

DELIVERY DELAYED.
THE ROYAL COMMISSION ON NEW REPRODUCTIVE TECHNOLOGIES.

by

JUDY G. MORRISON
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APPROVAL

NAME: Judy G. Morrison
DEGREE: Master of Arts
TITLE OF THESIS: Delivery Delayed. The Royal Commission on
New Reproductive Technologies.
Examining Committee:
Chair: Peggy Meyer

Marjorie Griffin Cohen
Professor
Senior Supervisor

Patrick J. Smith
Associate Professor
Second Supervisor

Marilyn MacDonald
External Examiner
Department of Women's Studies
Simon Fraser University

Date Approved 5 June 1997

ABSTRACT

Over the past twenty years, Canadians have witnessed a veritable explosion in technological interventions into the creation of life through human reproductive and genetic technologies. What has failed to come with these new ways of making babies are ways to effectively deal with the myriad of social, legal, ethical, and political perplexities that mire these profitable proliferating fields. Instead, the fascination with how far the scientific and technological boundaries can be pressed has obscured the need for critical, citizen-based assessments of the technologies themselves and how they are developed.

Reproductive and genetic technologies are developed by the biomedical industrial complex, predominantly made up of biomedical researchers and practitioners, industrial groups including pharmaceutical companies, and the state. These groups must mutually rely upon each other for resources, forming a powerful community which not only serves to ensure reproductive and genetic technologies continue to be developed but also tends to exclude the very groups who stand to be directly - and adversely - affected by the use of these technologies.

Women have been called the "test-sites" for many of the reproductive and genetic technologies, although the techniques affect many more segments of society, particularly in the case of genetic engineering. In Canada, some feminist groups became critical of the interests driving the technologies, which seemed to be radically divergent from their own. They called for a mechanism for both assessment and subsequent regulation of the technologies. In response, the Canadian federal government created the Royal Commission on New Reproductive Technologies.

In this thesis I explore the groups that control the development and delivery of reproductive and genetic technologies. I posit that these powerful interests are not capable of conducting adequate assessments of the technologies of their own creation, nor is it reasonable to assume that they are able to regulate themselves. The Royal Commission offered great hope for a truly democratic debate about the technologies and how to best

regulate them. It was riddled instead with controversy, delays in reporting and suspicion that it was dominated by the very interests which were in need of regulation.

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For some, the title of this study "Delivery Delayed" rings true with respect to the Royal Commission, the powers involved in the creation of the technologies and possible alternatives to how we grapple with the reproductive and genetic technologies. To others, the title is most appropriate to the author herself, for truly, the delivery of this thesis has been a long time coming. There are many people who have helped me get here and to them I extend my heart-felt thanks.

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CHAPTER ONE

INTRODUCTION: REPRODUCTIVE AND GENETIC TECHNOLOGIES IN THE CANADIAN CONTEXT

I. Introduction

The past two or three decades have produced what many have termed a new revolution generated by technological change. Included in this revolution are developments in human reproduction. National and international headlines about 'brave new babies,' or 'techno-genesis' appear regularly. The recent cloning of sheep has raised the spectre of similar applications to humans.¹ As a society, our discussions about the implications of these technologies have lagged dangerously behind the development of them. Without coherent regulations arrived at through democratic means, applications such as human cloning may well become a part of science instead of science fiction. What was formerly considered to be unthinkable may be assumed probable.

In Canada, there exists little legislation which effectively governs reproductive and genetic engineering as it is practised upon humans. The most recent attempt, the Human Reproductive and Genetic Technologies Act (Bill C-47),² recently died on the order paper when the Liberal government called a federal election. Had this bill passed, it would have criminalized thirteen human reproductive and genetic technologies, including the cloning of human embryos. It also would have marked the beginning of essential and enforceable federal action to regulate these technologies based on the recommendations of a national inquiry of these issues.³

The Royal Commission on New Reproductive Technologies was a state-sponsored inquiry created in 1989 in response to the demands for a public debate about, and

¹ Gina Kolata, "Adult mammal cloned successfully," Globe and Mail, (Toronto), Feb. 24, 1997, A1, A11. Stephen Strauss, "Hello Dolly, it's so scary to see you," Globe and Mail, (Toronto), March 1, 1997, A5.

² Minister of Health, Canada, *Bill C-47, An Act respecting human reproductive technologies and commercial transactions relating to human reproduction*, First Reading, June 14, 1996. The House of Commons of Canada, Ottawa: Canada Communication Group, 1996.

³ Bill C-47 was to be the second phase in the management of reproductive and genetic technologies in humans. The third phase was an entire regulatory regime to deal with all technologies in this area. See Government of

subsequent regulation of the new technologies as applied to humans. Up to the time of the Commission's creation, the development of reproductive and genetic technologies had been driven by particular interests which were not positioned to properly consider the many serious and far-reaching ethical, moral and other societal questions. These interests I have broadly termed the biomedical industrial complex. The most prominent actors in this policy complex or community include biomedical doctors and researchers, industry groups, and the state. This exclusive complex is comprised of groups who have a mutual interest in the continued development of technological applications in humans. Their power translates into wide societal privilege which has as its starting point the ability to define and create knowledge. By controlling what constitutes knowledge, one has the ability to continually define both the questions and subsequent solutions. There has been a tendency to push the scientific margins without an adequate understanding or even questioning of the consequences.

The conception, development and delivery of science and its applications as technology and engineering are seen as neutral or progressive by many in society, particularly those who develop and offer these technologies. Science and technology⁴ are dominant sources of knowledge in western societies. Science and technology are better described as specific (and not the only possible) interpretations of our world:

At present, some social critics of science argue that, much like writers, all scientists can do is tell stories, and that, as in literature, these stories are grounded in social and political realities of our time ... scientists do not simply go out and look at nature or hold up a mirror to it. They define and isolate the pieces of nature they choose to look at and, in so doing, change them by removing them from their natural context.⁵

Canada, New Reproductive and Genetic Technologies: Setting Boundaries, Enhancing Health, Ottawa: Minister of Supply and Services, 1996.

⁴ Following various authors, I believe that science and technology are sufficiently inter-connected that they must be referred to together and cannot be adequately analyzed apart from each other. For further discussion of this point, see, for example, Ursula Franklin, The Real World of Technology (CBC Massey Lectures (Montreal: CBC Enterprises, 1990)), Ruth Hubbard, The Politics of Women's Biology, (London: Rutgers University Press, 1990), Hilary Rose, Love, Power and Knowledge (Bloomington: Indiana University Press, 1994), Maureen McNeil, Ian Varcoe, Steven Yearley, eds., The New Reproductive Technologies, (Houndmills: MacMillan, 1990).

⁵ Hubbard, The Politics of Women's Biology, p. 4.

The identity of the scientist is equally important when choices are made about how science is practiced and applied. The scientific method tends to produce knowledge about an "experimentally manipulated nature," which is not the same as understanding nature itself.⁶

Underlying reproductive and genetic science and technologies are strong and varied social forces which shape them. Some of these interests include: the desire to control and alter nature, including human life; the belief that technology can and should universally be used to provide solutions to social and health problems; and, the motivation to generate profit. A quick survey of commentary describing the recent sheep cloning, not only by the media but also by the professionals that were responsible for this work, provides some insight into these forces. The lamb was described as "immaculately conceived" or as a "pharm animal." Owners of the highly profitable Alta Genetics in Alberta described how cloning would be done on only the "truly superior animals" that are known to be "the top producers."⁷

Reproductive and genetic technologies are designed to control or manipulate organisms. They represent a move away from understanding biological organisms to aggressively utilizing them. Proponents of these technologies would have us believe they offer an expanded array of choices or opportunities. What they do not tell the public is who the opportunities are for and at what cost. "Products" like Dolly the cloned lambs, were made possible by the deliberate collaboration of scientific researchers, governmental bodies and industry. These groups have continually failed to incorporate the interests of broader society (i.e. basic or adequate, and preventative health-care) into their decision-making with respect to the technologies. While there are people who may benefit from the use of some of these technologies, of particular importance are those numerous groups who stand to lose and be harmed by poorly-tested, poorly-conceived uses of technologies. Further, due

⁶ Elisabeth Abergel, "Conceptual Foundations of Genetics and the Engineering Ideal of Molecular Biology," Unpublished Manuscript, (Toronto: York University, 1995), pp. 45-6.
⁷ Strauss, "Hello Dolly, it's so scary to see you," A5.

to some of the irrevocable changes, (some of which are still unknown), all Canadian society stands to be negatively affected by some of these technologies.

One of the great opportunities is for profit, be it for the researcher who develops the idea/ 'product,' the government who either enables or actively promotes it, or the industry that funds and subsequently markets it. This has been described as a "science-industrial push."⁸

Whether cloning animals (including humans) or helping couples overcome infertility, biotechnology may have more to do with political and economic choices than with ethics, public interest or need. This has been seen in the use of atomic science, or the use of particular iatrogenic pharmaceuticals, where technologies were "pushed" ahead only to create major problems. By devising more inclusive, democratic systems of decision-making and regulation, such disasters may have been averted, or at least reduced. Now more than ever, the power structures must be substantively broadened to incorporate the perspectives of not just those who stand to benefit from these technologies, but also all those who stand to be affected by them.

It has been eight years since the Royal Commission on New Reproductive Technologies was first created by the Progressive Conservative Government of Canada in 1989. The technologies themselves continue to be developed and make international headlines at a relentless rate. Canada remains one of the only industrialized countries without legislation governing these technologies that can no longer be called "new."

This thesis investigates and analyzes the attempt by the Canadian government to foster a public debate about human reproductive and genetic technologies. Such a national discussion was seen to be necessary given the apparent technological imperative that seemed to have little regard for social implications. In fact, critics were concerned that the technologies were being controlled by powerful interests who could best benefit by

⁸ Maureen Press Merkur, "The Biotechnology Council of Ontario and New Reproductive Technology," in Maureen Press Merkur and Mark S. Winfield, Enabling Biotechnology? An Analysis of the Report of the Biotechnology Council of Ontario (Toronto: CIEI AP, 1995), Appendix 1, p. 7.

ensuring few rules did exist. The Royal Commission on New Reproductive Technologies offered the hope for a truly democratic discussion. Many who were concerned about the technologies hoped that the Royal Commission would translate directly and immediately into the creation of a regulatory regime to govern these contentious technologies.

II. Problems with and Debate about Human Reproductive and Genetic Technologies

If you want to have an optimum baby just like you'd want to have an optimum automobile, you will have to transform the process of generation closer and closer to one of manufacture. The cost of this will be that the object upon which you are working, admittedly to make it perfect, will cease to be something you have reverence for itself. Whatever goodness it will be that product of your own will and doing. And there will be certain necessary dehumanization in the result, no matter how good the product is."

Observers of biotechnology have noted that if you want a glimpse into what is in store for human applications in this area, you need only look to the barnyard for clues. Human reproductive and genetic technologies have sprung directly from experimentation and applications in the agricultural sector. While the sites of experimentation and the "products" are different, the processes, the motivations and the dangers are remarkably similar.

The applications of biotechnology in humans raise new - and old - ethical questions. Increasingly such technologies allow the conception of life outside of the human body. Some medically-mediated reproductive techniques can create up to five parents of a single child. The woman and man who supply the gametes (eggs and sperm), the woman who carries the fetus to term and the person or couple who raise the child, post-delivery.¹⁰ Other techniques generate multiple embryos outside the body which can be "diagnosed," allowing decisions to be made about which embryos to keep and which to discard. Increasingly health care is being reduced from a broad spectrum which includes physical, environmental and social understandings to one of "geneticization" where one's health is reduced to one's

¹⁰ Leon Kass, Toward a More Natural Science. As cited in Press Merkur, "The Biotechnology Council of Ontario and New Reproductive Technology," p. 1.

genetic traits.¹¹ The cloning of sheep and other mammals necessarily raises questions about the cloning of humans. Such arrangements and techniques raise questions not simply about health and safety, but they raise social and ethical dilemmas which the biomedical industrial complex can not autonomously solve through mechanisms such as self-regulation.

Debate about the use of these technologies is wide and varied. Some support the technologies and view them as progressive. These people may generally support increased access to any techniques that assist women and men to have babies. Others object vehemently to them, and view them as regressive and dangerous. Still others are concerned about the trajectory these technologies seem to be on. While a small minority of Canadians come from a formal scientific or technological background, almost everyone in Canadian society has some opinion on reproductive and genetic technologies. And while groups tend to lean a particular way, or to highlight certain aspects of the technologies as important, it must be underscored that consensus does not necessarily exist within them. Similarly, while I may frequently refer to the technologies collectively, a critical and individual assessment of each one is necessary.

In this thesis I investigate a number of questionable assumptions about reproductive and genetic technologies. These assumptions include: the notion that science and technology are neutral and by extension, that the creators are similarly free of bias in the work they do; that reproductive and genetic technologies offer (the best) hope for people who are infertile; that the existing technologies expand women's reproductive choices or options; that the technologies are safe and appropriately tested; and, that the state will or can take action to protect societal interests.

¹¹ For further on this, see Patricia M. Lee, A New Procreation Story: The Contested Domain of in vitro Fertilization in British Columbia, Ph.D. Thesis, (Vancouver: University of British Columbia, 1995).

Abby Lippman, "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities," American Journal of Law and Medicine, Vol. 17, 1&2 (1991), p. 19, and Lippman, "Worrying and Worrying About The Geneticization of Reproduction and Health," in Gwynne Basen et al. eds., Misconceptions: The Social Construction of Choice and The New Reproductive and Genetic Technologies, Vol. 1, (Hull: Voyageur, 1993), p.

What began as a limited number of relatively uncomplicated techniques aimed at assisting fertile and infertile couples, has grown to include all sorts of biomedical interventions to aid a woman in preventing birth or in conceiving. The medical profession has defined reproductive technologies in the following way:

...[C]overing anything to do with the manipulation of gametes (eggs or sperm) or the fetus, for whatever purpose, from conception other than by sexual union, to treatment of disease in utero, to the ultimate manufacture of a human being to exact specifications ... Thus the earliest procedure ... is artificial insemination; next ... artificial fertilisation ... next artificial implantation ... in the future extracorporeal gestation (artificial womb) ... and finally, what is meant by reproductive engineering, the production - or better, the biological manufacture - of a human being to desired specification.¹²

Strictly speaking, reproductive technologies in humans are those techniques which are involved in the conception and subsequent delivery of children. Broadly, they range from: contraceptive technologies, which are designed to prevent pregnancy (birth control methods like the Pill, intrauterine devices, sterilization, Depo Provera, Norplant, etc.); fetal technologies, which are used in attempts to assess fetal health (ultrasound, amniocentesis, chorionic villus sampling); birthing technologies, used during childbirth (techniques and drugs that induce or monitor labour); conceptive technologies, used to help create pregnancy (including the use of fertility drugs; reversal of sterilization procedures; assisted/donor insemination; *in vitro* fertilization or "test tube babies," "surrogacy," etc.) and genetic engineering, used to assess or alter the genetic material (cloning, pre-natal diagnosis, etc.).¹³

As in other applications of biotechnology, in human applications there is a need for critical assessment of the technologies, beyond that done by the largely self-regulating biomedical industry. As will be documented in this thesis, the actions on the part of the Canadian government have fallen short in this regard, allowing industry to continue to take the lead in determining what is efficacious.

¹² JAMA, "Genetic Engineering Reprise," Journal of American Medical Association Vol. 10, No. 220 (1972), pp 1356.

¹³ While some of these techniques will be further defined in subsequent chapters, each of them have constituted entire volumes. For brief definitions of these and other technical terms used in this study, consult the glossary in Appendix 1 at the end of this thesis.

While medical science has provided many important findings that have served to benefit various communities, it is inappropriate to conclude that the same science is unbiased or value-free. As with scientific knowledge in general, medical knowledge comes from asking particular questions based on who the 'asker' is. It is unlikely that medical researchers and practitioners have malevolent intent in the practicing of medicine, but their questions are motivated by their values. Nor is it fair to say that all medical knowledge is illegitimate, "bad" or harmful.

Medical research is increasingly subsumed under the less virtuous umbrella of the pharmaceutical and medical devices industries. These latter groups provide research funding. The boundaries between profit-motivated research and development and pure scientific and medical research have become blurred, if not completely eradicated. For example, Networks of Centres of Excellence are government-conceived partnerships between itself, industry and research centres (primarily Universities, but also including research-hospitals) across Canada. They have created a situation where independent researchers are explicitly encouraged to market their ideas. "Increasingly medical and scientific research is being initiated and evaluated to meet the needs of the marketplace. Research which does not correspond to the corporate criteria of profitability is becoming increasingly underfunded and marginalized."¹⁴

In reproductive and genetic technologies there are several examples of high-tech, high-cost "solutions" that have been pursued *at the expense* of safe, preventative or low-technological alternatives. The most frequently cited example of this is *in vitro* fertilization (IVF, literally "in glass"). This technology has been used in humans since 1978, with the first IVF birth of Louise Brown. Since that time, *in vitro* fertilization continues to be the dominant technology utilized to overcome all kinds of infertility (including cases of male infertility, where a fertile woman is subjected to IVF for her partner's infertility.¹⁵) It also

¹⁴ Press Merkur, "The Biotechnology Council of Ontario and New Reproductive Technology," p. 6.

¹⁵ This has been well documented. See, for example, Andrea L. Bonnickson, *In Vitro Fertilization: Building Policy From Laboratories to Legislatures*, (New York: Columbia University Press, 1989), pp. 20-2; Renate Klein, ed.

continues to have a poor success rate of between 10 to 15%, although many clinics are currently claiming far higher rates of success, without adequately defining what their indicators are. Both the World Health Organization¹⁶ and the Canadian Royal Commission on New Reproductive Technologies¹⁷ continue to deem *in vitro* fertilization experimental only, because there is significant doubt about associated risks and effects. Critics have questioned the use of such high-risk, lowly-effective technologies, particularly when they come at the expense of cheaper, safer alternatives.¹⁸

The persistent use of *in vitro* fertilization is motivated primarily by profit.¹⁹ The fertility drugs used in conjunction with this technique yield millions of dollars world-wide for pharmaceutical companies. Indeed, the entire market of pharmaceuticals in Canada and internationally is one of the fastest growing and most profitable manufacturing industries in the world. Profits are estimated at \$300 billion per year internationally and projected to reach over \$500 billion by the year 2000.²⁰ In Canada, such profits are protected by legislation, such as the twenty year drug patent protection passed by the Federal Government in the late 1980s.

This situation is all the more sadly ironic given that many who search for a means of bypassing their infertility, do so due to past failures of reproductive technologies. For example, the use of the Dalkon Shield, an intrauterine device used to prevent pregnancy, was responsible for the death of several women and rendered countless others infertile

Infertility: Women Speak Out About Their Experiences With Reproductive Medicine (London: Pandora Press, 1989), pp. 253, 4; Christine Overall, Human Reproduction: Principles, Practices, Policies (Toronto: Oxford University Press, 1993), pp. 139-156.

¹⁶ World Health Organization, Regional Office of Europe, Summary Report: Consultation of the Place of In Vitro Fertilization in Infertility Care, Copenhagen, June 18-22, 1990 (Geneva: World Health Organization, 1990).

¹⁷ Royal Commission on New Reproductive Technologies, Proceed with Care: The Final Report of the Royal Commission on New Reproductive Technologies, Vol. 1 (Ottawa: Minister of Government Services Canada, 1993), p. 526.

¹⁸ Bonnicksen, In Vitro Fertilization, pp. 11-24; Leon R. Kass, Toward a More Natural Science (New York: Free Press, 1985).

¹⁹ Certainly there exists demand for access to IVF, arguably due to the paucity of alternatives.

²⁰ Report of the Health Industries Advisory Committee to the Minister of Health, "Healthy and Wealthy," (March, 1994).

before it was finally pulled from the market.²¹ The use of diethylstilbestrol, DES, was prescribed to prevent miscarriage and was later found to cause uterine cancer and infertility.²² Other factors (not strictly reproductive and genetic technologies) which could have been ameliorated have contributed to infertility. Included in these are environmental or workplace hazards, underdiagnosed sexually transmitted diseases and pelvic inflammatory diseases - many of which are preventable.²³

It is assumed that technologies, such as *in vitro* fertilization, actually expand women's reproductive choices - a point which has been hotly debated both in the media and within the women's movement. Women often undergo tremendous pressure to have children.²⁴ This is a socially reinforced pressure which serves to support the use of any technology which purports to aid conception. What has evolved is the situation where the technologies that receive funding may benefit some women, but as demonstrated above, are primarily created to benefit others who will never directly use the technology itself (i.e. pharmaceutical industries, some infertile men, etc.) It is unclear that reproductive technologies even benefit those women who walk away with a child. All too often, they have a history of providing more access and power to medical researchers to fulfill their objectives while limiting women's reproductive autonomy. Lesley Brown, the mother of Louise Brown, was forced to sign a consent form stating she would abort the IVF fetus if the doctors felt it was warranted. This type of control, at the expense of women's rights, is

²¹ Mark Downie and Tracy Johnston, "A Case of Corporate Malpractice and the Dalkon Shield," in Claudia Dretfus, ed., Seizing Our Bodies (New York: Vintage, 1978), pp. 86-104.

²² Harriet Simand, "1938-1988: Fifty Years of DES - Fifty Years Too Many," in Christine Overall, ed., The Future of Human Reproduction, (Toronto: The Women's Press, 1989), pp. 95-104.

²³ See for example: Joan E. Bertin, "Women's Health and Women's Rights: Reproductive Health Hazards in the Workplace," in Kathryn Strother Ratchiff, ed., Healing Technology: Feminist Perspectives (Ann Arbor: University of Michigan Press, 1989), pp. 289-304; Adele Clarke, "Subtle Forms of Sterilization: Abuse - A Reproductive Rights Analysis" in Rita Arditti et al., eds., Test Tube Women: What Future for Motherhood? (London: Pandora Press, 1989), pp. 188-212; Lin Nelson, "Women's Lives against the Industrial Chemical Landscape: Environmental Health and the Health of the Environment," in Ratchiff, ed., Healing Technology, pp. 347-370.

²⁴ See, for example, Klein, Infertility; Jan Rehner, Infertility: Old Myths, New Meanings (Toronto: Second Story Press, 1989); Linda S. Williams, But What Will They Mean For Women? Feminist Concerns About the New Reproductive Technologies (Toronto: CRIAW, 1986); and Williams "No Relief Until the End: The Physical and Emotional Costs of In Vitro Fertilization," in Overall, ed., The Future of Human Reproduction, pp. 120-138.

not far removed from a recent case in Winnipeg where a woman was forced into a drug program in order to safeguard the health of her fetus.²⁵

From this first successful assisted conception, the new technologies and genetic screening have together offered unprecedented powers to biomedicine about who is to mother and which foetus is to be permitted to survive. Such a fusion of powers was symbolized in the agreement that Lesley Brown was required to sign as a condition of her being treated with the new experimental techniques, that she would have an abortion if the foetus was abnormal. The year 1978 was an important one for the Petri dish, patriarchal power and the private market.²⁶

Some fertility drugs have been tenuously linked to cancer; at very least, they have been inadequately tested. Rather than having an array of technologies that are created for the benefit of women, many are poorly tested and limit women's options. The cost alone of IVF is prohibitive to many women and couples. Another prohibition is that clinics have denied access to lesbians, single women, women with disabilities, or others deemed by clinic practitioners to be inappropriate as mothers.²⁷ Surely this is not an expansion of options for women.

III. The Solution: The Royal Commission on New Reproductive Technologies

In Canada, as elsewhere in the world, those who govern are caught in the middle of the debate about reproductive technologies. Which technologies should be permitted? Which will be covered under Medicare? Which ones should be banned? How can they be regulated? These and other questions of governance have been posed with increasing urgency by practitioners offering the technologies, researchers, people who want access to the technologies, and people who want some of them banned. And while the groups

²⁵ Brian Laghi, "Abuse care ordered to save fetus," Globe and Mail, (Toronto) August 7, 1996, A1, 8; Canadian Press, "Manitoba judge to rule on protection of fetus," Globe and Mail, (Toronto), August 3, 1996, A3.

²⁶ Rose, Love, Power and Knowledge, p. 177.

²⁷ See for example, M.A. Coffee, "Of Father Born: A Lesbian Feminist Critique of the Ontario Law Reform Commission Recommendations on Artificial Insemination" Canadian Journal of Women and the Law, Vol. 1, No. 2, (1986), pp. 424-433; Canadian Disability Rights Council and Disabled Womens Network Canada, Four Discussion Papers on New Reproductive Technologies, September, 1991; Margaret Denike, "Normalizing Lesbian Mothers: Thoughts on the Royal Commission's Recommendations on Donor Insemination," in Reproductive Rights, Reproductive Wrongs Conference Proceedings (Victoria, Centre for Sustainable Regional Development, 1994), pp. 23-29.

themselves have differing opinions with respect to the technologies, they all tend to agree that there is a need to determine what will be permitted and how it will be legislated.

I understand reproductive and genetic technologies to be driven, and delayed, by specific powerful groups because of their shared and vested interests in seeing the continued proliferation of the technologies. The medical profession has the ability to alter, control or literally delay delivery of a baby through technical interventions. Biomedical industries, primarily pharmaceutical transnational corporations, are able to control the direction of the technologies by proffering or denying much-needed funding. Governments are able to enable or delay the technologies through funding, legislation, regulation or a lack thereof.

My interest in this topic is driven by the understanding that legislation and regulation was and is needed in the area of reproductive and genetic technologies in humans and tangentially in the entire area of biotechnology. For the Canadian government to have stood by and allowed the technologies to proliferate is an explicit and unacceptable endorsement of the current corporate marketing and industrialization of life through under- or de-regulation. The process of a royal commission offered some hope that the government of the day was truly prepared to consult broadly and act to better regulate these technologies in the public's interest.

An understanding of why this Royal Commission failed must be preceded by a discussion of why such an investigation was necessary. In chapter two, this thesis begins with questions about the social structures which underlie the technologies, refuting the notion that science and technology are somehow innocent and free of bias. It is precisely because those responsible for creating the reproductive and genetic technologies are not neutral, but have significant interest in the proliferation of them, that the technologies have developed in problematic, even dangerous ways. Further, those responsible for the development and delivery of the technologies have *de facto* become the ones to make critical and broad decisions about which technologies are developed and to whom they are offered.

They have become the arbitrators and ethical decision-makers, even though they are precisely the wrong groups of people to be making such assessments (in terms of conflicts of interest or proper arm's-length regulation.) In chapter three I have selected examples of reproductive and genetic technologies which illustrate some of these social, ethical and health concerns that were developing which prompted the call for a more broadly inclusive investigation.

In chapter four, I outline the mechanism which was utilized for this public investigation, the royal commission. The call for a Royal Commission on New Reproductive Technologies in the mid-1980's was a call for a broad, socially-inclusive investigation of the relative interests and assumptions underlying these technologies with the ultimate purpose of creating the much needed rules. While certainly nobody was expecting a social consensus on all of the issues, most were hopeful that the government would act decisively to protect not just consumer interests²⁸ but collective public interests which had been on a continual collision course with market interests. I chronicle the history of this particular Commission and demonstrate how from its inception this was an inquiry of unprecedented governmental involvement, to the detriment of the process itself and final outcomes.

Chapter five and six present analysis of the Royal Commission on New Reproductive Technologies and the outcomes. In order to do this I rely extensively upon federal court documents from a case that was filed against the Royal Commission Chair, Dr. Patricia Baird, and the Federal Government by four of the original seven Commissioners. An analysis of these documents how the interests of the powerful groups responsible for creating the reproductive and genetic technologies and the need for a royal commission in the first place, in fact prevailed in the work of the inquiry itself and subsequent outcomes.

²⁸ I use the term "consumer" a number of times in this thesis, for the lack of a better term to refer to those directly using the technologies. I acknowledge the problems with using the term "consumer." In some cases no actual

I also utilize and critically assess the documents of the Royal Commission on New Reproductive Technologies, including (but not limited to) the final report *Proceed With Care* and the companion research volumes. Other governmental reports, documents and draft legislation have also been used, in addition to media accounts. Where relevant, I have used a number of secondary sources to aid in my analysis throughout the thesis. Interviews were conducted with many directly involved with the call for an investigation of the reproductive and genetic technologies, and with some of the people who worked for or participated in the Commission itself. Many organizations contributed to the work of the Royal Commission, to some of which I have had access. Some of these and other organizations were critical of the Commission and I have been able to use correspondence or press releases to piece together some crucial segments in the history of this inquiry. Having been directly involved in the Vancouver Women's New Reproductive Technologies Coalition, the British Columbia Biotechnology Circle and a national network of feminists currently lobbying the government, I have also been able to draw on my own experiences and resources as they relate to this study.

I will look critically at the ability of Royal Commissions, both in this particular case and as a public policy tool, to offer a real potential for public debate and participatory decision-making. In fact, this Royal Commission was only a chimera of such a potential and was designed in such a way that industry was permitted to continue to determine what is good, what is acceptable, what is profitable, and in short, to mutate democracy.

CHAPTER TWO

SOCIAL STRUCTURES IN QUESTION

I. Introduction

Reproductive and genetic technologies are a direct result of scientific research. As such, they are imbued with the same tensions that underlie scientific and technological, and, by extension medical knowledge. Scientific knowledge has been and continues to be misrepresented as unbiased, objective and neutral; when in fact it bears the imprints of particular groups who have created and maintained control over what constitutes scientific knowledge. In addition, scientific knowledge is frequently endorsed and legitimized by societal elites and professionals, notably including the State. The result is particular kinds of knowledge which reflect the interests of the very groups who have created them and do not adequately reflect the interests of those groups who have been traditionally excluded.¹

Choices about what is important to an understanding of a particular problem are made by those who are practicing the scientific inquiry. When entire groups are excluded from determining what constitutes knowledge, that which results is necessarily partial and unrepresentative. Even the conception of what is to be researched or what constitutes a problem for study is inherently political in this sense.²

Reproductive and genetic technologies have been developed by particular interests which I broadly term the biomedical industrial complex. Predominant in this complex are medical practitioners and researchers, industry groups and the State. These groups have evolved towards each other through mutual interest and a reliance upon one another for their respective resources. Excluded are many groups of people who stand to be affected by

See, for example, Barbara Ehrenreich and Deirdre English, For Her Own Good (New York: Anchor Press, 1978), Sandra Harding, Whose Science? Whose Knowledge? (New York: Cornell University Press, 1991), Ted Schrecker, "The Mobilization of Bias in Closed Systems: Environmental Regulation in Canada," Journal of Business Administration Vol. 15, (1984-85), pp. 43-63.

See, for example, Ruth Bleier, Feminist Approaches to Science (New York: Teachers College Press, 1991), Helen Logino, Science as Social Knowledge: Values and Objectivity in Scientific Enquiry (Princeton: Princeton University Press, 1990), Carol Pateman, "Feminism and Democracy," in Graeme Duncan, ed., Democratic Theory and Practice (Cambridge: Cambridge University Press, 1983), pp. 204-217, Thomas W. Simon, "Feminist Science and Participatory Democracy," Philosophy and Social Action, Vol. 14, No. 2 (1988), pp. 13-22.

the outcomes or applications of the various technologies. In fact all of society stands to be affected by reproductive and genetic technologies, yet they are largely locked out of the decision-making process with respect to these technologies. The task of setting priorities, including ethical considerations, has been largely withheld from those excluded groups.

Critics of reproductive and genetic technologies have been concerned that a number of flawed assumptions were being implicitly or explicitly accepted, allowing a number of the techniques to move forward when perhaps they should be more rigorously assessed and regulated. The assessment and regulation that has occurred has been in the form of self-regulation by the medical profession (through such mechanisms as medical associations and colleges, clinical trials, etc.) It is questionable whether this profession is adequately equipped to perform assessments, particularly with respect to ethics and delivery, into techniques of its own creation.

This chapter will argue that the medical establishment is not adequately equipped to assess these technologies. In fact, some of the resultant ethical and social problems associated with reproductive and genetic technologies are due to the disproportionate power this profession has had to determine which technologies are developed and to whom they will be offered. This decision-making needs more inclusive.

II. Biomedical Research: Conceptions of Science and Technology in Society

Reproductive and genetic technologies have been and continue to be developed by biomedical researchers. Purportedly, these technologies are developed for the benefit of couples wanting to control their reproduction yet they are primarily designed for and used on/by women. In addition, the many sectors that interact to create and offer these technologies have tended to be disproportionately dominated by males.¹ As a result, reproductive and genetic technologies have become part of a broader debate with respect to the role of science and technology in society.

¹For example, Anne Witz, Professions and Patriarchy (London Routledge, 1982)

Science and technology provide people with the understanding and the tools or systems with which to function within our world. Technology is thought to be the logical and necessary application of scientific findings. However, the relationship between science and technology is not so clear or discrete. "Science and technology today have parallel or side-by-side relationships; they stimulate and utilize each other. It is more appropriate to regard science and technology as one enterprise with a spectrum of interconnected activity than to think of two fields of endeavour - science as one and science and technology as the other."⁴ Technology is understood broadly to incorporate not only the artifacts or physical objects produced from scientific research, but also the practices, norms, and what people actually do with the objects of technology.⁵

Knowledge (or the sociology of knowledge),⁶ for industrial societies is considered most legitimate when formed via the *scientific method*, the way in which one systematically forms and tests theories based on observation, experimentation and measurement. An hypothesis is made about a phenomenon and discrete parts of the physical universe are investigated to prove or disprove this hypothesis. From this investigation, generalizations about the phenomenon are made. By using the same standardized deductive, quantifiable practice, the findings of one scientist should then be reproducible by another. The gender, ethnicity, social standing and all other social factors of the scientist are said to be inconsequential to the practice of science. Science and scientific knowledge are thus understood to be objective and free of bias.

Critics of the scientific method contest the notion that scientific knowledge (including its applications) is objective or neutral. Thomas Kuhn, for example, argues in

⁴ Franklin, The Real World of Technology, p. 38.

⁵ See, Jacques Ellul, The Technological Society, trans. by John Wilkinson (New York: Vintage Books, 1967); Ursula Franklin, The Real World of Technology and Will Women Change Technology or Will Technology Change Women? (Ottawa: CRIAW/CRLE, 1985); William Leiss, Under Technology's Thumb (Montreal and Kingston: McGill-Queen's University Press, 1990); David Noble, Progress Without People (Toronto: Between the Lines, 1995); Judy Wajcman, Feminism Confronts Technology (Pennsylvania: Pennsylvania State University Press, 1991); Langdon Winner, Autonomous Technology: Techniques out of Control as a Theme in Political Thought (Cambridge, MA: The MIT Press, 1977).

his theory of scientific revolutions that scientists are members of a community trained to understand and research the world in a particular way (or paradigm) and that "revolutions" in scientific knowledge occur when, upon an accumulation of phenomena, a certain phenomenon does not fit into (or cannot be explained by) existing paradigms.

Kuhn argued in *The Structure of Scientific Revolutions* that the scientific method could be broken down into three main phases: the conception of the problem or question (including the formation of a hypothesis); the experimental phase derived from the first phase (including the actual experiment [data collection, observation, measurement and so on]); and the evaluative phase where the experimenter evaluates the data. Kuhn argues that the first and third stages of this process are extremely subjective, calling into question the integrity of the claim of objectivity in the middle phase of the research. In the conceptive phase, the individual researcher defines what the 'problem' is, what should be included for (and/or excluded from) study, and what process will be utilized to achieve this.

Subsequently, while the same raw data obtained in the experimental phase may be identical from one experiment to the next, how this data is interpreted may vary greatly from one scientist to the next. In the evaluative phase, the role of the researcher is similarly crucial in how she or he interprets the findings - which can markedly differ from one person to the next, depending upon what they choose to highlight as significant.⁷

Margaret Benston, a scientist and critic, outlined four main assumptions of science which augment Kuhn's assessments: that an objective reality exists; that this reality is knowable via rational inquiry; that knowledge is gained by measurement or quantification; and, that the goal of scientific understanding is to predict and control natural phenomena.⁸

These assumptions can be used to further unravel what Kuhn termed the second, "experimental" phase. During this phase, the scientist attempts to isolate the item under

⁷ I acknowledge there are many ways of "knowing" and developing "knowledge". In this thesis, however, I refer to the knowledge that dominates Western thought, that based on scientific, deductive methods.

⁸ Thomas Kuhn, *The Structure of Scientific Revolutions* (Chicago: University of Chicago Press, 1970).

⁹ Margaret Lowe Benston, "Feminism and the Critique of the Scientific Method," in Angela R. Miles and Geraldine Finn, eds., *Feminism: From Pressure to Politics* (Montreal: Black Rose Books, 1989), pp. 63-4.

investigation and "control" for any other confounding factors (that is, eliminate these factors as variables which could be causal). By stripping something away from its natural environment one arrives at a reductionist, partial view at best; or a flawed and dangerous view at worst.⁹ While scientific knowledge has yielded useful information and applications (understanding and control of illnesses, for example), critics have tended to object to not only the control or domination of naturally-occurring processes, but also argue that this scientific method yields partial and often biased information.

Scientists ask questions - particular questions - as well as interpret the answers according to who they are (class, ethnicity, gender, etc.) Who the researcher is has direct implications for the type of science being done and, by extension, the types of claims to knowledge that are being made. Crises, such as those arising from Three Mile Island, or the use of chemicals, whether Agent Orange or poorly-tested pharmaceutical drugs (such as Thalidomide or Diethylstilbestrol, "D.E.S.") not only call into question the claims to absolute knowledge generated from research in science and technology, they also demonstrate the claims' inherently political nature.

These painful examples of failed science and technology and continuing debates about the validity of scientific knowledge together with increased numbers of women scientists and the second wave of feminism have inspired a number of "feminist critiques of science" (including those of Margaret Benston). These critiques provide a greater understanding of some of the political aspects of scientific knowledge. Particularly useful is the work of Sandra Harding, who attempts to narrate and consolidate feminist criticism.¹⁰

Related to this point is the work of Barbara McClintock, an American geneticist who worked in the first half of the 20th century. Her theory of transposition, the "jumping genes," served to bring to the fore this notion of looking at phenomena (in this case, the genes) as an integral, interactive part of its environment. Evelyn Fox Keller provides a biographical account of McClintock's life and links it to more recent critiques of science in A Feeling for the Organism: The Life and Work of Barbara McClintock (New York: W.H. Freeman, 1983).

For an excellent overview, see Sandra Harding, The Science Question in Feminism (New York: Cornell University Press, 1986) and Harding, Whose Science? Whose Knowledge? (New York: Cornell University Press, 1991). For the particular feminist critiques, see, for example, Margaret Lowe Benston, "Feminism and the Critique of the Scientific Method," and "Questioning Authority: Feminism and Scientific Experts," Resources for Feminist Research, Vol. 15, No. 3 (Nov. 1986), p. 71-3.

These critics generally assert that there are serious gaps in scientific knowledge. They acknowledge that science and technology have developed in a way that includes or represents certain perspectives (that is, those who are creative active agents in science) and excludes or underrepresents others who have no direct role to play in either the making of science or science policy. While there are several strains in the feminist critique of science, they each tend to address the premise that "science embodies a strong androcentric bias."¹¹ Feminist critics see science and technology as products and reflections of patriarchal and in some arguments, capitalist values.

As Elizabeth Fee points out, it is important not simply to describe science as being 'male.' She outlines various streams of research and finds that across several boundaries (specifically class, ethnicity and gender, although arguably there are several other distinctions including sexual preference, physical or mental ability, age, etc.), power is articulated and reproduced through scientific knowledge.

The idea of a pure knowing mind outside of history is simply an epistemological conceit. Reflected within science is the particular moment of struggle of social classes, races, and genders found in the real, natural and human world.... Thus you cannot be a woman without being a woman of a certain class, race and country... All of these terms are continually being redefined in the context of ongoing political and ideological struggles; they are never static.¹²

Natural science and its applications in technology are political in that they represent particular choices being made by individuals (or groups of individuals) who have influence and power to make them. Decisions are made on the basis of what is important, productive,

Nancy Hartsock, "The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism," in Discovering Reality, eds., Sandra Harding and Merrill Hintikka (Dordrecht: Reidel, 1983); Hilary Rose in Love, Power and Knowledge, and in "Hand, Brain and Heart: A Feminist Epistemology for the Natural Sciences," in Signs: Journal of Women in Culture and Society, Vol. 9, No. 1 (1983); Dorothy Smith, The Everyday World as Problematic: A Feminist Sociology (Boston: Northeastern University Press, 1987); Harriet Zuckerman et al., The Outer Circle: Women in the Scientific Community (New York: W.W. Norton & Company, 1991). It should be noted that many have been critical of Harding's typology, stating that it serves to introduce rather plastic groupings and new, unneeded jargon to what is already a rather inaccessible debate. In addition, women scientists may well approach science critically but would not necessarily identify with the labels or categorizations in this literature.

Evelyn Fox Keller, "Feminism and Science," in Signs: Journal of Women in Culture and Society, Vol. 7, No. 3 (1982), p. 590.

Elizabeth Fee, "Critiques of Modern Science: The Relationship of Feminism to Other Radical Epistemologies,"

and/or profitable. As in the making of science, the options not explored (or even conceived of) in the making of technology are at least as important as those that are. The choices of what to include and what to exclude are made within a political context, usually prompted and endorsed by powerful interests who own or legitimate the means of production. "The design, development and implementation of technology is fundamentally a political phenomenon closely related to the distribution of power and the practice of social control. Technology shapes and is shaped by society; therefore it is important to examine the power relations which inform the design, development and use of particular technologies."¹³

All too often, it is by examining the effects or outcomes of particular technologies or scientific discoveries, that one can discern their political underpinnings. The Nestle's baby formula project provides a chilling example of how a technology can produce different effects in different contexts. Baby formula was developed in highly industrial nations such as the United States and Britain. When the formula was sent to parts of Africa to assist mothers and their babies, little thought was given to the socio-economic and political realities and differences. The outcome was more harmful than beneficial, resulting in deaths and other serious health risks to both the babies and lactating mothers. The technology itself (the baby formula) was the same. The context in which it was introduced and distributed was completely different. In hindsight, it was clear that the needs of the consumers (lactating mothers in Africa) were not well investigated. What was clear was that the technology's access to an entirely new market increased profits for Nestle. In the end, the technology was withdrawn and it was determined that the healthiest, albeit least-profitable for Nestle, option was breastfeeding.¹⁴

in Ruth Bleier, ed. Feminist Approaches to Science (New York: Pergamon Press Ltd., 1986), p. 52-3.

¹³ Sue Cox, Dissenting Voices: New Reproductive Technologies and Feminist Analysis MA Thesis (Burnaby: SFU, 1991), p. 80.

¹⁴ For a discussion of Nestle's historical role linked with recent debates about breastfeeding versus baby formula see: Rence Helth, "Breastfeeding: Protection, Promotion, and Support: The Health Professional's Role," in BC Medical Journal Vol. 34, No. 2, (February 1992), pp. 95-99. Recent studies indicate that breast feeding is optimal for the health of babies and that formula has been linked to increased an increased prediliction for some types of illnesses, regardless of country. See: Canadian Broadcasting Corporation Ideas: "Birth: The Public Issues

The creation of professions allows specific groups of people to work together to achieve recognition and power. In her book, *Professions and Patriarchy*, Anne Witz investigates how and why professions are established. "Professional closure," as she terms it, serves to legitimate those who are included in the designated profession, while frequently bringing material benefits and rewards. Some are more immediate - prestige and higher income - while others are more systemic - control of professional education, self-regulation, and a monopoly in the generation of 'expert knowledge.' Within the realm of science and technology, the establishment of professions has been crucial for generating expert knowledge as well as the experts themselves. Generally, expert knowledge is passed on from one generation to the next through schools with entrance requirements (or restrictions) where individuals study, train and develop credentials with which to practise their chosen profession. While these schools have demonstrated their ability to produce qualified and gifted professionals, they have also had a lengthy history of being virtually inaccessible to entire groups of people (white women, women and men from ethnic minorities, people from working or impoverished classes, people with disabilities, and to some extent, older people).¹⁵ This legacy of excluding whole groups of people limits the types of science and scientific knowledge generated. Scientific knowledge is generally created from theories developed by scientists who came before. All are trained in the scientific method which is seen to be the appropriate means for developing widely-accepted knowledge. Knowledge developed in an alternate fashion (i.e. without using the scientific method, for example, experiential knowledge or intuition) are deemed, by the scientific profession, to be 'unscientific.'

In general the idea of an "expert" is that of someone with privilege and authority. An expert has not merely knowledge but a status and position that are part of the structure of power and control in our society. It is not surprising that, in all fields, experts are

Program on 11th Annual Baltimore Conference on Childbearing (Aired on CBC Radio on November 22, 1996)," *The Public Good Reader* (1996), pp. 63-73.

¹⁵ For example, Juarne Nancarrow Clarke *Health, Illness and Medicine in Canada* (Toronto: McLelland Stewart, 1990), pp. 180-205.

overwhelmingly white and male.Their pronouncements are weighty and not to be questioned except by other scientific experts.¹⁶

"Occupational imperialism" has been achieved when "an occupation which has successfully struggled for the right to control its own work and has gained legitimate organized autonomy, usually endorsed by the dominant elite or the State."¹⁷ The 20th Century continuation of these principles is the extensive and accelerating use of patents.

The Role of the Medical Profession

The medical set of professions are reputedly based on accumulated scientific knowledge and is comprised of trained and accredited professionals including medical doctors, researchers, nurses and other health care providers. Reproductive and genetic technologies are not simply developed to benefit couples or individual women. Rather, they are conceived and developed by, and representative of specific interests. These interests may or may not correspond to the needs of those using the technology in question. Furthermore, those with the decisive voice are not necessarily obliged to consider consumer or more broadly societal concerns. In the case of medical or reproductive technologies the choices made by various elite actors have predominated over the possible preferences and requirements of those with relatively less influence in society. The technologies are thus deeply political. At every level they involve some form of decision-making or a choice. At issue is whether the very professions, which hold significant interest in perpetuating their development, should be responsible for conducting broad-ranging assessments about the technologies.

In general, these professions enjoy legitimacy and considerable influence within society. This has been derived directly from the construction of scientific knowledge and professionalization as described in the previous section. While this profession has been responsible for a great number of discoveries that have led to decreased suffering and increased health, this does not lead to the popular assumption that this profession is

¹⁶ Benston, "Questioning Authority: Feminism and Scientific Experts," p. 71
¹⁷ Witz, Professions and Patriarchy, p. 42

somehow apolitical, unbiased or without interests. Health care is extremely political, a quick survey of recent Canadian or American health care debates is sufficient to determine this fact.¹⁸ Due to their long struggle to associate self-governance with professionalization, the medical establishment has developed considerable autonomy with respect to determining which health care priorities are explored and which are not.

Historically, reproduction was forcibly removed from the domain of midwives (who successfully practiced a women-centred approach to pregnancy, in limited collaboration with medical doctors) and was recast as an illness that needed treatment.¹⁹ Male physicians and surgeons who had long provided other types of care (mostly prescriptive, reactive treatment dealing with disease, healing bones and wounds, conducting surgery, etc.), took deliberate steps to become an exclusive profession through creating guilds, professional associations and other self-regulating bodies. The medical profession developed by subordination (of health care providers such as midwives); limitation (by professional designation such as 'dentist,' or 'pharmacist'); and, exclusion (of health care providers such as chiropractors or naturopaths).²⁰ Various governments have actively assisted these moves.

Moves in the eighteenth and nineteenth centuries away from midwifery in favour of hospital births (governed by the medical profession) had more to do with expanding the purview of medical doctors than enhancing the care of pregnant women.²¹ Medical doctors, who at the time had relatively little to do with the management of pregnancy and childbirth (unless something went wrong), were able to successfully develop new instruments to gain

¹⁸ For more on this point, with specific reference to Canada, see for example Michael Rachlis and Carol Kushner *Second Opinion* (Toronto: HarperCollins, 1989) and Nicholas Regush *Condition Critical* (Toronto: Macmillan, 1987).

¹⁹ For the classic book on the appropriation of midwifery reproduction by male doctors and how this is linked to the oppression of women, see Barbara Ehrenreich and Deirdre English *For Her Own Good* (New York: Anchor Press, 1978). For an excellent Canadian overview see Brian Burch *Trials of Labour* (Montreal & Kingston: McGill-Queen's University Press, 1994).

²⁰ Clarke, *Health, Illness and Medicine in Canada*, pp. 204-5. For an excellent Canadian historical overview, see Wendy Mitchinson, *The Nature of Their Bodies: Women and Their Doctors in Victorian Canada* (Toronto: University of Toronto Press, 1991).

²¹ Burch, *Trials of Labour*, pp. 4-18.

access to this area of health-care. The use of the forceps and "twilight sleep" (a combination of morphine and scopolamine, used to relieve acute pain during labour) by medical doctors transformed expectant mothers into patients and pregnancy into a medical condition. "The ascendancy of male obstetrics was the result of a number of interrelated factors ... however, the invention of one of the first technological aids to birthing [the forceps] provided a crucial resource for male medical practitioners."²² More than a century later, the midwifery profession still has not been able to regain the same foothold they once had in the maintenance of pregnancy in North America - to the apparent detriment of women and their fetus' health. "Of the industrialized nations the Netherlands, where midwives attend over half of all the births, has the lowest mortality and morbidity rates. Canada and the U.S. [where midwifery is not well established] both come very near the highest."²³ Usurping the legitimate work of midwives, coupled with developing risky technologies, represent overt actions of the medical profession to extend their influence by limiting access to other groups of people.

That the impact of some reproductive (and contraconceptive) technologies might not wellresearched is not a surprise to many women. Critics need only turn to inventions such as the forceps (created to get the baby out of the birth canal when stuck) and Dalkon Shield (an intra-uterine contraceptive device, I.U.D.), or pharmaceutical drugs such as D.E.S. (diethylstilbestrol, prescribed to prevent miscarriages) or Thalidomide (prescribed to prevent morning sickness) for examples of poorly-reviewed technologies. With the introduction of forceps, countless women and babies died due to use in the wrong conditions, coupled with poor technique on the part of doctors delivering the baby.²⁴ Thousands of women who were exposed to D.E.S. while *in utero* developed cancer as adults.²⁵ Thousands of individuals who were exposed to Thalidomide were born with

²² Wajcman, Feminism Confronts Technology, p. 64

²³ Patricia O'Reilly "Small 'p' Politics: The Midwifery Example," in Overall, ed., The Future of Human Reproduction, p. 170

²⁴ Wajcman, Feminism Confronts Technology, pp. 63-66

²⁵ Simand, "1938-1988: Fifty Years of DES - Fifty Years Too Many," pp. 95-104

physical disabilities.²⁶ Finally, the Dalkon Shield resulted in several women dying and thousands of others rendered infertile.²⁷ In each case, these technologies were developed by the biomedical profession with inadequate research to establish their safety and effectiveness. As well, each technology went from being prescribed for rather specific conditions (although it was determined in each case that the technology was not even effective for those conditions) to becoming standard and widespread in its use.

These examples of failed reproductive and contraceptive technologies illustrate the failure of the medical profession to take the time and money needed to ensure a minimal level of risk to women (and the children borne of these technologies) and thus a safe and effective product. Each of these technologies are examples of 'the revolving door of medical technology.' This occurs when an otherwise healthy woman becomes ill or injured due to the application of these technologies. This is termed iatrogenic²⁸, that is, medical conditions or injuries induced by a physician. These same women are forced to come back to the medical profession in search for a cure or solution to the outcome of the failed technology. Thus, women whose infertility was caused by failed older technologies such as the I.U.D., the Pill etc. are now searching for new ways to overcome their infertility. Rarely is there an opportunity to investigate broad areas of health policy, such as reproductive health. Ironically (as shall be demonstrated), the solutions to failed technologies have been found in newer reproductive technologies.

The Biomedical Industrial Complex: The Role of the State and other Societal Actors

The medical profession could not have developed into the powerful structure it is today without the support of other dominant forces. These include the governments of the day, the researchers in governmental bureaucracies - increasingly those of research institutions, and private enterprise (including the pharmaceutical and biotechnology industries). Important linkages between economic, professional and political power serve to

²⁶ Barbara Katz Rothman, *In Labor: Women and Power in the Birthplace*, (New York: W.W. Norton Company, 1991), pp. 135-137.

continually reinforce the medical profession. Medical practitioners have been able to create "professional closure"²⁸ through schools of medicine (where course content is determined by collaboration between the university and medical associations, and where certification is restricted to those who complete a set program of academic and experiential training). This has safeguarded and extended a virtual monopoly on medical techniques, knowledge and practise. This has permitted considerable freedom for practitioners of medicine to create their own body of expert research and knowledge, and to exclude other forms (or ways) of knowing. Governments have traditionally acted in ways to support and further legitimize the medical profession by establishing and funding the medical schools, recognizing self-regulating colleges (such as the Canadian College of Physicians and Surgeons), and by creating legislation to support these professional bodies (through billing structures and by not establishing State-run regulatory agencies). Industry, notably the pharmaceutical industry, holds a powerful linking role with respect to government and the medical profession. Health care priorities have become increasingly influenced by the motivations of the pharmaceutical industry as it takes on growing funding responsibility for clinical trials and other research. Taken together, those involved (primarily the medical profession, industry and the State) in reproductive and genetic technologies can be termed the biomedical industrial complex. In the end, this complex has far-reaching powers including not only what we are offered and how, but also in terms of assessment (health, safety, ethical and otherwise).

Public policy is defined as the "exercise and structuring of power, influence and legitimate coercion, as well as the expression of normative intent and therefore of ideas, values and purposes."²⁹ It is the deliberate exercise of influence in the form of laws, regulations, general guidelines by the State made legitimate by the implicit or explicit

²⁸ Downie and Johnston, "A Case of Corporate Malpractice and the Dalkon Shield," pp. 86–104.

²⁹ Witz, *Professions and Patriarchy*, pp. 42–3. See also the now classic Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception*, 1973, and Schrecker, "The Mobilization of Bias in Closed Systems: Environmental Regulation in Canada," pp. 43–63.

consent of society for the general good of that society. Science policies, then, refer to those State-created policies that govern the development and applications of scientific and technological knowledge. State actors, however, must frequently rely upon scientists for much of their understanding of what it is that needs to be regulated. It is this intersection that creates what is termed a *policy community*.³⁰ The actors and the nature of their interactions within a given policy community, therefore, are highly important.

The role of the State is central in the formation of public policy. However, State actors themselves are often constrained by structures and traditions of a given State. Crucial to these structures is what is termed "State capacity," or, the relative resources and ability of a State to generate its own information to form public policy.³¹ If a State does not have large amounts of information and resources available to it on a certain issue, it must turn to societal groups or individuals to provide this. There has been some very instructive policy research dealing with the interactions between the State and societal actors. Societal actors include a broad range: individuals who take an interest in a policy area, the media, loosely conceived lobby groups, on up to tightly organized, highly resourced (sometimes professional) interest and corporate groups. Given that scientific and technological knowledge is deemed expert, the State routinely must call upon those with this knowledge to provide this crucial information. In so doing, it surrenders at least some of its power to control the outcomes of the policy issue under consideration.

What becomes important in the making of public policy is the question of who is included in the deliberation and who is not. This is often determined by the degree of power any actor or group of actors holds. Franz Van Waarden describes this power as "a function of the distribution of resources and needs among the actors, and of their mutual

³⁰ Bruce G. Doern and Richard Phidd, Canadian Public Policy: Ideas, Structures and Processes, (Toronto: Methuen, 1983), p. 34.

³¹ For an extensive discussion in the Canadian context, see William D. Coleman and Grace Skogstad, eds., Policy Communities and Public Policy in Canada (Mississauga: Copp Clark Pitman Ltd. 1990).

³² William D. Coleman and Grace Skogstad, "Policy Communities and Policy Networks: A Structural Approach," in Coleman and Skogstad, eds., Policy Communities and Public Policy in Canada, pp. 15-17.

organizational structures when these are organizations.”³² Others term these “political resources ... a means by which one person can influence the behaviour of other persons. Political resources therefore include money, information, food, the threat of force, jobs, friendship, social standing, the right to make laws, votes, and a great variety of other things.”³³ Highly organized and developed interests, such as the Canadian Medical Association (CMA), the College of Physicians and Surgeons (CPS), or the Pharmaceutical Manufacturers Association of Canada (PMAC) are characterized by a strong association with secure resources and the ability to autonomously conduct long-term planning. Other interests are less influential because they tend to be volunteer-based with few resources. They usually proceed with less coordination than the well-funded groups and thus have less overall power or influence. Examples of these groups, include the National Coalition for a Royal Commission on Reproductive Technologies, the Reproductive Alternatives Society or the Vancouver Women’s Reproductive Technologies Coalition (and the numerous provincial or municipal equivalents of the latter two groups across the country). Intermediate groups, such as the National Action Committee on the Status of Women (NAC), who have some degree of funding (which is often governmental in part) but who tend to be consulted, but ultimately excluded from substantive decision-making and influence. Political resources tend to determine access to policy communities and the relative ability to concretely influence or affect public policy.³⁴

By virtue of their resources, large industries are crucial actors in decision-making deliberations. Of primary significance is the dubious situation (and community) which arises wherein government, who has the power and must create policy, regulates industry and professionals who in turn are the providers of the essential information with respect to what should (or should not be) regulated. The medical profession relies on industry for similar types of information, including clinical trial results and other types of assessments.

³² Franz Van Waarden, “Dimensions and Types of Policy Networks,” European Journal of Political Research, 21 (1992), p. 36.

³³ Robert A. Dahl, Modern Political Analysis, 4th Ed. (Englewood Cliffs: Prentice Hall, 1984), p. 31.

It is by using this information that practitioners prescribe treatments and researchers use the accumulated scientific studies to build upon or create new theories.³⁵ This type of policy network is termed "clientele pluralism" where the state surrenders at least some of its authority to private-sector actors to determine policies.³⁶ These actors come together due to their mutual needs, interests and resources.

Reproductive and genetic technologies are relatively new and highly-specialized. The reliance upon the technical experts by the government is precisely what has transpired in this area.³⁷ Assessment occurs primarily through clinical trials, which are financially and time expensive. These are conducted primarily by medical researchers and the pharmaceutical industry, not government. The trials function "not merely as testing procedures for the selection of drug profiles but also as major devices in bringing the relevant groups of actors together it seems no longer adequate to make any analytic distinction between the marketing process, laboratory research, and testing procedures in the clinic."³⁸

Left outside of this critical decision-making loop are the many who cannot enter due to their relative lack of resources or power. These include not-for-profit interest groups, 'consumer' groups, individuals, and the general public. Much regulation that occurs in

³⁵ Coleman and Skogstad, "Policy Communities and Policy Networks: A Structural Approach" pp. 22-8.

³⁶ John B. McKinlay, "From 'Promising Report' to 'Standard Procedure': Seven Stages in the Career of a Medical Innovation," in Milbank Memorial Fund Quarterly Health and Society, Vol. 59, No. 3 (1981), pp. 374-411.

³⁷ For excellent overviews of this condition, particularly as it relates to the Canadian Health System, see Michael Atkinson & William Coleman, The State, Business and Industrial Change in Canada (Toronto: University of Toronto Press, 1989); Atkinson and Coleman, "Corporatism and Industrial Policy," in Alan Cawson, ed. Organized Interests and the State: Studies in Meso-Corporatism (London: Sage, 1985), pp. 22-44; Coleman and Skogstad, "Policy Communities and Policy Networks: A Structural Approach" pp. 22; and Joel Lexchin "Drug Makers and Drug Regulators: Too Close For Comfort: A Study of the Canadian Situation," Society, Science and Medicine, Vol. 31, No. 11 (1990), p. 1260.

³⁸ See, for example, Robyn Rowland, "Motherhood, patriarchal power, alienation and the issue of 'choice' in sex preselection," in Gena Corea et al., Man Made Women, (Bloomington and Indianapolis: Indiana University Press), p. 74.

³⁹ Nelly Oudshoorn, "United We Stand: The Pharmaceutical Industry, Laboratory, and Clinic in the Development of Sex Hormones into Scientific Drugs, 1920 - 1940," Science Technology and Human Values, Vol. 18, No. 1 (Winter 1993), pp. 20 and 6.

Canada with respect to scientific policy is created out of the public eye and constitutes a problematic "closed system."³⁹

What has developed is a fundamental conflict between profit and health. The role of industry is to generate profit for itself. The role of the Health Protection Branch of the Canadian government is to "protect and improve the well being of Canadians by determining, evaluating and managing risks to human health"⁴⁰ by regulating drug safety, efficacy and quality. However, due their reliance upon industry they are left with less power to determine which health care objectives are pursued and even how they are regulated.

Other significant factors further exacerbate this condition. Governmental legislation has further contributed to this problematic situation through legislation such as Bills C-22 and C-91, which extended patent protection for drugs to 20 years.⁴¹ Foreign domination of these industries translates into a marked erosion of Canadian interests and objectives. The 1985 *Report of the Commission of Inquiry on the Pharmaceutical Industry* (the Eastman Report) notes that of 25 industrial countries, Canada ranks 21st in terms of domestic control of the pharmaceutical market.⁴² Global trade agreements including the North American Free Trade Agreement (NAFTA) or the General Agreement on Tariffs and Trade (GATT) have had enormous influence upon the ability for individual countries to regulate technologies or even ideas (through intellectual property rights).⁴³ Governments have

³⁹ Schrecker, "The Mobilization of Bias in Closed Systems: Environmental Regulation in Canada," p. 51

⁴⁰ Health Protection Branch, 1991, as cited in Rosanna Baraldi, "The Evaluation of Pharmaceutical Products: Problems of Phase IV," in Basen, Eichler, Lippman, eds., Misconceptions: The Social Construction of Choice and the New Reproductive and Genetic Technologies, Vol. 2, (Prescott: Voyageur, 1994), p. 74

⁴¹ Linda Diebel, "How Trade Deals Work for U.S. Corporations: The Case of Patents and Pharmaceutical Drugs," in Duncan Cameron and Mel Watkins, Canada Under Free Trade, (Toronto: James Lorimer & Company, 1993) pp. 92-98

⁴² Commission of Inquiry on the Pharmaceutical Industry (Eastman Report) Report of the Commission of Inquiry on the Pharmaceutical Industry, (Ottawa: Supply and Services Canada, 1985)

⁴³ See for example: Barbara Cameron, "Brave New Worlds for Women: NAFTA and New Reproductive Technologies," in Janine Brodie, Women and Canadian Public Policy, Toronto: Harcourt Brace and Company, 1996; Ecumenical Coalition for Economic Justice, Intellectual Property Rights in NAFTA: Implications for Health Care and Industrial Policy in Ontario, Toronto: ECEJ, 1993; Colleen Fuller, "A Matter of Life and Death: NAFTA and Medicare," Canadian Forum, LXXII (October 1993), pp. 14-19; Laura Sky, "Commercial Interests and New

increasingly deregulated and privatized formerly publicly-funded institutions, rather than creating mechanisms to curtail the control of policy and regulatory directions by profit-motivated interests.

At universities, researchers have shifted away from being professors generating knowledge to a role better described as entrepreneurs generating profits for private business ventures. The potential for conflicts of interest is high.

In British Columbia there are 45 private sector companies, eight government institutions, one technical college, and three universities involved in biotechnology. B.C.'s biotech industry includes all industrial sectors, but the health care sector dominates on both private and public fronts. Over 75% of the biotech companies have been established since 1981. ... (M)ost of these companies are spin-offs of B.C. universities.⁴⁴

Perhaps more unambiguous is the arrangement or "active liaison" between Saskatchewan drug researchers and several pharmaceutical companies to create the Saskatchewan Drug Research Institute.⁴⁵ These alliances have been further and explicitly encouraged by cash-strapped governments through such ventures as the federally-funded (and often matched by provincial equivalents to) Networks of Centres of Excellence. The Networks are established research and development links between government, industry and research institutions (universities and research hospitals). Critics point to the growing importance of corporate prerogatives over public ones.⁴⁶

The biomedical industrial complex has generated many important discoveries and better understandings of disease, for example in the cases of penicillin, cancer treatments, neurological conditions, and so on. However such a closed system, often with the assent (either implied or expressed) of the general public and the State, allows medical personnel to determine which priorities are important, how these priorities are researched and what constitutes safety or risk to the lesser informed, hence excluded, consumptive public.

Reproductive Technologies," Canadian Women's Studies Les Cahiers De La Femme, Vol. 14, No. 3 (1994), pp. 105-109.

⁴⁴ Laura Sky, "The Regulation of Reproductive Technology," in Press Merkur and Winfield, Enabling Biotechnology?, pp. 4-5.

⁴⁵ Sky, "The Regulation of Reproductive Technology," p. 5.

III. Ethical Considerations

Above all, it is clear that women are the best subjects for experimentation. As opposed to mice or monkeys, women are intelligent and talk. They are conscious of how and when their ovulation occurs; they can observe and describe to the doctors the effects of different medications; they don't have to be purchased, fed, or kept in a clean cage; they come to the hospital all by themselves, on the right day, at the right time, and ... they pay for that privilege (sometimes exorbitantly).⁴⁷

Reproductive and genetic technologies involve new changes to how children are born. Reports of these technologies frequently appear in national and international headlines because of their novelty and the ethical questions they raise. In Canada, those pressing for an inquiry into the various technologies did so in part because ethical discussions about these technologies seemed to be a closed one, and limited in extent. Given the predominance of the biomedical industrial complex, it was likely that the ethical discussions that were taking place (if any) were at the discretion of these powerful bodies. This raised serious concerns about conflicts of interest and whether the medical profession, in conjunction with related groups responsible for the technologies, should be entrusted with evaluation on behalf of all of society.

Reproductive and genetic technologies, particularly (but not only) the more recent ones, are interventions into the creation of life. Regardless of ideological stance, the reproductive and genetic technologies seem to evoke strong, often moral responses from just about everyone. There is (at least grudgingly) a recognition of the sheer vastness, finality and ethical quagmire created by these technologies. The boundaries separating acceptable from unacceptable interventions are not ones that can be readily agreed upon. Indeed, ways by which to create any consensus have not been forthcoming, highlighting the need for an informed discussion beyond the limited, closed and potentially questionable ones of the biomedical industrial complex.

⁴⁷ David Noble, "Religion of Technology," Keynote Address for *Making the Links: a Critical Look at Community and the Internet*, SEU Harbour Centre, March 20, 1997. Press Merkur, "The Biotechnology Council of Ontario and New Reproductive Technology," pp. 5-6.

⁴⁸ Francoise Laborie, "New reproductive technologies: news from France and elsewhere," paper delivered at Forum International sur les Nouvelles Technologies de la Production Humaine, organized by the Conseil du Statut de la Femme, Gouvernement du Québec, Montreal, October, 31 1986, p. 15.

Some of these ethical questions include: should we Canadians, as a society, technologically and genetically tinker with the creation of human life - is there adequate knowledge (scientific or otherwise) to do so? Does the buying and selling of reproductive parts of women and men constitute the commodification of life and is this acceptable? Do frozen embryos have rights? Is society prepared to deal with new familial configurations (such as those created through preconception arrangements)? What are the implications for the children born of these technologies, and is there adequate follow-up in place to monitor any resultant long-term effects on these children? Is there a need for highly expensive, highly technological interventions and are they the best solutions to infertility; who determines this? Do the technologies result in oppression or threats to particular groups in society or in the world? What is the relationship between individual and societal preferences? Are we, as a society, "playing God?", or are we making legitimate use of the fruits of science and just needing to better safeguard, manage and deliver them?

Reactions to these questions, predictably, vary. Some would agree that, yes, we are playing God and as such, any intervention into what has arguably, heretofore, been the 'natural' process of childbirth is unethical. According to anti-abortionists, technologies that manipulate what constitutes a life, or "unborn child," is unethical. So, for example, the creation and selective abortion of extra embryos created in the *in vitro* fertilization technique would be unacceptable. Others argue that childbirth has always been socially mediated and subject to interventions (technologically or otherwise) and that such interventions are acceptable and helpful. Still others argue that where the technology exists, individuals should have full access to it and should assume any associated risks. In the above *in vitro* fertilization example, since the creation of extra embryos is both possible and may yield better chances at creating a child, the technology should be available, even if it carries particular risks to either the mother or the child/ren produced from such procedures. To make the technologies unavailable, then, would be unethical.

Susan Sherwin, a feminist bioethicist, outlines feminist concerns about reproductive technologies in her book *No Longer Patient*. Generally, she argues the critical question to ask is: who ultimately has control? Having determined this, she then examines how a particular phenomenon fits into existing systems of oppression (based on class, gender, ethnicity, etc.); or, more simply, how is this control being used?⁴⁸ With technologies such as those utilized in *in vitro* fertilization example, one must ask, who (if anyone) reasonably knows what the level of risk is? How is this information passed along to those ultimately making direct use of the technologies? Clearly the answer is the doctors, researchers or other health care providers who develop and deliver the technologies, usually safeguarding the use of informed consent. Informed consent is a mechanism intended to ensure that people have full information about a given treatment or procedure prior to their agreement to receive it. However, the practice of informed consent does not adequately address power relationships where individuals may feel intimidated or even coerced into particular treatments. Examples of this frequently have been pointed to in the field of mental health or in guardianship arrangements. Nor are recipients always made fully aware of all the details of a particular technology or treatment. Classically, *in vitro* fertilization has been proclaimed by practitioners for many years to be an effective and proven 'treatment' for infertility, when in fact, the World Health Organization and many Canadian health groups have continually deemed this procedure to be highly unproven, ineffective and experimental.⁴⁹ In addition, the term *treatment* is a misrepresentation. At best, the technology merely bypasses infertility, but does not actually cure it. Couples attempting to overcome the inability to have a child through conventional means, then, are often misled by those offering this expensive set of technologies. Questions arise as to whether a 'high-tech,' economically prohibitive technology is the best answer for the question of reproductive health. Ethical issues arise

⁴⁸ Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press, 1992), pp. 115-136.

⁴⁹ Gena Corea and Cynthia de Wit, "Current Developments and Issues: A Summary: IVF: Patients are experimental subjects. World Health Organization official tells international IVF Congress," *Reproductive and Genetic Engineering*, Vol. 2, No. 3 (1989) pp. 253-4.

when health care spending is allocated to technologies such as *in vitro* fertilization at the expense of alternative, more practical, effective, even preventative measures (such as a good pelvic inflammatory disease monitoring program). Authors Jill Rakusen and Nick Davidson conclude that "the single most significant contribution to a cut in the death and handicap rate among newborn babies would be a comprehensive anti-poverty program."⁵⁰

Given that reproductive technologies have tended to outrun any formal discussions with respect to social, economic or health impacts, many ethical questions have been raised about the key groups of researchers, doctors and practitioners who control the direction, development and delivery of these technologies. The links between researchers and large pharmaceutical or biotechnological companies are clear. The companies provide much of the funding for the research, creating concerns with respect to motivation for producing such technologies. Is the central motivation better health care or economic profit? In her description of the biotechnological field in North America, Varda Burstyn states:

Biotechnology has been declared by business, the media and government alike to be the most dynamic industrial growth sector of the 1990s. In the U.S. alone in 1989, some 200 companies vied for the profits to be made in what *The Economist* describes as "one of the biggest industrial opportunities of the late 20th century." The Science Council of Canada estimated in 1989 that biotechnology will be worth \$180 billion worldwide by 1996.⁵¹

Genetic technologies, particularly those effecting permanent changes in characteristics of offspring and subsequent generations of humans, raise the ethical stakes. The changes are important and the results of such changes are not clear and cannot be until those children and possibly their children grow up.

Concerns have been raised, particularly by people with disabilities, that inherent in genetic engineering are attempts to eradicate disability, or to create particular kinds of babies (of a particular sex or race) - a goal, that is both discriminatory and misguided.

Jill Rakusen and Nick Davidson, Out of Our Hands: What Technology Does To Pregnancy, (London: Pan, 1982), p. 152

Varda Burstyn, "Making Perfect Babies," The Canadian Forum, Vol. LXX, No. 808 (April 1992), p. 13

A central ethical question for virtually all of the reproductive and genetic technologies is that of control. Is this power used to benefit or to further oppress? "The questions that feminists must ask ... are: Who makes the rules? Whose needs and interests are being catered to? Who profits from this control? Who benefits? And who pays the price?"⁵²

IV. Individual Versus Collective Rights

An overarching tension in the reproductive and genetic technologies is that of rights: the individual's right to access versus the risks to the same individuals and to society, generally.⁵³ There are those who argue that any technology that carries a chance for a baby should be "accessible" on the free market.⁵⁴ At the other end of the spectrum are those who argue that most or all of the newer technologies constitute invasive, overly-medicalized or commercialized procedures that carry grave risks to not only the women, but also to their offspring.

Among feminists concerned with the impact of reproductive and genetic technologies, rights are intimately related to "choice." Choice has long been used in the feminist movement with respect to access to safe abortions for women and reproductive and contraceptive techniques generally. So too with the newer reproductive technologies, choice represents those options that are low in risk to the woman (and/or man) and successive generations. At issue is whether or not women are given real choices or whether the options

⁵² Renate Duelli Klein, "What's 'new' about the 'new' reproductive technologies?," in Gena Corea et al., Man-Made Women: How new reproductive technologies affect women (Bloomington and Indianapolis: Indiana University Press, 1987), p. 67.

⁵³ For a good sense of both of these viewpoints see Lori B. Andrews, "Position Paper: Alternative Modes of Reproduction," in Sherrill Cohen and Nadine Taub, eds., Reproductive Laws for the 1990's (New Jersey: Humana Press, 1989), pp. 361-403 and in direct response, Maria Mies, "From the Individual to the Dividual: In the Supermarket of 'Reproductive Alternatives'" Reproductive and Genetic Engineering Vol. 1 No. 3 (1988), pp. 225-237.

⁵⁴ Most of the new reproductive technologies are prohibitively expensive. In Australia, for example, IVF procedures are estimated to be 4.5 times the cost of having a child by conventional means, as cited by Cynthia de Wit and Gena Corea in "Current Developments and Issues: A Summary: Cost of IVF baby in Australia: \$42,927" Reproductive and Genetic Engineering, Vol. 2, No. 1, (1989), pp. 63-4. By offering the technologies through privately-run clinics (versus publicly-funded ones) many people are unable to access them either by virtue of the associated price tag, or due to physical location of the clinics (which tend to operate in urban settings).

offered them constitute an extension of the specific interests of those offering the technologies.

The notion of choice is a liberal one. One assumes the chooser is a fully autonomous individual with a full array of choices available. The difficulty with this conception, as lawyer Margot Young points out, is that women are not fully autonomous, nor do they truly have a full range of choices. "[T]he imagery of the autonomous chooser is also best understood as gendered because the choices that women do have in their lives are usually significantly constrained by gender stereotypes and gendered social and economic relations."⁵⁵ As well, many 'choosers' may not have adequate information about each of the options available to them. If, for example, pregnant women knew the risks associated with the drug D.E.S., it is doubtful they would have elected to take it. Also, because of the position of doctors (as carriers of expert knowledge) relative to the pregnant women (who frequently feel they lack this knowledge), the women may have had their fears about D.E.S. overruled by the prescribing doctor. Or, these women may have taken the drug out of fear that if they did not take it, the health of their fetus would be threatened. Women are frequently in the position of having to choose from the options conceived and developed by people whose interests do not necessarily coincide with theirs.

Critics argue that by framing these issues in terms of access or choice, one is actually skipping a critical step in assessing the *nature* of opportunities being offered. "In other words, when the talk is centred primarily about access, it means that the use of the technologies is already taken for granted and implies that they are scientifically tested, ethically legitimate and socially accepted."⁵⁶ The interests of those offering the technologies may have more to do with profit or prestige than they do with providing appropriate maternal health care. Critics are concerned that the technologies are not adequately

⁵⁵ Margot E. Young, "Reproductive Technologies and the Politics of Choice," in Reproductive Rights and Reproductive Wrongs, Proceedings of Conference held in Victoria BC, January 14-16, 1994, p. 100

⁵⁶ Louise Vandelac, "The Baird Commission: From 'Access' to 'Reproductive Technologies' to the 'Excesses' of Practitioners or the Art of Diversion and Relentless Pursuit," in Gwynne Basen et al. eds. Misconceptions, Vol. 1, p. 257

scientifically tested, they are not ethically legitimate, they are not socially acceptable and therefore they do not constitute a real choice.

When choice is assessed in this way, it somewhat deflates arguments about access. Who would want or fight for access to techniques of dubious merit? However, many are willing to forego the potential risks if there is an opportunity to achieve their desired goal: to conceive and bear a child for themselves. Advocates for access to the technologies argue they have a right to the techniques, particularly if they are willing to pay for them privately. Additionally, they might argue, by using the reproductive technologies in their early stages, these consumers may be paving the way to safer, more effective ones. They may well acknowledge that the interests of practitioners, pharmaceutical companies or others diverge from their own, but that the relationship between the deliverer and consumer is a rather symbiotic one, coming together to serve the interests of both.

V. Conclusion

Reproductive and genetic technologies are creations of the biomedical industrial complex. The voices of those directly affected by the technologies tend to be vastly underrepresented in all phases from development through to delivery. These technologies are an example of the creation by established and powerful groups of technologies which are purported to unproblematically benefit infertile couples and women, when they do, in fact, give rise to grave ethical, social, economic and health risks. Those in control of the technologies are able to determine how the technologies will be offered and to whom, resulting in discriminatory and dangerous outcomes. In the end, the technologies gain acceptance by virtue of their existence as creations of the biomedical industrial complex, leading to debates around access in place of rejections of unacceptable technologies. And while many, including those operating to develop the technologies, are concerned about ethical implications of the technologies, this acceptance and push for access tends to overshadow considerations about the ethical implications. Those who are legitimately searching for options and choices, are offered technological fixes (that perpetuate and/or

create problems)⁵⁷ that may result in more harm, not only to themselves, but to generations who follow. Critics of these applications of science and technology have been quick to draw parallels to past disasters at the hands of technological progress. They call for a broader, more inclusive process of decision-making with respect to what constitutes knowledge and how it gets used.

For science and technology to be useful and responsive to people's needs, scientists, along with everyone else, will have to recognize that science is no more immune from ideological commitments than are other human activities and that we therefore need better and more democratic mechanisms than we now have to decide what science needs to be done and how best to do it.⁵⁸

Arnold Pacey, The Culture of Technology, (Oxford: Basil Blackwell, 1983)

⁵⁸ Hubbard, The Politics of Women's Biology, p. 211

CHAPTER THREE

EXAMPLES OF PROBLEMS ARISING FROM TECHNOLOGY

I. Introduction: Hitting the Public Agenda

Representative Examples: Concerns About the Technologies - Or - Why the Call For A Royal Commission on Reproductive and Genetic Technologies?

Louise Brown was born in 1978. She was the world's first "test-tube baby."¹ modern miracle of science, or so she was hailed by her self-proclaimed medical "fathers" Patrick Steptoe and Robert Edwards.² While many of the reproductive and genetic technologies had been evolving prior to the birth of Louise Brown, this event was pivotal in heightening the public and corporate interests in the technologies.

Roughly four years after the birth of Louise Brown, an Ontario woman gave birth to a child by utilizing the same technique (*in vitro* fertilization). This was the first such instance in Canada, and together with events such as the first preconception agreement court case, it served to heighten the awareness of these new ways of having children. While there was a general sense that these new techniques existed, there was little known about what they actually entailed in terms of financial, social, health or ethical costs.

Canada mirrored many Western countries with respect to the extent to which the technologies began to escalate in their development and delivery. However, it was not until legal contests began to surface that Canadian governments began to address some of the complexities related to the technologies. Many provincial governments began to investigate specific technologies at this time, although the federal government failed to become involved in any meaningful way.³ One report in particular, the *Report on Human Artificial*

¹ The term "test tube baby" is popularly used to describe the set of reproductive techniques called *in vitro* fertilization. Both of these terms (and many others associated with the reproductive technologies) obscure the involvement and work done by the woman who still gestates, carries and delivers the baby or babies that result from the technologies.

² Gena Corea, The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs (London: The Women's Press, 1985), pp. 100-125.

³ Some provincial reports included: British Columbia Royal Commission on Family and Children's Law, Report on Artificial Insemination (Vancouver: Minister of Human Resources, Attorney General, 1975); Law Reform Commission of Saskatchewan, Tentative Proposals for a Human Artificial Insemination Act (Saskatoon: Law Reform Commission of Saskatchewan, 1981). The federal government did produce some reports on these matters, including: Advisory Committee to the Minister of National Health and Welfare, Storage and Utilization of Human

Reproduction and Related Matters produced by the Ontario Law Reform Commission, opened up limited discussion on at least some of the issues concerned with reproductive technologies.⁴

In this chapter I present some of the reproductive and genetic technologies that were available or under development at the time of the call for a national public inquiry into these matters. Discussions of the technologies presented below are limited to a representative few, in order to illustrate the respective technology itself and the central benefits and concerns related to each. They are presented as cases where at the time, the technologies had not been adequately assessed (and needed to be) in terms of the interests involved in creating them.

a. Preconception Arrangements and related technologies

Preconception arrangements, or contract motherhood - more popularly known as "surrogacy"⁵ - is available in a variety of ways and may or may not involve the exchange of money. "Altruistic arrangements," can occur between family members or close friends. At the time of the call for a Royal Commission, there were a number of concerns with these arrangements. Increasingly, legal contests over the contracts used meant that the creation of policy and law governing such arrangements was being made in the courts incrementally and with no public debate. Additionally, the techniques used came with significant, poorly assessed health risks and other ethical concerns.

Sperm (Ottawa: Health and Welfare Canada, 1981). Possibly the absence comprehensive investigations into these matters was since health matters tend to fall mostly within provincial jurisdiction. The federal government of the day may have felt the issues of new reproductive and genetic technologies did not fall within their mandate.

⁴ Ontario Law Reform Commission, Report on Human Artificial Reproduction and Related Matters (Toronto: Ministry of the Attorney General, 1985).

⁵ Virtually every feminist writing on this issue vehemently objects to the term "surrogate." The woman ("surrogate") who conceives, gestates, labours and delivers a baby is under any other circumstances the mother of the child. The term "surrogate" then obscures what is actually occurring. See, for example, Rita Arditti, "Surrogate Mothering? Exploits Women," Science For The People, Vol. 19, No. 3 (1987), p. 22-3; Arditti, "A Summary of Some Recent Developments on Surrogacy in the U.S.," Reproductive and Genetic Engineering, Vol. 1, No. 1 (1988), pp. 51-64; Dianne M. Bartels, et al, eds., Beyond Baby M: Ethical Issues in New Reproductive Technologies, New Jersey: Humana Press, 1989, p. 60, and Margit Eichler, "Reflections on the 'Temporary Use of Normally Functioning Uteri,'" in Gwynne Basen et al, eds., Misconceptions: The Social Construction of Choice and The New Reproductive and Genetic Technologies, Vol. 2 (Hull: Voyageur, 1994), pp. 193-214.

Preconception arrangements take one of two basic forms: genetic-gestational (where the gestational mother carries an embryo created by her egg and the contracting father's sperm, thus the child born of such an arrangement is genetically related to the gestational mother); and those termed gestational arrangements (where the gestational mother is not genetically related to the embryo she is impregnated with). Both sets of arrangements are risky, although for different reasons. These arrangements raise ethical, legal and economic questions. "In all cases there is a potential conflict between contractual rights and the biological criteria of parenthood."⁶ In instances where money changes hands for the successful delivery of a child, issues around the commodification of human beings are also of concern.

Altruistic arrangements usually occur when a woman is unable to conceive and a family member or friend agrees to carry a fetus to term for her.⁷ If no money changes hands, the potential for exploitation may be decreased. These arrangements, however, bring with them new and unresolved definitions of what constitutes a family member. In Europe, a daughter gave birth to a baby who was genetically related to her mother and father. Was the newborn her brother or son?⁸ In Africa when a woman bore triplets for her daughter (using her daughter's eggs and son-in-law's sperm) who was the mother?⁹ What happens if the woman who carries and gives birth to the child(ren) decides she wants to keep them? What are the general implications for all involved? Margrit Eichler, who conducted a survey for the Law Reform Commission of Canada on preconception arrangements in Canada, found that the impact on those commissioned and those

Following Eichler, I use the term "preconception arrangements," which seems to best capture these transactions, which very often end up not being "agreements."

⁶ Verena Stolcke, "New Reproductive Technologies: The Old Quest for Fatherhood," Reproductive and Genetic Engineering, Vol. 1, No. 1 (1988), p. 14.

⁷ For a good overview of some concerns with altruistic arrangements, see Uma Narayan, "The 'Gift' of a Child: Commercial Surrogacy, Gift Surrogacy, and Motherhood," in Patricia Boling, ed. Expecting Trouble: Surrogacy, Fetal Abuse, & New Reproductive Technologies, (Boulder: Westview Press, 1995) pp. 177-201.

⁸ Corea and de Wit, "Current Developments and Issues: Italian physician goes into hiding after arranging IVF birth in which a teenager gave birth to her brother," Reproductive and Genetic Engineering, Vol. 3, No. 1 (1990), p.

54.

commissioning the arrangements (and their families) is never simple, even in instances of altruistic dealings.¹⁰

In contractual arrangements, profit motive, contract rights, and responsibilities come into play. The gestational mother may be in a vulnerable position as her basic rights become secondary to the rights of 'the product', or fetus she is carrying for the contracting couple.¹¹ In essence, she becomes a fetal carrier or "surrogate" even though she ovulates, conceives, gestates, labours and delivers the baby. Any number of legal and emotional conflicts can arise should the gestational mother not submit to the demands of the contracting man or should she change her mind and break the contract by deciding she would like to keep the child once born.¹² Who are the parents, or more specifically, who is the mother, in these cases: the woman who carries the fetus to term or the contracting couple?

Perhaps one of the most sensational legal battles with respect to just these issues was that of "Baby M" in the United States.¹³ In 1985, William Stern, a biochemist, contracted Mary Beth Whitehead, a homemaker, to carry a fetus to term for himself and his wife Elizabeth, a pediatrician. Mary Beth Whitehead would receive US \$10,000 upon successfully delivery a baby to the Sterns (which was genetically related to Whitehead and William Stern.) Once the baby was born, Whitehead decided that she had made a terrible mistake and could not live up to the contract. She attempted to keep the baby she called Sara Whitehead. The Sterns tracked down the Whiteheads, who had fled with the child,

¹⁰ Michelow, M.C. et al. "Mother-daughter in vitro fertilization triplet surrogate pregnancy," Journal of In Vitro Fertilization and Embryo Transfer, Vol. 5, No. 1 (1988), pp. 31-34.

¹¹ Eichler, "Reflections" in Misconceptions, Vol. 2, p. 208.

¹² Certainly similar pressures may exist in altruistic arrangements.

¹³ Such demands are not limited to merely carrying a fetus for the contracting couple. What the contracted mother can eat or drink, where she can go, etc. are all subject to contractual restrictions. For an excellent example of how severely a woman's rights are curtailed, see the contract between Mary Beth Whitehead and William Stern in the case of Baby M. *In RE BABY M*, 525 A.2d 1228 (N.J. Super. Ct. 1987); this contract is also reproduced in Dianne M. Bartels, et al, eds., Beyond Baby M: Ethical Issues in New Reproductive Technologies, New Jersey: Humana Press, 1989, pp. 263-267.

¹⁴ For details on this case see *In RE BABY M*, 525 A.2d 1228 (N.J. Super. Ct. 1987) and, for example, Rita Arditti "A Summary of Some Recent Developments on Surrogacy in the U.S.," Reproductive and Genetic Engineering,

and took them to court over the broken contract. New Jersey Judge Sorkow awarded full custody of the baby now called Melissa Stern, to the contracting couple. The landmark case explicitly considered commercial contracts, making clear the respective rights: "The biological father pays the surrogate for her willingness to be impregnated and carry his child to term. At birth, the father does not purchase the child. It is his own biological genetically related child. He cannot purchase what is already his."¹⁴ There was a similar court battle five years earlier in Canada when a Florida woman was contracted to carry a child for a Scarborough, Ontario couple.¹⁵ The woman was to deliver the baby in Canada. When the woman decided to leave Canada without giving the baby to the contracting couple, the Metro Toronto Catholic Children's Aid Society seized the child. In the ensuing court case, the judge ruled that the contracting man was the legal and biological father and awarded custody to the Scarborough couple.¹⁶

The woman who carries the fetus and delivers the child are seen by the courts, the contracting couples, and the brokers who arrange these transactions to be providing a service:

[T]he surrogate does not sell the child, she is paid for her collaboration with the child-project conceived by the [contracting] couple. It may be said that the surrogate is placing her 'procreative force' at the couple's disposal, in the same way as a worker does for his employer with his 'working force,' and this undertaking can be perfectly accepted from both the ethical and legal standpoint.¹⁷

Critics of such arrangements liken the labour power of women to economic conditions as well. However, unlike the New Jersey or Ontario judges, the contract issue is not so

Vol. 1, No. 1 (1988), pp. 51-61, Dianne M. Bartels, et al, eds., Beyond Baby M: Ethical Issues in New Reproductive Technologies, New Jersey: Humana Press, 1989

¹⁴ Superior Court of New Jersey, 1987-70 and 71, as cited in Arditti "A Summary of Some Recent Developments on Surrogacy in the U.S.," p. 54

¹⁵ Somer Brodribb, "Off the Pedestal and Onto the Block? Motherhood, Reproductive Technologies, and the Canadian State," Canadian Journal of Women and the Law, Vol. 1, No. 2 (1986), pp. 407-423

¹⁶ Brodribb, "Off the Pedestal", pp. 415-416. It should be noted that in both cases, appeals took place which overturned the original judgements. However, the original judgements continued to have had a profound affect upon perceptions with respect to these arrangements. In the New Jersey case, custody was restored to Whitehead (with visiting provisions for the Sterns) and "surrogate mother contracts" were deemed illegal in New Jersey. Conversely, in the Ontario case, custody was awarded to the "genetic father," upholding preconception arrangements.

simple: the women contracted to do such work are seen to be exploited and the resultant children as commodities. It has been estimated that the nine months of work involved in conceiving of, gestating and delivering a baby works out to about \$1.50 per hour for the women contracted in preconception arrangements.¹⁸

Surrogacy is not motherhood. It is not even a service, because the woman is not paid for the service she does for the contracting father. What she is paid for is the 'product,' the child. Surrogacy is thus a new 'piece work industry' which functions analogously to the exploitation of women whose labour power at home is contracted.¹⁹

Proponents of contractual arrangements view them as willingly entered into by all parties. The gestational mother freely agrees to give up some of her liberties in exchange for monetary gains. These arrangements are not inexpensive; the average payment to the gestational mother is approximately US \$10,000 and associate broker fees are over US \$15,000, for a total of at least \$25,000.²⁰ Eichler compared a number of socio-economic differences between the commissioned women and commissioning men. The results support what critics of these arrangements have argued: that there tends to be a distinct class and thus a power difference with wealthy couples contracting the services of relatively poor women.²¹ The choices for the latter are not truly open. The gestational mother stands to profit monetarily upon delivering a healthy baby for the contracting couple. The contracting couple stands to have a child of their own, in some cases, fully genetically related to them. In Canada, only in Quebec are such commercial arrangements against the law.

Sacha Geller, "The child and/or the embryo: To whom does it belong?" Human Reproduction Vol. 1, No. 8, p. 562

¹⁸ Brodribb, Reproductive Technologies, Masculine Dominance and the Canadian State (Toronto: Ontario Institute for Studies in Education, 1984), p. 12

¹⁹ Mies, "From the Individual to the Dividual," p. 229

²⁰ Dianne M Bartels "Surrogacy Arrangements: An Overview," in: Bartels, et al, eds., Beyond Baby M: Ethical Issues in New Reproductive Technologies, p. 176 and Eichler, "Reflections" in Misconceptions, Vol. 2, p. 205

²¹ Margrit Eichler and Phebe Poole, The Incidence of Preconception Contracts for the Production of Children Among Canadians (Canada: Law Reform Commission of Canada, 1988), p. 40

Generally, gestational arrangements involve the use *in vitro* fertilization²², where multiple eggs are withdrawn from a woman's body and are combined with a man's sperm *in vitro*. As the fertilized egg divides and subdivides (in the zygote stage), it is then implanted into the gestational mother. These arrangements, too, may involve commercial or contractual arrangements and can become mired in contractual or legal battles. An equally significant risk is that associated with the technology itself.

The technologies related to *in vitro* fertilization are perhaps some of the most dubious of the reproductive technologies for they allow the creation and manipulation of the zygote outside of the woman's body. Genetic technologies such as cloning or the manipulation of genetic materials are made possible by these techniques. These complex technologies are seen to be some of the most cutting-edge and profitable. Many genetic technologies would not be possible without reproductive technologies such as *in vitro* fertilization. While genetic technologies will not be fully explored in this thesis, the link between reproductive and genetic technologies is crucial.²³

Due to the many risks associated with the fertility drugs and the techniques themselves, the World Health Organization has classified *in vitro* fertilization as highly experimental and not appropriate for widespread use. Risks include: potential links to cancer from the fertility drugs used; significantly increased chance of multiple pregnancies (risky for both mother and developing fetuses; expensive for parents); unknown health risks of using frozen zygotes; increased chances of spontaneous abortion or miscarriage; increased risk of infection (due to invasive instruments used in egg extraction; zygote implantation; amniocentesis); increased risk of ectopic pregnancy (where the embryo

IVF is but one step in a series of technologies, although many use the term "IVF" to refer to the entire process. For a proper sense of the actual steps, see for example, Andrea L. Bonnicksen, In Vitro Fertilization: Building Policy From Laboratories to Legislatures, (New York: Columbia University Press, 1989); Sue Cox, Dissenting Voices: New Reproductive Technologies and Feminist Analysis, 1991, Law Reform Commission of Canada Medically Assisted Procreation Working Paper 65 (Ottawa: CJC, 1992), pp. 11-13; Louise Vandelac, "The Industrialization of Life," in eds. Basen et al., Misconceptions Vol. 2, 1993, pp. 99-114.

²³ On issues of genetic technologies, see Andrew Kimbrell, The Human Body Shop: The Engineering and Marketing of Life (New York: HarperCollins, 1993) and Marjorie Luisa Moringoff, The Social Costs of Genetic Welfare (New Jersey: Rutgers University Press, 1991).

embeds itself and develops in the fallopian tubes rather than the uterine wall); increased chance of ovarian hyperstimulation syndrome (responsible for at least 10 known deaths); depression; migraine headaches; extreme stress to woman and other family members; loss of income (the woman must miss work for the two weeks of monitoring, and additional time if complications arise); increased chance of premature birth or low birth weight; and increased chance of cesarean birth and other potential, but undetermined risks (since the technologies are not very old or well-tested).²⁴

The World Health Organization (WHO) emphasizes that research on these technologies has mainly been concerned with perfecting clinical protocols and broadening admissibility criteria [by changes to definitions of infertility or by expanding it from the original use for women with blocked fallopian tubes]. The WHO document states as well that this research serves the interests of those who benefit from the spread of these services, rather than assisting in rational health planning based on the needs of the population.²⁵

In vitro fertilization, whether it is used in conception arrangements or by infertile women or couples, represents an extremely profitable industry for practitioners and researchers. The founder of this technology in humans, Doctor Robert Edwards (along with Doctor Patrick Steptoe) has benefited in many ways: he is the founder of England's Bourn Hall Clinic which is now a part of a commercial chain of fertility clinics (owned by Ares-Serono); and he is the acknowledged leader in many of the innovations related to *in vitro* fertilization. Perhaps more disturbing is the extent to which these practitioners have the ability to exert control over the women they are purporting to assist. When Edwards and Steptoe attempted *in vitro* fertilization techniques with Ms. Brown, she had to agree in writing that she would abort if these doctors felt this was necessary.²⁶

²⁴ Risks associated with these techniques are well documented. See, for example, Marian L. Carter and David N. Joyce, "Ovarian Carcinoma in a Patient Hyperstimulated by Gonadotropin therapy for in vitro fertilization: A Case Report," Journal of in Vitro Fertilization and Embryo Transfer Vol. 4, No. 2 (1987), pp. 126-8; Francoise Labovic, "New Reproductive Technologies: News from France and Elsewhere," Reproductive and Genetic Engineering, Vol. 1, No. 1 (1988), pp. 77-85; Jan Rehner, Infertility: Old Myths, New Meanings (Toronto: Second Story Press, 1989), and Vandellac, "The Industrialization of Life," p. 108.

²⁵ Vandellac, "The Industrialization of Life," p. 109.

²⁶ The Boston Women's Health Collective, The New Our Bodies, Our Selves (New York: Simon & Schuster, Inc., 1984), p. 321.

The pharmaceutical industry profits enormously from the use of fertility and other drugs (Ares-Serono, for example, made over \$71 million in profit in 1991). The segments of the biomedical industry who make the medical devices also profit financially. The couples making use of these technologies also may benefit from having a baby (or multiple babies), however, the technique itself is (at best) 9.5% effective at delivering to couples a live baby. According to Dr. Marsden Wagner, Director of Maternal and Child Health, European Regional Office of the World Health Organization, this may be more accurately defined as a failure rate of 90%.²⁷ *In vitro* fertilization is an example where members of the medical profession are tenaciously pursuing a technology that is of dubious merit to society, but provides benefits to themselves and many related institutions or industries.

b. Prenatal Diagnosis and Sex Selection

While prenatal diagnosis and sex selection are discrete from one another in terms of the procedures themselves and the primary groups affected by them, they appear together here due to similarities in their features and issues. In both cases, identifiable groups in society may be the targets of discrimination through the use of these technologies. Conversely, women have argued that they have a right to knowledge about their own bodies. If a technology exists which provides this type of insight it is paternalistic to deny access to it. While both sets of technologies carry some health risks, they are presented here as examples of technologies which are contested, morally and ethically.

Prenatal diagnosis permits both medical doctors and prospective parents to know about the physical traits of the developing embryo. Based on this knowledge of genetic traits such as sex or eye colour, or of congenital anomalies, changes to the embryo can theoretically then be made. Abortion can eliminate those embryos or fetuses with what some would call undesired traits. Sex selection is generally conducted using prenatal diagnosis. Both technologies open the door to genetic engineering, and the sensationally

²⁷ Gena Corea, "Current developments and Issues: IVF patients are experimental subjects, WHO official tells International IVF Congress (Israel: 1989)." Reproductive and Genetic Engineering, Vol. 2, No. 3 (1989), pp

termed "designer babies", and have been raised as examples of potentially disastrous technologies in terms of selective breeding, or eugenics.

Prenatal diagnosis involves the use of techniques to test the health (and attempt to detect disorders present at birth or disorders inherited genetically from one or both of the biological parents) of the developing embryo or fetus. Some of the most commonly practiced diagnostic techniques include: amniocentesis, the drawing and analyzing the DNA of a sample of the amniotic fluid; chorionic villus sampling, the drawing and analyzing the DNA of a sample of the membrane surrounding the fetus or embryo; maternal serum alpha fetal protein test, a blood test (of the mother's blood) which tests the protein produced by the fetal liver; and ultrasound scanning, high-frequency waves focused on the body which produce video images of the fetus or other tissues. The first three are invasive (a needle is used), while ultrasound is conducted outside of the body. Physical risks include increased rates of infection (which may threaten the successful term of the fetus or the fertility and health of the mother) or heightened risks of cancer.

All of these techniques were developed for what is termed "high risk" pregnancies, yet each are becoming an increasingly routine part of pre-natal care for greater numbers of women. For example, when first introduced, amniocentesis was prescribed by doctors for pregnant women over the age of 40, or those who were statistically at higher risk for bearing a child with a congenital abnormality. Currently, amniocentesis is recommended for pregnant women over the age of 35. While the inclusion of a greater age range may have occurred due to an increase in the understanding of genetically linked disorders, critics have noted that incentives such as profit motive, fear of medical malpractice suits or a desire to eliminate disability seem to underlie the change.²⁸

253-4. While these figures are somewhat dated and practitioners are currently claiming success rates of up to 30-40%, they have yet to disclose any documentation to support such figures.

²⁸ Barbara G. Hanson, "The Myth of Biological Time Clock," Presented at the Session, "Gender and Health Reproductive Concerns," at the 1992 annual meetings of the American Sociological Association. Abby Lippman, "Access to Prenatal Screening Services: Who Decides?" Canadian Journal of Women and The Law Vol. 1, No. 2 (1986), pp. 434-445. Lippman, "Prenatal Diagnosis: Reproductive Choice? Reproductive Control?" in Overall ed. 1989, pp. 188-9. Lippman, "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing

Attempts to eliminate disability through prenatal diagnosis are highly objectionable and discriminatory to people living with disabilities. Sandra A. Goudry of the Canadian Disability Rights Council argues that prenatal diagnosis, as it is used to detect congenital or genetic birth defects is both misguided and discriminatory.²⁹ If the goal is to prevent disability, prenatal diagnosis is neither accurate or effective. Genetically-linked and congenital disabilities account for only approximately 3% of all disabilities.³⁰ Prenatal diagnosis may detect the existence of an abnormality, but it can not determine the extent or true nature of it: making the link between detection and disability a more tenuous one. Further, there are no known cures for the conditions that are being screened for. Prenatal diagnosis and other reproductive and conceptive technologies are not serving to increase the choices of women, but instead are limiting them as increased societal and professional pressures tend to force them to abort high risk fetuses, or to not conceive at all.

The emphasis on eliminating disability diverts public attention and resources away from disability discrimination, that is, the social, economic and legal consequences of disability are ignored and remain entrenched. A public policy which supports detection technologies for the purpose of eliminating fetal anomalies, reinforces the discriminatory view that existing persons with disabilities are inherently lacking as human beings.³¹

The underlying desire or goal is to have healthy children. The solution, disability rights advocates assert, is more readily attained by focusing on the combined or linked health of

Inequities." American Journal of Law and Medicine Vol. 17, Nos. 1&2 (1991), pp. 15-50; Lippman, "Worrying and Worrying About: The Geneticization of Reproduction and Health," in Misconceptions, Vol. 1, pp. 39-65; Yvonne Peters et al, NRTs: The Contradictions of Choice: The Common Ground Between Disability Rights and Feminist Analyses, Conference Summary Report (Vancouver: DAWN NAC, 1994); Marsha Saxton, "Prenatal Screening and Discriminatory Attitudes Towards Disabled People," in Transition February (1991), pp. 15-17. In response, see, Dorothy C. Wertz and John C. Fletcher, "A Critique of Some Feminist Challenges to Prenatal Diagnosis," Journal of Women's Health, Vol. 2, No. 2 (1993), pp. 173-188.

²⁹ For an overview of concerns of women with disabilities see, for example, Sandra A. Goudry, "The New Reproductive Technologies, Public Policy and the Equality Rights of Women and Men with Disabilities," in Misconceptions, Vol. 1, pp. 154-166; Yvonne Peters et al, Four Discussion Papers on New Reproductive Technologies (Winnipeg: DAWN CDRC, 1991); Maria Barile, An Overview of New Reproductive Technologies Women with Disabilities, Vol. 1 (Montreal: Action Des Femmes Handicapees de Montreal, 1994); Special Edition on New Reproductive Technologies in Transitions, Vancouver: Transition Publication Society, Feb. 1991; Yvonne Peters et al, NRTs: The Contradictions of Choice: The Common Ground Between Disability Rights and Feminist Analyses, Conference Summary Report (Vancouver: DAWN NAC, 1994).

³⁰ Marsha Saxton NRTs: The Contradictions of Choice Paper Presented at Conference (Vancouver: DAWN NAC, 1994); also Royal Commission on New Reproductive Technologies, Proceed With Care, Vol. 2, (Ottawa: Minister of Government Services Canada, 1993), p. 753 cites a figure of 4%

both the mother and fetus and ensuring adequate resources for education, counselling and preventative measures (such as reducing environmental risks, poverty and abuse) which are non-discriminatory.

Should individuals and medical practitioners ethically have control over whether to carry on with a pregnancy, based on information gleaned from the (inexact) technologies? "In fact, determining whose risk is 'high enough' and specifying what conditions are 'undesirable enough' involve personal, ethical and social values. They cannot be resolved by scientific/technical analysis or by medical fiat."¹² Of primary concern is the extent to which prejudiced attitudes or stereotypes influence people to make choices that not only continue to discriminate against people with disabilities (or female embryos, as will be posited in the case of sex selection), but also take money away from technologies and programs that can be effective in ensuring the health of both the mother and fetus.

Sex selection involves identifying the sex of the developing embryo and making decisions based on this information, either to carry through with an implantation of the embryo, or to terminate the developing embryo or fetus. Information about the sex of the embryo or fetus may be obtained in three basic ways: by using "sperm treatment with assisted or donor insemination" whereby a woman's egg is fertilized with sperm with chromosomes that will lead to a child of the desired sex; by determining the sex prior to implanting a developing embryo (a woman's egg which has been fertilized with a man's sperm) into a woman's womb, known as "pre-implantation diagnosis" and uses the technique *in vitro* fertilization (described below); and "prenatal diagnosis" by which the sex of the fetus can be established through the use of ultrasound, or sampling of the embryonic fluids (chorionic villus sampling or amniocentesis) and the fetus is either kept or aborted based on the results.

Sandra A. Goudry, "Final Recommendations to the Royal Commission on New Reproductive Technologies," (Winnipeg: The Canadian Disability Rights Council, 1992), p. 1.
"Lippman, "Access to Prenatal Screening Services: Who Decides?" p. 441

Advocates of sex selection for non-medical reasons believe that it allows them to complete their families. Generally this increases reproductive choices as women or couples do not have to have additional children in these attempts, which is both costly and difficult for the women. If as many believe, there is a societal preference for males over females, these types of technologies may lead to selecting male fetuses over female ones. Whether or not this is statistically proven, critics argue that aborting an otherwise healthy fetus for no reason other than its sex is irresponsible and discriminatory. Pro-life/anti-abortion groups protest against any measures to abort fetuses on ethical or religious grounds and do not support prenatal diagnosis or sex selection.

Practitioners have targeted specific cultural groups with prenatal diagnosis services, such as the Indo-Canadian communities. Dr. Stephens, a Washington State practitioner who consistently targeted South Asian communities in Vancouver for his pre-natal diagnosis (through ultrasound), costing US \$500 per test, did so based on "racist stereotyping of Indo-Canadian culture and the devaluation of women for centuries."³³

Those who stand to profit include practitioners who run private clinics; doctors who offer the technologies in a public setting (through increased billing); the biomedical industry (who make the related instruments including catheters, ultrasound equipment, storage facilities etc.); and the pharmaceutical industry which produces related fertility and other drugs or chemical compounds. Couples argue that they benefit by having the healthiest possible fetus (and ultimately, child) and have increased ability to control what kind of children they will have (sex, physical traits, etc.). Some proponents argue that society benefits due to decreased social costs related to caring for children with disabilities. Those at risk from these tests include particular groups in society who are being discriminated against: people with disabilities argue their right to reproduce, their access to funding and

³³ Sunera Thobani, "More Than Sexist," Kinesis November 1990, pp. 12-3, and, Jackie Brown, "Sex Selection: The Ultimate Sexist Act," Kinesis, October 1990, p. 7 and Forum Against Sex Determination and Sex Preselection Group, "Using Technology, Choosing Sex: The Campaign Against Sex Determination and the Question of Choice," in Vandana Shiva, ed., Close To Home: Women Reconnect Ecology, Health and Development Worldwide (Philadelphia: New Society Publishers, 1994), pp. 78-87.

general perceptions about disability may be imperiled by these technologies; people from specific ethno-cultural groups are at risk due to stereotypes of their culture and marketing ploys by practitioners acting on such representations; women and girls who may be selected out if preferences for males supersedes that for females. As well, women, the fetus and the children born of the technologies are open to health risks associated with these technologies.

c. Assisted or Donor Insemination

Assisted or Donor Insemination (AI or DI) is a relatively straightforward technique that has been used for centuries to assist women to conceive in various instances: where a woman's male partner is infertile or sterile; where a woman is a lesbian and wishes to conceive; where a woman wishes to conceive without a partner; where a woman is unable to conceive for undetermined reasons. Sperm is placed in the uterus either using an alternate male partner or via an intrauterine device (as simple as a turkey baster or a sterile syringe). In Canada, Assisted or Donor Insemination is available through public institutions (teaching and other hospitals); private clinics and some individual medical doctors. In addition, women are able to by-pass any of these medical setting options by inseminating themselves with donated sperm. Assisted or Donor Insemination can be a highly effective, relatively inexpensive option for those wishing to conceive. However, in the past thirty or forty years since its first documented use in Canada, the risks of this technique have become more obvious and have increased as well.

Many of the risks and negative aspects are preventable. For example, women have become infected with HIV, hepatitis, genital warts and other sexually transmitted diseases through assisted insemination. A simple screening of sperm used in inseminations can be done to ensure that rates of infection are limited. The Canadian Fertility and Andrology Society guidelines indicate that this type of screening should take place, but this is only a recommendation, it is not compulsory. Currently, there is no way to easily determine which institutions or clinics are following such recommendations. Those who are

practicing self-insemination would likely not have access to screening facilities. According to the New Reproductive Alternatives Society, a group of British Columbia women who have had children by Assisted or Donor Insemination (and who made a submission to the Royal Commission pressing for better regulations associated with these techniques), testing is woefully inadequate or in some cases, non-existent.³⁴ Testing sperm involves added time, procedures/steps and money. The knowledge that sexually transmitted diseases can occur through sperm has been established for decades. That the existing regulators (such as the Canadian Fertility and Andrology Society) have failed to make testing compulsory constitutes a lack of will and, arguably, an iatrogenic action. By avoiding testing, individual doctors and clinics reduce their expenses associated with offering this technique but increase the risks to women using it and their offspring.

A second, highly controversial, concern associated with Assisted or Donor Insemination is that of record-keeping. There is no requirement to keep records about the sperm donors. The New Reproductive Alternatives Society uncovered ethically questionable examples of doctors who used their own sperm for countless inseminations. The Society also found instances of doctors and clinics who destroyed all records (including those of the women using the services.) The women and men who raise these children have expressed concern about the lack of knowledge of the child's medical history, something that most Canadians take for granted. This information has been lost through the destruction of records. As well, should the child wish to contact their genetic parent, they would not be able to do so. Parents from groups like the Reproductive Alternative Society project that there will be an increasing demand for genealogical information as well as an increased need for counseling services or other forms of support when this information is not available. Conversely, donors argue they have a right to anonymity and would not otherwise "donate"³⁵ their sperm to clinics.

³⁴ Presentation and Submission to Health Canada, Vancouver B.C., September 20, 1994

³⁵ Arguably, the men are not truly *donating* their sperm as they are provided with monetary compensation. Proponents argue the donation truly is a donation (hence not subject to exploitation or other risks), since donors

Ethically, questions arise around parenthood: who is the father, the sperm donor or the legal partner? In a recent Ontario case, a judge found that the former husband of a woman who conceived a child through donor insemination could claim custodial rights even though he was not the sperm donor, nor was he still living with the mother of the child. The mother was forced to remain in Ontario against her wishes. Women's rights advocates argue that such a decision discriminates against the mother who may need or want to move in order to find work, to advance her career, to be close to her supports or for any other reason.³⁶

Finally, there are issues of access. Many of the practitioners who provide the service of Assisted or Donor Insemination operate private clinics. This allows them to create their own fee schedule, it also permits them to determine who is appropriate as both a sperm donor and a sperm recipient. Practitioners are independently determining who is a "good" sperm donor and who is a "bad" one: a highly subjective determination which is open to discrimination. There are several documented cases where single women, heterosexual couples or lesbians were denied access. One lesbian couple took their case to the B. C. Human Rights Commission when Vancouver practitioner Doctor Corn explicitly denied services to them because of their sexual orientation.³⁷

Those who can benefit from this technology include: women (who wish to conceive and are otherwise unable to do so); practitioners who run clinics (they stand to make attractively large sums of money); the biomedical industry who produce the related instruments (sterile catheters, sperm storage facilities, etc.); the pharmaceutical industry for any fertility drugs used in these procedures (highly profitable), and to a lesser extent, the legal system (through custody or access challenges). Women and the children born through

are being compensated for their time and travel, not for their sperm body products. Interestingly, those who donate blood or blood products in Canada are not provided with similar compensation.

³⁶ Sean Fine, "Man declared baby's father though his sperm not used," Globe and Mail (Toronto) Feb. 15, 1995, A1, 2.

³⁷ Judith Lavoie, "Lesbians 'show and tell examples' of bad moms," Times Colonist (Victoria) Jan. 16, 1994, C1; Raj Takhar, "Dykes with tykes okay," Angles (Vancouver) Jan. 1994, p. 1, and Rebecca Wigod, "Artificial Insemination: Lesbian Couple who want child denied sperm," Vancouver Sun (Vancouver) July 22, 1993, A1.

the use of assisted insemination are both medically and socially at risk. Assisted or Donor Insemination, is an example of an older, lowly-technological and potentially low-risk option for people who wish to conceive. Due to the way it has been developed and offered as a medical treatment however, it represents a technique with significant (and readily preventable) health risks as well as social and ethical complications.

II. Conclusion

Reproductive and genetic technologies such as preconception arrangements (including the use of *in vitro* fertilization), prenatal diagnosis, sex selection and assisted insemination are selected examples of technologies which were available prior to the call for a federal Royal Commission. They are presented here as cases which ultimately led to the call for a public investigation by feminist and other critics. Issues raised by the technologies were importantly not limited to ones of physical health, but included a broad array of rights, ethical, financial and human rights concerns.

By the mid-1980's a group of women based in central Canada converged to examine these issues and spread the word to other interested organizations and individuals in Canada and abroad. Originally called the Canadian Coalition on New Reproductive Technologies, they coalesced out of an expressed need for a critical and broad debate, national in scope, and more inclusive of women and feminist principles in general.

The Canadian Coalition on New Reproductive Technologies grew out of our concern that the social issues surrounding these technologies and new social arrangements are of tremendous social significance. Canadians need to understand what these technologies involve and begin to debate these issues. Public education and debate should involve as many people from as many walks of life and parts of the country as possible. It is particularly important that women become involved in this debate which so far has been dominated by male lawyers and physicians.³⁸

Together, this coalition pressed for a national public inquiry that would raise awareness on these issues with the ultimate end of creating some form of regulation of the technologies themselves.

³⁸ Eichler, Margrit, et al. Outreach Letter of the Canadian Coalition on New Reproductive Technologies (Toronto, Ontario) August 5, 1987, p. 1

CHAPTER FOUR

THE ESTABLISHMENT OF A ROYAL COMMISSION

I. Introduction

By the mid-eighties, the reproductive and genetic technologies described in Chapter Three were well established both within the medical community and the public marketplace. Some of these technologies were covered under some provincial medical insurance plans and others not. For example, *in vitro* fertilization was covered by the Ontario Health Insurance Plan, while the procedure was not even offered, much less covered, in Saskatchewan. Many of the technologies existed with little enforceable regulation or policy governing their use and inconsistent tracking of their occurrence. They were offered through individual doctors, hospitals or private clinics. This created a patchwork of services across the country as well as a growing concern about the implications of the technologies themselves as articulated by groups such as the Canadian Coalition on New Reproductive Technologies, the Reproductive Alternatives Society, infertility groups and others such as some medical and legal groups and researchers.¹

The federal government needed to act upon this broad policy area. While it had a wide range of policy mechanisms to choose from, it was clear that the public was demanding a process that would deliver a means for all sectors in society to be involved. There was concern that the government would further enable those groups who already had significant interest in and control over the technologies to determine what policies should be in place which would affect all of Canadian society. Should this occur, it seemed certain these interests would argue for the *status quo*, that is, continued lack of any meaningful regulation governing the technologies.

¹ Andrea Calver, "Document: Introduction to 'The New Reproductive Technologies: A Technological Handmaid's Tale,'" Issues in Reproductive and Genetic Engineering, Vol. 4, No. 3 (1991), p. 275.

Margrit Eichler, a sociologist at the Ontario Institute for Studies in Education, had brought others together to press for this broader public discussion of reproductive and genetic technologies.

In 1987 ... I started quite consciously at that time running around and saying: "We need to do something and we want a Royal Commission." Then I realized you can't do that: run around the country and say that without doing anything. Then we started the Coalition, which was just five women in the beginning [Rona Achilles, Margaret Buist, Margrit Eichler, Anne Rochon Ford and Linda Williams]. We eventually grew to become the Coalition [The Canadian Coalition for a Royal Commission on New Reproductive Technologies] and then we got the Commission!²

Together, they approached the federal government in June 1987 outlining their concerns and calling for governmental action: "[w]e feel that the best way to achieve public education, debate, and resolution of these issues is through a Royal Commission on the Social Aspects of New Reproductive Technologies."³

This chapter will outline briefly some of the policy mechanisms available to the federal government for the purposes of conducting an investigation of reproductive and genetic technologies. Particular emphasis is given to the vehicle called the royal commission, since this was ultimately the instrument selected by the federal government. The Canadian Coalition seemed to have gotten what they wanted in the establishment of the Royal Commission on New Reproductive Technologies. It did not take long, however, for concerns to be raised about whose interests were being served through what was supposed to be a multi-disciplinary and critical public investigation of the technologies.

II. Royal Commissions in Canada: quaint tradition; cadillac public policy instrument?

When attempting to decide which policy vehicle to pursue, the women in the Canadian Coalition on New Reproductive Technologies were faced with trying to unravel which policy mechanism would best deliver the public debate and decision-making with

² Margrit Eichler, interview, Toronto, Ont., January 30, 1995.

³ Rona Achilles et al. Letter from Canadian Coalition on New Reproductive Technologies to Hon. Jake Epp (Toronto, Ontario), June 27, 1987, p. 2. This letter from the Coalition sent to Jake Epp, then Minister of National Health and Welfare, was endorsed by 29 individuals (including Maureen McTeer who was to become a

respect to the myriad of issues related to the technologies. The options included: ombuds investigations; the courts; advisory councils; parliamentary committees; the bureaucracy; task forces; and royal commissions or public inquiries.

Ombuds investigations and the various levels of courts in Canada, while unique from one another, are similar in their limitations with respect to creating effective public policy. Neither were designed to be instruments of policy creation, although frequently they dramatically affect policy through their decisions or findings. Both mechanisms are complaint-driven and hence tend to deal with issues after-the-fact in a reactive, remedial way. Their respective investigations may be limited to matters involving the public office and/or bureaucracy (this is particularly the case for Ombuds offices). As well, they tend to investigate specific matters of alleged wrong-doing, not broad issues of public concern or interest. The result, in terms of public policy, tends to be a patchwork of decisions that may not relate to one another in any coherent way. Finally, there exists no mechanism for public consultation, one of the key demands of those pressing for governmental action on issues relating to reproductive and genetic technologies.

Undoubtedly one of the most influential groups of contributors to the making of public policy is the bureaucracy. Many public servants are employed specifically for the task of creating or evaluating policy for the government. However the bureaucracy, as a permanent structure within the government, is not designed to conduct large-scale investigations or consultations (although they frequently aid in some of this work). As well, the government is structured into departments which are not necessarily well positioned to conduct the inter-disciplinary work required for an investigation into reproductive and genetic technologies. Finally, it would be difficult for the bureaucracy to manage a critical investigation of some of the very work it is responsible for enabling; particularly given the linkages between senior civil servants and members of the scientific and academic communities. "[W]ithin a closed system of governmental decision-making,

Commissioner) and 12 organizations, including the National Action Committee on the Status of Women, all of

scientists, especially at a relatively senior level, do not function *just* as scientists.”⁴ These scientists generally become part of a closed policy community, as described in chapter two, where they function either formally or informally to direct decision-making in their respective policy field.⁵

Advisory councils and parliamentary or other *ad hoc* committees are important contributors to the creation and evaluation of public policy. They tend to be relatively small in size, hence flexible. They can and do consult with the public, although the degree of consultation is generally limited. Given that they are frequently comprised of elected Members of Parliament, these committees or councils may suffer from political pressures that affect the scope or depth of their investigations. And while these committees may come up with sound policies, they may never make it to implementation due to an unfavourable climate (for example: an election, the budget, etc.), or to the nature of advisory bodies *per se*.

Task forces are similar to royal commissions. Like commissions, they are *ad hoc* investigatory bodies formed by an Order-in-Council. Although they vary in degree of formality and size or area of study, task forces generally function at an arms-length from the formal mechanisms of government. They are thus able to make recommendations that might otherwise not be considered by government. This same freedom serves to bind them: if the recommendations are unattractive to the government in question, it is relatively simple to bury the report of a task force. “As far as governments are concerned, the great advantage of a task force is that its work can usually be kept secret. Consequently, if a

whom were active across the country.

⁴ Schrecker, “Mobilization of Bias in Closed Systems: Environmental Regulation in Canada”, p. 56.

⁵ Michael M. Atkinson and William D. Coleman, “Strong States and Weak States: Sectoral Policy Networks in Advanced Capitalist Economies,” British Journal of Political Science, 19 (1989), p. 57; Peter F. Cowhey, “The International Telecommunications Regime: The Political Roots of Regimes of High Technology,” International Organization, 44 (1990), p. 173; Stephen Wilks and Maurice Wright, Comparative Government Industry Relations: Western Europe, United States and Japan (Oxford: Clarendon Press, 1987), pp. 302-3.

government does not like what it is told, it simply fails to publish the task force's report and makes its priority determination in favour of the status quo."⁶

In the December 1987 *Report to Canadian Coalition on New Reproductive Technologies Endorsers*, steering committee member Margrit Eichler wrote:

Some of them [Members of Parliament, Senators and "top officials in government" at a meeting with Coalition members] raised the question: "Why not a Parliamentary Committee instead of a cumbersome Royal Commission?" Our response to that was that Parliamentary Committees are composed of M.P.s. With a federal election looming in the not too far future, it does not seem the best time to set up a Parliamentary Committee now. Beyond that, we feel strongly that only a Royal Commission has the overall status to ensure a widespread public education function, and that any commission should be staffed by lay people who have a history of concern with issues of reproduction, rather than mostly specialists of any type. In addition, Royal Commissions usually conduct their own independent research.

No policy instrument save the commission offered the opportunity for massive public input "Although there is a case to be made for greater reforms to our operation of parliamentary committees in this system of government, committees of inquiry are a poor substitute for commissions of inquiry for the purposes of policy analysis."⁷ In the end, the organization's name change to the Canadian Coalition for a Royal Commission on New Reproductive Technologies (in the autumn of 1987; hereafter referred to as "the Coalition") reflects their decision to press for a federal inquiry or royal commission.⁸

Royal commissions or commissions of inquiry are State-sponsored mechanisms which usually examine specific incidents or matters of policy concern. They typically gather information and issue a report of findings and/or recommendations.⁹ Federal royal commissions are created either by the Governor in Council or by any "minister presiding over any department of the Public Service."¹⁰ The powers and structure of the commission are outlined in the Federal *Inquiries Act* (see Appendix 3); but some 47 other statutes may

Richard J. Van Loon and Michael S. Whittington, *The Canadian Political System: Environment, Structure and Process*, 3rd Ed. (Toronto: McGraw-Hill Ryerson, 1981), p. 521.

⁶ Eichler, Letter, "Report to Coalition Endorsers," (Toronto, Ontario) December 14, 1987, p. 3.

⁷ Peter Aucoin, "Contributions of Commissions of Inquiry to Policy Analysis: An Evaluation" in A. Paul Pross, Innis Christie, John A. Yogis, eds., *Commissions of Inquiry* (Toronto: Carswell, 1990), p. 205.

⁸ Eichler, Letter, December 14, 1987, p. 2.

⁹ Frank Jacobucci, "Commissions of Inquiry and Public Policy in Canada," in A. Paul Pross, Innis Christie, John A. Yogis, eds., *Commissions of Inquiry* (Toronto: Carswell, 1990), p. 23.

also be invoked as they relate to subpoenas, counsel, judges, et cetera. Strictly-speaking inquiries tend to investigate allegations of wrong-doing while royal commissions research and deliver policy recommendations on broad areas of public or national interest. In this study, the terms *inquiry* and *royal commission* will be used interchangeably to refer to public inquiries which are generally structures independent from but mandated by the government to research or fact-find, report and recommend.¹²

Royal Commissions are seemingly a favoured policy instrument of the Canadian government: Russell J. Anthony and Alastair R. Lucas estimate that nearly 400 inquiries of all types were conducted between 1867 and 1947 in Canada,¹³ while political scientist Alan Cairns cites figures ranging from 352 to 383 for federal commissions alone in the first century of Canada's existence.¹⁴ They are variously regarded with fond affection; with hope for a truly democratic and public exercise; or with disdain for their false promises.

Structurally, the commission is simultaneously desired and despised for a multitude of characteristics. Liora Salter, who has written extensively on commissions, aptly captures this when she states:

Inquiries send out mixed messages. To the public, inquiries offer the possibility of a discussion about public policy that knows few limits in terms of its participants, the information it can gather or the proposals it can entertain. This is not a false promise, although many inquiries fail to deliver upon it ... The [public] inquiry ... offers the public an unlimited opportunity for experiencing direct democracy, that is, widespread political participation in the formation of specific policies. It offers an opportunity to define public issues, in public view, with the participation of the clients of these policies. It provides an avenue for a public investigation of public and private conduct, far in excess of that conducted by the ombudsmen[sic].¹⁵

¹² *Federal Inquiries Act*, Part II 6, R.S.C. 1970, c. 113.

¹³ There exists some debate over terminology with respect to "commissions" versus "inquiries." However, given commissions often combine both broad policy and investigatory functions, it is appropriate and legitimate to use the terms interchangeably. See for example, Law Reform Commission of Canada, Report, Advisory and Investigatory Commissions (Ottawa: Minister of Supply and Services, 1979); A. Paul Pross, Innis Christie, John A. Yogis, eds., Commissions of Inquiry (Toronto: Carswell, 1990); Liora Salter and Debra Slaco, Public Inquiries in Canada (Hull: Canadian Government Publishing Centre, 1981).

¹⁴ Russell J. Anthony and Alastair R. Lucas, A Handbook on the Conduct of Public Inquiries in Canada (Toronto: Butterworths, 1985), p. 1.

¹⁵ Alan Cairns, "The MacDonald and other Royal Commissions: Their Role in Public Policy," David Alexander Lecture delivered at Memorial University, (Newfoundland) Nov. 3, 1986.

¹⁶ Liora Salter, "The Two Contradictions in Public Inquiries," in A. Paul Pross, Innis Christie, John A. Yogis, eds., Commissions of Inquiry (Toronto: Carswell, 1990), pp. 174, 181.

Related to the democratic feature, the public inquiry is favoured for its perceived objectivity and flexibility. Commissions are appointed by the government, but are independent from it, thus distancing them from the traditional, formal governance structures.¹⁶ This may permit commissioners to conduct their work in more open or less conventional ways and to entertain ideas or recommendations that may otherwise be unsavoury to the political structures of the government and the bureaucracy. Given this arms-length status, many of the bureaucratic, judicial or overtly political barriers of decision-making or policy consideration are diminished. Commissions such as the MacKenzie Valley Pipeline Inquiry ("Berger Inquiry") and the Royal Commission on the Status of Women ("Bird Commission") were examples where groups traditionally disenfranchised or discriminated against had significant voice under the auspices of a royal commission. The Berger Inquiry was intended to investigate environmental concerns, but shifted in focus unexpectedly (primarily due to the flexibility created by novel intervenor funding arrangements and other mechanisms through the innovativeness and encouragement of the chair of the Commission, Thomas Berger) to address native issues, placing these latter concerns solidly on the political agenda.¹⁷ The Bird Commission, too, began with the broad mandate of addressing the concerns of the status of women in Canadian society and developed into a propulsive force which put the women's liberation movement - or the second wave of feminism - firmly on its feet in Canada.¹⁸ The MacKenzie Valley Pipeline

Anthony and Lucas, A Handbook on the Conduct of Public Inquiries in Canada, p. 20; and Jacobucci, "Commissions of Inquiry and Public Policy in Canada," p. 28.

See Thomas R. Berger, The Report of the MacKenzie Valley Pipeline Inquiry (Ottawa: Minister of Supply and Services, 1977) and, for example, Berger, "The MacKenzie Valley Pipeline Inquiry," Queen's Quarterly 83 (1976); Salter, "The Two Contradictions in Public Inquiries," pp. 177-185.

See, for example, Nancy Adamson, Linda Briskin and Margaret McPhail, "Our History Histories," in Feminists Organizing Change: The Contemporary Women's Movement in Canada (Toronto: Oxford University Press, 1988), pp. 43-97; Sylvia B. Bashkevkin, "Independence Versus Partisanship," in Veronica Strong Boag and Anita Clair Fellman, eds., Rethinking Canada: The Promise of Women's History, 2nd Ed. (Toronto: Copp Clark Bruman, 1990), pp. 434-437; Naomi Black, "The Canadian Women's Movement: The Second Wave," in Sandra Burt, Lorraine Code and Lindsay Dorney, eds., Changing Patterns: Women in Canada (Toronto: McClelland and Stewart, 1988), p. 80-102; and, Jane Jenson, "Commissioning Ideas: Representation and Royal Commissions," in Susan D. Phillips, ed., How Canada Spends 1994-95: Making Change (Ottawa: Carleton University Press, 1994), pp. 42-47.

Inquiry and the Royal Commission on the Status of Women Commissions are generally thought of by social movement activists and social justice advocates as success stories.

Public inquiries are not without their foibles: many of which are related to the relationship between the inquiry itself and the government. Commissions of inquiry are often used to legitimate the State.¹⁹ Governments generally establish royal commissions in response to some sort of pressure: "Policy-making in most democracies is, most often, in a response to concerted pressures on the political executive 'to act on or solve' a social problem."²⁰ A commission may be established as a stalling mechanism (usually for particularly contentious issues - like those of new reproductive and genetic technologies - that may be deemed to be 'political suicide' for the government), or otherwise assuaging public demands for action, while not really acting, or altering policy at all. By establishing a public process to inquire into 'hot' or contentious issues, the government in question appears to be taking action and showing concern. Instead, the issue along with any potential embarrassment, is effectively deferred to external experts who will report back to the government with recommendations. "Inquiries provide governments with the opportunity to delay, obfuscate and defuse political controversy, and with advice that they are free to ignore."²¹

Once a commission is created, there are other barriers to achieving decisive or representative policy recommendations. The commission may also be threatened by fiscal considerations. A royal commission is an expensive means for the government to avoid political discomfort. The inquiries are disparagingly viewed as Canada's biggest industry. "[T]he Royal Commission on Bilingualism and Biculturalism featured nine commissioners with a staff of hundreds and managed, for a few brief years, to eliminate almost completely

¹⁹ Adam Ashforth, "Reckoning Schemes of Legitimation: On Commissions of Inquiry as Power Knowledge Forms," *Journal of Historical Sociology*, Vol. 3, No. 1 (March 1990), pp. 1-22.

²⁰ A. Semour Wilson, "The Role of Royal Commissions and Task Forces," in G. Bruce Doern and Peter Aucoin, eds., *The Structures of Policy Making in Canada* (Toronto: MacMillan, 1971), p. 116.

²¹ Salter, "The Two Contradictions in Public Inquiries," p. 174.

unemployment among Canadian social scientists"!²² It has been estimated that between 1958 and 1968, seven major royal commissions cost close to twenty million dollars.²³ Since that time, the price tag has risen considerably: between 1977 and 1993 seven major royal commissions cost over one hundred and forty-four million dollars.²⁴ Pressures to keep costs down may in reality mean that communities or interested groups deemed 'less crucial' to the commission's considerations get passed by. It may also mean less money is spent on disseminating information directly to the public, leaving the task to the media who often misinterpret or misrepresent facts, or present them out of context. The price of perceived objectivity is expensive too, if it entails hiring many legal counselors, judges or other highly trained and prestigious experts.

In addition to the cost of the commission, the government may use the excuse of expense to undermine the commission itself. In considering the recommendations of the commission's report, the government may opt to shelve the findings as inappropriate and impractical due to the high cost of either continuing with the review or implementing the recommendations. These very concerns have been recently raised with respect to the Somalia Inquiry.²⁵

Commissions typically end up with massive amounts of information from two main sources: by the public hearings or consultative process, and by contracted research. Commissioners must then wade through this information to produce a summary of recommendations for the government to consider for implementation. At this critical turn, the commissioners find themselves in a dilemma: there is a need to reduce the information down to a form that the government will realistically utilize, but in so doing, the authors of such reports run risks of altering the intent or meaning of the information. The authors of the report may be overwhelmed by the sheer volume; some may not have even been present

²² Van Loon and Whittington, The Canadian Political System: Environment, Structure and Process, 3rd Ed., p. 520.

²³ Wilson, "The Role of Royal Commissions and Task Forces," p. 114.

²⁴ Staff Writer, "Notable Past Inquiries," The Globe and Mail, June 24, 1996, p. A6.

at many of the hearings (so while they may have access to transcripts, they will not have had the full impact of the spirit of what was being brought forward); and if they were present, may have become biased in the process.²⁶ This further compounds the potential for the distortion of information.

Overriding these considerations is the consideration of what the government is likely to implement. Governments, often comprised of political individuals who shy away from risk-taking, are not well suited to making radical changes to policy, or implementing new policy that may be perceived of as extreme or revolutionary. As political scientist Jane Jenson notes, the Canadian system of brokerage party politics "lacks the capacity for innovation;" governments at best, frequently opt for incremental reforms to existing policy.²⁷ Given that in the past some governments have simply shelved the recommendations of commissions, the process gets turned into a guessing game of what is feasible or reasonable. This dictates to the commissioners faced with the writing of a report, often quite clearly, what stays and what goes. Salter identifies this action as "self-censorship." To this end words may be lifted out of context and used to "strategically advance certain arguments." It becomes a game of horsetrading, of give and take.²⁸

Once the commission has made its findings and/or recommendations, it compiles these into a report which is formally delivered to the government. Significantly, the commission cannot implement its own recommendations. This provision is in place to minimize political stakes for the commissioners or those who are working with the commission.

The government has no obligation to implement any of the recommendations. "Commission recommendations, ... are inputs into the black box of government decision-

²⁶ Murray Campbell, "Royal commissions dying under their own weight," The Globe and Mail, March 29, 1997, p. A1, A3.

²⁷ Courtenay, "In Defence of Royal Commissions," p. 201.

²⁸ Jenson, "Commissioning Ideas: Representation and Royal Commissions", p. 51.

²⁹ Salter, "The Two Contradictions in Public Inquiries," p. 183.

making..."²⁹ Given that a commission cannot implement its own recommendations, there is no real direct pressure that can assure the issues will be addressed. However, due to the public exposure commissions generally enjoy, the public can apply pressure (compared to the relatively shrouded life of the task force). Should the government seek to implement some of the policy, it passes these to the bureaucracy to be converted to implementable form. However, the bureaucracy has no stake in preserving the original spirit of the recommendations (which by this time are likely to be much different than their original form). Once the report is commended to the hands of the bureaucracy, it must be transformed from broad policy statements in plain language into the language of the legal profession. Where every word is pivotal, this can critically alter what was intended by the original recommendations.

Feminists active in the issues of reproductive and genetic technologies were well aware of the pros and cons of royal commissions. They debated these issues, many resisting the work of the Coalition for fear of having the needs of women submerged by the needs of the more powerful actors (the State, biomedical researchers and professionals, etc.) The outcomes of the inquiries in Britain and Australia were held up as ready examples of this.³⁰ For the people in the Coalition, however, pressing for this public policy process seemed the best way to achieve their goals. Typically, broad mandates are issued to provide flexibility in interpretation; large sums of money are allocated for conducting primary investigative research and finding facts, public education, public hearings - all of which may ultimately lead to the alteration of existing policy and/or the formulation of new policy.³¹

²⁹ Christie and Pross, "Introduction," p. 13.

³⁰ Nancy Pollak, "Reproductive Technology: Royal Commission is a volatile mix," *Kinesis*, Nov. 89, p. 3.

³¹ Wilson, "The Role of Royal Commissions and Task Forces," p. 114. For an excellent overview of the public participation potential of the royal commission, see Christine Massey, The Public Participation Program of the Royal Commission on New Reproductive Technologies: An Evaluation, MA Thesis (Burnaby: SFU, 1994).

III. The Royal Commission on New Reproductive Technologies

On April 3, 1989 the Coalition got what they had been working for: Progressive Conservative Prime Minister Brian Mulroney announced in his Throne Speech the intent to create a public inquiry on issues related to new reproductive technologies.³² The Royal Commission on New Reproductive Technologies was formally created by a federal Order-In-Council on October 25, 1989 with a budget of \$24.7 million. Royal commissions, as described above, operate independently from the government. In a sense, however, those responsible for creating the Commission are the ultimate managers of such an investigation, no matter how hands-off they are. The government has two avenues of influence over the work of the commission: the mandate and the selection of the commissioners.

Mandate

The mandate of a royal commission is determined by the government and is crucial. How the problem(s) under study is defined has direct implications for the outcomes or solutions.³³ Mandates provide clues to the general stance toward the given area of investigation. Of particular interest for this commission was the standpoint with respect to the technologies. In other words, did the mandate critically challenge the existence of the technologies or did it (implicitly or explicitly) accept them and seek to manage them? Unfortunately, the mandate did not explicitly call into question the technologies themselves, rather, in a seemingly accepting stance it termed them "developments." However, the mandate of the inquiry was quite broad:

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.³⁴

³² "Inquiry to look at reproductive technology," Globe and Mail, (Toronto) April 4, 1989

³³ Connie P. Ozawa, Recasting Science: Consensual Procedures in Public Policy Making (Boulder, Westview Press, 1991), p. 84

³⁴ Order in Council No. P.C. 1989 2150, for full mandate, see Appendix 2

The mandate also provided a list of specific sets of issues to include for consideration. At the top of the list: "implications of new reproductive technologies for women's reproductive health and well being..." The mandate was even more ambitious given its timeline, the Commission was due to deliver its report back to the Progressive Conservative Government by October 1991. More than a year before, the Coalition had written a mandate for the use of such an inquiry, in which they had specifically called for a Royal Commission on the *Social Aspects* of New Reproductive Technologies (emphasis added). The Coalition mandate listed many of the same techniques to be researched as the federal Royal Commission mandate did, but placed far more emphasis upon the role and need for education on these issues and the social implications of the technologies; in terms of their development, uses and eventual effects, particularly upon women.

The commission shall investigate these issues in terms of their separate and joint implications for women, men, the resulting children, other relatives, the professional and other personnel involved, and the public good in general. The commission shall actively seek input from women's groups, health groups, fertile and infertile women and men, people who have already been involved in these techniques and arrangements, legal and medical practitioners, and a cross section of the population at large. Public hearings shall be held in every province and territory. A critical component of the commission shall be to establish and conduct an independent research program. This shall include commissioning and conducting research on all relevant aspects in a non-sexist manner. Since many of the ramifications of these techniques and arrangements are not widely known, yet affect the very fabric of human social life, it is an important part of the mandate of the commission to communicate their findings of current techniques and arrangements in the broadest possible manner, including the use of non-print media. In particular, people and groups who wish to submit briefs shall be informed of the preliminary findings of the commission on the topics of their particular interest at their request, in order to enable them to consider the social consequences in the most informed manner.³⁵

Although the two mandates differed in tone and actual wording, when compared to other inquiries on reproductive and genetic technologies, both placed an unprecedented emphasis upon women and social implications of the technologies. In a later *Update* from the Commission, it was noted that: "few inquiries [internationally] have been charged to examine the impact of the technologies on women's reproductive health and well-being."³⁶

³⁵ Coalition for a Royal Commission on New Reproductive Technologies "Proposed Mandate," (Toronto, Ontario) February, 1988, pp. 1-2

³⁶ Royal Commission on New Reproductive Technologies "Update" (Jan. 1991), p. 3

And while the Royal Commission's mandate failed to mention the consultative and research processes (which were detailed in the Coalition's mandate), both the *Inquiries Act* and the tradition of previous commissions make provisions for public hearings, education programs and research protocols. This may account for the absence of these topics in the actual mandate.

Commissioners

Royal commissions vary in their membership from a single chairperson, to an inquiry comprised of several commissioners. Where issues are broad both in definition and implications for the public, commission membership will tend to be larger. In Canadian royal commissions - where the topic must be considered in light of two official languages, regional sensitivities and federal/provincial divisions of power - representation may be a delicate task indeed.

The commissioners themselves are crucial to ensuring that the process be perceived as legitimate, and as objective and representative as possible. The rationale for establishing commissioners who are formally unrelated to the government is twofold. First, it permits the government to extend more rigorously beyond its internal pool of experts to seek out the most credible and knowledgeable people to be involved in the fact-finding process. Second, as the individuals are distanced from the formal machinations of government, they are less likely to be influenced by political pressures, party discipline and other forms of influence that may affect Members of Parliament or other civil servants. Realistically, the links between the government and the commission may be far closer in practice than they are in theory. The government is prone to selecting commissioners from the traditional elite: judges, academics, and other professionals who have a high probability of being familiar with the government due to networks between themselves and government (as outlined in Chapter Two). A recent example of this is the Royal Commission on the Economic Union and Development Prospects for Canada ("the MacDonald Commission"), which had three streams: economics, law and political science. Many of the commissioners and researchers

were chosen from the established elite, rather than attempting to incorporate individuals from some equally capable grassroots organizations. As Richard Simeon, who worked for the MacDonald Commission, points out

commissions rely upon disciplinary norms to locate their researchers and are thus likely to reflect the prevailing paradigms in those disciplines ... Royal Commissions are appointed by governments in power. By their very nature, they can be no more than meliorative and reformist, rather than revolutionary. Members are representatives of the established elites.³⁷

Alan Cairns, who was hired to conduct research within the political science stream of the MacDonald Commission, supports appointing or hiring the 'aristocracy' of the public to commissions: "commissioners are appointed by governments, typically drawn from established elites, and work within terms of reference set by the appointing body."³⁸ Cairns critically fails to recognize two problems. First, if the commissioners themselves are biased, it is likely they will be inclined to hire other individuals who fit into that same spectre of partiality. If the commissioner is part of the established elite, as Simeon has pointed out, it is likely they will miss at creative policy innovations that fall outside of their mode of thinking. Similarly, an elite researcher probably suffers from the same limitations. This notion may be defined as trickle-down partisanship. Sylvia Bashevkin argues that while the royal commission attempts to address wide public opinion in its mandate "majority elite views are apparently more significant to the unfolding of federal policy on the national level."³⁹

While the mandate of the Royal Commission on New Reproductive Technologies did not seem to be contentious, the selection of Commissioners was. The Coalition had explicitly argued for a commission chair with a social science background, not a medical one. The appointment of Dr. Patricia Baird, a pediatrician and former head of the Department of Medical Genetics at the University of British Columbia, as chair and the only full-time Commissioner, was perceived as a disaster by the lobbying feminists. Her

Richard Simeon, "Inside the MacDonald Commission," Studies in Political Economy, 22 (1987), p. 168,9

³⁸ Cairns, "The MacDonald and other Royal Commissions: Their Role in Public Policy," p. 5

³⁹ Sylvia Bashevkin, "Does Public Opinion Matter?," Canadian Public Administration, Vol. 31, No. 1 (Fall 1988).

curriculum vitae was impressive nonetheless. The medical establishment was pleased with her appointment and described her in the following way: "Dr. Patricia Baird, a pediatrician and geneticist of unimpeachable reputation from the University of British Columbia."⁴⁰ Baird's primary area of research expertise (which, according to her biography included over 250 published papers and abstracts) focused on "the distribution and natural history of birth defects and genetic diseases in the population."⁴¹ She was highly active on a number of committees, including: the Canadian Institute for Advanced Research; the Medical Research Council; the study Committee on Genetic Predisposition and the National Advisory Board on Science and Technology. She attended the G-7 Summit Conference in Rome (1988) on International Bioethics as one of three official Canadian delegates. Finally, her biography lists membership in a number of professional and community board organizations.

The fact that Baird was a medical doctor/researcher should not have necessarily limited or compromised the Commission. However, Baird's background coupled with her initial public comments upon being appointed raised suspicions about her ability to transcend her medical background: "These new technologies provide new tools and we must make sure to use these tools wisely to the benefit of the people."⁴² Commissioners take the given mandate, which itself influences or limits the policy outcomes, and interpret it. By defining the reproductive and genetic technologies as "tools," when they might more properly be considered areas of research, Baird had aligned herself with what already seemed to be an accepting or permissive stance to the technologies.

The six other appointees to the Commission were on a part-time basis and with the exceptions of Maureen McTeer and Louise Vandelac, were largely unknown to those involved in lobbying for the inquiry. Margrit Eichler's reaction to the appointments was a

p. 407

⁴⁰ Charlotte Gray, "Controversial 'reprotech' royal commission faces growing criticism," Canadian Medical Association Journal, Vol. 145, No. 10 (1991), p. 1371

⁴¹ Royal Commission on New Reproductive Technologies, "Biographical Notes on Commissioners," Dec. 1991, p. 1

guarded "not ecstatic, of course. We don't know most of them."⁴³ As the wife of Joe Clark, (one-time Prime Minister and at the time of her appointment, External Affairs Minister for the Progressive Conservative Government) McTeer's appointment was quickly labeled one of patronage.⁴⁴ McTeer, a lawyer, was known for her activism with respect to rights to abortion, her work with the Planned Parenthood Association and as a member of the Coalition for a Royal Commission on the Social Aspects of New Reproductive Technologies. Interestingly, Suzanne Scorsone who had a Doctorate in Anthropology and was director of the Office of Catholic Family Life, Archdiocese of Toronto was also selected. While her position at work was related to the mandate of the commission, there was conjecture that she provided 'balance' to McTeer, given her opposition to abortion and contraception.⁴⁵ Scorsone, however, had been active on these issues in the early eighties. During the 1985 pre-conception arrangement case in Ontario she was spokesperson for the Metro Toronto Catholic Children Aid Society which claimed temporary custody of the child born of the arrangement.⁴⁶

Louise Vandellac, a professor of Sociology at University of Quebec in Montreal, a member of the National Bioethics Council on Research on Human Subjects and noted researcher and critic of reproductive technologies, was seen to be most closely aligned with what Coalition members were looking for. Noted in her biography was a sociology doctoral thesis from the University of Paris on infertility, sterility and reproductive technology. She had since published widely on these and related topics. As well, she was active in the following organizations, many of which were feminist or women-centred: the Quebec Advisory Council on the Status of Women; Quebec Senior Education Council; a

⁴³ Al Sheehan, "Reproduction study called chance to learn," The Vancouver Sun (Vancouver) Oct. 26, 1989, B6

⁴⁴ Pollak, "Reproductive Technology: Royal Commission is a volatile mix," p.3

⁴⁵ Graham Fraser, "Ottawa appoints panel on reproduction issues," Globe and Mail (Toronto) Oct. 26, 1989, A3 and Rod Mickleburgh, "Controversy dogged inquiry from outset," Globe and Mail (Toronto) Nov. 30, 1993, A5.

⁴⁶ Pollack, "Reproductive Technology: Royal Commission is a volatile mix," p.3

⁴⁷ Brodribb, "Off the Pedestal and Onto the Block? Motherhood, Reproductive Technologies, and the Canadian State," Canadian Journal of Women and the Law, Vol. 1, No. 2 (1986), pp. 415-419

university/union research centre on workplace health, "Le CINBIOSE", and a women's studies research centre with the Resources for Feminist Research.⁴⁷

Grace Janzten formerly taught as a philosophy professor in Canada. At the time of her appointment, she was a lecturer in philosophy of religion at the Department of Theology and Religious Studies at Kings College in London, England.

Bruce Hatfield was a medical doctor who specialized in internal medicine and worked at Foothills Hospital in Calgary. He was also a clinical associate professor of Medicine at the University of Calgary Medical School. He was a member of the Canadian and Alberta Medical Association Committees on Ethics, the Canadian Bioethics Society and the Society of Internal Medicine.

Martin Hebert specialized in medical law and was practicing in Montreal. He was a member of ethics committees for various hospitals. Between 1982 to 1987 he held several senior positions in the Quebec government including the principal/Private Secretary to the Leader of the Opposition of the Quebec National Assembly, Secretary to the Minister of Justice, Political Advisor to Quebec Minister of Health and Social Affairs. He founded and was a member of the Board of Directors of the Society of Medicine and Law of Quebec. He completed a Masters degree in medical law and bioethics from King's College in London, England.⁴⁸

In August 1991, two additional Commissioners were appointed by the Federal Government: Bartha Maria Knoppers and Susan E. M. McCutcheon. Bartha Knoppers was a Montreal lawyer with an extensive background in new reproductive and genetic technologies. Her biography lists the fields of genetics, ethics and law, children and the law, and family law as her areas of expertise. At the time, she had published widely, including five books "relating specifically to the areas under the mandate of the Royal Commission." Her doctoral thesis (awarded from the University of Paris I, Pantheon-

⁴⁷ RCNRI "Biographical Notes on Commissioners" August 1990, pp. 4,5

Sorbonne) was on reproductive technologies, the law and responsibilities of physicians. She was also highly involved in the Human Genome Project as a Canadian representative.⁴⁹

Susan McCutcheon was probably the only person who could come close to being called a member of the general 'lay' public. She was a secondary school teacher active on a number of hospital boards in the greater Toronto area. She was also listed as being a member of: the Business Board at University of Toronto; the Presidential Investment Advisory Committee; the Governing Council, University of Toronto and held "directorships on the Boards of several business companies."⁵⁰

Two areas of representation seemed to be uppermost for the designers of this Commission: that of women and of region. Seven of the nine Commissioners and the key chair position went to women, giving at least perfunctory recognition of the potential impact these technologies had upon women. Many regions of the country were represented. However, all of the commissioners came from urban settings and there was no representation of the Maritime provinces or the North. The Commissioners were purportedly appointed for their diverse and interdisciplinary backgrounds. Overall, they constituted a decidedly academic and professional group. Two of the nine were medical doctors; two were lawyers; four had doctorates in the social sciences - all had at least one university degree. Interestingly, each had at least some experience on committees or boards that dealt directly with ethics. While perhaps there is a basis for "interdisciplinarity," the groups could hardly be termed "diverse" in terms of representativeness.

What was clear to onlookers was the notable lack of other key representatives: there was no one who publicly had direct physical experience of infertility; there were no people with disabilities, or people of colour. The need to include representatives from these latter groups was not a matter of token appointment. As demonstrated by the representative

⁴⁹ Statement of Claim (Document #F303591) laid in Federal Court, Trial Division, Ottawa, December 6, 1991 by Bruce Hatfield, Martin Hebert, Maureen McTeer and Louise Vandelac vs. the Queen, the Attorney General of Canada and Patricia Baird, Article 11

⁵⁰ Bartha Maria Knoppers, Interview, Montreal, PQ, Feb. 2, 1994 and RCNRT "Biographical Notes," Dec. 1991, p. 2

examples in Chapter Three, reproductive and genetic technologies as they had developed up to that point had direct implications for these groups of people in particular. Their inclusion among those in positions of power at the Commission would have demonstrated a clearer commitment to engaging with the social and ethical implications of the technologies themselves. The task of being perfectly representative was nearly impossible (given the need for regional and linguistic representation not to mention the various stakeholders who are generally associated with the technologies), however, the above were glaring omissions. The appointments generated criticism quickly after the Commission was announced.

The work of the Commission

Commissioners are charged with deciding how to interpret and implement the mandate. This task is far-reaching: ranging from budget allocations, to hiring, to what sort of research will be conducted and what form the consultations will take. The individual identity of each respective Commissioner will affect how she or he will undertake each of these tasks. It will also affect how they view the technologies under study themselves. While having a strong background in ethics was laudable, ethical considerations were but one aspect of the mandate. Inclusion of at least some of the groups directly affected by the technologies (beyond that of merely 'women') would have added depth to the work of the Commission. A person with disabilities who had been active on these issues or a woman who had direct experience with infertility or *in vitro* fertilization, for example, would have been appropriate choices to round out the group charged with heading up the work of the Commission.

It was hoped that the multidisciplinary composition of this group of seven would augment the broad mandate given them. Even with the subtle stance of acceptance toward the technologies within the mandate, the group had the power to interpret it still more broadly or critically than the authors (the government) may have intended. When Thomas

Berger as Commission chair of the MacKenzie Valley Pipeline Inquiry interpreted the mandate more broadly than had been intended by the government, he was able to achieve remarkable participation from native groups who had been traditionally shut out of decision-making that directly affected them.⁵¹ While perhaps more difficult for a Commission that had seven people interpreting the mandate instead of one, this had the potential to occur as the Commissioners refined and defined what exactly the mandate meant in practical terms.

The Commissioners of the Royal Commission on New Reproductive Technologies seemed to spend much time attempting to interpret the mandate and create a plan of action. While this foundational work is crucial, it is also time-expensive. This was compounded by the notable lack of clear guidelines for Commissioners (usually they are given a copy of the commission “bible:” Anthony and Lucas’ *A Handbook on The Conduct of Public Inquiries in Canada*) and were otherwise left to conduct the Commission as they saw fit.

According to the four Commissioners⁵² who would later be stripped of their appointments, the ability to bring together their varying perspectives on this and other issues was denied them. They stated that decisions with respect to the mandate and other critical areas were beyond their access and control. They intimated that this work was inappropriately usurped and conducted solely by Patricia Baird.

Unfortunately, from the very first meeting, the collegiality hoped for has not materialized. Instead, any attempts at collegiality have been continually undermined and over time it became apparent to the plaintiffs that all substantive decisions about every aspect of the Commission’s work were being made under the authority of one person, namely the Chairperson, Patricia Baird. In fact, the plaintiffs have been progressively distanced and prevented from participating in every important decision concerning the Commission’s on-going operations including the nature of the Royal Commission’s research, its consultation and communication program its organizational and financial priorities with the result that any notion of collegiality and multidisciplinary within this Commission has been illusory.⁵³

⁵¹ Salter, “The Two Contradictions in Public Inquiries,” pp. 177 - 185; Frank J. Tester, “Reflections on Tin Wis,” in *Alternatives*, Vol. 19, No. 1 (1992), pp. 38-9.

⁵² These Commissioners were Bruce Hatfield, Martin Hebert, Maureen McTeer and Louise Vandelac. Throughout the remainder of the thesis I refer to them variously as “the four,” “the dissenting Commissioners,” “the fired Commissioners,” etc.

⁵³ Federal Court Statement of Claim, Articles 13, 14.

The task of interpreting the mandate may have been accomplished entirely by Patricia Baird. Given her background, this was troubling. John B. McKinlay's description of how medical procedures and techniques move from the experimental phase to "standard practice" has particular relevance to the debates on interpretation of the mandate of this Royal Commission. McKinlay outlined phases, commencing with the stage of a "promising report" on a particular technique, and proceeding through professional adoption to public acceptance. Professional acceptance of the technologies *precedes* public approval, giving the public little ability to be truly critical of it. In fact, he argued, based on the influence and power (including vital information and access to it) which the medical profession has, the public is usually left in a rather reactive and passive role of ratifying the decisions already made. Baird's public description of reproductive technologies as "tools," rather than as processes that needed to be questioned, exhibited an approach one might expect to hear from a medical geneticist, one that resembles McKinlay's description.⁵⁴ This stance was exactly what was not needed in heading up such a critical investigation and public debate on the technologies. Had the other Commissioners been able to be more active in the refining or interpreting of the mandate, perhaps the Commission might have had different outcomes. Abby Lippman, Montreal epidemiologist and Commission critic, shared this concern with respect to Baird:

A person who comes out of a biomedical community, and who has been trained, socialized and acculturated in a biomedical context, is likely to take a very biomedical approach to these problems. From this point of view, these [technologies] are seen as a therapeutic, as important for dealing with health problems. My guess is that this will be the direction of anything that comes out of the commission.⁵⁵

The internal problems between the commissioners were many and varied. A majority of the Commissioners (Hebert, Hatfield, McTeer, Vandelac and less frequently, Knoppers) wrote several joint and individual letters of concern or complaint over a variety of issues. They raised concerns about: the content and release of significant documents or

⁵⁴ McKinlay, "From 'Promising Report'" pp. 374-411

⁵⁵ Heidi Walsh, "Tight Lips Sink Ships," *Kinesis*, February (1992), p. 12

findings to the public; the form, timing and location of meetings;⁵⁶ the degree of consultation or input they were entitled to give; extensions to the mandate of the Commission;⁵⁷ the lack of information given regarding the research plan; the public and follow-up consultations and the general lack of regard for their input as Commissioners. The Commissioners argued that the original Order-In-Council gave decision-making power to all of the Commissioners, not just Baird. In their opinion Baird had interpreted the Order-in-Council to limit this power to herself alone. Overall, the four dismissed commissioners complained of inadequate and token consultation. As those publicly held accountable for the work of the Commission, they argued, they should be incorporated in a meaningful way into all major decisions.

Indeed, the background stakes, the major directions, the priorities and the establishment of the modes of work were progressively out of the commissioners' hands. Thus, from meeting to meeting, we were "informed" of the structure that had been set up, of the people who had been hired, or the budget that had been presented, all of this without any real and effective possibility for intervention, despite our numerous protests. And yet, we've alluded to it, certain budgetary orientations seem questionable to us. It makes us even more uncomfortable, in the present context of budgetary cuts, that the results seem to us today very small and that the adopted modes of work do not make us more optimistic, unless corrections are made immediately.⁵⁸

While the management of the Commission was struggling, they did establish the infrastructure from which to operate. The Commission hired staff and rented offices in downtown Ottawa. The offices were complete with a reception area where members of the public could come to pick up literature and information produced by the Commission. A toll-free line was established that connected to an answering machine by which members of

⁵⁶ The Commissioners asked on several critical occasions (notably during a conflict about confidentiality) to go into *in camera* discussion which was denied by Baird. See the various letters contained in the Federal Court Statement of Claim. On another occasion, Baird requested that all the Commissioners and key staff come to Vancouver (where she resided) for a meeting. The timing and location of the meeting were questionable, given that 5 days later they would be required to fly west again (all the staff and a majority of the Commissioners lived in Central Canada). The extra cost for this meeting was estimated to be \$20,000 of public money. See, Lichler, "Frankenstein meets Kafka," note 10, p. 219.

⁵⁷ Both Vandelaac (Jan 14, 1991) and Hebert (Jan 8, 1991) wrote to complain about this issue. They discovered after-the-fact that the first extension to the mandate had been granted. Both felt this extension was both irresponsible and unnecessary. Hebert noted that if the Commission was managed effectively, the work could have been completed on time. Had they been aware that this was under consideration (which they were not), they would have protested it. See letters in the Federal Court Statement of Claim, Schedule 22 and 21 respectively.

⁵⁸ Federal Court Statement of Claim, Schedule 8 (Letter from Louise Vandelaac et al to Patricia Baird July 9, 1990, trans. by P. Mendez), p.5.

the public could order the same information. Key staff hirings included: John E. Sinclair as Executive Director; Dann M. Michols, Director of Consultations and Coordination; Mary Ann Allen, Director of Administration and, in the spring of 1990, Susan Mann-Trofimankoff, Director of Research. All four positions were based in Ottawa. Two of the four (Sinclair and Michols) had extensive service working for the federal government; Allen had comprehensive senior administrative experience from involvement in numerous previous Royal Commissions and Mann-Trofimankoff was a feminist historian from the University of Ottawa. One Commission employee described the senior management in the following way:

At the Director and Deputy Director level you had a group of fairly mediocre and wildly ambitious people (none of them feminists [Mann-Trofimankoff resigned soon after she was appointed]), most of whom were drawn from various backwaters in the federal government: fisheries, the Law Reform Commission, the Advisory Council on the Status of Women, the defunct Meech Lake team ... From the first day these people saw and attempted to use the Commission as their route to a more prestigious job in the public service - in fact they all spent more time talking about what they hoped to do next (Assistant Deputy Minister what their most common objective) than doing any of the work at hand. The sort of questions which took up hours of management's time were who could fly first class, who could have free French lessons.....⁵⁹

The Commission had planned to conduct its work through two main mechanisms: research and consultations. However, given the breadth of the mandate and the short timeframe in which to fulfill it, the Commissioners needed to find a way to manage the workload in a way that did not duplicate work or research already done or under way. By early 1990 it was decided to conduct some work that would help to narrow or focus the massive task before them. Two main mechanisms were pursued: a "search conference" held in Wolfville, Nova Scotia and the use of public opinion polls. Both of these were contentious decisions with a majority of those who were Commissioners at the time.⁶⁰

Other early efforts on the part of the Commission included three sets of Colloquia held in Ottawa between March and May 1990. A total of eight recognized experts (in

⁵⁹ Anonymous 1, "Inside the Royal Commission," in *Misconceptions*, Vol. 1, p. 224

⁶⁰ Both the Search Conference and the use of polls will be further discussed in chapter 5

various fields related to the technologies) attended these colloquia. Half of these were international participants; the remaining four lived and worked in Canada.⁶¹

By late May 1990, the first information kit was released to the public. It contained a copy of the biographies of the appointed Commissioners, a copy of the Commission's Mandate, a press release advertising the deadlines for the Public Consultations and a document created to assist people in their preparations for the consultations ("A Guide to Public Participation in the Work of the Royal Commission on New Reproductive Technologies"). The Commission articulated the plan for the upcoming months: first they would focus on consulting with the public, then the substantive research would begin.

The press release outlined the public consultation program which was made up of five key components: the toll-free line where members of the public could express their views on a recording or could request Commission information; the public hearings planned for 26 Canadian communities throughout the autumn of 1990; roundtables on specific issues of importance bringing together representatives from various groups; individual "armchair" sessions for people who wanted to meet privately with the Commission, and; written and recorded messages that would be accepted until December 31, 1990.

Roughly at this time the newly hired Director of Research, Susan Mann-Trofimankoff, resigned from her position for personal reasons - after a mere three weeks of work. The Commission, now well into its mandate, was without someone to coordinate the important research that first, needed to be informed by the consultative process and second had to commence in short order if the work was to be completed in time.

An executive search firm (George Enns Partners Inc.) was then contracted at the cost of \$55,000 to locate a replacement for Mann-Trofimankoff, which did not occur until

mid-August 1990 with the appointment of Sylvia Gold - ten months into the twenty-four month mandate.⁶²

On August 15, 1990 Sylvia Gold was announced as the permanent Director of Research and Evaluation. Gold was the former head of the Canadian Advisory Council on the Status of Women and a member of the federal training school, the Canadian Centre for Management Development. According to a biography, she had "conducted research into the transmission of values between interest groups and commissions of inquiry" as part of her studies at the Ontario Institute for Studies in Education.⁶³

Throughout the summer, the Commission worked on preparing for the upcoming consultations. Members of the public were asked to submit by July 31 a short letter of request to appear at the public hearings. Given the almost total lack of information that had come from the Commission to the public thus far, such a deadline was daunting to many groups, particularly volunteer groups like the Vancouver Women's Reproductive Technologies Coalition. In a letter to Chair Patricia Baird requesting an extension to the July deadline, Vancouver Coalition spokeswoman Catherine Martell wrote :

Our access to the whole process of the Commission has been unduly limited. In particular, the limitation imposed by the July 31, 1990 deadline for submission is a major impedimentPublic notice of the deadline was not issued until June yet the hearings are scheduled to begin in September....summer is a difficult time to do any kind of organizational networking or consultation.⁶⁴

While Baird did not alter the July 31 deadline, in her response she did attempt to downplay what was required in the letter of intent and offered to make alternate proposals for those groups and individuals who needed it. There was, however, no recognition of the fact that very little information had been provided to assist groups grappling with these complex issues nor that summertime was likely the least productive time for any organization.⁶⁵

⁶² Dean Beeby, "Reproduction panel lashed over spending," Vancouver Sun, Dec. 24, 1991, C2, and "Reproductive Spending," Vancouver Sun, Dec. 28, 1991, A14.

⁶³ RCNRT "Royal Commission on New Reproductive Technologies Announces Appointment of Director of Research and Evaluation," Press Release, August 15, 1990.

⁶⁴ Catherine Martell, Letter to Patricia A. Baird, Chairperson, RCNRT, July 18, 1990, p 1.

⁶⁵ Patricia A. Baird, Chairperson, Letter to Catherine Martell, July 25, 1990.

The Commission itself did organize one major consultation during the summer of 1990. On August 1, the Commission held a symposium on the Impact of New Reproductive Technologies on Women's Reproductive Health and Well-Being in Vancouver, British Columbia. It was a trial-run for subsequent sessions like it. The symposia were intended to bring together representatives from various groups who had a stake in the topic under discussion. For the Vancouver sessions twelve participants, mostly women, attended the meeting (by invitation only). The results of the meeting were not available to the public. One individual who managed to gain access as a silent ("unwelcome") observer noted what was soon to become a major issue for the Commission: dissension among the Commissioners.⁶⁶

By the summer of 1990 Hebert, Hatfield, McTeer and Vandelac felt that the work of the Commission was in serious trouble. Decisions continued to be made without their input and information about the research plan was not forthcoming. Given that the important work was about to begin in earnest (the public consultations in the upcoming months and, presumably, the bulk of the research), they chose to act immediately and dramatically. They felt the only way to have any effect at this point was to try bring the work of the Commission to a halt - they stopped attending the Commissioner's meetings. Given the four Commissioners as a group constituted a majority, their absence created a quorum problem. Decisions could not be legitimately made without a majority of Commissioners involved.

They wrote a letter to Paul Tellier, Clerk of the Privy Council and Secretary to the Cabinet. In it they notified Tellier, as the governmental representative responsible for the Order-in-Council creating this Commission, of the consistent difficulties they had, the seriousness of the nature of their complaints and the fact that they were no longer attending Commissioners' meetings. "Please note that this means that the majority of the Commission membership is missing, including women and men, a doctor, lawyers and a sociologist

⁶⁶ Catherine Martell Report to the Vancouver Women's Reproductive Technologies Coalition Re: Royal

which leads to quorum problems and puts into question the legitimacy of the Commission itself....”⁶⁷ They asked Tellier to intervene as soon as possible as they remained willing to fulfill their roles as Commissioners. Maureen McTeer wrote an letter to Baird (copied to Tellier) wherein she also chronicled the difficulties that precipitated their withdrawal from the Commissioners’ meetings. She pinpointed the terms of reference of the Order-In-Council which gave authority of the work of the Commission to *all* the commissioners, not any one individual. She also noted that it seemed the Chair had been dismissing their concerns as personal attacks rather than substantive, legitimate concerns.⁶⁸ Hatfield, Hebert and Vandelac followed-up with a letter noting that having a geneticist as the sole person responsible for a report on the broad ranging issues of reproductive and genetic technologies would represent a conflict of interest and “a significant lack of objectivity....”⁶⁹ In his response, Tellier predictably noted that the government functions at arms-length to the work of Royal Commission and thus it was inappropriate to intervene in the problems of it. He noted that there were provisions for “minority”, or dissenting, reports that could address disagreements. He offered to meet with the Commissioners to provide advice on Royal Commissions. Had the issue been left there, it is uncertain what would have occurred at the Commission, but the government’s role with respect to it would have remained unnoteworthy and generally acceptable.

At the meeting with Tellier on August 9, 1990, all the Commissioners were present with one notable exception: Patricia Baird. She was expected to have attended and provided no “reason or notice” to explain her absence. The six Commissioners discussed with Tellier their concerns and he reiterated the inability of the government to intervene in such matters. He suggested, again, that they resolve the matter internally.⁷⁰

Commission Theme Consultation August 1, 1990, Vancouver, B.C.

⁶⁷ Federal Court Statement of Claim, Schedule 5 (Letter from Bruce Hatfield et al to Paul Tellier June 26, 1990)

⁶⁸ Federal Court Statement of Claim, Schedule 6 (Letter from Maureen McTeer to Pat Baird, copied to Paul Tellier June 28, 1990)

⁶⁹ Federal Court Statement of Claim, Schedule 7 (Letter from Martin Hebert, Louise Vandelac, Bruce Hatfield to Pat Baird, copied to Paul Tellier June 29, 1990)

⁷⁰ Federal Court Statement of Claim, Article 22

On August 28, 1990 the Federal Government intervened in the proceedings of the Royal Commission on New Reproductive Technologies by changing the original Order-in-Council. Such action was unprecedented in the history of federal commissions of this magnitude. Two new Commissioners, Knoppers and McCutcheon solved the problem of quorum. Altering the Order-in-Council to give all power to the Chairperson, Patricia Baird served to "clarify"⁷¹ who had legitimate authority over all aspects of the Commission and who did not (see Appendix 4 for the relevant changes). Previously, the responsibility for all the work of the Commission was intended to be shared between the seven Commissioners appointed in 1989.

This action on the part of the government constitutes remarkably active, political and unparalleled interference into the work of the Commission. Given the nature of the intervention, it also calls into serious question the legitimacy of the this Commission. While it is difficult to prove or assert any formal connection between such occurrences as Baird's absence at the meeting with Tellier followed in quick order by the change to the Order-in-Council, these do also raise questions about the distance between the Chair and the commissioning government itself. Commissions of inquiry are valued for their *perceived* objectivity and distance from the government. This Commission was already having credibility problems. Where professionals such as the medical profession - specifically those involved in human genetics - are some of the very clusters of people who are responsible for the technologies under consideration, this distance - real and perceived are critical. By its actions the government signaled its support for Baird as chair and her problematic dominance of the work of the Commission. The actions of the government were such that they not only intervened, they did so in a way that supported giving complete authority to one person about whom the public, and a majority of her Commission peers, had already raised concerns.

⁷¹ Baird sent a letter to Vandelac on August 28 to notify the latter in response to earlier concerns raised, which were now clarified by the Order in Council

The actions of the four renegade Commissioners are of interest as well. Given that at least two of them would as lawyers have some insights into commissions of inquiries it is curious the route they chose for action. The same two individuals, McTeer and Hebert, should have had an extremely good working knowledge of the government due to their respective backgrounds. Given their documented attempts at intervention, it is understandable that the Commissioners felt they had no other alternatives. However, for the reasons chronicled above, the government would surely have been loathe to step into what were already the delicate and charged issues of reproductive and genetic technologies - even with respect to issues of the implementation of the inquiry. By not intervening, the government could have safely walked away with its political reputation unsullied. It is almost as surprising that these Commissioners thought that the government would intervene on their behalf, as it was that the government intervened by changing the Order-In-Council.

After the upset regarding the revised order-in-council, some of the commissioners were approached by French media representatives for comments. Three of the Commissioners (McTeer, Hebert and Vandelac) made comments alluding to their concerns about the operations of the Commission and their apparently token involvement. "When asked, Commissioner McTeer had to admit that she knew nothing about the Commission's total budget. *Le Soleil* and *Le Journal de Québec* ran articles quoting the Commissioners."⁷² This resulted in a clear division between the Commissioners: Baird, Scorsone, McCutcheon on one side; Hatfield, Hebert, McTeer and Vandelac on the other. Knoppers and Janzen, apparently, managed to distance themselves from such extreme positions. What resulted, was a complete alienation of the three Commissioners who had been involved in an alleged breach of confidentiality (Hatfield, although similarly estranged, was permitted to continue to actively work on the Commission since he was not seen to have breached confidentiality). Each were denied access to Commission documents and meetings until such time that they wrote (unique) letters of agreement regarding policies of confidentiality.

⁷² Eichler, "Frankenstein meets Kafka," pp 200-202

Vandelac had to resort to the services of a lawyer to regain her access to Commission work, even though she had submitted a written agreement to Baird as requested.⁷³ While the decision to "go public" with some of the internal problems of the Commission did not constitute a legal breach in confidentiality, it was irregular and would surely signal to the watchdogs that things were not well at the Commission. As it was, it provided Baird the occasion to flex her newly legitimated muscle as sole arbitrator of such activities, demonstrating to the Commissioners that open discord would not be tolerated.

The Commission appeared to put aside the internal wrangling and proceeded with the public consultations in the fall of 1990. The September 4th press release stated that the Commission was about to hear from over 500 groups and individuals on the issues in 17 (revised downward from the original 26) communities. Most of the communities were large urban centres in each province. From the North, the Commission heard from participants who attended hearings in Whitehorse, Yukon and Yellowknife, Northwest Territories. In all, the Commission took three months to attend all the consultations which amounted to 28 days in total. As the first year of the work of the Commission drew to a close, Baird hinted to the public that an extension to the mandate might be sought.⁷⁴

The January 1991 *Update* served to re-cap the consultation program to date and outlined the plan for research to the public. The public consultations were now complete, but the Commission extended the deadline for written and taped submissions to April 31, 1991. The "armchair" consultations were to be held in early 1991 with some 225 people. Also noted were the three regional roundtables that had occurred (the North, Halifax and Vancouver) as well as the Vancouver Theme consultation/symposium in August.

The Commission had divided the work of the Research and Evaluation program into four main workstreams. These were: causes and prevention of infertility; methods of

⁷³ Federal Court Statement of Claim, Schedule 10

⁷⁴ Anne Mullens, "Commission ready to examine future of reproductive issues," *Vancouver Sun*, Nov. 23, 1990, A2.

assisted human reproduction; pre-natal diagnosis and genetics, and embryo and fetal tissue research.

In May 1991, the Royal Commission issued a press release stating it had received a one year extension to its mandate to "undertake an additional year of consultation activities and rigorous and comprehensive research." The communiqué also stated there would be panel discussions throughout the year and the release of the publication "What We Heard: Issues and Questions Raised During the Public Hearings." Four such panel discussions occurred in Halifax (June), Calgary (September), Ottawa (October) and Winnipeg (December). These were locally televised discussions between local experts in the field of reproductive and genetic technologies. The "What We Heard," a 44 page summary document of the public hearings held the previous fall, was released on September 9, 1991. Other publications released were summaries of two research studies: one on international issues and one on embryo and fetal tissue research.⁷⁵

During this year, the Commission spent a great deal of time conducting follow-up or supplemental consultative work. Large fora were held called 'Liaison with Community Leaders and Organizations' in each of the four cities where the televised panel discussions occurred. These meetings were attended by anywhere from 23 to 56 individuals. In addition, the Commissioners sought out meetings ("colloquia") on specific topics or questions across the country. Twenty-one such meetings were held between January 23 and December 12 of that year. Finally, the Commission held eight consultations with key stakeholder groups, mainly industry-based. Approximately twenty organizations that were either professional or industry-based were represented at these consultations.

While the exterior face of the Commission appeared intact (at least in the early part of 1991), the internal management was continuing to crumble. The four Commissioners who had been raising concerns throughout 1990 with respect to Baird's management style,

⁷⁵ Respectively, Rebecca J. Cook, "New Reproductive Technologies: International Legal Issues and Instruments," RCNRT, Dec. 1991 and Bernard M. Dickens, "Legal Issues in Embryo and Fetal Tissue Research and Therapy," RCNRT, Dec. 1991.

continued to protest her lack of consultation when they all were publicly accountable for the completion and reporting of the Royal Commission's work. For example, they were not informed until after the fact that there had been an extension granted to the mandate (until October 1992); the four were joined by Knoppers in letters of protest with respect to how the second round of consultations should be conducted; they vigorously protested the release of the "What We Heard" document and they continued to have inadequate information with respect to the research plan.⁷⁶

The internal difficulties of the Commission became public on December 6, 1991 when Hatfield, Hebert, McTeer and Vandelac filed a court case against the Federal Government of Canada and the Chair of the Royal Commission on New Reproductive Technologies, Patricia Baird. By taking the issues to a more neutral setting - that is the Courts - the Commissioners hoped to attain a fair hearing for their concerns. The main issue that the four Commissioners brought before the Courts was the incongruity between the revised Order-in-Council and the *Inquiries Act*. They argued that where multiple Commissioners are appointed to a royal commission, the *Act* makes provisions for those appointed to share decision-making power and ultimate responsibility for the delivery of the findings in a report. By changing the Order-in-Council, the Commissioners had been effectively obstructed from doing their work as described in the *Act*. Further, it was not their desire to be involved in *all* decisions pertaining to the operations of the Commission, only those that they reasonably should be consulted in and privy to. As remedy, they sought to have the new Order-in-Council revoked and the old one reinstated so they could continue their work as Commissioners. They also wanted official recognition that Patricia Baird had herself conducted the Commission in a manner that contravened the provisions in the *Inquiries Act*.⁷⁷

⁷⁶ Louise Vandelac, Letter to Pat Baird, January 14, 1991, McTeer et al, Letter to Pat Baird and other Commissioners, October 1, 1991, and, Federal Court Statement of Claim, Schedule 20 which includes several rounds of correspondence between the four plus Knoppers and Baird and Dann Michols (the Director of Consultations and Communications)

⁷⁷ Federal Court Statement of Claim, Article 59

This case might have succeeded and created yet another precedent in the history of royal commissions had the government not stepped in and created one of their own. Within ten days of their first appearance in court, the Federal Government intervened in the operations of the Royal Commission a second time and stripped these four Commissioners of their appointments. Ultimately, the four were left with no legal standing and were forced to abandon their suit.

Importantly, the Commissioners were dismissed during the Christmas recess of Parliament which meant there could be no debate in the House of Commons on what was the second major intervention on the part of the Conservative government in the work of the Royal Commission. The government likely hoped that the dismissals would not receive much coverage by the media. While the story was picked up, it is surprising that these extraordinary and seemingly partisan measures on the part of the government have not received more extensive attention than they have. The firings did trigger significant activity on the part of many interesting organizations and groups of people including members of the media, women's watchdog groups (NAC and the Coalition, most notably), the Social Science Federation of Canada and others.⁷⁸

The Royal Commission headed into 1992 minus four Commissioners: two of them the only men appointed, as well as one of the two medical doctors; leaving the remaining five Commissioners to complete the work. By this time, credibility, which had already been questionable, was at an all-time low. The media began to conjecture about whether the Commission would survive.⁷⁹ New public information released in February of that year, sent the fragile image of legitimacy spiraling still further downward.

Through a Freedom of Information request, the Canadian Coalition for a Royal Commission (now turned from lobby group to watchdog) was able to evaluate the nature of the research plans of the Royal Commission. On February 3, 1992, the Coalition released a

⁷⁸ For some of these other groups, see Buchler, "Frankenstein meets Kafka," p. 221, note 59.

stinging assessment of the contracts awarded between November 1989 and October 1991. Of the research, Eichler (who conducted the analysis) stated: "Literature reviews and overviews do not constitute empirical research and cannot be considered groundbreaking."⁸⁰ Perhaps more serious were the allegations of "highly questionable" practices engaged in by Commission Staff where research documents/reports had been altered without the permission or knowledge of the authoring researcher. Additionally, the sizable contracts awarded to the firm Burson-Marsteller (a U.S.-based public relations firm which counted many pharmaceutical firms as clients) spawned charges of conflict of interest.⁸¹

Based on this information and the concerns raised by the ex-Commissioners, the National Action Committee on the Status of Women (NAC) issued a press release the following day calling for the disbandment of the Commission and asking women's groups to boycott future consultations. Varda Burstyn, spokeswoman for NAC and co-chair of their Reproductive Technologies Sub-Committee, stated that this was the first time NAC had ever pulled out of a consultative process, but that the organization had deep concerns over the "legitimacy and credibility" of the Royal Commission's work.⁸²

Patricia Baird responded by stating that the literature reviews were essential to identifying research gaps before the primary research could commence. She challenged members of the public to come to the Commission for information with respect to its activities: "I would suggest that those who are truly interested in the research that this

⁸⁰ Ken Pole, "Firings spark debate over commission's fate," The Medical Post, Feb. 1992, p. 2, 46; Helen Branswell, "Reproductive Technologies: Willing to hang in there, Baird says in wake of lawsuit end," Vancouver Sun, Feb. 25, 1992, A3.

⁸¹ Margit Eichler, "Briefing Paper on the Research Program of the Royal Commission on New Reproductive Technologies," Canadian Coalition for a Royal Commission on New Reproductive Technologies, Feb. 3, 1992, p. 2.

⁸² Contract between The Royal Commission on New Reproductive Technologies and Burson-Marsteller, #91.C-060, October 1, 1991 and Contract between The Royal Commission on New Reproductive Technologies and Burson-Marsteller, #91.C-061, dated the 18th Day of October, 1991.

⁸³ Rod Mickleburgh, "NAC attacks commission over research," Globe and Mail, Feb. 4, 1992, A1,2 and NAC, "Nac Calls for Disbanding and Boycott of Royal Commission on New Reproductive Technologies," Press Release, Feb. 4, 1992, pp. 1,2.

commission is doing contact the commission directly for information we are only too pleased to share."⁸³

The Social Sciences Federation of Canada (SSFC), the national organization that represented over 15,000 social scientists across Canada, decided in March of 1992 to take the Commission up on its offer. In his March 13, 1992 letter to Commission Chair Baird, SSFC President Robert Stebbins outlined growing concern about the Commission's research program. He sought "clarification of the research mandate of the Royal Commission on New Reproductive Technologies."⁸⁴ More specifically, the SSFC was concerned about the lack of transparency of the research program, including the peer review process and how contracts were being managed. A meeting was set up between SSFC representatives and Research Director Sylvia Gold and Commissioners Scorsone, Janzen and McCutcheon (April 3, 1992). The Commissioners and Gold promised to provide information to the SSFC. When this was not forthcoming to the satisfaction of the SSFC, a volley of letters went back and forth between Stebbins and Baird which culminated in the SSFC's public call for remedial action with respect to the Royal Commission. On June 19, 1992 Stebbins wrote on behalf of the SSFC to Prime Minister Brian Mulroney: "The secrecy surrounding the Commission and its refusal thus far to produce the information it has promised is seriously jeopardizing the credibility of its work. We urge you to intervene immediately to ensure that the information requested by the social science community is produced as soon as possible."⁸⁵ Three days later the SSFC issued a press release that was picked up by the media, detailing its concerns about the integrity of the Commission's research program.

The Commission conducted six more consultations with stakeholder groups and two more colloquia. In addition, they released two substantive *Updates* (January 1992 and

⁸³ Patricia Baird, "Commission criticism based on out-of-date information," *Letters*, Vancouver Sun, Feb. 8, 1992, B4

⁸⁴ Robert Stebbins, Letter to Dr. Patricia Baird, March 13, 1992, p 1. A letter raising similar concerns was sent on behalf of the Canadian Association of University Teachers (representing 60,000 professors in Canada) by President Alan Andrews to Dr. Baird, July 21, 1992

August 1992). The first *Update* provided overviews of the four workstreams and a brief description of the types of research that was being conducted and why. The second *Update* took the form of a closing report, advising that the Commission was now moving into the Report-writing phase. It also provided an "exhaustive list" of the researchers and their research conducted for the Commission. This, however, was still found to be unsatisfactory to the SSFC, which had requested specific information about the peer review process that was undertaken, and more detailed research data. The Commission released summaries of ten research studies conducted for the Commission throughout the year.⁸⁶

During the summer of 1992 many of the research staff were laid off or fired. Sylvia Gold herself resigned in response to this mass exodus of Commission employees. The Commission continued its work for the duration of the mandate with no Director of Research and Evaluation. Indeed, the Commission had someone in this critical role for only 25% (approximately 12 months) of its total 49 month lifetime.

It was not only staffing in the Research and Evaluation department that was in trouble. In general, staffing of the Royal Commission was in continual upheaval. The Commission had hired many women as researchers and staff, perhaps again in recognition of the importance in many women's lives these technologies potentially played. However, many did not remain as employees for very long. According to one researcher, her study was mishandled a number of times - from very basic administrative mistakes to the public release of significant errors. She was informed that at least some of this was due to inadequate staffing and that the consultation branch of the Commission had stepped in to assist with the work. Another researcher notes that there was a high turnover of secretarial and research support due to poor management. "...[S]ome researchers had their contracts handled by up to six separate staff members during the lifespan (about four months) of a single contract."⁸⁷

⁸⁶ Robert Stebbins, Letter to The Right Honourable Brian Mulroney, June 19, 1992, p. 2

⁸⁷ For a listing of these, consult RCNRT, "Update" August 1992, p. 2

⁸⁸ Anonymous 1, "Inside the Royal Commission," p. 224

All employees of the Commission, including the Commissioners themselves were required to sign a confidentiality agreement. This was in place to protect some of the research or other findings, and people who wished their contributions to the Commission remain confidential. However, many came to refer to this clause as "the gag order" which served to silence employees from talking about some of the more disturbing aspects of the Commission, most notably the management of the Commission itself and how the incoming information (research and consultations) was handled. Several employees of the Commission contributed to a collection of essays about reproductive and genetic technologies with respect to their experiences, on the condition that they would remain anonymous.⁸⁸ Several other researchers responded to a short survey Margrit Eichler sent out after reviewing the controversial information revealed through the *Access to Information Act*.⁸⁹ The results (from those who responded, about 62% or 148 replies) were almost uniformly negative, ranging from concerns about how the staff and researchers were treated; how the research itself was mishandled or "massaged"; to the characteristic "agenda" they perceived to be at work. Pervading the Commission seemed to be fear of retribution, particularly after the four Commissioners were dismissed.

Following the removal of Maureen McTeer, Louise Vandelac, Bruce Hatfield and Martin Hebert as Commissioners, the staff of the Royal Commission were asked to resign the "gag order" (as we came to call it). So legally, it is quite problematic to speak about what really went on there. The four Commissioners who tried to speak publicly about what happened were very quickly silenced. Given that these four people, with more status and influence than staff members, could be silenced with the full strength of the Federal Government, the message to the staff was clear; dissent is not allowed and will be dealt with aggressively.⁹⁰

The scheduled reporting date in October, 1992 came and went. In a one-page November *Update*, Patricia Baird announced that the Commission had sought and obtained

⁸⁸ Anonymous, "Inside the Royal Commission," pp. 223-236.

⁸⁹ (Outlined and described in Eichler "Frankenstein meets Kafka," pp. 196-222

⁹⁰ Anonymous 2, "Inside the Royal Commission," p. 225

another extension to the mandate until July 15, 1993. This caused public protests from - by now -predictable fronts: the SSFC, NAC and the four ex-Commissioners.⁹¹

The Commission kicked off the new year with one of what was to be a series of pieces intended for (and printed in) editorial columns across the country. This first position piece - "An Ethic of Care"⁹² took the form of a rebuttal to articles and a small pamphlet Maureen McTeer had published in December of 1992.⁹³ Subsequent features were: "Framework for Decision Making;" "Judicial Intervention in Pregnancy and Birth: New Ethical Issues for Society;" and "Preconception Arrangements: Ethical Dilemmas for Canadian Society." In addition, two final research summaries were released: a survey of Canadian fertility programs and an analysis of the use of prenatal diagnosis.

The Globe and Mail reported on June 29, 1993 that the Commission had once again sought and received an extension to its mandate. Baird noted that the time was needed to translate and edit the mass of information that was to become a two-volume report and sixteen volumes of research. This third and final extension was until November 15, 1993.⁹⁴ The Commission issued a summer Update in July 1993 which outlined the activities of the Commissioners and provided some excerpts from speeches given throughout the year.

Proceed With Care, the Final Report of the Royal Commission on New Reproductive Technologies, was delivered to the Liberal Government on November 30, 1993 (an election had occurred in the intervening four months since the last extension. Some critics have argued that the reasoning behind the third extension had more to do with the federal election than it did with the actual work of the Commission).⁹⁵ It consisted of two volumes and 16 companion research volumes. The final cost of the work of the

⁹¹ SSFC Press Release, "Social Scientists to Study Research Procedures at Royal Commissions," Nov. 23, 1992; Bruce Hatfield et al. "Nouvelle technologies de reproduction: prolongement de mandat inacceptable," *la presse*, Nov. 18, 1992, B3.4; Hatfield et al. "Replique des ex-commissionnaires," *Le Droit*, Nov. 17, 1992, p. 19.

⁹² RCNRT, "An Ethic of Care," *The Ottawa Citizen*, Jan. 13, 1993, A9.

⁹³ "Maureen McTeer *The Tangled Womb: The Politics of Human Reproduction* (Toronto: HarperCollins, 1992).

⁹⁴ Rod Mickleburgh, "Reproductive panel misses deadline again," *Globe and Mail*, June 29, 1993, A5.

⁹⁵ Eichler, "Frankenstein Meets Kafka: The Royal Commission on New Reproductive Technologies," in *Misconceptions Vol. 1*, p. 213.

Commission was \$29.5 million, \$4.8 million more than in the original budget, and 25 months over the 1st deadline.

In December 1993, the Commission offered its final *Update* in which it provided a brief overview of some of the main recommendations. In all, the Commission offered 293 recommendations in a lengthy (1275 pages) document. According to the Commission, this was based on the participation of over 40,000 Canadians and over 130 original research studies. Perhaps the most important set of recommendations, and certainly ones that Patricia Baird would continue to raise after her tenure with the Commission had ended, were those to do with a proposed national regulatory agency (National Reproductive Technologies Commission) which would license and regulate the existing and developing technologies (Recommendation # 1 made provisions for the NRTC, several other recommendations made specific suggestions for licensing).

In a classic finale, Patricia Baird once again stepped beyond what seemed to be appropriate by releasing embargoed copies of the *Report* and the Executive Summary to selected news outlets before the Liberal Government had released it.

Prime Minister Chretien's office was unaware of the briefing. The government had received the report from Baird earlier in November and was keeping it under wraps until Health Minister Diane Marleau released it Tuesday morning. Chretien's office also tried unsuccessfully to get Baird to hold a public news conference, as is normally done when royal commissions release their reports....⁹⁶

IV. Conclusion

In the end, the management of the Royal Commission under the leadership of Patricia Baird managed to estrange not only four commissioners and several staff, but also considerable numbers of the groups from whom the Commission might have otherwise heard more extensively. It may well be that the Commission succeeded in alienating more people than they claimed to have consulted.

The early eighties bore witness to the proliferation of the fruits of the biomedical establishment. There seemed to be no corresponding debate with respect to the overall

⁹⁶ "Early release angers Liberals," Vancouver Sun, Dec. 1, 1993, A4.

efficacy of the technologies on a variety of levels, ranging from practical health and safety, to issues concerning new (and undebated) notions of family or the social effects upon women and children. Together with several other concerned individuals and groups, the Canadian Coalition for a Royal Commission New Reproductive Technologies began to lobby for a broad debate on these issues. They decided to pursue the vehicle of the royal commission, the cadillac policy option which could earmark large sums of money for education and new, badly needed original research on these issues with a view to creating policies and laws where none had previously or coherently existed.

Clearly what they got in the Royal Commission on New Reproductive Technologies was not what they bargained for. After three extensions, that some would argue were unjustifiable; the firing of four Commissions; the firing, lay-offs or resignations of several staff; the accusations of secrecy and generally "questionable" and undemocratic process; it is uncertain what they did achieve. The subsequent chapter will investigate in closer detail these very issues.

CHAPTER FIVE

THE RESULT: THE ROYAL COMMISSION ON NEW REPRODUCTIVE TECHNOLOGIES - THE (PUBLIC) DEBATE THAT NEVER WAS

I. Introduction

Reproductive and genetic technologies, as a general classification, developed out of particular sets of expertise and interests. While no individual researcher, ~~scientist~~, medical doctor, or politician necessarily had malevolent intent with respect to the many technologies that purportedly assist women and men to procreate, the concern that the technologies had proceeded without adequate debate or discussion about their implications led to the Royal Commission on New Reproductive Technologies.

The Royal Commission on New Reproductive Technologies presented an opportunity for important new research to be done and for a public discussion on them. Fear that the technologies which were racing ahead without any regard for social implications was replaced by an optimism that the general public and the government in particular would recognize the need for mechanisms to evaluate and safeguard the technologies.

This chapter will evaluate the Royal Commission on New Reproductive Technologies. I will demonstrate that the government carefully constructed this Commission so as to maintain the *status quo* of a highly under-regulated, industry-dominated sector. This plan included a carefully worded mandate and strategic choices of Commissioners (although some of these choices clearly backfired). Most significant, however, was the choice and overt support (through unprecedented interventions) for Commission Chair, Dr. Patricia Baird. Baird conducted the Commission in a manner that parallels the hubris displayed by some of those who created the reproductive and genetic technologies. She showed little regard for democratic practice, be it with fellow Commissioners, Commission staff or members of the public participating in the Commission. The result was a deeply flawed commission. The credibility it lacks is unfortunate, for some of the studies, recommendations, and findings of the Royal

Commission are useful and should have been immediately implemented. It is likely the federal government is using this credibility problem to take the easy route by failing, some three and a half years later, to have implemented even one recommendation of the Royal Commission on New Reproductive Technologies.

Even prior to its inception, the Royal Commission was destined to have problems. Some critics of public inquiries see them as stalling mechanisms that only serve to make the government appear to be taking action on politically risky or contentious issues. Related to this is the belief that governments (and, in fact other powerful groups in policy communities) are not truly interested in sharing power with the public. As environmental writer, Frank J. Tester notes: "Recent government responses to citizen participation demands suggest a conscious effort to control the expansion of opportunities for public involvement so that the scope of deliberations is carefully constrained and so that final decision-making authority remains in present hands."¹

The "present hands" include a very deliberate, closed policy community of members or actors who are there because of their power, political resources, and interests. Government has the power to regulate and legislate. In order to do so, however, they need to know what it is they are to regulate. This creates a relationship or network of "friendly adversaries" where government looks to industry for its information.² With respect to scientific, specifically medical, technologies government chooses to turn to the medical profession for their information. In the development of medical procedures and knowledge, much of the decision-making is completed by those in the medical industry long before it gets to the public agenda (including that of government). Decisions about which technologies are developed and how their efficacy is determined are governed almost exclusively by medical doctors and researchers themselves. They in turn are directly, and significantly, influenced by the pharmaceutical industry. "With regard to physicians,

¹ Frank J. Tester, "Reflections on Tin Wis: Environmentalism and the Evolution of Citizen Participation in Canada," *Alternatives*, Vol. 19, No. 1, (1992), p. 34

² Schrecker, "Mobilization of Bias," p. 45

several studies have shown that a physician's adoption of a drug and his or her subsequent prescribing behaviour is largely determined by drug industry sources."³ The public (including the government) is left to evaluate the product or technique in a much more reactive manner.

These very relationships were at play within the Royal Commission on New Reproductive Technologies. I will investigate three main areas of the Commission: the Consultation and Communications program; the research conducted for/by the Commission; and the outcomes of the Commission, which includes both the findings (as presented in the *Final Report* and Research Volumes) and subsequent governmental action.⁴ While there were some useful findings, in general, the Royal Commission was an example of poor management and dubious research and consultation at an extremely high cost. The result, perhaps not altogether surprising, was the continued domination of the process by those same powerful interests the government allegedly sought to evaluate and regulate. This begs the question, as Tester has put it, of whether the Canadian government was ever interested in involving citizens in a meaningful way. One must also question whether there was ever the political will to alter the existing policy community. In the almost ten years since the call for a Commission first came, reproductive and genetic technologies have pressed ahead and close to thirty million dollars have been spent on them. Canadians are still left without any new legislation and with the sense that a truly public debate never really happened.

II. Consultations

The [public] inquiry ... offers the public an unlimited opportunity for experiencing direct democracy, that is, widespread political participation in the formation of specific policies. It offers an opportunity to define public issues, in public view, with the participation of the clients of these policies..⁵

³ John B. McKinlay, "From 'Promising Report' to 'Standard Procedure': Seven Stages in the Career of a Medical Innovation," in *Milbank Memorial Fund Quarterly Health and Society* Vol. 59, No. 3 (1981), p. 384.

⁴ The critical discussion of outcomes (including governmental initiatives post-Commission) will appear in chapter six.

⁵ Salter, "The Two Contradictions in Public Inquiries," p. 174.

Consultations of the Royal Commission on New Reproductive technologies were organized in an attempt to reach as many Canadians as possible. The early literature of the Commission identifies their style as "total society." The press release issued from the Commission just prior to the public consultations in the fall 1990 states: "The Commission has set up an extensive Public Consultations Program to give Canadians from all walks of life and from all regions of the country the opportunity to contribute to its work, as it studies the origins, effects, and impacts of the technologies."⁷ Included in their consultation plans were the following: Public and Private hearings; submissions and letters of opinion; personal experiences and private sessions; information meetings; a search conference; public opinion research; toll-free lines.⁷

The final *Report* states that the Royal Commission succeeded in consulting broadly: they claim to have involved more than 40,000 people in various venues of the inquiry, through submissions, surveys and clinical studies. Further it is noted that special attempts were made to reach those who might have difficulty reaching the Commission: "In particular, we looked for ways to facilitate involvement by people living in rural or isolated areas and women with both a job outside the home and family responsibilities, who might otherwise have found it impossible to participate..."⁸ A closer assessment of the consultation efforts of the Commission reveals that the numbers are misleading and the types of involvement vary from an abbreviated telephone survey with an Angus Reid representative, to a special interview between the Commission and a representative of a powerful pharmaceutical company. The consultation program of the Commission had some very real limitations that have been obscured from the public eye.

The Wolfville Search Conference, June 18 to 20, 1990

One of the first public efforts on the part of the Royal Commission was the Wolfville Search Conference, held eight months into the twenty-four month mandate. The

⁷ RCNRT, "Royal Commission takes 'total society' approach to new reproductive technologies," Press Release, Sept. 4, 1990.

⁸ RCNRT, Proceed With Care, p. 136.

Conference provides early hints about the overall direction and style of the Commission and merits assessment. It was also one of the earliest indications, both publicly and behind the Commission's closed doors, that all was not well at the Commission.

The purpose of the Conference was to assist the Commission with refining its mandate. Had this exercise occurred earlier, with a more diverse group of people, it might have been an interesting and creative means of engaging the public to help in defining the work of the Commission. As it was, the Commission demonstrated poor leadership and insight. With this conference they sent the message that they were incapable or unable to decide what to do with the mandate and needed to hold an exclusive, expert-only session to help them do so.

The search conference occurred over three days: from June 18 to 20, 1990 in Wolfville, Nova Scotia. The purpose of the conference was stated in the agenda to participants as: "to bring together forty of the most knowledgeable, experienced and articulate people to 1) exchange views of the mandate given to the Royal Commission on New Reproductive Technologies and on the issues raised by that mandate, and 2) to suggest how the Commission might execute its mandate and what activities might be undertaken."¹ The workdays were divided into syndicate sessions, where participants grappled with six key questions related to the technologies and the work of the Commission. Plenary reports, shared findings of the syndicate sessions and a report which was completed after the conference were the main outcomes.

The majority of participants at the Search Conference were women.² This provided some affirmation of the expertise which women had in the area of reproductive and genetic technologies and the impact they had on their lives. At least one participant praised this composition, but noted the minimal presence of "disabled persons, people of colour, native people, lesbians and gay men, single parents, and poor and working class people, as well

¹ RCNRT, Proceed With Care, p. 135

² RCNRT, "Agenda: Search Conference on New Reproductive Technologies," June 18th - 20th, 1990, Wolfville, NS, p. 4

as groups and organizations representing these groups." She also noted the absence of mothers and women who have made use of the technologies either successfully or unsuccessfully.¹¹ The final number of participants was not forty but thirty. These thirty were heavily weighted from the medical establishment to represent the views already well-established in the production of the technologies. Excluding this group was certainly out of the question, for their input and insight was crucial to a full understanding of the technologies within Canadian society. But it seems that the efforts to include a number of representatives from medical associations and institutions resulted in an exclusion of many other important representatives. Of groups directly affected by the outcomes of the technologies only Pat Israel, the Chair of the DisAbled Women's Network (DAWN) and Nancy Jackson, a representative of the Infertility Awareness Association of Canada (IAAC) were invited. Only two independent authors on the subject were invited. The rest either worked for the government (or governmental agencies), medical associations/institutions, pharmaceutical companies, legal associations or academe. Concerns were raised that some of the participants were excluded from the discussions by others who were more "dominant." "It is essential that facilitators be aware of the social privileges carried by some group members, and of the disadvantages endured by others."¹² Although the hiring of facilitators for these discussions was one effective way to moderate, a different format, which accounted for the differences in power, would have made the conference more meaningful for all.

The four fired Commissioners also questioned the merit of having a "search conference" eight months into the Commission at which time forty experts would be asked about how to interpret the mandate, a job that the Commissioners themselves were appointed to do. This is illustrated in an excerpt from the letter from the four Commissioners to Baird on these matters. It is worth noting that issues raised in the letter

¹¹ RCNRT, "Agenda," p 1

¹² Christine Overall, "Report on the Search Conference Held by the Royal Commission on New Reproductive Technologies, Wolfville, N.S. June 18-20, 1990," (Kingston) July 1990, p 1

with respect to ignoring the needs of francophone participants in the Commission (including Vandelac and Hebert themselves), are ones that surface a number of times in the various pieces of correspondence that can be located in the Federal Court Statement of Claim.

Finally, even though many of us expressed our hesitation in light of the vagueness of the exploratory [June 1990 Wolfville Search] conference and questioned the pertinence of this operation as it was designed, we were once more presented with the done deal, learning about the content and the way the conference would unfold at the same time as the external participants. Now, how not to feel extremely uneasy when we had to confess to the invited researchers that we did not know anything more about this conference than they did? How not to notice that the Chair did not speak in French once, not even to say "merci" to the attending experts or to invite whomever in the Commission to say some words in French? How not to feel betrayed when the experts asked us why the Commission invites them to define the reproductive technologies or to interpret the mandate, eight months after the work started? "What did you do all this time?", we were asked by some of them, rightly so. In the mistaken belief that the commissioners constituted "the Commission," it was difficult to allow this illusion to go on, when the facts had reduced us to the role of multidisciplinary and democratic alibis.¹³

If the search conference was to produce concrete direction for the research program, it was interesting that the Commission had as yet failed to hire a permanent Director of Research and Evaluation. Not only were a majority of the Commissioners unclear about the direction of the work of the Commission, the entire research branch of the inquiry was also lacking this vital information.

It is unclear what the point of this search conference was. Possibly, given the amount of time that had passed, it was an attempt to send a message out to key groups and organizations that the work of the Commission was underway. Perhaps it was to draw these groups and organizations into the work of the Commission. The search conference was a failure in many ways. The late timing of it set off alarm bells. The exclusivity of the event, coupled with its decidedly professional weighting, sent a message about whose input was really important. Patricia Baird's exclusionary behaviour at the conference itself presumably sent the message to Francophone communities that they were unimportant or

¹³ Overall, "Report on the Search Conference," p. 2.

¹⁴ Federal Court Statement of Claim, Schedule 8, p. 7.

excluded. It was a shaky start as one of the first consultative and public actions of the Commission.

Public Consultations

The public consultations of any royal commission are the primary vehicle by which 'ordinary citizens' may participate in the making of public policy. Women's groups had argued that a public debate was required on issues of reproductive and genetic technologies. Given the immense social stakes, they argued, the decisions could not simply be left to medical associations, university ethics boards or to the individual discretion of doctors or clinics. They lobbied for the Royal Commission on New Reproductive Technologies because of its potential for extensive consultation and public participation.

Commissions present an exceptional and rare opportunity for direct democracy and meaningful participation. Both Connie Ozawa and Rene Parenteau, who write about public participation, argue that to have effective and meaningful consultations with the public certain mechanisms must be in place. These include: adequate education, access to technical information; appropriate time and resources; "expertise;" and legitimacy, voice and a recognition of the relative public standing which various participants may have.¹⁴ The format of the consultations themselves are also critically important. Without a well-designed consultation program, tokenistic sessions may result which have no significant translation into the final recommendations. This structure is useful when investigating who was able to participate in the public consultations of the Royal Commission on New Reproductive Technologies.

The public consultations were planned for the autumn of 1990. A public notice was released to major media outlets in mid-May of that year advertising the Commission hearings, and calling upon members of the public to submit letters of request to appear by

¹⁴ Ozawa, 'Recasting Science,' pp. 87-102 and Rene Parenteau, Public Participation in Environmental Decision Making (Ottawa: Minister of Supply and Services, 1988), p. 57.

July 1990. The notice appeared as a legalistic announcement in the newspapers with the header: "PUBLIC NOTICE." Included was the mandate, a brief description of the consultation program and a lengthy list of technologies in fairly technical language. It was hardly inviting to the general public, particularly the final lines which seemed particularly daunting: "You are encouraged to discuss these issues from a social, legal, ethical, health, research, legal and economic perspective."¹⁵ With little background in the issues, people may have been wondering why their contribution would be important, particularly if they did not see themselves as an expert in the areas listed. As the first introduction to the Commission for many, this notice may have alienated potential participants.

The notice gave individuals and groups the summer to coordinate whether they would attend such meetings, and determine what they were going to say. While this may seem to have been a reasonable amount of time, it is important to recall that summer is often a bad time to coordinate committees, groups, or even individuals (i.e. a mother with children who are off from school for the summer.) The notice contained an assumption that the public was aware of the Commission and its work, something that was perhaps not the case. As well, other large policy questions, notably Meech Lake, were preoccupying the media and the Canadian public:

[L]ess than 15% of the Canadian population knows about the existence of the Commission and only 1% would refer to it. As to the official notice placed in the media, it seems to have been largely drowned by Meech Lake... With two months notice, at the end of the school year, at the end of the activities of associations, in the middle of the summer and with the notice requesting submission of documents at the end of July, we have serious reservations to such consultation process.¹⁶

The issues of reproductive and genetic technologies were complex and far-reaching and the Commission should have been providing pertinent information about them to the public. What was provided, the "Guide to Public Participation," was inadequate and lacked substance. As the first official introduction to the Commission, the "Guide" was an important document. It was intended to provide information about the technologies in

¹⁵ RCNRT, "Public Notice," Vancouver Sun, May 16, 1990, B2.
¹⁶ Federal Court Statement of Claim, Schedule 8, p. 6.

question and instructions on how to most appropriately participate in the work of the Commission. The Commissioners had spent a great deal of time discussing what should go into such a document only to have Dann Michols give them 72 hours over a weekend to read a draft and give back comments. In his letter to Michols, Hebert protested the lack of time given to provide proper feedback. The format of the pamphlet was one where questions were assumed and posed on behalf of the reading audience, then answered by the Commission. He noted that it was patronizing in tone, provided few real facts or definitions, and was too simplistic for those who did have knowledge. Hebert also raised concerns with the perceived bias in the pamphlet, framing the technologies in a favourable light:

I find it necessary to use, at this stage, in the public and official documents of this Commission, a lexicon that is neutral and that does not attempt to qualify certain realities. For example, I find it preferable to talk about development rather than progress of the new technologies. In the same way, real terms such as "the improvement of these methods" or artificial insemination as "remedy" seem inappropriate in this case ... Indeed, the main goal of this kit is to provide a certain amount of information and not a list of our questions.¹⁷

One thing the Commission could have done was to provide a list of additional reading on some of the key topics. As it was, none of this was provided and many terms were referred to without definition. For an area already highly scientific and full of jargon, providing sound, useful educational tools was essential if people were to participate. Of the question and answer format, researcher Christine Massey wrote:

The presumption involved in posing questions and responding and reacting on the public's behalf seemed to be at odds with the pamphlet's goal of inviting the public's opinions and thoughts. This presumption had the effect of demonstrating a lack of respect for the public's intellectual abilities As the major means of informing Canadians and attracting people to participate in the Commission's work, this kit was both uninformative and uninviting.¹⁸

¹⁷ Federal Court Statement of Claim, Schedule 21 (Letter from Martin Hebert to Dann Michols re: the Guide to Public Participation May 29, 1990, trans. by P. Mendez), p. 4

¹⁸ Massey, "The Public Participation Program of the Royal Commission," p. 80-1

While there were some alterations to the "Guide," overall, it remained unchanged, despite concerns raised by a majority of the Commissioners.¹⁹ The Canadian Research Institute for the Advancement of Women (CRIAW) took it upon themselves to respond to this informational void by producing its own guide. It provided a useful glossary of technical terms, some articles outlining concerns about the technologies, and a practical guide to assist people who wanted to participate in the hearings of the Royal Commission ("writing and presenting a brief.")²⁰ The Commission would have been wise to make use of a guide much like the one CRIAW produced rather than the brief, rather uninformative documents they offered.

The Commission had advertised that it would be conducting hearings in 26 communities. In the end this number was whittled down to 17, almost entirely urban, centres. Given the Commission's stated commitment to "rural or isolated areas" it is striking that most of the communities that were dropped from the itinerary were the smaller, more rural ones.²¹ The government, when seeking public input, will sometimes provide funding or other forms of support to facilitate participation (as evidenced, for example, in the Berger Commission). Such contributions, however small, encourage participation and partially off-set the limitations which many volunteer, non-profit or small groups and individuals encounter relative to professional and business groups. Ironically, given the subject, the Commission provided no such funding, nor did they offer child care at the sites of the hearings!

The Commission also chose to conduct the hearings in an intimidating and unfriendly format. Commissioners traveled to 17 major cities in Canada (we will never know how many rural women were excluded by this) where they were set up in large ballrooms of luxurious hotels. No childcare was offered. Seating arrangements at the hearings were such that the commissioners were seated at a large table in the front of the room, facing a smaller table where the speaker sat. Communication was a one-way process, from the intervenor to the commissioners. Opportunity for questions was only given to the

¹⁹ Federal Court Statement of Claim, Schedule 8 (Letter from Louise Vandelac et al to Patricia Baird July 9, 1990), trans. by P. Mendez), p. 6.

²⁰ Janis Wood Catano et al, Our Bodies Our Babies? Women Look at New Reproductive Technologies (Ottawa CRIAW, 1989).

²¹ Federal Court Statement of Claim, Schedule 10, p. 4.

commissioners. There was no opportunity for formal discussion among the participants.²²

According to the Commission, they heard from "more than 550 people, appearing on their own behalf, or on behalf of nearly 250 organizations."²³ While the Commission avoided doing further analysis of these numbers, they can be broken down by going through the list of participants. The two categories of people that appeared the most were, perhaps predictably, non-profit or volunteer organizations (123 groups represented) and medical groups/organizations (88 groups were represented; of this group, 15 were individual doctors - i.e. not formally representing a medical organization). The remaining intervenors were: twenty-two governmental organizations; twenty-one professional or university groups; and forty-two individual or unaffiliated people.²⁴

The opportunity to participate in public hearings may be structurally filtered or eliminated.²⁵ Professional groups, like medical associations or even individual medical doctors may have legitimacy both in society and before a commission. Non-profit or volunteer groups, who have less resources, such as 'religious' groups or 'feminist', 'survivor' or 'consumer' groups may represent particular perspectives which are perceived to be biased. This may serve to limit their credibility, particularly if they wander from the issues that fall within their 'domain.' Volunteer groups or individuals who may not be as polished or as knowledgeable about terminology or most recent research studies, may have to earn recognition or standing before such bodies, if in fact, they appear at all.

Apparently, individuals did not feel they could come to present their views to the Commission via these consultations. This was probably due to a number of factors such as: an inadequate educational campaign; inappropriate literature (the Guide and the public

²² Judy Morrison and Christine Massey, "Royal Commission on New Reproductive Technologies: Been a Long Time Coming" *Kinesis*, Nov. (1993), p. 10

²³ RCNRT, "What We Heard: Issues and Questions Raised During the Public Hearings," Sept. 1991, p. 7

²⁴ The numbers do not add up to the cited 500+ groups/individuals. This is due to the fact that many groups/organizations had multiple people presenting as intervenors, which has not been captured by my breakdown.

²⁵ Parenteau, *Public Participation in Environmental Decision-Making*, p. 57

announcement); lack of support for individual submissions; an intimidating consultation structure/setting and the perception that they would have nothing to contribute.

A significant number from the medical establishment did choose to present at these hearings. Included were: individual practitioners; doctors from non-profit agencies (Canadian Physicians for Life); various provincial/territorial Medical Associations; the Canadian Medical Association; the Canadian College of Medical Geneticists; the Canadian Fertility and Andrology Society; the Canadian Nurses Association; the Royal College of Physicians and Surgeons of Canada; the Society of Obstetricians and Gynecologists of Canada; representatives from hospitals or clinics offering new reproductive or genetic technologies; and several other related medical societies. Many of these representatives and colleagues should have been well known to Chair Patricia Baird.

Perhaps equally significant is the notable absence of the pharmaceutical industry: not one representative from this sector appeared at the hearings. Possibly this powerful group felt they did not need to contribute in such a venue. The government had already been active in representing and safeguarding the interests of the pharmaceutical industry through patent protection (Bills C-22, C-91) and other measures. The pharmaceutical industry may have felt a certain confidence that their interests were above such mechanisms as public consultations. The Royal Commission acted in a way that signaled a continuation of the pharmaceutical industry's privileged standing. While no plans were originally in place to do so, in response to their absence they received private sessions with the Commission in the following months.²⁶ What is striking here is not that the Commission went to great lengths to ensure consultation with the pharmaceutical industry, but that similar efforts and accommodation was lacking with respect to 'the public.'

The Commission presented all of the submissions from the public consultations together, without pointing out significant differences between them. Many potential

²⁶ There were five such private meetings with sixteen pharmaceutical and related industries, including PMAC (Pharmaceutical Manufacturers Association of Canada) RCNRT, Proceed with Care, pp 1197-1228

participants were "filtered out" of the consultations by inadequate information, education, and a lack of resources. Each individual or group of intervenors was given exactly the same amount of time, with a similar format, in each city. This format tended to favour those who are comfortable in such settings (professionals, academics and business people) and to disadvantage groups from the non-profit and volunteer sectors, and individuals. The overall point of public consultations is purported to be to hear from the public: to get as many representative views as possible. Both Jenson and Parenteau posit that public hearings must first acknowledge, then account for, the considerable differences that exist in various (potential) participants. Taking the example of a pharmaceutical firm and an individual contacted in a random telephone poll, clearly the former has both a more explicit interest and usually significantly more resources by which to make a viewpoint known. A commission must level the playing field so that those who have less access or polish are able to have a fair hearing and legitimate standing before a mechanism as daunting as a royal commission hearing.²⁷ No such attempts were evident in this Commission's public consultation efforts. The consultation process might have been far more successful and informative had the Commission provided more lead-time for preparation, more appropriate educational materials, more support in general (intervenor funding, childcare), and an interactive format more conducive to discussion of the ideas. As it was, the consultations were designed in a way that tended to hinder poorly funded groups from appearing. This is unfortunate given the whole point of a royal commission which is to hear broadly, particularly from those who would not otherwise have access to the policy-making that affects them.

Private (Armchair) Sessions

The Commission appropriately recognized that issues of reproduction, and particularly of unsuccessful reproduction, are private and sometimes painful experiences. They advertised and organized a variety of ways which individuals or couples could

²⁷ Jenson, "Commissioning Ideas," p. 42, 44, 52

communicate confidentially to the Commission about their views of the technologies and their related experiences. Given the issues under consideration, and the low turn-out by individuals at the public hearings, these sessions were a creative, perhaps less intimidating way to communicate directly to the Commission.

It is difficult to assess the results of these sessions, since the Commission did protect people's anonymity and confidentiality. There are some indications of the outcomes of these exchanges in the Commission publication: "Personal Experiences with New Reproductive Technologies Report from Private Sessions."²⁸ There were four basic ways by which people could privately communicate with the Commission: private meetings with a Commissioner and a facilitator; small group discussions, with 6-8 people who had had similar experiences (usually with IVF); telephone interviews; and written or taped submissions.

The Commission reports that they heard from nearly 500 individuals and couples in this way. Thirty private meetings occurred between the Commission and individuals or couples. The report from the private sessions notes that most people who wanted to discuss their experiences with the technologies wanted to address *in vitro* fertilization. This would not be surprising, given that *in vitro* fertilization was perhaps one of the most publicly accepted, and popular reproductive technologies. However, other parts of the report are revealing: most of the participants were concentrated in Ontario and many of the people who came forward "to the Commission said they were responding to a letter from their *in vitro* fertilization program encouraging them to do so."²⁹ Indeed, the Canadian Fertility and Andrology Society had sent out a mass mailing to all of its members in June 1990 encouraging them to find "individuals through some of the IVF clinics or other clinics for assisted reproduction to identify individuals or groups who would be willing to present

²⁸ The same information, slightly altered, appears in RCNRT Staff, "Personal Experiences with New Reproductive Technologies Report from Private Sessions," in RCNRT Social Values and Attitudes Surrounding New Reproductive Technologies, Research Volume Two, (Ottawa: Canada Communications Group Publishing), 1993, pp. 469-491.

their viewpoint to the Royal Commission.”³⁰ Without question, the experiences of individuals who had direct insight into *in vitro* fertilization were crucial. However, the fact that they were solicited by an organization and related practitioners who have considerable interest in the continuation of this technology calls into question their representativeness. Perhaps not surprisingly, none of the participants interviewed wanted *in vitro* fertilization stopped. Similar numbers of people were not forthcoming for those who’d had negative experiences with *in vitro* fertilization or other reproductive technologies. Only a small percentage of women who use *in vitro* fertilization actually become pregnant and produce a live baby (10 to 13%) and the notable absence of other voices at these sessions raises considerable doubt about a balanced view.

With respect to the format of the armchair sessions, the Commission report notes that “although interviews were not formally structured, an interview guide was developed to draw out baseline data to assist with the synthesis and analysis of the information obtained.”³¹ This statement raises at least two concerns. First, was the point of the sessions to obtain “baseline data” or was it to achieve more qualitative information not so readily quantified? If the point of the individual sessions was to consult, then there should have been an opportunity to have open-ended discussions led by the informants, not by those conducting the interviews. Second, it is unclear how much “structure” was imposed in these sessions, which ultimately would have affected how and to what extent people gave their viewpoints. As with the mandate of the Commission, the way questions are posed can have significant effects on answers or outcomes. Holding these private sessions was an extremely important means of obtaining information about the impacts the technologies had upon people’s lives. While it is important to provide structure, this over-

³⁰ RCNRT, “Personal Experiences with New Reproductive Technologies Report from Private Sessions,” May 1992,” pp. 1-6

³¹ Kenneth D. Roberts, President of The Canadian Fertility and Andrology Society, letter to the membership June 14, 1990

³² RCNRT, “Personal Experiences” p. 1

structured approach may have jeopardized the Commission's intent to provide people with the opportunity to share their concerns and views.

As it was, the Commission heard some interesting insights into the technologies. Lack of information and support during all procedures related to the various reproductive technologies were of concern. An incredible twenty-three women who participated in the private sessions had experienced multiple pregnancies (i.e. were pregnant with multiple fetuses). It is unclear from the report whether this represented twenty three from a total of thirty private sessions, or if this number is from all private sessions (which would likely be roughly 100 women.)³²

A second set of private sessions were held as small group discussions. A group of 6 to 8 people who'd had experience with the same technology were brought together for discussions. At least one such discussion was organized by the doctor who provided the medical care. The doctor was present and part of the small group discussions: hardly a place where patients could raise their concerns about treatment or practices.³³

Most of these 'consultations' were not consultations at all but took the form of taped or written submissions. This meant there was no opportunity for an interactive dialogue where individuals could clarify or expand positions, nor could they be certain that the information they provided was interpreted correctly. As with all of the information the Commission took in, it had to be woven into the final report. The Commission may have lifted key phrases or sections from their original context, which may have created a very different meaning.

³² RCNRT, "Personal Experiences" p. 16

³³ Massey, "The Public Participation Program," p. 121 and RCNRT, "Personal Experiences" p. 13

Public Opinion Polls

The Commission used four sets of public opinion polls. The total cost of these was over \$570,171.³⁴ Polls provide quantitative information about that which can be extrapolated or otherwise used as a representative sample of a larger population. Public opinion polls are questionable instruments. Purported to provide a snapshot of where public opinion is at a particular moment, they often tend to create public opinion when released in the media. Polling companies specialize in designing, conducting and assessing polls, and may not be specialists in the subjects they survey. All too often, polls are inadvertently conducted with inadequate or, in some cases, flawed background information, leaving the people being surveyed to make a best guess or an uninformed comment. Depending on who is financing a particular poll, the potential for biased or leading questions may result in a narrowing of possible responses to a desired outcome.

In terms of consultation, public opinion polls rate poorly because of some of the concerns raised above. Their contact with the individual is indirect. Poll results are sometimes difficult to comprehend, as individuals may have little opportunity to clarify her/his responses or to expand them beyond a one or two-word answer. The Commission was able to say they consulted broadly, but this consultation was far from meaningful.

Concerns similar to these were raised at the Wolfville Search Conference when participants were asked for feedback on the use of polling. Questions were also raised about the purpose of polls, and it was felt that the use of polls as a route to determining public policy was a dangerous, flawed course.³⁵

The decision to conduct an Angus Reid poll had been made early by the Commission (before the Search Conference), as a quick way to glean Canadians' views regarding reproductive technologies. This telephone poll of 1503 Canadians asked a broad

³⁴ Louise Vandelac, "From Bird to Baird: The Royal Commission ne suivent mais ne se ressemblent pas." Presented at the Association Nationale de la Femme et du Droit, Vancouver, BC, February 19-21, 1993, p. 5.
³⁵ Overall, "Report on the Search Conference," p. 6.

range of questions about reproductive technologies and “the ethical, social and economic issues concerning them.”³⁶

The four dissenting commissioners lodged complaints with respect to the use of the Angus Reid opinion poll, conducted on behalf of the Commission in May 1990. They were generally concerned about whether the results of the poll could legitimately be used to aid the general research of the Commission. Baird assured the Commissioners that the poll would be used for internal purposes only.³⁷ Mann, Director of Consultations and Communications, noted that the poll was simply a quick way to obtain a fairly good snapshot of where the general public stood on these issues and could guide the Commissioners in their research deliberations.³⁸

Commissioner Louise Vandelac, the only social scientist with extensive experience with surveys and opinion polls, raised several concerns about the design of this particular survey. Reproductive technologies and infertility are complex, personal subjects. There is not even agreement around basic issues such as what constitutes infertility. Vandelac argued that such topics were inappropriate for a telephone survey. A number of terms were used without being defined. In the poll, notions of infertility and sterility were conflated.³⁹ She felt this would result in inaccurate answers and would further confusion about this topic in the public. She found that many of the questions were presented in a misleading, vague, even “extremely biased” way, without sufficient background information provided. For example, question 4, b) of the poll read: “In your opinion, is the *ability of medicine* to *overcome* infertility by using *advanced* techniques a positive or negative *development*?” (emphasis added)⁴⁰ The question presents the technologies as powerful and favourable. It

³⁶ RCNRI, *Proceed With Care*, p. 25.

³⁷ Federal Court Statement of Claim, Schedule 12 (Louise Vandelac, Memo to Pat Baird, Commissioners and Senior Staff Re Public Opinion Poll, May 9, 1990) and Federal Court Statement of Claim, Schedule 8, pp. 6-7.

³⁸ Federal Court Statement of Claim, Schedule 12, (Memo from Louise Vandelac to Pat Baird, commissioners and senior staff, quoting memo from Dann Michols, May 7, 1989), p. 21.

³⁹ Federal Court Statement of Claim, Schedule 12, (Memo from Louise Vandelac to all the Commissioners and key staff, re the Public Opinion Poll, May 9, 1990) pp. 8-10.

⁴⁰ Federal Court Statement of Claim, Schedule 12, pp. 11-12. Other examples of problematic questions in this poll include many of the questions pertaining to IVF. The poll is not in the public domain, but Vandelac's

would be difficult for someone to say that the ability of medicine to overcome a condition is a negative enterprise, particularly with little information about the condition itself and the related technologies. The respondent may be led into answering in a particular way which may not represent their point of view at all. Their answer may only represent inaccurate information used by those conducting the poll.

Vandelac suggested that, given the seriously flawed nature of the poll, it be revised and postponed until the autumn. She was joined by Hebert in this call. Their suggestions were ignored. The poll was conducted intact in May 1990. Although it was to be used for internal purposes only, the results were released to the media in September 1990, without the knowledge or consent of those raising the initial concerns. It indicated that less than 15% were knowledgeable about reproductive technologies, still fewer were aware that a Royal Commission was investigating them. More than one-third of those surveyed "greatly overestimated the prevalence of infertility."⁴¹ This suggests a lack of public understanding of what infertility is and brings into question responses to queries about attempts to bypass the condition. Yet the results of this poll were made broadly available. According to some media coverage, it indicated that one in six Canadians are infertile and there was an overestimated success rate for *in vitro* fertilization. These statistics were called into question by four Commissioners:

We were shocked to see the article in Le Droit on September 20, 1990 on the Angus Reid poll commissioned last June 1990, despite vigorous opposition of several commissioners..... we know of no research that says this [that supports the published findings in the Le Droit article] ... One Commission staff member told us that these figures come from the Angus Reid poll. If this is true, it represents a flagrant manipulation of public opinion.⁴²

memo critique provides many of the questions followed by her concerns about them. See also Margaret de Groh, "Key Findings from a National Survey Conducted by the Angus Reid Group: Infertility, Surrogacy, Fetal Tissue Research, and Reproductive Technologies," in RCNRT, Social Values, Vol. 2, pp. 203-242.

⁴¹ de Groh, "Key Findings," pp. 203-4.

⁴² Federal Court Statement of Claim, Schedule 12 (Letter from Vandelac, Hebert, McTeer, Hatfield to Baird Oct. 12, 1990) and David Vienneau, "Few favor government funding for test tube babies, study shows," *Toronto Star*, Oct. 16, 1990, p. D1; *Le Droit*, September 20, 1990, pp. 36-7; "Most Canadians know little of reproductive issues poll," *Montreal Gazette*, Sept. 19, 1990, p. B4.

Not only was the poll a problem in terms of the misinformation brought in, there was also concern about the erroneous information it released. This release of misinformation would have occurred at least two separate times: during the polling itself (due to the descriptive information given by those conducting the poll prior to specific questions) and during the release of the poll results to the general public via the media.

The Survey of Ethnocultural Communities by Shyla Dutt was perhaps the most interesting of all the quantitative surveys done. The Commission's decision to seek out specific input from these communities is commendable. The choice of a survey, rather than the creation of a more direct mechanism for receiving these views, is unfortunate. Given the impact of reproductive and genetic technologies upon people with disabilities, it is surprising similar attempts were not made for these communities. Dutt surveyed 100 key representatives from "ethnospecific and ethnocultural women's communities" about their views on reproductive technologies. She used a mail-out survey, followed up with discussions. The survey, given its size and focus, was perhaps less prone to the foibles of larger, mega-polls. Interestingly, the results of the survey indicated that "attitudes expressed by organizations reflected patterns similar to those in the general public."⁴³ Dutt further comments that "many organizations felt unable to express support or opposition, indicating that they did not have enough information or felt the issue was too contentious within their membership."⁴⁴

The Canadian Health Monitor (CHM) was a polling mechanism already in place at the time of the Commission. The Monitor, by Price Waterhouse, is conducted semi-annually on different health-related themes. Two themes (Canadian Health Monitor #6 and #7) were conducted on behalf of the Royal Commission in 1991: "Health Issues Affecting Women." 5448 Canadians were consulted. These cost approximately \$39,000. A Decima survey was conducted by phone and in writing between December 1991 and July 1992. It

⁴³ RCNRT, Proceed With Care, p. 25

⁴⁴ Shyla Dutt, "Survey of Ethnocultural Communities on New Reproductive Technologies," in RCNRT, Social Values, Vol. 2, pp. 411-412

surveyed 7664 Canadians on Social Values and Attitudes of Canadians Toward New Reproductive Technologies. It cost approximately \$284,400.

The polls were conducted by telephone and took approximately 33 minutes to complete in full.⁴⁵ Vandelac, in her critique of the lengthy Angus Reid poll (45 minutes) stated that the optimal length of a telephone survey is approximately 10 minutes. Of course, many respondents required far less time. For example, in some of the Monitor surveys, if you happened to be male and agreed to answer the survey, you could expect to be on the phone for under five minutes and could answer one question only. If you were a woman under 18 or over 44 years of age, you could answer two of the possible twenty-six questions.⁴⁶ In fact, the target sample was women, between the ages of 18 and 44, living in a heterosexual married, common-law or couple relationship. So, of the 2723 respondents in the CHM #6 survey, 297 women fit this target (about 11%).⁴⁷ The results of the surveys found that between 7.7% and 8.7% of women surveyed were infertile (that is, aged 18-44, married or cohabitating for at least one year). Both the definition and the surveys themselves lacked a key question: were these women actively trying to become pregnant? There were a number of questions about birth control and operations that might prevent pregnancy, but there was no direct question about intent in this regard. It is unclear and troubling why such a basic element was left unasked.

The choice of the polling firms utilized by the Commission is also of interest. Of the \$570,171 spent on polling and follow-up, at least \$320,900 can be linked back to companies with close ties with the Progressive Conservatives - the party in power and that appointed the Royal Commission on New Reproductive Technologies. Anderson Strategic Research was awarded a \$36,500 contract while \$284,400 went to Decima Research. Decima was run by Allan Gregg - a well-known conservative party hack who is a personal

⁴⁵ Connie S. Dulberg and Thomas Stephens, "The Prevalence of Infertility in Canada, 1991-1992: Analysis of Three National Surveys" in RCNRE The Prevalence of Infertility in Canada, Research Vol 6, p. 90

⁴⁶ Dulberg and Stephens, "The Prevalence of Infertility in Canada" pp. 85-89

image consultant to the Prime Minister and the Progressive Conservative Party," and owned by Hill and Knowlton, an international public relations and lobby firm.⁴⁸ Hill and Knowlton have several pharmaceutical firms among its clients, including: Burroughs-Wellcome, Glaxco and Monsanto (the latter who has significant interests in the promotion and development of genetic engineering). In a more complex set of linkages, Anderson Strategic Research was owned by Bruce Anderson had less direct links to Prime Minister Brian Mulroney, but who was also formerly an executive for Decima. Rick Anderson, the brother of Bruce, was the Executive Vice-President of Hill and Knowlton.⁴⁹ These connections add significantly more doubt to the credibility and objectivity of the polls and their findings. They also begin to raise questions with respect to some of the choices made by the Commission and more specifically, by Baird herself.

The Royal Commission chose to report the full number of those consulted via public opinion polls: 15,000. Only a fraction of this number actually contributed substantively to the polls, that is, got beyond the first three or four filtering questions. It was extremely misleading to lump all of these contributors together. The type of information gleaned from at least one of the surveys was very questionable, as demonstrated by Vandelac. The surveys account for 37.5% of the total number (40,000) who participated in the Royal Commission. It seems completely misleading to group together the input of a person who takes two minutes to state their sex or age and the contribution of Ares-Serono pharmaceuticals, which profit in the millions from the sales of fertility drugs. In sum, the public opinion polls led some of the Commissioners to state what other critiques quickly echoed: the Royal Commission on New Reproductive

⁴⁸ Dulberg and Stephens, "The Prevalence of Infertility in Canada" pp. 71. The other sample sizes were: CHM #7 441 women, Decima 50 women. I have utilized CHM #6 because the complete figures of calls attempted versus end sample utilized were fully reported whereas the same clarity is not presented for the other two surveys.

⁴⁹ Vandelac, "From Bird to Baird" pp. 6.

⁵⁰ Vandelac, "From Bird to Baird" pp. 5.

Technologies was more a public relations campaign than it was an exercise in public participation.⁵⁰

Other sessions

The Royal Commission held other sessions, such as the stakeholder meetings, and commission liaisons, with community leaders and organizations. These sessions are of interest in terms of their membership and how members were consulted. It is interesting to deal with these two consultative efforts together because the Commission's stance to them is quite different. The stakeholder meetings were with small groups of people whom the Commission identified as important and legitimate. The Liaison sessions tended to be attended by people who self-selected (although they were invited by the Commission) and these latter meetings were large, awkward affairs.

After the first round of consultations was complete, concerns arose about those who did not participate. In a memo to the Commissioners, Dann Michols (Director of Communications and Consultations) urged them to consider a follow-up round for those groups who might have more to contribute. In the memo he stated that certain sectors of society had not been heard from included "industry, the francophone community, various ethnocultural communities, youth, religious groups and aboriginals." He went on to hypothesize that perhaps these groups did not contribute "because they had nothing to say on our mandate or because they did not understand the issues or our process."⁵¹ This caused a great flurry of correspondence from five Commissioners protesting his implications and use of patronizing and discriminatory language. They also raised their concerns that the research program was still not well established.

The outcome of this activity was a set of stakeholder meetings with industry and professional organizations (Canadian Bar Association, Canadian Medical Association,

⁵⁰ Federal Court Statement of Claim, Schedule 8, p. 8

⁵¹ Federal Court Statement of Claim, Schedule 20, part 2 of 9, (Memo to Commissioners, cc: P. Baird, from Dann Michols, August 20, 1991), p. 1

etc.). None included youth, ethnocultural representatives, the francophone "community," religious groups or aboriginal groups. Interestingly, the Commission did not publish a "What We Heard" document for this set of consultations, as was done for both the 1991 private sessions and public round of consultations in the autumn of 1990. This indicates at least some distinction between professional organizations and 'the public.' It is likely, given the stance and outcomes of the Commission, that this distinction had everything to do with the standing and legitimacy which professional groups already have in society. These consultations appear to be an indicator of who held more value to the Commission.

The community liaison sessions were held in four major cities. Had these sessions been used as a template for other substantive work of the Commission, their much heralded "total society" approach might have come closer to being realized. While these sessions were diverse in their membership, or at least more diverse than other sessions undertaken by the Commission, they were unwieldy. There were an average of 38 participants - hardly a size conducive to in-depth discussion. These community liaison sessions occurred at roughly the same time as the stakeholder meetings and it is likely they were intended as a mechanism for consulting with the non-professional members of the public. As it was, many doctors and professionals were also part of these sessions.⁵²

The public consultations were supposed to be as inclusive as possible, given the immense impact the technologies could have on all segments of society. Indeed, Baird and much of the literature continued to proclaimed the Royal Commission approach as one of "total society." The consultations, however, were structured in a way that "filtered" out participation. The standing and legitimacy that professional and industry groups already enjoy in society seemed to be upheld in this segment of the work of the Commission. These same trends were reflected in the research, evaluation and the final recommendations of the Royal Commission.

⁵² RCNRI, *Proceed With Care*, pp 1207-1224

III. The Research and Evaluation Program

The Royal Commission on New Reproductive Technologies had divided its mandate into two key components: consultations and research. The research of the Commission was an opportunity to dedicate substantial sums of money to novel and ground-breaking research. Several other international inquiries had already occurred and the Commission research could have feasibly built upon what was already known and applied it to the Canadian context. The research program of this Commission was, like the consultation program, severely limited by poor leadership.

The Commission's research was divided into four key areas, each of was to be multidisciplinary. These were: the prevalence, risk factors, and prevention of infertility; methods of assisted reproduction; prenatal diagnosis (PND) and genetics; and research involving human zygotes and the use of fetal tissue. The Commission stated that they looked at both the technologies in question and their broader implications. They commissioned 130 studies. Not surprisingly, these studies found that with respect to reproductive and genetic technologies "general statements about them seldom held true."⁵¹ Much of the research conducted for the Commission is useful. However, it suffers by association, with the research manipulated or poorly managed by the Commission or by those contracts that were deemed questionable by critics. The research studies are surveyed only briefly here. Of more importance to this thesis is information about who contributed, how this work was managed, and how it affected the final results and overall work of the Commission.

The role of the Director of Research and Evaluation should have been central to the research work of the Commission. As the name implies, this position should have, in consultation with the Commissioners, decided what the research priorities were and solicited research proposals. This person would have also aided in assembling this information for not only the research volumes which are typically published, but also in

⁵¹ RCNRT, *Proceed With Care*, pp. 129-30

integrating or creating linkages between the consultations and the research contracted. It seems reasonable to assume the person hired should have experience in the research and evaluation of reproductive and genetic technologies, specifically. It appeared instead that this role was more window dressing than it was substantive. According to Margrit Eichler, one of the candidates for the job, the correspondence sent to her, before the position of Director was finalized, indicated that the research plan had already been put in place and researchers were being slotted into the four streams or task forces. In fact, this work had only been done by Baird herself and the Executive Director (John Sinclair).⁵⁴ The first-hired Director, Susan Mann-Trofimankoff, resigned after just three weeks for personal reasons. As was revealed through the Freedom of Information request, a "head-hunting firm" was hired at considerable expense and against the wishes of several Commissioners, meaning that the Commission spent the first ten months without a person coordinating the research work. The Wolfville Search Conference occurred during this time to clarify the mandate of the Commission. It is unclear how the findings of this conference fed into the work of the Commission research plan, if at all, given that the permanent Director of Research and Evaluation would not be hired until over two months later. It is likely that Baird took on this role herself, given that the Commissioners continually complained about the lack of information and consultation regarding the research plan.

Sylvia Gold was hired in August of 1990 as Director of Research and Evaluation. Of the Commissioners, only Baird, had input into this hiring. Gold admitted to knowing "nothing of the subject."⁵⁵ Thus, her role in the work of the Commission is unclear, particularly since she was hired well into the mandate. She resigned in response to the firing of several researchers in the summer of 1992. This means that she had little to do with the creation of the research program and less still to do with the evaluation. The research team existed for only half of the entire mandate.

⁵⁴ Eichler, "Frankenstein meets Kafka," pp. 206, 220

⁵⁵ Federal Court Statement of Claim, Schedule 8, pp. 2-4

At least four of the original six part-time Commissioners were continually pressing for basic information and more involvement in the research program from the very beginning. From the statements of claim submitted in their federal court case, there are several pieces of correspondence documenting their repeated attempts. In April of 1991, the Commissioners were presented with a research proposal review mechanism. However, according to the four Commissioners, this lacked very basic information that would allow them to actually review the research itself - including descriptions of most of the proposals. By the autumn of 1991, the Commissioners still had no clear understanding of the research process or of the specific topics under study, nor had they any knowledge whatsoever of "fully half of the research program."⁵⁶

What the Commissioners did receive in response to their requests was a skeletal document, a project array, listing the project number and title, the status of the work, whether a manuscript had been sent to Commissioners and a space for their notes.⁵⁷ This came nowhere near their request for: a description of the proposed project, including methodology, relevance and objectives; identity of the researcher(s) conducting the study; proposed timelines; budgets allocated for each; and comments from other Commissioners on each study. When asked why the information was being withheld, Baird responded that it might create bias or be "misleading" if such information was released to the Commissioners.⁵⁸ She left details unstated and unacknowledged about what mechanisms were in place to ensure that she, as the only Commissioner with the full research plan, would not suffer the same side effects.

By mistake, the Commissioners discovered the full research plan, with much of the information they had been requesting, through non-official channels.⁵⁹ They learned that many of the research projects that had been given to them for their review and input, had

⁵⁶ Federal Court Statement of Claim, Schedule 15 (Memo from McTeer, Hebert, Vandellac to Baird, Oct. 21 - Nov. 11, 1991)

⁵⁷ Federal Court Statement of Claim, Schedule 17 (Research and Evaluation Branch, Project Array, October 1991)

⁵⁸ Memo from Patricia Baird to Commissioners, Oct. 15, 1991 as cited by Eichler, "Frankenstein meets Kafka," p. 208

already been approved six months prior by Patricia Baird. Some research projects were given to the Commissioners well after they had been started and were then sent for publication just over a week later. This seems to indicate that the input of the Commissioners was little more than a rubber stamp. The Commissioners were purportedly appointed to create a multidisciplinary Commission. Given their strong academic backgrounds, it seemed reasonable to assume that one area of work of the Commission for which their perspectives would be invaluable, would be the research and evaluation program. The fact that the vital information was withheld from them; coupled with the fact the Director of Research was also restricted in her ability to perform indicates a severe limitation in the research area of work. "....[T]hat a single person, and a geneticist to boot, would be responsible for such a dossier, would no doubt be considered as a flagrant lack of objectivity and deep conflict of interest....."⁶⁰

One of the *Final Report's* central guiding principles was that of "evidence-based medicine." This generally means measuring the safety, efficacy, costs and implications of a particular treatment. This approach, however, uncritically accepts the principles and underpinnings of the medical and scientific model. Rather than questioning how the technologies are conceived of and developed, evidence-based medicine accepts existing mechanisms of evaluation (such as the reliance on clinical trials). While evidence-based medicine is more advantageous (safer, possibly better assessed) than purely profit-motivated technologies/medicine, it does not go nearly far enough to challenge the existing and powerful biomedical industrial complex. It seems presumptuous to have commenced the work of the Commission with this stance or 'finding,' particularly when a critical investigation of what the Report terms evidence-based medicine is exactly what many groups were calling for:

Many of us who joined the Commission as analysts and researchers soon after its inception came with a particular expertise and staunch commitment to the

⁶⁰ Federal Court Statement of Claim, Article 46

⁶¹ Federal Court Statement of Claim, Schedule 7, (Letter from Hebert, Vandaele, Hatfield, cc: Feltner to Baird, June 29, 1990)

interdisciplinary investigation of the multitude of issues raised by the mandate of the RCNRT. It meant that medical and scientific issues could be analyzed in a different way - there is no consensus even in these communities about them. Sadly, however, the powers that be had a different agenda. From the outset, the conventional medical model of research prevailed, augmented with a rigid hierarchical bureaucratic structure. ... Discrete medical and scientific categories structured the Research Working Groups.... The technologies drove the research categories and any other classification of research was rejected. No wonder the last year of the Commission has been spent "filling gaps." Moreover, the privileged methodology was that of the scientific models. Projects that could not yield "hard" data were not conducted or regarded as highly suspect. The scientific paradigm was the only norm to which everything else was to aspire. Facts could only be objectively produced through this method. But human interaction and social data are more complicated than this and not so easily reduced to quantifiable or observable data.⁶¹

This seems to indicate a tightly closed network where specific forms of knowledge were given legitimacy and others were placed lower down on the agenda, with less standing. Baird, with the overt support of the government, was able to ensure that the medical model, paradigm or epistemic framework was the one that prevailed.

Concerns about the pre-eminence of a specific agenda and the type of research and contracts awarded came under public scrutiny after the successful Freedom of Information request by the National Action Committee on the Status of Women. Margrit Eichler released a summary of the research contracts, finding almost half to be literature reviews, glossaries, bibliographies or overviews. Eight contracts were for research related to the on-going Canadian Fertility Study, which was not designed or contracted specifically by the Royal Commission.⁶²

Baird publicly denounced the accusations, stating that the Commission was committed to full disclosure of the research plan and those who wanted this information need only come directly to the Commission with such a request.⁶³ Such a response must have seemed pathetically comical to the Social Sciences Federation of Canada (SSFC) which had spent over six months pursuing, unsuccessfully, these very details from the Commission.

⁶¹ Anonymous 5, "Inside the Royal Commission," in Basen et al, eds Misconceptions, Vol. 1, pp. 233-4

⁶² Canadian Coalition for a Royal Commission on New Reproductive Technologies, "Briefing Paper on the Research Program of the Royal Commission on New Reproductive Technologies," Feb. 3, 1992, pp. 1-2

⁶³ Patricia Baird, "Commission criticism based on out of date information," Vancouver Sun, Feb. 8, 1992, B4

As described in chapter four, the SSFC sought specific information with respect to the research, in methodology, and peer review mechanisms. This was the same information which the four fired Commissioners had been attempting to get. The Federation was concerned with what seemed to be secrecy surrounding the entire research of the Commission. This mysteriousness was paradoxical compared to the preface from the Chairperson which appeared in many of the publications released during the life of the Royal Commission. It stated:

The Royal Commission is committed to an open and transparent research process with high standards and protocol which includes peer review. Specialists in academic disciplines ranging across law, history, ethics, medicine, sociology, and philosophy are examining the implications of the technologies through a variety of methods. The Commission is in contact with various communities across the country to solicit advice and commission research projects. Guidelines have been developed to help ensure the quality, integrity, and usefulness of all research studies. Research projects are subjected to rigorous internal and external review processes, first at the design stage and later at the report stage. Peer review for content and methodology is a key feature of the process.⁶⁴

Baird and Sylvia Gold responded to the SSFC stating that they could not disclose information about the particular research being conducted since researchers had been asked to sign a legal contract designed to protect them from possible harassment. As the President of the SSFC pointed out, "research is routinely conducted on sensitive questions" and such procedures as adopted by the Royal Commission were "highly unusual."⁶⁵ Four months later, two representatives of the SSFC had a statement published in the *Ottawa Citizen* that outlined that the clauses did not exist. "...[T]he director of research told the federation that the names of researchers could not be revealed. We were indeed told that there is a clause in the contract stipulating this. We were quite astonished, of course, to learn a few weeks later that no such clause exists. This sort of behaviour in no way coincides with the commitment to openness and transparency."⁶⁶ This led to growing international concern with the work of the Commission, and prompted a group of European experts, including renowned

⁶⁴ Patricia Baird, "Preface from the Chair," in, for example, Rona Achilles, "Donor Insemination: An Overview," RCNRT, (March 1992), p. 5.

⁶⁵ Robert Stebbins, Letter to Patricia Baird, April 8, 1992, p. 1.

infertility researcher Jacques Testard of France, to write letters of protest to Prime Minister Brian Mulroney.⁶⁷

The SSFC never got a satisfactory response to their questions about peer review.⁶⁸ According to at least one researcher contracted by the Commission, the peer review process was indeed questionable given that some of those reviewing her work did not seem to have even a rudimentary understanding of qualitative research.⁶⁹ Other researchers who came forward anonymously cited similar concerns about how their research was handled or treated by the Commission. Ann Pappert, who had been contracted to prepare reports, sued the Commission for copyright infringement when she discovered that at least one of her reports was altered by the Commission without her permission or knowledge.⁷⁰ Another researcher determined her research had been substantively changed ("to tone down a point"), to suit the purposes of the Commission. Additionally, although her research was qualitative, the Commission asked her to quantify her findings, which, in her opinion would misrepresent the data.⁷¹ Others report similar exchanges with the Commission and a seeming lack of respect for qualitative, or, non-quantitative research.

The categorization of the research was curious as well. From the project arrays discovered by the Commissioners, five of the thirteen proposed studies of embryo/fetal tissue research (working group four) were divided in the following way: "one mainstream study, one feminist study." This typification seems to indicate that "feminist studies" are somehow distinct from the "mainstream," but it is unclear exactly how from the array or subsequent work. These distinctions are important as the work of the Commission was portrayed as divided, generally along these very lines, even by some of the Commissioners

⁶⁷ Marshall Conley and Marcel Lauziere, "Royal commission ought to realize there's no reason for secrecy," *Ottawa Citizen*, August 24, 1992, A14

⁶⁸ Vandelac, "From Bird to Baird" p. 4

⁶⁹ The concerns raised by the SSFC led them to create a set of proposed guidelines for future royal commissions. See SSFC, *Research at Royal Commissions: Guidelines and Procedures*, Ottawa: Social Sciences Federation of Canada, 1993

⁷⁰ Anonymous 4, "Inside the Royal Commission," pp. 231

⁷¹ Walsh, "Tight Lips Sink Ships," pp. 12-13 and Canadian Coalition, "Briefing Paper" p. 2

⁷² Anonymous 4, "Inside the Royal Commission," pp. 229-231

themselves. When the Commissioners were fired, the press quickly labeled it as the feminists against the medical establishment ("mainstream?").⁷² When NAC made public the discovery of the contracts commissioned through the freedom of information request, this was once again termed the feminists against the Commission. When the SSFC issued its press release detailing concerns with respect to the integrity of the research at the Commission, this was termed a division between the "soft" sciences and the "hard" sciences.⁷³

Also alarming was the discovery of contracts of indiscernible or even dubious merit. Perhaps the most striking examples of this are the two contracts awarded to Burson-Marsteller, totaling over \$68,000. Baird defended the choice of Burson-Marsteller by stating "the firm was chosen because of its in-depth knowledge of the pharmaceutical industry."⁷⁴ The firm in question is a public relations company, counting among its clients several pharmaceutical corporations. This was hardly a choice that would provide unbiased research. One of the responsibilities assigned to them was to provide "an analysis of the criticism levied against the industrial (pharmaceutical and other) sector generally, by women, consumers, interest groups and others...." The contract also sought a "collection of recommendations made by the interviewees, explicitly or implicitly, as to what the RCNRT [Royal Commission on New Reproductive Technologies] should do and/or recommend with regards to industry."⁷⁵ It seems at least one purpose of the contract was to defend industry against attacks from specific groups. It is also interesting that the company was asked to formulate recommendations for the Commission. Surely this was the task for which the Commissioners were appointed. As well, one would hope that any recommendations would be made within the broader context of what was heard from other participants. As defenders of industry, perhaps the choice of Burson-Marsteller was

⁷² For example, Ted Byfield, "Feminist ideologues get in way of progress," Financial Post, Jan. 4, 1992, S31. Peter O'Neil, "Feminists' bias cited in firings," Vancouver Sun, Dec. 17, 1991, A1.

⁷³ Peter Calamai, "Now the secret's out, will the science of squabbling disappear?" Ottawa Citizen, Aug. 15, 1992, Editorial Page.

⁷⁴ Ruth Teichroeb, "Reproductive panel hit for 'secrecy,' grants," Winnipeg Free Press, Feb. 5, 1992, B15.

particularly apt, although clearly problematic. Varda Burstyn, then co-chair of the National Action Committee on the Status of Women's Health and Reproductive Technologies Committee, derided the choice stating: "NAC suggested that this was perhaps the single most important issue to address concerning the momentum for these technologies. The report was done by a public relations company. It is shocking that a public relations company would be entrusted with an issue of such major economic and social importance."⁷⁶

The Coalition, armed with this disturbing knowledge, coupled with the recent firings of the Commissioners, demanded the immediate disbandment of the Royal Commission and the establishment of an alternative investigatory mechanism.

Unsurprisingly, the government responded in a manner supportive of the Chair of the Commission. It noted that the Commission was a mechanism independent of the government itself and could best develop mechanisms for conducting its work on its own.⁷⁷ By not acting at this juncture, the government was truly sending a decisive message.

Baird noted that the information that NAC, the Coalition and the media had with respect to the research conducted was out of date. The secondary research, she claimed, was to identify what research was already completed and what gaps there were in knowledge. This seems a reasonable way to attack the massive job of the Commission. However, from the initial research conducted it seems that many gaps were left unfilled (for example, prevention of infertility and other alternatives; the role of NAFTA and other international trade agreements upon Canadian legislative ability; a full discussion of federal-provincial jurisdictions, etc.) Additionally, significant resources went into reinventing the wheel with respect to publications. Publications included at least eleven literature reviews; five overviews or summaries; fifteen surveys (some that were not commissioned by the Commission, but were evaluated); and four bibliographies. Vandellac was highly critical of

⁷⁶ Contract between RCNRI and Burson-Marsteller, Toronto, October, 18, 1991, Appendix A, p. 1.

⁷⁷ Walsh, "Tight Lips Sink Ships," p. 12.

⁷⁸ Tuchler, "Frankenstein meets Kafka," pp. 210-211.

the caliber of some of the research and choice of some of the researchers. Of the 300 listed researchers, 46 were evaluators, 28 were participants in colloquia and over 100 were assistants to collaborative projects. Significant resources were spent on research already in progress, not specifically designed for the purposes of the Royal Commission's investigation.⁷⁸

Upon comparing the critique of the Commission's research work in 1992 and the final product, it appears Eichler's concerns were well-founded. For even though Patricia Baird had discounted the Coalition and Eichler's critique as outdated, many of the gaps remained final research.

⁷⁸ See the fifteen research volumes of the RCNRT. A condensed listing also appears in RCNRT, Proceed With Care, vol. 2, Appendix E, pp 1252-1271.

CHAPTER SIX

THE ROYAL COMMISSION AND BEYOND

I. Introduction

The Royal Commission came to life because of concerns about the lack of evaluation and regulation of reproductive and genetic technologies. It was likely recognized that many of the technologies were going to be here to stay and that attempts to stop them would be like closing the barn door after the horse had gone. It was hoped, however, that the Commission would provide a clear template of governance which could be reasonably applied to existing technologies, and, more importantly, that it could deal effectively and proactively with those technologies on the horizon.

Attempts to regulate or even evaluate technologies after they are developed and offered are limited and possibly misguided. Certainly the experiences with many of the reproductive and genetic technologies developed in the past 20 years are proof of this point. For even though many of the technologies are potentially iatrogenic, people are increasingly pressing for access to them, in some cases at all costs.

The decision-making needs to occur *before* the technologies are at the point of delivery. This is important in at least two major ways. First, if technologies continue to be developed in the way they currently are, then decision-making power has not been shifted or broadened as it needs to be. Second, once the technologies are developed, there is significant motivation for drug companies, practitioners and the public to press for acceptance of them. The opportunity to say no to them, or to seek alternatives has usually vanished. Viewing the technologies in this reactive way tends to limit discussions to ones of access and/or choice.

The Royal Commission's Final Report: *Proceed With Care* is a document that tries to deliver to both the need for assessment and the need for access. Many of the recommendations of the *Report* are ones by which feminists can stand. However, the central recommendations which respond directly to the need for assessment and regulation,

fall short. Perhaps this is unsurprising given the predominance of the medical model in the management of the Royal Commission on New Reproductive Technologies.

II. Outcomes of the Royal Commission on New Reproductive Technologies

The Final Report of the Royal Commission on New Reproductive Technologies is entitled: *Proceed With Care*. The title clearly reflects what was a prevailing theme from the very outset for this Commission: issues of reproduction and genetic engineering raise difficult, social and ethical questions. The medical establishment, however, already has the tools and mechanisms already in place to manage them. Whether or not this is problematic, certainly the Commission gave medical doctors, researchers, industry, and government the green light to proceed, albeit with caution. The technologies and those responsible for developing them have continued to proceed during the Commission and in the recent years since the *Report*.

Proceed With Care: The Final Report of the Royal Commission on New Reproductive Technologies.

The Commission ostensibly utilized an ethical framework to guide their work in creating the final *Report*. This framework included the following principles: individual autonomy, that people should be free to choose how to lead their lives; equality, each member of society is entitled to equal concern and respect (fetuses are not mentioned in this context); respect for human life (including embryos and fetuses, with the distinction that they are not legally persons); protection of the vulnerable; non-commercialization of reproduction; appropriate use of resources and prevention; accountability, those who hold power should be accountable for how they use it; and balancing individual and collective interests.¹ These ethical pronouncements are fairly uncontested in society when so generally stated. As the Canadian Advisory Council on the Status of Women analysis points out, this ethic of care is detailed at the very beginning of the *Report* but seldom referred to again.²

RCNRT, *Proceed With Care*, Vol. 1, pp. 49-66.

CACSW, "An Analysis of Proceed with Care: The Report of the Royal Commission on New Reproductive Technologies," March 1994, pp. 4-6.

Prior to the creation of the Royal Commission, Margrit Eichler of the Coalition had created eight guiding principles. They provide an interesting contrast to the ethical principles outlined in the *Report*. These were: first, that each reproductive technology needs to be evaluated separately with respect to its overall social desirability. Second, in choosing a particular technology, in all instances the safest, least invasive, simplest technique available should be employed before others are tried. Third, any woman or man has the sole right to accept or refuse all treatments affecting her or his reproductive processes. Fourth, stringent criteria as to what constitutes informed consent/decision-making must be developed and enforced. Fifth, legislation should prohibit individuals and organizations from arranging, for their own profit, transactions involving genetic materials and reproductive processes, and provide penalties for those who do. Sixth, semen, eggs and embryos can be used only with explicit informed consent of the donors. Seventh, national standards must be set up for compulsory short-term and long-term follow-up of all reproductive technologies. Eighth, everybody has the right to an environment free of agents that create and contribute to infertility.³

Groups like the Vancouver Women's New Reproductive Technologies Coalition questioned the Commission's apparently perfunctory use of the ethical framework and the language of the *Report* itself. The language sounded suspiciously familiar: it had been skillfully crafted in the language and rhetoric of feminists, using words like "informed consent," "choice," "social construction." The Royal Commission had even adopted the terminology of Margrit Eichler, supplanting the previously used term "surrogacy" for "pre-conception arrangements," something no other public documents had done. Possibly the *Report* structured in such language was crafted to somehow appease feminists, in attempts to downplay some problematic conclusions beneath nuanced language.

In fact, the *Report* was surprisingly good, given its circumstances. The 1274 page, two-volume *Report* contained 293 recommendations, many of which were in direct

Margrit Eichler, "Some Minimal Principles Concerning the New Reproductive Technologies" in Christine

response to feminists' and other groups' demands. Most of the recommendations related to the two-pronged foundation of the *Report*: evidence based medicine, and the need for a regulatory and licensing body. For the authors of the *Report*, the solutions to the dilemmas posed by the technologies were found in better management. Such a response is limited. The Commission *Report* does little to shift the power balance away from the medical establishment's hold on all aspects of the technologies. In fact, the use of the construct "evidence based medicine" actually upholds the right of the medical profession (and the entire biomedical industrial complex) to continue to oversee and manage the reproductive and genetic technologies.

Instead of using the ethical principles to guide decision-making about reproductive and genetic technologies, the guiding principle of evidence-based medicine is used throughout the Commission's documents. The *Report* defined evidence-based medicine in the following way: "medical practice and management of the health care system based on knowledge gained from appropriate evaluation of treatments and their results."⁴ Ironically, just prior to this definition, the *Report* deems a "significant proportion of health care [in Canada] to be ineffective, inefficient, and unevaluated..." Evidence-based medicine does not leave any room for alternative models of health care rather, it finds the solution to any deficiencies in medical practices are to be remedied by conducting appropriate evaluation. In the medical and scientific community, this means clinical trials. The need for more rigorous evaluation is necessary given such techniques as *in vitro* fertilization have been able to exist while so many organizations, including the Royal Commission itself, have raised serious doubts about their use. As critic A. L. Cochrane blithely states of this part of the medical profession: "G and O stands for gynecologists and obstetricians but it could also stand for GO ahead without evaluation!"⁵ However, as developed in chapter two, the model for

Overall, ed. *The Future of Reproduction* (Toronto: The Women's Press, 1989), pp. 226-235.

⁴ RCNRI, *Proceed With Care*, Vol. 1, p. 70.

⁵ A. L. Cochrane, "1931-1971: A Critical Review with Particular Reference to the Medical Profession," *Journal of the Royal College of Physicians of London* Vol. 14 (1979), p. 11.

creating scientific knowledge and understanding is subject to biased or impartial knowledge.

The system of clinical trials in Canada has severe limitations.⁶ In evidence-based medicine and the reliance on clinical trials, left unstated is who, exactly, will determine what is appropriate for trial. There are no mechanisms built in to ensure that those outside of the traditional medical community are able to contribute, nor is there any mention of the role of education. Prevention is not mentioned. Clinical trials should not be the only evaluative process for reproductive and genetic technologies. The assumption is that medical treatment is the only way of dealing with conditions of infertility or illness.

Commissioner Suzanne Rozell Scorsone submitted a dissenting opinion in which she offered a limited critique of the powers of the medical establishment. She stated that she agreed with most of the recommendations and conclusions of the *Report*, thus her comments did not constitute a dissenting report. The six subjects of her dissenting opinion were as follows: educational strategies for sexually transmitted diseases; access to new reproductive technologies; embryo research; termination as an appropriate response to pre-natal diagnosis; the genetic link in donor insemination; and judicial intervention in pregnancy.⁷ Included in it, she stated that leaving broad powers to the medical profession was unacceptable. It should be noted, however, that she limited this criticism to who determines access, leaving unaddressed broader evaluative powers *before* a technology is even offered. She stated that that with respect to the provision of new reproductive technologies: "I cannot agree ... with a recommendation which would impose on all health care institutions and personnel the use of a single and solely medical set of criteria, to the absolute exclusion, always and everywhere, of other factors."⁸

⁶ See, for example, Rosanna Baraldi "The Evaluation of Pharmaceutical Products, Problems of Phase IV," in *Misconceptions*, Vol. 2, pp. 71-81; Joel Lexchin, "Drug Makers and Drug Regulators: Too Close for Comfort: A Study of the Canadian Situation," *Soc. Sci. Med.* Vol. 31, No. 11 (1990), pp. 1257-1263.

⁷ Commissioner Suzanne Rozell Scorsone, "Six Dissenting Opinions," in RCNRT, *Proceed With Care*, Vol. 2, Annex, pp. 1053-1146.

⁸ Scorsone, "Six Dissenting Opinions," p. 1056.

The Royal Commission's recommendation to establish a central regulatory agency, at the very least provides recognition that regulation and licensing mechanisms are necessary. The first recommendation of the *Report* was that: "The federal government establish an independent National Reproductive Technologies Commission [NRTC] charged with the primary responsibility of ensuring that new reproductive technologies are developed and applied in the national public interest."⁹ The proposed licensing and monitoring functions of the NRTC would be broken down into five key areas: sperm collection, storage, distribution and artificial insemination; assisted conception services, including egg retrieval and use; prenatal diagnosis; research involving human zygotes; and the provision of human fetal tissue for research and other specified purposes. The Report looks to another regulatory agency as a template for how the NRTC could operate: the Canadian Radio-Television Commission (CRTC). While created to regulate and license, the CRTC's role shifted to such an extent that it has, according to some critics, become beholden to industry.¹⁰ Additionally, the CRTC is largely inaccessible to members of the public. Such a model would be inappropriate and dangerous for reproductive and genetic technologies. In her dissenting views, Scorsone raises similar concerns.

There is a need for a regulatory mechanism, particularly given the rapid rate at which new technologies are being developed. The agency as suggested would have significant implications for provincial health care. It would also be expensive to set up and maintain. The Royal Commission suggests that industry bear part of the cost. Such a scheme may seem desirable, but it is flawed as proposed. The Commission suggests that licensing fees from clinics be used to fund the NRTC. This strategy puts the regulatory agency in a potential conflict of interest, particularly should public funding be substantively withdrawn. An alternative model developed by lobbyists in the environmental movement is "reverse-onus" arrangements whereby those wanting to introduce a new technology or industry would have to prove no harm (over a broad spectra of criteria) and would have to

RCNRT, Proceed With Care, Vol. 1, p. 112

finance such studies.¹¹ Having industry partially finance the NRTC in this way, might provide similar safeguard mechanisms. It is unclear how arrangements like NAFTA and intellectual property rights agreements might curtail such moves by the Canadian government. The notion of a central and independent watchdog agency has merit. In the *Report*, the regulatory committee is described as being comprised of a broad spectra of representatives, including people directly affected by the technologies (people with disabilities, people who are infertile, etc.)¹² This type of representation and general public accessibility need to be ensured in any regulatory agency constructed.

The regulatory agency (and the proposed evidence-based medicine system of evaluation) fail to encompass assessment before the technologies are at the point of delivery. This permits the biomedical industrial complex to continue to be the gatekeeper to what moves forward and what is left unexplored in terms of technologies or even research priorities. As a result, members of the public generally and those directly affected by the technologies specifically, remain peripheral to decision-making about priorities for general health-care objectives including reproductive and genetic technologies. Additionally, representatives on any regulatory agency created are rendered token and far less effectual. Their decision-making is funneled into a far more reactive, access-oriented role in place of the far more critical role of determining what should be in place and what is needed. "In other words, when the talk is centred primarily about access, it means that use of the technologies is taken for granted and implies that they are scientifically tested, ethically legitimate and socially acceptable."¹³

Critics of the central regulatory agency, who tended to be critics of any regulation, stated it would be too expensive to implement. It would also interfere too much with the

¹¹ Herschel Hardin, Closed Circuits: The Sellout of Canadian Television, (Vancouver: Douglas & McIntyre, 1985)

See for example, Conrad G. Brunk, et al. Value Assumptions in Risk Assessment: A Case Study of the Alachlor Controversy, (Waterloo: Wilfrid Laurier University, 1991), pp. 40-48, and Special Edition on "Regulatory Initiatives and the Environment," Alternatives, Vol. 20, No. 4 (Sept./Oct. 1994)

¹² RCNRT, Proceed With Care, Vol. 1, pp. 122-3

provincial frameworks that cover health care (as stipulated in the *BNA Act*). There was a strong sense that such a body would limit individual choice and freedoms. Contrary to imposing a mechanism that walked down the path of reverse-onus, one writer pressed for a framework of "prove harm." "Before it curtails access to techniques that allow childless couples to have children, it must prove conclusively that those techniques cause serious harm to individuals or society at large."¹⁴ This sentiment seemed to capture the sentiments of many Canadians, notably, the Society for Gynecologists and Obstetricians of Canada (SOGC). In a press release issued following the release of the *Report*, the SOGC stated their concern for women and their "undeniable right to free choice" and access to the technologies: "The last thing the women of this country need is H.G. Wells' Big Brother watching over them and controlling their every move."¹⁵

The *Report* has some very strong sections and recommendations. For example, chapter 30, on Judicial Intervention in Pregnancy and Birth, upholds the right for women to make decisions over their own bodies (recommendations 273, 274, 275). Had these recommendations been in place, the recent case involving the pregnant Manitoba woman, who was ordered into drug-program custody, might never have occurred.¹⁶ In chapter 12, the recommendations that address aging and infertility are remarkably progressive, calling for comprehensive and affordable childcare programs (recommendations 32, 33, 34.) The Commission itself failed to provide such mechanisms for people wanting to appear before it, so these recommendations are truly surprising!

Many of the recommendations take a strong stand against commercialization - calling for either an overt ban on procedures such as preconception arrangements

¹⁴ Vandaele, "The Baird Commission: From 'Access' to 'Reproductive Technologies' to the 'Excesses' of Practitioners or the 'Art of Diversion and Relentless Pursuit'" in Basen et al, eds., *Misconceptions, Vol. 1*, p. 257

¹⁵ Editorial "Proceed with care indeed," *Globe and Mail*, Dec. 2, 1993, A20

¹⁶ SOGC, "Statement to the Media: Initial Response to the Report of the Royal Commission on New Reproductive Technologies," *Journal of Society for Gynecologists and Obstetricians of Canada*, Vol. 16 (1993), pp. 1259-1260

(recommendations 199, 200, 201, 202), or licensing restrictions in the case of sex selection (recommendations 242, 261-6). The restrictions that apply to sex selection do not translate into similar restrictions with respect to other forms of pre-natal diagnosis. Critics of many of the prenatal diagnosis techniques, particularly people with disabilities, argue that there is a contradiction in these two sets of regulations. Prohibiting sex selection, but allowing selection based on perceived disability, they argue, is eugenic. They point to the survey results conducted for the Royal Commission which illustrates discrimination which exists within the medical system with respect disability and people who are disabled. The survey found that "sixteen percent of referring physicians believe that intentionally giving birth to a child with a genetic defect at the time when both PND [pre-natal diagnosis] and abortion are available is socially irresponsible."¹⁷ The Commission acknowledged the repugnance of such views and the dangers of allowing medical practitioners liberty to act upon them. They made several important recommendations with respect to pre-natal diagnosis (recommendations 207-260), many dealt with social perceptions about disability and the need for balanced counseling in conjunction with pre-natal diagnosis. Several others dealt with issues of access. Given many pre-natal diagnosis techniques have been available for several years, a ban of these was unlikely. Such a ban would probably result in criminalizing individual women rather than creating the needed systemic change regarding disability.

The crucial recommendations surrounding fertility drugs suffer from the dependence upon risk assessment and cost-benefit analysis (example, recommendation 66.) These forms of assessment are advocated throughout the *Report*, but they stand out particularly in this section. Risk assessment implies an acceptance of the technology in question; narrowing or closing off the ability to say no. It implies the weighing of benefits versus risks, which could mean that individuals or agencies would be willing to take risks

¹⁷ "Manitoba judge to rule on protection of fetus," Globe and Mail, August 3, 1996, A3, Brian Laghi, "Judge's order for care 'ethical'," Globe and Mail, August 8, 1996, A1.6, Fiona Miller, "The legal intervention in Winnipeg is wrong," Globe and Mail, August 8, 1996, A17

because of the purported benefit. If one then adds in the vested interest of pharmaceutical companies to portray fertility drugs in a positive light, it becomes clear that an assessment of risk is difficult and subject to manipulation.¹⁸ The Commission identifies the power of industry, but the solutions are weak: recommendation 71, for example, suggests that “inappropriate activity [on the part of companies marketing drugs] be publicly identified.”¹⁹

The recommendations for Assisted Insemination (recommendations 82-103) address some of the inconsistencies in family law (which falls under provincial jurisdiction). For example, in recommendation 82, it makes provisions for sperm donation to be legally recognized and that the donor is understood to have no legal relationship with the children that result from these arrangements (i.e. he would not be considered to be the “father.”) These recommendations were carefully constructed, however, so as to stay within the existing bounds of family law. The final section of this recommendation, however, does acknowledge same-sex couples : “(f) if the female partner of a DI [donor insemination] child’s mother acts as a parent toward the child, such a relationship shall be recognized by the courts in determining the best interests of the child for purposes of custody, access, and support, or in the event of the death of the child’s mother.”²⁰ The vast majority of the remaining recommendations for these particular technologies/techniques, cover issues of access, safety and record-keeping.

The responses to the *Report* were varied. It seems from both the *Report* itself and responses to it, that the Royal Commission worked to give something to everybody: perhaps strategically, to garner enough public support to pressure the federal government to implement the recommendations immediately. Medical associations tended to be uniform in their responses. They favoured many of the recommendations, except the ones that involved banning or strict regulation of any of the technologies. They all noted concerns

¹⁸ RCNRT, *Proceed with Care*, Vol. 2, p. 777

¹⁹ For a critical discussion of risk assessment, see for example, Janine Marie Morgall, *Technology Assessment: A Feminist Perspective* (Philadelphia: Temple University Press, 1993)

²⁰ RCNRT, *Proceed with Care*, Vol. 1, p. 411

²¹ RCNRT, *Proceed with Care*, Vol. 1, p. 468

about restricting access.²¹ Particularly telling is the public statement from Roger Rittmaster, president of the Canadian Fertility and Andrology Society (CFAS). He defended the use of surrogacy from a classically medical perspective, showing the bias of many practitioners with respect to the broader implications of these technologies and procedures: “[Surrogacy] is her best option it’s a *medically reasonable* procedure.” (emphasis added)²² The CFAS, the SOGC, the Canadian College of Medical Geneticists (CCMG) and the Infertility Awareness Association of Canada (IAAC) joined to vigorously protest the proposed withdrawal of access to *in vitro* fertilization (see the *Report*, specifically recommendations 106 and 107. IVF procedures are addressed by recommendations 106-159), stating that the evidence cited by the Royal Commission was out-of-date and the procedure was now successful and “appropriate” for widespread use.²³ Interestingly, none of the organizations came forward with specific new information about how it was now more safe and effective, nor was there any publicity of revised “success” rates.

The response of Eike Kluge, who wrote the Canadian Medical Association’s code of ethics with respect to reproductive and genetic technologies, was perhaps the most interesting and candid. He slammed the *Report*’s findings as unoriginal, a waste of money and “largely the same as the Canadian Medical Association’s.”²⁴ Vandellac echoed Kluge’s comments stating that the Commission came up with what other countries had already found. She also noted the suspiciously coincidental timing of the release of findings from a Commission study of infertility centres in Canada. The study in question noted the problems of using fresh sperm as they related to the transmission of AIDS. It was released at the same time as an SOGC report on “Ethical Considerations on the new reproductive

²¹ Canadian Fertility and Andrology Society, *Response to the Royal Commission Report on New Reproductive Technologies* (Montreal: CFAS/SCFA) 1994. CFAS, “Response to the report of the Royal Commission on New Reproductive Technologies: a summary,” Canadian Medical Association Journal, Vol. 151, No. 10 (1994), pp. 1425-1435. SOGC, “Statement to the Media,” pp. 1259-1260.

²² Rod Mickleburgh, “Action urged on birth report,” Globe and Mail, Dec. 1, 1993, A5.

²³ Terry Murray, “IVF recommendation based on outdated data,” The Medical Post, Dec. 21, 1993, pp. 1, 53.

²⁴ Rebecca Wigod, “\$28 million cost of report queried,” Vancouver Sun, Dec. 1, 1993, A4.

technologies dealing with the banking and handling of gametes and embryos.” Both commence from the same starting point with the concerns about AIDS and fresh sperm.²⁵

NAC and the Coalition raised serious concerns about the lack of insight or regulation in one of the most troubling aspects of the technologies: genetic engineering. The Canadian Advisory Council on the Status of Women was generally supportive, particularly of recommendations that called for the ban of commercialization of reproduction.²⁶

In her critique of the *Report*, Vandelaer describes how the Commission relied upon clinical trials and increased experimentation as the solution to narrowly conceived problems. By recommending that *in vitro* fertilization be offered only in controlled, experimental settings, the technology is permitted to continue and ironically funding through agencies and research institutions is better secured. She argued that in these instances the *Report* does not challenge the existence of some of the technologies at all, rather it is simply assumed the technologies are here to stay and need to be better managed through clinical trials, etc. More broadly, she believes the Commission, more specifically Patricia Baird, narrowly interpreted the mandate in terms of medical implications and neglected ethical and social considerations. Were the recommendations of the *Report* to be implemented, the result would be the continued proliferation of the technologies, not the halting of them.²⁷

The *Report*, then, offered some limited hope and much reason for concern. While some of the recommendations included what many women had hoped for in terms of slowing down the proliferation of the technologies until adequate assessment had been performed, there was concern that some of the troubling technologies would still be permitted to be developed. Additionally, the degree of dissent about the process of the

Vandelaer, "The Baird Commission: From 'Access'..." pp. 261-264.

Mickleburgh, "Action urged..." A4 CACSW, "An Analysis of Proceed with Care: The Report of the Royal Commission on New Reproductive Technologies," March 1994, various unpublished analyses by the National Coalition, NAC and Vancouver Women's New Reproductive Technologies Coalition, 1993-4.

Vandelaer, "The Baird Commission: From 'Access'..." pp. 253-272.

Commission and its findings meant that the government could hold off generating any formal response to the *Report*.

Governmental (in)action since the *Report*

The Final Report of the Royal Commission was delivered in November of 1993 to the newly elected Liberal Government. This change of governing parties gave the government the golden opportunity to sit on the *Report*. McTeer urged the government to wait and consult, by setting up a "parliamentary committee which would consult with women's organizations, disabled people and other interested groups."²⁸ Over the summer and fall of 1994 Diane Marleau, then Minister of Health, announced that the government needed more information on how the public felt about the Royal Commission's *Report*. They pointed to the controversies that riddled the Royal Commission itself as justification. To gather more information, the Liberal government created a mini-royal commission in which it consulted with key stakeholder groups they identified. Among them were several women's groups who had been involved with the Coalition, including NAC, the Feminist Alliance on New Reproductive and Genetic Technologies, the Victoria ad-hoc Committee on New Reproductive and Genetic Technologies, the Vancouver Women's New Reproductive Technologies Coalition, etc. Groups with experience with the technologies were also consulted, including the Infertility Awareness Association of Canada, the New Reproductive Alternatives Society, etc. Those consulted were asked to respond specifically to federal/provincial jurisdictions and to the recommendation of the proposed regulatory agency. The government was able to portray itself as acting on particular aspects of the *Report*. However, beyond this second round of consultations there was nothing to indicate that this was actually occurring. By November 1994, NAC issued a press release urging

²⁸ Geoffrey York, "Reproduction panel finally finished," Globe and Mail, Nov. 16, 1993, A1, A6

the government to move on the regulations prohibiting the commercial trade of eggs and preconception arrangements.²⁹

Finally, on July 27, 1995 Marleau announced a voluntary moratorium in nine areas: sex selection for non-medical reasons; preconception arrangements; buying and selling of eggs, sperm and embryos; egg donation in exchange for IVF services; germ-line alteration; ectogenesis; human embryo cloning; the forming of animal-human hybrids by combining animal and human gametes; and retrieval of eggs from fetuses and cadavers for the purposes of donation, fertilization or research.³⁰ “While these practices all occur in the US, only the first six are currently [as of 1995] known to be available or are being developed in Canada. Within 24 hours of Marleau’s announcement, many clinics and practitioners offering these services in Canada said they would not comply with the moratorium and that it was ‘business as usual.’”³¹

By January 1996 an Advisory Committee was set up with representatives from across Canada to monitor the moratorium. While the people chosen for the Committee were commendable, it did not take long to see that the Committee was little more than window dressing. The Committee did not have any substantive terms of reference; they had no legal clout to oversee the moratorium; they did not even have sufficient funds to meet regularly. While it was never formally disbanded, the Committee gradually faded from view. The change in Health Ministers from Diane Marleau to David Dingwall seemed to indicate the end of the Committee.

In the summer of 1996 Health Minister David Dingwall tabled Bill C-47, *the Human Reproductive and Genetic Technologies Act*. This was a two-phase introduction of regulations. Part one, to be acted upon immediately, was to ban 13 unacceptable reproductive and genetic practices derived directly from Marleau’s voluntary moratorium

²⁹ NAC “While Marleau Stalls, Babies and eggs bought and sold,” Press Release, Nov. 29, 1994.

³⁰ Health Canada, “Health Minister Calls for Moratorium on Applying Nine Reproductive Technologies and Practices in Humans” and Speaking Notes for the Honorable Diane Marleau for News Conference announcing voluntary moratorium, July 27, 1995.

(although five new areas were added). The second phase, to come later, would establish the regulatory agency modeled in part after the one outlined in the Commission's *Report*.³²

While the *Act* was not perfect (for example, serious concerns were raised about how some of the criminalization may affect women and reproductive autonomy), it was seen to be something women's groups could accept, given the alternative of no regulation at all.

Once again, the government seemed at last poised to take action. Once again, none was forthcoming. The Government opened its doors to comments from interested groups and individuals, particularly in preparation for the second reading and committee phase of the *Act*. Women's groups across Canada that had been active throughout the Royal Commission, again rallied to provide input and to lobby for governmental action and regulation. Several groups made submissions to Health Canada in the autumn of 1996 and spring of 1997. In April 1997, the Standing Committee on Bill C-47 conducted hearings on the legislation with selected stakeholder groups.³³ During the hearings, some of the Committee staff intimated to feminist groups presenting that they would be pleased with many of the changes to be made in preparation for the third reading.³⁴ This seemed to indicate the changes had already been decided upon, raising questions about why people were being flown in from across the country at great public expense. Given the impending federal election, such actions were likely in the interest of political gain rather than in actually consulting in a meaningful way.

³² Judy Morrison, "Marleau fails to take action on reproductive technology," *Pacific Current*, Vol. 2, No. 2 (Sept/Oct. 1995), p. 7.

³³ Health Canada, "Comprehensive National Policy on Management of New Reproductive and Genetic Technologies Proposed," Press Release, June 14, 1996, Government of Canada, *New Reproductive and Genetic Technologies: Setting Boundaries, Enhancing Health*, June 1996 and Bill C-47 Human Reproductive and Genetic Technologies Act.

³⁴ Included were the following feminist groups who submitted briefs: Joint Submission by the Vancouver Women's New Reproductive Technologies Coalition/Victoria Committee on Reproductive and Genetic Technologies/British Columbia Biotechnology Circle, Oct. 14, 1996; National Association of Women and The Law, November 1996; The Feminist Alliance on New Reproductive and Genetic Technologies, October 1996; The Winnipeg Health Collective, October 1996. Also included were a number of clinics, such as ReproMed in Toronto; consumer advocate groups such as IAVC; two of the fired Commissioners (McTeer and Vandelac) and numerous practitioners.

³⁵ Standing Committee Hearings on Bill C-47 The Human Reproductive and Genetic Technologies Act (Ottawa April 1997).

Prime Minister Jean Chretien did precisely what the media had long been speculating he would do - he called a federal election. Bill C-47 promptly died on the order paper in late April 1997. Those who were active in calling for the Royal Commission will have to wait until Parliament changes for a third time before there is any renewed hope for regulations.

III. CONCLUSIONS

The Royal Commission on New Reproductive Technologies represents the continued predominance of the already privileged interests that prevail in reproductive and genetic technologies. The process of this Commission itself was fundamentally flawed, primarily due to the weighty agenda of geneticist Doctor Patricia Baird - propped up by the Tory Government on at least three occasions. This served to discount and exclude the views of four Commissioners, innumerable staff and researchers, and large segments of the concerned Canadian population.

An extremely tight and closed policy community exists with respect to these technologies, including medical doctors, practitioners and researchers, the government and industry. The call for a royal commission was in the recognition that reproductive and genetic technologies may be created and supported by these groups, but that they stand to have impact on everybody in society. The groups directly involved in the creation of the technologies are not well equipped for ethical decision-making on matters so far-reaching and yet, this is precisely the situation that existed at the time of the call for the Commission and indeed continues to prevail today. There was an expressed need for education and a democratization or broadening of those involved in the making of policies governing the technologies.

What resulted was strikingly similar to what occurred in another recent inquiry, the MacDonald Commission. In both cases, the definition of the problem, as stipulated by the federal government, and most importantly how the Commissions chose to interpret that mandate, left only a restricted set of recommendations that could be reached. In this way the

government was able to control the outcomes while still appearing to be open to direct democracy on the part of its citizens. By taking Simeon's comments with respect to the MacDonald Commission and changing a single key word, one would have a near-perfect description of what was at work at the Royal Commission on New Reproductive Technologies: "given their definition of the problems to be addressed, there was no credible alternative before the Commissioners. Their choice, ultimately, was between the *medical* model [the original reads "economics"], or no model at all."³⁵ Clearly Baird exerted significant power in the Royal Commission on New Reproductive Technologies over and above the control the government sought to impose. The government stood by her again and again, indicating their careful selection in a head Commissioner in the first place and their approval of her methods and perspective.

In its actions during and following the work of the Royal Commission, the federal government (notably two different parties), continued to support the policy community that already existed with respect to the technologies. For in a time of neoconservative agendas and NAFTA exerting influence over Canadian society, perhaps it was foolish to hope that credible, democratic processes and alternatives would be born. However, as with the neoconservative economic agenda, there are significant - and growing - numbers of people who are critical of such formulations of the biomedical problems facing Canadians and present hope for a shift in the definitions and the solutions.

DELIVERY DELAYED - AN ALTERNATIVE PERSPECTIVE

The reproductive and genetic technologies are a direct result of what I have termed the biomedical industrial complex. The prominent actors in this exclusive policy community have a mutual interest in the continued development of technological applications in humans. Their power translates into wide societal privilege which has as its starting point the ability to define and create knowledge. By controlling what constitutes knowledge, one has the ability to continually define both the questions and subsequent solutions.

³⁵ Simeon, "Inside the MacDonald Commission," p. 173

In the case of human reproductive technologies, the question or problem has been defined as that of infertility, a condition that affects a small segment of the Canadian population. The answer from the point of view of the biomedical industrial complex is to meet this apparent need with reproductive technologies such as *in vitro* fertilization. Perhaps such a technology is imperfect, but it offers hope to people struggling to have children, it offers researchers an incredible experiment, and it offers industry an opportunity to yield profit for itself.

In the case of human genetic technologies, the question or problem is that of imperfection, perceived suffering or disease. The answer from the point of view of the biomedical industrial complex is to strive to control and hopefully eliminate these conditions, sometimes through such problematic and potentially discriminatory technologies as pre-natal diagnosis. This may also be attempted by identifying the gene responsible for a condition or a disease and altering it. These genetic technologies offer the hope of eliminating pain and suffering through the control and manipulation of genetic materials. While in principle, a worthy goal, such endeavours miss the mark in their applications by those in power. When research goals are guided by the desire to control life, one must question: whose lives? and, who makes (or controls) these decisions?

It has been demonstrated that the biomedical profession has narrowly constructed what a human life is and how it is best managed. The conception of life as exclusively a genetic organism which can be controlled through treatment or other manipulations is seriously limited. Scientists tend to isolate the object of study so they can control it and understand it. But this yields only the understanding of the object under certain, specified, strictly controlled conditions. When the conditions change, by either looking at the organism as part of the entire entity (for example, the individual gene as part of its larger complex we call a human body) or as part of its broader environment (for example, the human body as it exists within a social and physical environment), an understanding and prescription becomes more elusive.

By framing the problems in a scientific manner, the avenues for social solutions are often compromised or eliminated. Additionally, membership of the scientific and medical professions is socially created in such a way to provide access to some and deny it to many others in a discriminatory way. The same can be said for those other groups of the biomedical complex who tend to enable or support the work and knowledge of the scientific and medical communities. The knowledge that is created, the framing problems and solutions, only reflects that of these actors and tends to ignore or silence others. In this way, technology has become the solution and has been repeatedly termed "progress." In the words of David Noble, however, this is "progress without people," which cannot be said to be progress at all.³⁶

That any new technology created by the biomedical profession is necessarily progress must be critically examined in terms of who benefits from their proliferation and who pays the price socially, physically and economically. Equally important, although not fully addressed in this study, are the connections between choices and benefits in one part of the world and how they are necessarily linked to those denied elsewhere, frequently through coercive treatment of select peoples.

Those who called for a broad-based, participatory inquiry into the reproductive and genetic technologies recognized the limitations and the dangers of the biomedical industrial complex. They knew that powerful actors held the ability to push or delay certain types of science and technology. Critics wanted the opportunity for an assessment that would allow for the possibility of a different kind of delay, one more democratic and more deeply critical of the narrow interests involved in the technologies in question. They saw the Royal Commission on New Reproductive Technologies as a vehicle for conducting research that went beyond the standard scientific inquiry to one which would encompass issues of ethics and human rights. This hope for a democratic process, which would broaden not only the

³⁶ David Noble, Progress Without People: New Technology, Unemployment, and the Message of Resistance (Toronto: Between the Lines, 1995).

debate but also the decision-making was not ill-founded. Examples existed of other inquiries which had yielded positive change.

The mechanism of the Royal Commission on New Reproductive Technologies was perhaps evidence of a naive hope on the part of activists working to unravel the complex interests wrapped up in the making of such troublesome biotechnologies. This Commission should not be viewed as solely a tool for the establishment, however. Many who came and worked for the Commission were eager to contribute to a critical understanding of the interests that underlie these sets of technologies. Indeed, without the efforts of the four fired Commissioners, the many staff and researchers who spoke out during and after the Commission and the countless women and men who worked to contribute to what they hoped would be a truly democratic process, the level of debate would never have reached where it stands today. For while the prevailing actors in the Commission and the government that enabled it had specific interests - both implicitly and explicitly - many others came to realize through these former groups' actions (and inactions) what/who precisely those interests were.

In the words of Margaret Benston, a scientist and a feminist:

We cannot afford to give up the struggle to understand and to come to terms with our world. As women and as feminists, we must begin to deal with the science and technology that shapes our lives and even our bodies. We have been the objects of a bad science; now we must become the makers of a new one. What is needed in such a new science is, first of all, a sense of the limits of appropriateness of reductionism ... [There] must come a consideration of the connections between the knower and the known and an understanding of the ways in which subjective factors are important in science. With this also must come a sense of limits - of what is not known or cannot be known or is not appropriate as a subject for scientific approach.³⁷

³⁷ Benston, "Feminism and the Critique of the Scientific Method," p. 74

APPENDIX 1

Glossary of Terms¹

Amniocentesis A test used to diagnose genetic problems which may cause disease or disability in the fetus. In amniocentesis, ultrasound is used to guide a needle through the mother's abdomen into the amniotic sac which surrounds the fetus. A small amount of fluid in the amniotic sac is removed and the fetal cells in it are checked for those abnormalities which can be detected. Amniocentesis can also show the sex of the fetus. Amniocentesis is usually done in the second trimester between the 14th and 16th weeks of pregnancy. The results are not known until the 18th or 20th week.

Assisted Insemination (also referred to as "Donor Insemination" or "Artificial Insemination") A way of becoming pregnant without having sexual intercourse. Sperm is placed in a woman's vagina when she is ovulating. This can be done by a variety of methods from those readily available (eg. turkey baster or similar tube-like vessels) to those which are medically-mediated.

Chorionic Villus Sampling A test in which a catheter (small tube) is inserted through the mother's vagina and cervix, and a sample of the fetal tissue embedded in the placenta is taken. Like amniocentesis, CVS is a test used to detect metabolic disorders and chromosomal problems. CVS can also show the sex of the fetus. CVS can be done during the 8th or 9th week of pregnancy and the results are usually known within a week. Like amniocentesis, CVS can induce abortion and can spread bacterial or other infections.

Cloning A form of asexual reproduction in which the nucleus of a single cell is used to produce an exact copy of the original organism, either by reproduction from a single cell, or by the substitution of a nucleus from one organism in the progenitor cell of another one.

D.E.S. - Diethylstilbestrol A synthetic estrogen first given to pregnant women in the 1960s, to prevent miscarriage. It was not proven effective in preventing miscarriage and was found to cause cancer in the offspring (genital tract and uterine anomalies), and thus decreased fertility or death in some individuals exposed to the drug.

DNA - Deoxyribonucleic acid The molecule that carries the genetic information for most living systems and which can help to determine the structure, function and development of an organism. DNA can replicate itself more or less exactly and is passed from generation to generation.

Dalkon Shield (see also: I.U.D.) An intrauterine device used to prevent pregnancy. Caused numerous deaths in women using the device and rendered many more women infertile due to scarring.

Depo Provera - Depot medroxyprogesterone acetate (DMPA) A high dose of hormones that is injected to prevent pregnancy for up to three months. It functions much like Norplant or the Pill, impeding conception by stopping ovulation and making the body inhospitable to pregnancy.

Ectogenesis Machine-based gestation, or creation of an artificial womb.

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

Genes The basic units of heredity. The segments of DNA/chromosome which are functional (versus the segments which appear to have no function). Some genes direct the making of proteins, while others serve to regulate the activity of other genes.

Genetic Engineering A technology used to alter the genetic makeup of living cells in order to make them capable of producing new substances or performing new functions. This is done by inserting, removing or altering individual genes.

Germ Line Alteration The cell or cell line that produces gametes (eggs or sperm) for reproduction is known as the germ line or cell. Any changes to the germ line are passed on to the next generation.

Human Genome Project A multi-national, multi-billion dollar initiative by scientists and governments which seeks to sequence the DNA in the entire human genetic structure, for selected cell lines.

I.U.D. - Intrauterine Device Contraceptive device, usually a loop made of plastic or metal that is inserted through the cervix into the uterine cavity in order to prevent pregnancy. It purportedly works by preventing the zygote from implanting. Use of IUDs has been associated with infections leading to pelvic inflammatory disease and to infertility. The Dalkon Shield, one kind of IUD, led to several women's deaths before it was removed from the market.

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

Infertility The inability to become pregnant as readily as most women or couples. In North America, a couple that has been having intercourse for one year and is not using any form of birth control, and has not conceived, is considered by medical experts to be infertile.

In vitro Fertilization (IVF) Fertilization which occurs in an artificial system as opposed to within an organism. In humans, the fertilization of a human egg outside of the womb. The eggs are removed from a woman's ovaries, fertilized with sperm in a laboratory, and then placed in a woman's uterus. The fertilized eggs may either be placed in the uterus of the woman who produced the eggs or in the uterus of another woman.

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

Norplant Consists of five or six small silicone strands filled with enough synthetic progesterone, a progestin called levonorgestrel, to supposedly provide contraception for five years. The rods or strands are inserted in the upper arm of a woman and sewn under the skin. Has numerous effects and unknown long-term risks.

Oocyte also known as an 'egg', cell produced in the ovaries. Its process of formation is termed oogenesis.

Preconception Arrangements (also referred to as “contract motherhood” or “surrogacy”) The contract a woman signs when she agrees to carry a child for someone else. Under the terms of the contract, the woman - who besides being the uterine mother, may also be the genetic mother - agrees to give up all rights to the child she carries.

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

Sex Selection Choosing the sex of a child before birth. Sex selection can be done before conception, by separating x-carrying and y-carrying sperm. The woman is then artificially inseminated with the sperm that is most likely to produce a baby of the desired sex. The most effective and commonly used form of sex selection is done after conception. Screening techniques like amniocentesis are used to determine the sex of the fetus, and if the fetus is not of the “right” sex, it is aborted.

Surrogacy - see *preconception arrangements*

Test-Tube Babies - see *in vitro fertilization*

Thalidomide A pharmaceutical drug prescribed from the 1940's through 1960's to prevent morning sickness. Many children who were exposed to the drug *in utero* were born with physical defects.

Ultrasound In fetal monitoring, sends high frequency waves through the mother's abdomen. These sound waves bounce off the fetus and are converted into a picture on a video screen. Ultrasound is useful for detecting pelvic tumors or ectopic pregnancy and for confirming a multiple pregnancy or an abnormal fetal presentation (a fetus that is in some position other than head downward in the uterus). Ultrasound is also used as part of the *in vitro* fertilization process to locate and determine the size of egg follicles on the ovaries.

Zygote The fertilized egg until approximately 14 days after the union of the egg and sperm; from two weeks to eight weeks of development the entity is termed an embryo; from eight weeks to birth it is termed a fetus.

Definitions are drawn from the following sources: Janis Wood Catano, Our Bodies - Our Babies? Women Look at New Reproductive Technologies, CRIAW, November 1989; Burkhard Mausberg and Maureen Press Merkur, The Citizen's Guide to Biotechnology, Canadian Institute for Environmental Law and Policy, CIELAP, May 1995; Royal Commission on New Reproductive Technologies, Proceed with Care: The Final Report of the Royal Commission on New Reproductive Technologies Volume 2, Ottawa: Minister of Government Services Canada, 1993.

APPENDIX 2

The Mandate of the Royal Commission on New Reproductive Technologies (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 tissues;
- 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.

APPENDIX 3

Inquiries Act

CHAPTER I-11

An Act respecting public and departmental inquiries

SHORT TITLE

1. This Act may be cited as the Inquiries Act.

R.S., c. I-13, s. 1.

PART I

PUBLIC INQUIRIES

Inquiry

2. The Governor in Council may, whenever the Governor in Council deems it expedient, cause inquiry to be made into and concerning any matter connected with the good government of Canada or the conduct of any part of the public business thereof.

R.S., c. I-13, s. 2.

Appointment of commissioners

3. Where an inquiry as described in section 2 is not regulated by any special law, the Governor in Council may, by a commission, appoint persons as commissioners by whom the inquiry shall be conducted.

R.S., c. I-13, s. 3.

Powers of commissioners concerning evidence

4. The commissioners have the power of summoning before them any witnesses, and of requiring them to

(a) give evidence, orally or in writing, and on oath or, if they are persons entitled to affirm in civil matters on solemn affirmation; and

(b) produce such documents and things as the commissioners deem requisite to the full investigation of the matters into which they are appointed to examine.

R.S., c. I-13, s. 4.

Idem, enforcement

5. The commissioners have the same power to enforce the attendance of witnesses and to compel them to give evidence as is vested in any court of record in civil cases.

R.S., c. I-13, s. 5.

PART II

DEPARTMENTAL INVESTIGATIONS

Appointment of commissioners

6. The minister presiding over any department of the Public Service may appoint, under the authority of the Governor in Council, a commissioner or commissioners to investigate and report on the state and management of the

business, or any part of the business, of the department, either in the inside or outside service thereof, and the conduct of any person in that service, so far as the same relates to the official duties of the person.
R.S., c. 1-13, s. 6.

Powers of commissioners

7. For the purposes of an investigation under section 6, the commissioners

(a) may enter into and remain within any public office or institution, and shall have access to every part thereof;

(b) may examine all papers, documents, vouchers, records and books of every kind belonging to the public office or institution;

(c) may summon before them any person and require the person to give evidence, orally or in writing, and on oath or, if the person is entitled to affirm in civil matters on solemn affirmation; and

(d) may administer the oath or affirmation under paragraph (c).

R.S., c. 1-13, s. 7.

Subpoena or summons

8. (1) The commissioners may, under their hands, issue a subpoena or other request or summons, requiring and commanding any person therein named

(a) to appear at the time and place mentioned therein;

(b) to testify to all matters within his knowledge relative to the subject-matter of an investigation; and

(c) to bring and produce any document, book or paper that the person has in his possession or under his control relative to the subject-matter of the investigation.

Idem

(2) A person may be summoned from any part of Canada by virtue of a subpoena, request or summons issued under subsection (1).

Expenses

(3) Reasonable travel expenses shall be paid at the time of service of a subpoena, request or summons to any person summoned under subsection (1).

R.S., c. 1-13, s. 8.

Evidence taken by commission

9. (1) In lieu of requiring the attendance of a person whose evidence is desired, the commissioners may, if they deem it advisable, issue a commission or other authority to any officer or person named therein, authorizing the officer or person to take the evidence and report it to the commissioners.

Powers for that purpose

(2) An officer or person authorized under subsection (1) shall, before entering on any investigation, be sworn before a justice of the peace faithfully to execute the duty entrusted to the officer or person by the

commission, and, with regard to the taking of evidence, has the powers set out in subsection 8(1) and such other powers as a commissioner would have had if the evidence had been taken before a commissioner.

R.S., c. I-13, s. 9.

Witnesses failing to attend, etc.

10. (1) Every person who

(a) being required to attend in the manner provided in this Part, fails, without valid excuse, to attend accordingly,

(b) being commanded to produce any document, book or paper, in his possession or under his control, fails to produce the same,

(c) refuses to be sworn or to affirm, or

(d) refuses to answer any proper question put to him by a commissioner, or other officer or person referred to in section 9,

is liable, on summary conviction before any police or stipendiary magistrate, or judge of a superior or county court, having jurisdiction in the county or district in which that person resides, or in which the place is situated at which the person was required to attend, to a fine not exceeding four hundred dollars.

Justice of the peace

(2) For the purposes of this Part, a judge of a superior or county court referred to in subsection (1) shall be a justice of the peace.

R.S., c. I-13, s. 10.

PART III

GENERAL

Employment of counsel, experts and assistants

11. (1) The commissioners, whether appointed under Part I or under Part II, may, if authorized by the commission issued in the case, engage the services of

(a) such accountants, engineers, technical advisers or other experts, clerks, reporters and assistants as they deem necessary or advisable; and

(b) counsel to aid and assist the commissioners in an inquiry.

Experts may take evidence and report

(2) The commissioners may authorize and depute any accountants, engineers, technical advisers or other experts, the services of whom are engaged under subsection (1), or any other qualified persons, to inquire into any matter within the scope of the commission as may be directed by the commissioners.

Powers

(3) The persons deputed under subsection (2), when authorized by order in council, have the same powers as the commissioners have to take evidence, issue subpoenas, enforce the attendance of witnesses, compel them to give evidence, and otherwise conduct the inquiry.

Report

(4) The persons deputed under subsection (2) shall report the evidence and their findings, if any, thereon to the commissioners.

R.S., c. I-13, s. 11.

Parties may employ counsel

12. The commissioners may allow any person whose conduct is being investigated under this Act, and shall allow any person against whom any charge is made in the course of an investigation, to be represented by counsel.

R.S., c. I-13, s. 12.

Notice to persons charged

13. No report shall be made against any person until reasonable notice has been given to the person of the charge of misconduct alleged against him and the person has been allowed full opportunity to be heard in person or by counsel.

R.S., c. I-13, s. 13.

PART IV

INTERNATIONAL COMMISSIONS AND TRIBUNALS

Authority to confer powers on

14. (1) The Governor in Council may, whenever the Governor in Council deems it expedient, confer on an international commission or tribunal all or any of the powers conferred on commissioners under Part I.

Exercise of powers in Canada

(2) The powers conferred on an international commission or tribunal pursuant to subsection (1) may be exercised by the commission or tribunal in Canada, subject to such limitations and restrictions as the Governor in Council may impose, in respect of all matters that are within the jurisdiction of the commission or tribunal.

R.S., c. I-13, s. 14.

RELATED PROVISIONS

1992, c. 20, ss. 230, 231:

Correctional Investigator

230. The person holding office as Correctional Investigator under the Inquiries Act immediately before the coming into force of this section continues in office as Correctional Investigator and shall be deemed to have been appointed under Part III of this Act for a term of one year beginning on the coming into force of this section.

Staff of Correctional Investigator

231. (1) A person whose services were engaged by the Correctional Investigator on a full-time basis pursuant to the Inquiries Act during any period immediately before the coming into force of this section shall be deemed to have been appointed in accordance with the Public Service Employment Act on the coming into force of this section, unless the person otherwise elects in writing within ninety days after the coming into force of this section.

Probation under Public Service Employment Act

(2) Notwithstanding subsection (1) of this section and section 28 of the Public Service Employment Act, a person who is deemed by subsection (1) of this section to have been appointed in accordance with the Public Service Employment Act

(a) is not subject to probation under that Act if the person's services were engaged on a full-time basis by the Correctional Investigator during a period of at least one year immediately before the coming into force of this section; or

(b) is subject to probation under that Act for a period equal to one year minus the period during which the person's services were engaged on a full-time basis by the Correctional Investigator immediately before the coming into force of this section, where the latter period is less than one year.

APPENDIX 4

Amended Order-in-Council P.C. 1990-1801

(The original may be consulted in the Federal Court Documents, Schedule 9)

On the 28th day of August, 1990.

The Committee of the Privy Council, on the recommendation of the Prime Minister, advise that a Commission do issue under Part I of the *Inquiries Act* and under the Great Seal of Canada, to appoint

1. Bartha Maria Knoppers.
of Montreal, Quebec; and
2. Susan E. M. McCutcheon
of Toronto, Ontario;

to be Commissioners to inquire into the matters described in the Commission issued pursuant to Order in Council P.C. 1989-2150 of October 25, 1989, together with the Commissioners appointed by the said Order in Council, and to amend the paragraphs of the Commission pursuant thereto, in accordance with the schedule hereto.

SCHEDULE

1. Paragraphs (2) through (4) of Order in Council P.C. 1989-2150 of October 25, 1989 are revoked and the following substituted therefor:

(2) the Chairperson be authorized to adopt such procedures and methods she may consider expedient for the proper conduct of the inquiry and sit at such times and in such places as she may decide;

(3) the Chairperson be authorized to rent such space and facilities as may be required for the purposes of the inquiry, in accordance with Treasury Board policies;

(4) the Chairperson be authorized to engage services of such experts and other persons as are referred to in section 11 of the *Inquiries Act* at such rates of remuneration and reimbursement as may be approved by the Treasury Board.

2. Paragraph (6) of Order in Council P.C. 1989-2150 of October 25, 1989 is revoked and the following substituted therefor:

(6) the Chairperson be directed to file the papers and records of the Commissioners with the Clerk of the Privy Council as soon as reasonably may be after the submission of the said report.

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