anomalies, sex selection techniques, embryo experimentation and fetal tissue transplants;
d) social and legal arrangements, such as surrogate childbearing, judicial interventions during gestation and birth, and "ownership" of ova, sperm, embryos and fetal tissue;
e) the status and rights of people using or contributing to reproductive services, such as access to procedures, "rights" to parenthood, informed consent, status of gamete donors and confidentiality, and the impact of these services on all concerned parties, particularly the children; and,
f) the economic ramifications of these technologies, such as the commercial marketing of ova, sperm and embryos, the application of patent law, and the funding of research and procedures including infertility treatment.

This Report . . .

- The first to cover such a broad range of technologies, practices, and conditions
- The first to benefit from such a wide range of input
- The first to systematically examine the impact on women, children, families, the disabled, minorities
- The first to bear in mind the consequences for the health care system

Consultations and Communications

- ✓ Public Hearings
  - 17 centres
  - 2,000 participants
- ✓ Toll-free telephone lines
  - 6,000 individuals left views
- ✓ Information meetings
  - with national groups interested in technologies
- ✓ National surveys
  - of values and attitudes
  - 15,000 participants
- ✓ Release of research studies
  - 14 studies
  - to inform and educate
- ✓ "Update"
  - Commission newsletter
  - 50,000 distributed
- ✓ Information to media
  - More than 250,000 pieces distributed

Research and Evaluation

✓ Wide range of involvement

- many disciplines: social sciences, law, ethics, medicine
- more than 300 researchers and academics across the country
- 21 universities and 27 hospitals

✓ 130 research studies available in 15 volumes

- analysis and inquiry into the technologies and practices and their implications
- analysis of experiences of other countries
- understanding of Canadian social, legal, and health context
- evaluation of relevant law and ethics

Framework for Decision Making

- Eight guiding ethical principles within an ethic of care
- Understanding of Canadian social values and attitudes
- Evidence-based medicine

Prevalence of Infertility

First Canadian data collection and research on prevalence

Looked at couples in which the female was aged 18-44 and:

1. had been cohabiting for 1 year/2 years
2. had not been using contraception
3. had not had a pregnancy

Results:

- One year: 8.5 %, or 300,000 couples unable to conceive
- Two years: 7%, or 250,000 couples unable to conceive

7% of Canadian couples of reproductive age

Risk Factors for Infertility

- Sexually transmitted diseases
  - education and preventive initiatives needed
- Delayed childbearing
  - decline of fertility with age should be factored into decisions on child-bearing
- Smoking
  - causes risks to the developing fetus
  - reduces fertility
- Exposure to agents in the workplace or environment
  - information needed for prevention lacking; research a priority

Adoption

- Commonly suggested alternative for infertile couples
- Data show it is no longer a feasible alternative for many people
- For each of the 1,700 infants adopted in Canada in 1990, 8 couples were waiting to adopt

Fertility Drugs

- Most common method of treating infertility
- Don't know how many children are born or if there are long-term effects
- Questionable treatment practices put patients at risk
- Non-adherence to standards

Donor Insemination

- Option when there is no fertile male partner
- Safe, effective, and inexpensive
- Need records linking donors and recipients
- Should be equally available to all women
- Poor record keeping means number of children born not known — probably several thousand
- Non-adherence to guidelines, including use of sperm from donors not tested for AIDS

In Vitro Fertilization

- Least common infertility treatment
- Fewer than 400 children born in 1991
- Only shown effective for women with blocked fallopian tubes, but used for other indications in about half of all cases in Canada
- Involves health risks
- Data to allow proper calculation of success rates not collected
- Incomplete and often misleading information given to women
- Commercial clinics exist in Canada
- Non-adherence to standards

Currently in the United States, without any legislation against commercial activities:

- brokers advertise and pay women $15,000 to conceive, carry a pregnancy, and hand the child over
- women 60 years old pay to have the egg of a younger woman fertilized and implanted
- commercial sperm banks sell sperm for profit
- there are franchised sex selection clinics

Canadians told us they do not want market forces to determine how reproductive technologies are used in Canada

Embryo Research

- Some information relevant to infertility treatment can only be gained through this research; essential to ensure safety and quality of procedures
- Without research, health of women and children would be put at risk
- Essential to ensure that zygotes are treated with respect because of their connections to the human community
- To date, no clear legal or public policy direction

Prenatal Diagnosis

- Permits couples at risk because of family history or age to have healthy children
- 84% of Canadians think PND should be available to those at risk
- Fourfold difference in referral rate across country (15-64% of eligible women) reflects physicians' personal beliefs regarding PND
- Field growing rapidly
- Routine ultrasound costs about $100 million each year in Canada without any proven benefit to outcomes
- No mechanisms in place to do multicentre trials and to decide on what will be offered as services

Sex Selection

1. Use PND to determine sex, and abort fetus of wrong sex
   - contrary to Canadian values
   - violates principle of respect for human life and dignity
2. Test zygotes created through IVF, and only implant those of the desired gender
   - invasive, expensive, and wasteful of medical resources
   - violates principle of respect for human life and dignity
3. Treat sperm to enhance x- or y-bearing sperm
   - intrusive and inefficient — usually requires several cycles
   - reinforces idea that the sex of a child is important

No mechanism in place to limit/monitor use of any method

Gene Therapy and Genetic Alteration

Somatic Cell Gene Therapy

- ✓ May be appropriate when it is the only hope for severely affected children or adults
- ✓ Use prenatally poses risks for woman as well as fetus; greater ethical scrutiny required

Germ Line Genetic Alteration/Non-Therapeutic Genetic Alteration

- ✓ Social and medical risks disproportionate to any benefit
- ✓ No research should be permitted in this area

No legislation or mandatory mechanisms in place

Judicial Intervention in Pregnancy and Birth

Contravenes women's rights to:

- bodily integrity
- equality
- human dignity

Is ineffective:

- does not protect fetus

Should not be permissible

Instead:

- Health of woman and fetus should be maximized through providing care, counselling, and assistance

Use of Fetal Tissue

Real possibility use of fetal tissue may alleviate considerable human suffering

Therefore unethical and uncaring to prohibit research

BUT

Since elective abortion is the only practical source of fetal tissue, controls needed to ensure its use does not encourage abortion

No current mechanisms in Canada to ensure the above

Areas of Criminal Prohibition

- Using embryos in research related to:
  - Cloning
  - Animal/human hybrids
  - Ectogenesis
  - Transfer of zygotes to another species
- Fertilization of eggs from female fetuses for implantation
- Sale of eggs, sperm, zygotes, or fetal tissues
- Payment for or acting as an intermediary for preconception (surrogacy) arrangements

The National Reproductive Technologies Commission

- Regulatory and licensing body
- Holds public hearings for licensing
- Oversees research, technologies, and practices in five activities
- 12 members with wide range of experiences and perspectives
- Women to make up half the membership

NRTC — Functions

- to licence, set standards and monitor practice
- to collect, evaluate, store securely and disseminate information
- to consult, help coordinate, and facilitate intergovernmental cooperation in the field
- to monitor future technologies and practices and set policies

NRTC — Areas of Regulatory Responsibility

- Sperm collection, distribution, and storage and the provision of assisted insemination services
- Assisted conception services, including egg retrieval and use
- Prenatal diagnosis
- Research involving human zygotes (embryos)
- The provision of human fetal tissue for research or other specified purposes

The Provision of New Reproductive Technologies Under the NRTC

Infertility treatments:

- provided only within the provincial health care system, by licensed facilities, and with national standards for information, consent, calculation of success rates, and record keeping
- national sperm collection and distribution system would ensure availability of safe sperm, for use in medical setting or for self-insemination, with comprehensive and confidential record keeping
- only treatments which have been assessed for safety and effectiveness would be offered as services; others could only be offered within context of research
- annual reporting to NRTC would enable long-term effects to be evaluated

Prenatal Diagnosis

- PND services to be provided only by licensed facilities with national standards
- screening tests on pregnant women to be provided only through provincially licensed or mandated programs
- only testing shown to be effective and safe to be offered as services; all other testing to be provided only in the context of research trials
- annual reporting would provide data to assess long-term outcomes

Embryo and Fetal Tissue Research

- any provision of fetal tissue to be licensed; to be used only for research relevant to human functioning and disease; permission for tissue use obtained separately from and subsequent to decision to abort; method of abortion not changed
- embryo research to be conducted only in licensed facilities , within 14 days after fertilization, for approved purposes, with informed consent of donors

Why a National Response?

NRTs:

- affect the nature of our society
- affect not just health, but law, prevention, education, commerce, science and research policy
- are important to the health and legal status of women and children and affect how they are viewed
- cannot be contained in one province (reproductive tourism)

A national response is needed soon to deal with a rapidly growing field. Canadians want the government to protect their interests.

Royal Commission on
New Reproductive Technologies

Commission royale sur les
nouvelles techniques de reproduction

P.O. Box/C.P. 1566, Station/Succursale "B", Ottawa, Canada K1P 5R5, (613) 954-9999 Fax: (613) 954-9998

News Release

1993-74
November 30, 1993

REPORT ON NEW REPRODUCTIVE TECHNOLOGIES RELEASED

OTTAWA - On behalf of the federal government, Health Minister Diane Marleau today released the Final Report of the Royal Commission on New Reproductive Technologies.

In thanking the Commission for its work, Mrs. Marleau said that its 293 recommendations have important social, legal, ethical and health implications for all Canadians, particularly women. "Fundamentally, we should remember that it is infertility, touching the lives of many Canadians, that generates the demand for reproductive technologies. In this respect, the Commission is to be highly commended for their hard work and for giving us the possibility to look at this issue in a comprehensive way," said the Minister.

Since many of the recommendations involve matters of provincial/territorial jurisdiction, the Minister wishes to consult with provincial and territorial governments.

In making the Report public, Mrs. Marleau said that she is moving quickly on health and safety issues identified in the Report. For example, she has directed Health Canada officials to follow-up with provincial medical authorities to protect women and babies from certain practices which may put them at risk of contracting sexually transmitted diseases. Federal regulations are currently being developed to ensure that the recommendations which call for the reduction of risks pertaining to women and children are implemented. Regarding potential health risks associated with fertility drugs, Health Canada will strengthen the process for assessing their impact after they are introduced onto the market.

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The Report of the Royal Commission on New Reproductive Technologies is available to the public through bookstores that carry government publications or through Canada Communication Group (CCG) - Publishing, 45 Sacré-Coeur Boulevard, Hull, Quebec K1A 0S9. Orders may also be placed through CCG by phoning (819) 956-4802 or faxing (819) 994-1498. The Report costs $52.00.

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Information:

Monette Haché
Health Canada
(613) 957-1803

Également disponible
en français

Communiqué

1993-74
Le 30 novembre 1993

PUBLICATION DU RAPPORT SUR LES NOUVELLES TECHNOLOGIES DE LA REPRODUCTION

OTTAWA - Au nom du gouvernement fédéral, la ministre de la Santé, Diane Marleau, a rendu public aujourd'hui le rapport final de la Commission royale sur les nouvelles technologies de la reproduction.

Tout en remerciant la Commission de son travail, M^me^ Marleau a reconnu que ses 293 recommandations auront une vaste portée sur les plans social, juridique, éthique et de la santé pour tous les Canadiens, en particulier les femmes. «Au fond, nous devons nous souvenir que c'est l'infertilité, qui représente un problème pour de nombreux Canadiens et Canadiennes, qui est à la base de la demande de techniques de reproduction. À cet égard, je tiens à féliciter la Commission d'avoir déployé tant d'efforts et de nous avoir donné la possibilité d'examiner la question de façon globale,» a dit la ministre.

Comme nombre des recommandations portent sur des questions de compétence provinciale ou territoriale, la Ministre souhaite consulter les gouvernements provinciaux et territoriaux.

En rendant le rapport public, M^me^ Marleau a indiqué qu'elle interviendrait rapidement sur toutes questions de santé et de sécurité soulevées dans le rapport. Par exemple, elle a ordonné aux fonctionnaires de Santé Canada de prendre contact avec les autorités médicales provinciales afin de protéger les femmes et les bébés d'être exposés aux maladies transmises sexuellement par certaines pratiques. Des règlements fédéraux sont en voie d'élaboration pour assurer la mise en application des recommandations devant permettre de réduire les risques pour les femmes et les enfants. Quant aux risques potentiels pour la santé que comportent les inducteurs de l'ovulation, Santé Canada renforcera le processus d'évaluation des effets de ces produits une fois qu'ils seront sur le marché.

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Le public peut se procurer le rapport de la Commission royale sur les nouvelles technologies de la reproduction dans les librairies où sont vendues les publications du gouvernement, ou l'acheter directement du Groupe Communication Canada (GCC) - Édition, 45, boul. Sacré-Coeur, Hull (Québec), K1A 0S9. On peut aussi commander le rapport du GCC par téléphone, au (819) 956-4802, ou télécopieur, au (819) 994-1498. Le rapport coûte 52 $.

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in English

COMMUNIQUE

Royal Commission on
New Reproductive Technologies

Commission royale sur les
nouvelles techniques de reproduction

30 November 1993

Royal Commission on New Reproductive Technologies Recommends National Action

OTTAWA — National action is essential to ensure that new reproductive technologies are only used in a beneficial way, to help Canadians to have healthy children, and that harmful consequences that could come from their misuse are avoided, according to **Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies.**

"Steps must be taken to prevent the harm to individuals, particularly women and children, and the violation of important social values that would come from uncontrolled use," said Dr. Patricia Baird, the Commission's chairperson. "There is a need to prohibit those uses of technology that contravene Canadian ethical and social values, and for regulation of other uses to ensure that only accountable, beneficial use of acceptable technologies occurs."

"Although some centres and practitioners are conducting responsible practice and guidelines have been developed, we found that in fact unproven procedures are being offered as treatments, poor or absent record keeping is common, unsafe practices (such as use of sperm where the donor has not been tested for HIV) occur and there is inadequate information prior to consent. In addition, the field is widening rapidly and the decisions about what uses should be permissible are not medical decisions but social policy decisions that physicians and researchers are not equipped to make."

The Work of the Commission

The Commission was established to examine current and potential reproductive technologies, considering the social, ethical, health, legal, and economic implications of use of these technologies. In particular, it was asked to examine the implications for women's reproductive health and well-being; the causes, treatment and prevention of male and female infertility; assisted conception treatments; social and legal arrangements related to reproduction; embryo research; sex selection; genetic alteration; and the use of fetal tissue. The Commission has carried out its task and has recommended the policies, structures, legislation and safeguards it finds necessary to protect both the public interest, and the interests of individual Canadians.

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The Commission came to its recommendations after consulting very widely. It is the first body on these issues that has been able to go directly to citizens for their participation, and in all more than 40,000 Canadians participated. The Commission was also able to carry out a wide range of research projects in many disciplines including the social sciences, ethics, law and medicine. Based on this widely based input and evidence, the Commission then came to its recommendations regarding how to deal with new reproductive technologies with three considerations in mind. These were: a clearly specified ethical framework, a conviction that medical practice should be evidence-based, and the context of the values and attitudes of Canadians. As a result of these considerations, the Report's recommendations are feasible, principled and comprehensive in scope.

The views of Canadians were sought in a variety of ways throughout the life of the Commission. More than 550 individuals, including those representing 250 groups, took part in Public Hearings across the country, almost 500 people discussed their personal experiences in private sessions, and close to 5000 submitted their views on toll-free telephone lines. Regional roundtable discussions were held to highlight the issues specific to certain regions, such as that held with Aboriginal women in the North. Theme conferences, such as one on "The Impact of New Reproductive Technologies on Women's Reproductive Health and Well-Being," were held to allow representatives from women's and other groups to share their views with the Commission. Representatives from all levels of government, national groups representing different sectors, and international experts were consulted. In addition, the Commission consulted many groups with interests in the technologies, such as the Canadian Advisory Council on the Status of Women, the Canadian Medical Association, the Canadian Bar Association, Vanier Institute of the Family and others.

The Commission's research program included more than 300 researchers and academics, representing close to 70 disciplines and subdisciplines including the social sciences and humanities, the health sciences, law, ethics and philosophy. More than 130 original research and analytic studies examined the origins, current practices, and future implications of new reproductive technologies.

Recognizing the urgency of the issues, the Commission asked the government for permission to release some of the research data from these studies to the public in advance of the Final Report, something done by no other Royal Commission; as a result, 14 research studies have already been released to inform the public and stimulate discussion. Much groundbreaking work has been completed including:

- the first reliable estimate of the prevalence of infertility in Canada.
- extensive investigations and analysis of the historical basis and legal, social, and ethical implications of the technologies and their impact on Canadian society.
- the first comprehensive evaluation of Canada's 41 fertility programs.
- an extensive examination of the patients, practices, and referral patterns of Canada's 22 prenatal genetics programs and 64 laboratories offering genetic testing.
- the first national survey detailing with the use and handling of ova, embryo and fetal tissue in hospitals, abortion clinics and other facilities.

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Main Recommendations

In light of the evidence collected and assessed according to an ethical framework, the Commission concluded that some reproductive technologies and some uses of the technologies are unethical and contrary to the values of Canadians — they should be prohibited. Others are potentially beneficial, provided they are used ethically and responsibly. This means two things are needed: legislation to outlaw certain activities, and a system to oversee, licence and monitor other activities in this field.

The Commission recommends that some current and potential practices are so harmful and so sharply contravene Canadian ethical and social values that they should not be permitted in Canada on threat of criminal sanction. These include research involving human embryos (zygotes) directed toward development of cloning, ectogenesis, creation of animal/human hybrids, or the transfer of embryos to another species; the maturation and fertilization of eggs for implantation from human fetuses; the sale of human eggs, sperm, zygotes, embryos, fetuses or fetal tissue; acting as an intermediary for a preconception arrangement, advertising for or paying for such an arrangement. The Commission also recommends that unwanted medical treatment and other interferences, or threatened interferences, with the physical autonomy of pregnant women be recognized under the *Criminal Code* as assault.

"Legislative prohibition can set limits and can protect against certain threats to human dignity and to women's equality and freedom," said Dr. Baird. "It cannot, however, regulate day-to-day research and treatments in the field. To ensure that new reproductive technologies are only provided in a safe, ethical and accountable way within the boundaries of acceptable practice and research, we recommend the federal government establish an independent National Reproductive Technologies Commission, charged with the primary responsibility of ensuring the technologies are applied in the national public interest."

The Commission recommends the federal government establish this regulatory and licensing body, to oversee research, technologies and practices. There is a need for urgent action in a rapidly evolving technological field, for comprehensiveness and similarity of approach across the country, and for public accountability in uses of the technologies. It is the only way to ensure that the appropriate mix of resources, skills and experience is brought to dealing with the technologies in all their dimensions: ethical, social, legal, scientific and medical. "A national body is essential since the implications of use affect others and spill over into many areas of our collective life," said Dr. Baird. "We all have a stake in the kind of community we live in, that it not be one where reproductive functions and people are commodified or harmed by inappropriate use of technology."

The Commission believes national action is necessary, but not sufficient. Strong provincial and professional leadership and participation is also recommended. Mechanisms to promote participation and cooperation from all parties are outlined that would ensure that the recommended system serves the interests of all Canadians.

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The Commission recommends the NRTC be composed of 12 members, with women making up at least half the membership. Membership should also include persons knowledgeable about the interests and perspectives of those with disabilities, those who are infertile, and those who are members of minority communities. A range of expertise should be represented, including reproductive medicine, ethics, law, and social sciences. One of the roles of the Commission should be to undertake broad consultation, to further enhance public input and involvement.

"Several requirements are common to all the technologies: the need for reliable information to guide policy and practice; the need for standards and guidelines for the organization and provision of services; the need for effective means to ensure compliance to those guidelines, and the need for accountability," said Dr. Baird. "The approach we propose builds on the best standards and practices of the medical specialties involved which already are in use in some Canadian clinics. We recommend these standards be expanded, and be embodied in a licensing system."

The proposed NRTC would have five areas of regulatory responsibility in which the provision of services would be subject to compulsory licensing through five sub-committees established for that purpose. They are:

- Sperm collection, storage and distribution, and the provision of assisted insemination services.
- Assisted conception services, including egg retrieval and use.
- Prenatal diagnosis for congenital anomalies and genetic disease.
- Research involving human zygotes (embryos).
- The provision of human fetal tissue for research or other specified purposes.

Licence hearings would be public, a licence would be conditional on compliance with certain standards and conditions of licence, which are outlined in the Final Report. The major functions in these five areas of regulatory authority are as follows:

- To licence, set standards, and monitor practice in the area.
- To collect, evaluate, disseminate and store information.
- To consult, help coordinate, and facilitate intergovernmental cooperation in the area.
- To monitor future technologies and practices and set policies.

The sixth sub-committee would have primary responsibility in the field of infertility prevention. Its responsibilities would include the compilation and evaluation of data pertaining to the causes of infertility, the promotion of cooperative research efforts in Canada and internationally, and the regulatory, public education and other options for preventing or reducing the incidence of infertility.

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Implications for Canadians

With full implementation of these recommendations, a consistent country-wide system for the regulation of reproductive technologies and the provision of related services would emerge, with the following attributes:

- Assisted conception services (such as *in vitro* fertilization, assisted insemination and related infertility treatments), would be provided only by licensed facilities, with national standards of service (related to matters such as counselling, only provision of treatments shown to be effective, informed disclosure and consent, standardized calculation of success rates, and consistent record keeping) as conditions for obtaining and keeping a licence to provide these services.

- A national sperm collection and distribution system would be in place to ensure the availability of safe sperm, quarantined until donors are tested for infectious disease, for use in assisted insemination in a medical setting or in self-insemination. The system would include comprehensive confidential record keeping on donors and recipients, with non-identifying information on the donor available to the recipient and child, and personal identification kept secure and available only in court-ordered cases.

- Prenatal diagnostic services would be provided only by licensed facilities, with national standards established and monitored through the licensing system. Prenatal ultrasound and testing of pregnant women's blood for congenital anomalies or genetic disease in the fetus would be provided only through provincially licensed or mandated programs. The structure would assure Canadians that genetic knowledge is applied in human reproduction in an accountable way and within acceptable limits — for example, not being used for purposes of sex selection or to identify other attributes without relevance to a serious disorder.

- A mechanism would be in place to facilitate multicentre trials and other research needed to assess the short- and long-term safety and effectiveness of reproductive technologies. It would promote interprovincial co-operation to mount the large-scale research projects needed to provide information on which to base health care service provision and resource allocation decisions. Once their risks and effectiveness had been assessed, any approved infertility treatment and prenatal diagnostic services would be provided solely through provincial health care systems. A condition of licensing would be that the service not be commercial or for profit.

- Other treatments or procedures would be provided only in the context of research, with fully informed participation by volunteer research subjects and with rigorous protections for them. Annual reporting to the National Commission by licensed facilities would provide data that would allow evaluation of any long-term effect of treatments on the health of women or on their children.

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- Any provision of fetal tissue for research, such as that into the use of fetal tissue for the treatment of diseases such as Parkinson Disease would be licensed, so that it is used only in an accountable and ethical way according to detailed guidelines, with permission for tissue use obtained separately from and subsequent to the decision to terminate a pregnancy.

- Any human embryo (zygote) research would be conducted only in licensed facilities, so that such research is carried out in an accountable and ethical way and in accordance with detailed guidelines, including limitations on the purposes for which research can be undertaken, and permitted only during the 14 days immediately following fertilization.

- A focal point for national action would be in place to support and encourage infertility prevention initiatives, to foster consultation and co-ordination of efforts among the many sectors involved, and to promote public education and research in Canada and internationally on the risk factors for and prevention of infertility, and to foster public discussion and input.

- Canada would have a visible and continuing forum to monitor developments, promote public discussion, and develop public policy advice on the use of assisted reproductive technologies, prenatal diagnostic technologies, embryo research, research involving the use of fetal tissue, and other rapidly evolving or emerging technologies.

The Commission believes strongly that the implementation of the recommendations contained in the final report must be an immediate federal priority. "We believe that the establishment of an ongoing National Reproductive Technologies Commission presents the only feasible response to the clearly demonstrated need and justified public demand for coherent, effective, and appropriate national limitation and regulation of new reproductive technologies," said Dr. Baird. "Canada's response to the technologies cannot be delayed or fragmented by the existing web of jurisdictional and administrative arrangements. To allow this would be, in Commissioners' views, a mistake of enormous proportions. The issues are important, they are growing as uses of technology increase and expand, and individual people and our society will be harmed unless limits are put in place, and unless we ensure that social policy, not the market, determines further use and development."

The Commission was established in October 1989, and submitted its Final Report to the government on November 15, 1993. The two-volume report embodies the main findings, and the reasoning and analysis followed in coming to the 293 recommendations made by the Commission. It is available from the Canada Communications Group and many Canadian booksellers. The Report is supported by 15 volumes of detailed research data and findings. A synopsis of the Report is available on audio tape, cassette or large-print format.

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(For more information, contact the Communications Department at (613) 957-0597. For copies of the Report, call Canada Communications Group Publishing at (819) 956-4802. This material is also available on audio tape, cassette or large-print format.)

MANDATE

(as announced by the federal government October 25, 1989)

The **Royal Commission on New Reproductive Technologies** will be established under Part I of the *Inquiries Act* and will inquire into and report on current and potential medical and scientific developments related to new reproductive technologies, considering in particular their social, ethical, health, research, legal and economic implications and the public interest, recommending what policies and safeguards should be applied.

The Commission will examine in particular:

a) implications of new reproductive technologies for women's reproductive health and well-being;

b) the causes, treatment and prevention of male and female infertility;

c) reversals of sterilization procedures, artificial insemination, *in vitro* fertilization, embryo transfer, prenatal screening and diagnostic techniques, genetic manipulation and therapeutic interventions to correct genetic anomalies, sex selection techniques, embryo experimentation and fetal tissue transplants;

d) social and legal arrangements, such as surrogate childbearing, judicial interventions during gestation and birth, and "ownership" of ova, sperm, embryos and fetal tissue;

e) the status and rights of people using or contributing to reproductive services, such as access to procedures, "rights" to parenthood, informed consent, status of gamete donors and confidentiality, and the impact of these services on all concerned parties, particularly the children; and,

f) the economic ramifications of these technologies, such as the commercial marketing of ova, sperm and embryos, the application of patent law, and the funding of research and procedures including infertility treatment.

BIOGRAPHICAL NOTES ON COMMISSIONERS

Dr. Patricia A. Baird was appointed by the Prime Minister in October 1989 to head the Royal Commission on New Reproductive Technologies. She is a pediatrician, receiving her medical degrees from McGill University, and her fellowship in pediatrics in 1968. She later specialized in human genetics, and was extensively involved in setting up services for parents and Children with genetic diseases, including outreach services to the Interior of British Columbia. Dr. Baird joined the Faculty of Medicine at the University of British Columbia in 1968, and was appointed acting head of the Department of Medical Genetics in 1978. She became Head of the Department the following year and held that position until 1989.

The author of more than 250 papers and abstracts, Dr. Baird's research work has focussed on the distribution and natural history of birth defects and genetic diseases in the population. Much of her work has focussed on bioethical questions, including the issues of allocation of resources and delivery of health services. She was also a consultant to the adoption placement section of the B.C. Department of Human Resources.

Dr. Baird was appointed Vice-President of the Canadian Institute for Advanced Research in February 1991. She is or has been a member of several national committees, among them the National Advisory Board on Science and Technology (and the Subcommittee on the Participation of Women in Science and Technology), chaired by the Prime Minister, the Standing Committee on Ethics in Experimentation of the Medical Research Council of Canada, the Research Council of the Canadian Institute for Advanced Research and the Ethics Panel of the International Pediatric Association. She was one of the three official Canadian delegates to the 5th International Bioethics G-7 Summit Conference in Rome (1988), is on the Science World Advisory Committee, and was Co-Chair of the National Forum of Science & Technology Councils held in Victoria, B.C. in 1991.

She has served in various capacities on a number of community boards and professional associations, including the B.C. Cancer Research Centre, B.C. Association for the Mentally Retarded, Canadian Club, B.C. Medical Services Foundation, Biomedical Research Centre, and Canadian Society of Academic Medicine. Dr. Baird has been honoured as the Distinguished Faculty Lecturer, Faculty of Medicine, University of B.C. (1989). She has also received the YWCA Women of Distinction Award for outstanding contributions to health and education (1988) and was the Sir Ronald Grieve lecturer at the 12th International Conference of Voluntary Health Service Funds (1988).

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Grace Marion Jantzen, of London, England, holds doctorates in Philosophy and Theology. She is currently a Reader in Philosophy of Religion, Department of Theology and Religious Studies, King's College, University of London. Doctor Jantzen has previously taught at several universities including the Universities of Calgary and British Columbia in Canada, and the University of Oxford in England. She is the author of many publications and articles in the Philosophy of Religion and has participated in international lecture tours and series.

She is a member of the Royal Institute of Philosophy, the Aristotelian Society, the Society for the Study of Theology, the European and British Associations of Philosophers of Religion, Women in Theology and the London Society for the Study of Religion.

She studied at the University of Saskatchewan, from which she holds a Bachelor of Arts, Honours Certificate and Master of Arts in Philosophy. She obtained her Ph.D. (Philosophy) at the University of Calgary and her D. Phil. (Theology) at the University of Oxford.

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Bartha Maria Knoppers is an Associate Professor, Faculty of Law at the University of Montreal. She is a Research Associate with the Centre de Recherche en Droit public de l'Université de Montréal and with the University of Quebec in Chicoutimi (SOREP). She has extensive and varied experience in both the research and academic fields of her specialization.

She specializes in the fields of genetics, ethics and law, children and the law, and family law, and has been the recipient of many awards. She has recently served as Legal Advisor to the working group of the World Health Organization on Advances in Reproductive Technology and to the Law Reform Commission of Canada. She has also written numerous articles and papers for medical and law journals, as well as being the author of five books relating specifically to the areas under the mandate of the Royal Commission.

Dr. Knoppers studied at McMaster University where she obtained a B.A. in French and English Literature in 1972. She received her M.A. in Comparative Literature in 1974 at the University of Alberta, an LL.B. in Common Law in 1978 at McGill University, a D.E.A. (Diplôme d'études approfondies) in 1979 at the University of Paris I., a B.C.L. in Civil Law at McGill University in 1981, and a D.L.S. (Diploma in Legal Studies) also in 1981 at Trinity College, Cambridge University (England). In 1985, she was admitted to the Bar in Quebec and later that same year received her Doctor of Laws at the University of Paris I, Panthéon-Sorbonne. Her doctoral thesis examined the comparative law on the responsibility of physicians and reproductive technologies.

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Susan E.M. McCutcheon graduated from Victoria College, University of Toronto, received her Secondary School Teaching Certificate from the Ontario College of Education and taught history for the North York Board of Education for 10 years.

She served as President of Jessie's Centre for Teenagers (1984-86), Vice-Chair of the Metro Action Committee on Public Violence Against Women and Children (METRAC) (1985-89), and Chair of the Palliative Care Foundation of Canada (1987-89). She was Vice-Chair (1983-86) and Chair (1986-89) of the Board of Directors of Women's College Hospital.

Ms. McCutcheon was a member of the Governing Council, University of Toronto (1989-91) and its Business Board (1988-90).

She currently holds several corporate directorships.

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Suzanne Rozell Scorsone is currently the Director, Office of Catholic Family Life, Archdiocese of Toronto, a position she has held since 1981. She is the spokesperson for the Archdiocese of Toronto on family and women's issues. She is a panellist on *The Stiller Report* with Vision T.V. and an author of various articles and publications.

Dr. Scorsone received her Ph.D. and M.A. in Social Anthropology from the University of Toronto. She obtained a B.A. in Anthropology from the University of Arizona. She is currently pursuing her studies, on a part-time basis, in the M.A. program, Historical Theology, at the University of St. Michael's College, in Toronto.

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December 1991