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OUR BODIES...
OUR BABIES?

WOMEN LOOK AT NEW REPRODUCTIVE TECHNOLOGIES

CANADIAN RESEARCH INSTITUTE FOR THE ADVANCEMENT OF WOMEN

CRIAW ICREF

INSTITUT CANADIEN DE RECHERCHES SUR LES FEMMES

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November 1989
Further copies of this kit can be ordered ($7.00 + $1.00 postage) from CRIAW, 151 Slater St., Suite 408, Ottawa, Ontario, Canada, K1P 5H3.

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The CRIAW Working Group on NRTs would like to thank the following women for their contributions to this kit: Abby Lippman, Jerilyn Prior, Patricia Sadoway, Jane Wright, Alexandra Keir, Gloria Mackline and the Victoria Status of Women Action Group.
CRIAW/ICREF gratefully acknowledges the financial assistance of the Health Promotion Contribution Program, Health and Welfare and the Women's Program, Secretary of State, in the production of this publication.
The ideas expressed in this document are those of CRIAW/ICREF's Working Group on NRTs and do not necessarily reflect those of the Health Promotion Program or Women's Program.

ISBN: 0-919653-55-3

What you should know about...
"EVERYDAY" REPRODUCTIVE TECHNOLOGIES

Not all reproductive technologies are new and dramatic. Some technologies are so common, ordinary and "everyday" that it's easy to forget that they are technologies and that they have drastically changed the way we think about pregnancy and childbirth.

"EVERYDAY" TECHNOLOGIES

- **ULTRASOUND** allows doctors to look at the fetus in the womb. The process sends high frequency sound 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). It can be used to diagnose ovarian cancer and placental separation, as well as to estimate the growth of the baby. Ultrasound is also used as part of the in vitro fertilization process to locate and determine the size of egg follicles on the ovaries.

  Ultrasound was in use for 20 years before any adequate studies were done on its effects. Its long term safety is still unknown and its usefulness in normal pregnancies is unproven. As a result, many organizations, including the Society of Obstetricians and Gynecologists of Canada, the US National Institutes of Health, and the International Childbirth Education Association recommend that ultrasound **not be used routinely**. In spite of these concerns, ultrasound is so common that 80% of women in Canada have at least one sometime during each pregnancy.

- **FETAL HEART MONITORING** is a process that continuously records the fetal heart rate. It is used during labour to detect fetal stress so that, if needed, a rapid delivery can be performed. Fetal monitoring can be done externally, by placing electrodes on the mother's abdomen, or internally, by attaching electrodes to the fetus.

  Fetal heart monitoring has become a routine procedure during labour, although there is no evidence that it does any particular good. In studies of high risk women, using fetal monitoring did not reduce the number of deaths or abnormalities in infants. What fetal monitoring did do was increase the number of unnecessary

cesarean deliveries. One reason for this is that the ways in which the fetal monitor shows fetal distress, and the ways in which the monitor readings are interpreted, have not been not standardized or validated. This means that concerns may be raised about fetal safety that are technological—that is related to the machine and the way that the information it gives is interpreted—rather than biological—related to the actual condition of the baby.

- **AMNIOCENTESIS** is a test to diagnose genetic problems 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 is removed and the cells in it are checked for abnormalities. Amniocentesis is usually recommended when a woman is over 35 (because the risk of Down Syndrome increases with the mother's age); when the mother has had other babies with chromosomal problems; or when there are certain hereditary diseases in either parent's family. It can also show the sex of the fetus.

  Amniocentesis is usually done after the 16th week of pregnancy, although some centres are now trying to use it as early as the 13th or 14th week. Because the cells have to grow in a lab, the results are often not known until the 18th or 20th week. If, based on the results of the amniocentesis, the mother chooses to have an abortion, the risks to her physical and emotional health are much greater at this stage than with an early abortion.

  Amniocentesis has less than a one percent chance of causing a miscarriage.

- **CHORIONIC BIOPSY or CHORIONIC VILLI SAMPLING (CVS)** like amniocentesis, is a test used to detect specific genetic disorders and chromosomal problems. Like amniocentesis, it can be used to learn the sex of the fetus.

  CVS can be done at about 9 to 12 weeks of pregnancy, much earlier than amniocentesis. The results are usually known within a week. CVS has about the same risk of causing a miscarriage as amniocentesis. About 10% of women having CVS may need to have an amniocentesis later in their pregnancy to verify the chromosomal diagnosis.

WHAT DO THESE TECHNOLOGIES MEAN FOR WOMEN?

Most obstetric technologies were developed for a particular reason and were intended to be used in limited, high-risk situations. But as the use of these technologies has become routine, and they have become part of the care of healthy, low-risk women, they have changed the way we perceive pregnancy and birth. For example, when ultrasound is used as a diagnostic tool in response to a symptom or indication of a possible problem, the implication is that a pregnant woman is healthy until shown to be otherwise. But when ultrasound is routinely used with all pregnant women, the implication is just the opposite—your are assumed to have a problem until proven to be healthy.

What this means for women is that the way in which many people view pregnancy and childbirth has changed. Pregnancy is no longer assumed to be a normal, healthy part of a woman's life. It is more often considered to be a potentially dangerous state, requiring a vast array of technological devices to assure effective management and a healthy outcome.

These "common" technologies have also changed the way we look at a woman's role in pregnancy.

It used to be that when a pregnant woman went to her doctor or midwife, it was **her** health that the caregiver was most concerned about. The feeling was that if the mother looked after her own health, her baby would be healthy too. The mother and her unborn baby were considered to be a unit. What was good for the mother, the logic went, would also be good for the baby.

These technologies have changed all that. Now, the health of the fetus can be monitored—and even treated—**separately** from the health of the mother.

Separating the health of the fetus from the health of the mother begins the process of separating the interests of the fetus from the interests of the mother. What is good for the mother may no longer be considered to be good for the baby. And what happens then?

- If the fetus is a patient, what is the mother? Another patient? A "walking womb" or container for the fetus? Or an autonomous individual with the right to control her own body?

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What you should know about...

INFERTILITY AND STERILITY

The terms "infertility" and "sterility" are often used interchangeably, but they don't mean exactly the same thing. "Infertility" is a relative term—it means that a woman or couple isn't able to conceive a child as readily as most others. For example, in North America, a couple that has been having intercourse for one year, isn't using any form of birth control, and hasn't conceived, is considered by medical experts to be infertile. In most European countries, a couple would not be considered infertile until after trying for at least two years.

Being infertile doesn't necessarily mean that you can't ever get pregnant. It means that for some reason it is more difficult or takes longer for you and your partner to conceive a child together. Being "sterile", on the other hand, **does** mean that you can't conceive children. "Sterility" is defined as the inability to conceive. Sterility may be primary, meaning that no conception has ever been possible, or secondary, which means that the sterility has been caused by surgery or disease.

HOW BIG IS THE PROBLEM?

Infertility has recently been receiving a great deal of publicity. Some articles cite statistics that would lead us to believe that infertility and sterility are rising quickly and drastically. Commonly cited figures state that between one in five and one in seven couples in the US are infertile. These figures come from studies done by the National Centre for Health Statistics, but what the NCHS actually found was that one in **twelve** couples were infertile. In fact, the NCSH found that neither the percentage nor the actual number of infertile couples had increased between 1965 and 1982, the last year for which figures were available.

This finding occurred despite increases in the number of women and couples delaying childbearing until later in life, using contraceptives over a long period of time, being exposed to chemicals and toxins in the environment, and developing sexually transmitted diseases, all of which affect fertility. But as of now, we don't know for sure if infertility is really increasing or just being discussed more openly.

A great deal of this publicity about infertility is related to the emergence of expensive, high tech infertility "treatments", like in vitro fertilization (IVF). IVF doesn't cure infertility—it offers a few couples a way around their problem at the cost of increasing the perception of failure on the part of many others. IVF and other new reproductive technologies require the perception that infertility is a widespread and growing problem to justify their existence and to justify the enormous economic and medical resources that are being spent on their development and refinement.

Using the North American definition of infertility, about 15% of couples have difficulty conceiving within a year of trying. Of these, about 20% have no physical problem. They simply require a bit longer than a year. It may also take longer for women to conceive if they have been using a method of birth control that supresses ovulation (like the pill).

WHAT ARE THE CAUSES OF INFERTILITY?

In understanding what causes infertility, it helps to think about what has to happen for a pregnancy to occur.

Male:

The male must be able to produce a sufficient number of normal, healthy sperm and he must be able to ejaculate them.

Male and Female:

These sperm must be deposited in the female in a way that allows them to reach the cervix, pass through the cervical mucous, travel through the uterus, and enter the fallopian tube at the time in the menstrual cycle that is appropriate for conception.

Female:

The female must produce a normal, healthy egg that is capable of being fertilized. The egg must enter the fallopian tube and be fertilized. The fertilized egg must move through the fallopian tube and implant in a well developed uterine lining and then develop.

If there is a problem at any point in this process, on the part of the male or the female, or both, infertility can occur.

No one knows all the causes of infertility, but when the known causes are considered, about 60% of infertility can be attributed to factors in women. They include:

- Problems with the production of eggs or with the glands that control ovulation;
- Problems with the fallopian tubes (scarring or blockage);
- Malformation of the uterus; and
- Problems with the cervix, like inflammation or rejection of the sperm by the cervical mucous.

The remaining 40% of infertility (with a known cause) can be attributed to factors in men. They include:

- Problems with the endocrine glands;
- Varicocele (an enlargement of the vessels in the testicles which increases the temperature and reduces the production and movement of sperm);
- Impotence or problems with ejaculation, including retrograde ejaculation, when sperm is emitted into the bladder instead of outward;
- Blockage of the vas deferens (the tube that carries the sperm from the testicles).

Between 30% and 40% of female infertility is caused by blocked or scarred fallopian tubes. The leading cause of this condition is Pelvic Inflammatory Disease (PID). PID is caused by sexually transmitted diseases like chlamydia and gonorrhea. It is also related to the use of the IUD as a birth control method. Endometriosis is another cause of damage to the fallopian tubes. (Endometriosis is a condition in which the endometrium, the lining of the uterus, moves outside the uterus and attaches to other organs.)

Some women (and men) have fertility problems caused by DES (Di-ethyl Stilbestrol), a drug given to their mothers during pregnancy.

Factors in the environment may also contribute to infertility. Men who have been exposed to chemical defoliants have developed fertility problems and men working with mercury show abnormally low sperm counts. There are many chemicals used in the workplace, as well as radioactive materials, to which pregnant women shouldn't be exposed, but we do not know if exposure to these substances will have long term effects on men's fertility or on women who later become pregnant.

Other, less tangible factors may also influence fertility. For example, lifestyle factors like stress and exhaustion may result in a decrease in sexual desire and frequency of intercourse.

CAN INFERTILITY BE TREATED?

When a couple seeks treatment for infertility, the first step should be a careful and extensive investigation to determine the cause of the problem. The investigation includes a thorough medical, social and sexual history as well as a variety of physical tests. The man will be required to supply a sperm sample for analysis and the woman will be asked to keep a daily record of her basal body temperature to pinpoint the time of ovulation and to show the optimal times for intercourse and for medical procedures. Women also undergo many other investigative procedures in the course of a fertility investigation.

Depending on the cause, infertility can be treated more or less successfully. For example, if the problem is damaged fallopian tubes, about 30% of women can conceive after surgery to correct the problem. If the problem is with ovulation, hormone treatments can often help but they carry the risk of multiple pregnancy.

If the fertility problem lies with the male, the principal treatments are antibiotics (if the problem is related to a sexually transmitted disease) or surgery (if the cause is a varicocele or a blocked vas deferens). About 50% of the time, no cause for the male infertility can be found. In these cases, there is little hope that anything can be done to help.

Often, infertility is a "couple" problem. That is, separately, the man and woman have no serious problems, but together they have difficulty in conceiving.

If the cause of the infertility cannot be found, or if it cannot be treated successfully, couples may feel compelled to try other, more interventive procedures, such as IVF.

WHAT DOES INFERTILITY MEAN TO WOMEN?

The cause of infertility may be physical, but its impact is social. Most of us take it for granted that we will be able to have children when we want them. Discovering that this isn't possible can be a major blow to self-esteem and to our sense of masculinity or femininity.

Many women believe that motherhood is necessary for their fulfillment as women, and considerable social pressure is exerted on them to have children. As Canadian sociologist Somer Brodribb points out in her report on "Women and Reproductive Technologies":

> "Infertility is commonly understood to be a medical problem, which should be treated through medical intervention. But participants at an international conference on reproductive technologies in Spain asked, "If infertility is a disease, is a child the cure?" This illuminates the most unexamined aspect of infertility: the social construction of the desire to have a child. This desire is so strong that some men and women are driven to what researchers have described as desperate attempts to conceive."

In the past, people had little choice but to come to terms with their inability to get pregnant and to learn to live with it. The development of new reproductive technologies, however, has changed this attitude and holds out an often unrealistic hope. These technologies have brought with them the belief that nothing is too extreme, too difficult or too expensive if it offers the smallest chance of producing a pregnancy. And IVF and other high tech procedures are offered as the solution.

But this expenditure of scarce resources on expensive procedures that benefit only a few, diverts attention from research into the causes and the prevention of infertility. For example, relatively little money is spent on research into the prevention of sexually transmitted diseases or pelvic inflammatory disease. In addition, large expenditures on highly technical procedures divert funds that could be used for day care and other services that support parents and children.

To quote Somer Brodribb once again:

> "Increased research on the iatrogenic (medically caused) and environmental causes of infertility, and on sexually transmitted diseases, is required. The unfairness of massive government expenditures and support for a highly experimental and unsuccessful technique to procure babies for economically advantaged couples is a point made consistently in the literature reviewed. The health concerns of elderly and non-white women are urgent. An investigation into the profit making aspects of IVF, especially in private clinics, and the use of government funding, especially in Ontario, is required."

At this time, women have no control over the way in which infertility is defined by the medical profession or over the way in which resources are allocated to deal with it. And as long as women allow infertility to be defined as a problem whose cure is an expensive and exotic technology, that control will remain in the hands of a powerful few.

What you should know about...

"SURROGACY"

On February 5, 1985, Mary Beth Whitehead was artificially inseminated with the sperm of William Stern. The two had a contract. For a fee of $10,000, Mary Beth Whitehead would bear a child and give it to William Stern and his wife. On March 27, 1986, Mary Beth Whitehead gave birth to a baby girl. At this point, she decided that she couldn't give her baby up. She kept the baby for four months until forced, by court order, to give the baby to Stern and his wife.

After a long and painful legal battle, custody of "Baby M" was awarded to the Sterns. Mary Beth Whitehead was stripped of all parental rights. She was not even allowed to visit her child because, according to the judge, a deal is a deal—"The contract is not illusory." As well, the Sterns were affluent and well-educated. Mary Beth Whitehead was neither.

A year later, another court overturned this decision and granted Mary Beth Whitehead liberal visitation rights and ordered that she and the Sterns enter into joint psychological counselling for the sake of the child they share.

The "Baby M" case was headline news around the world. It raised gut-wrenching questions about motherhood, fatherhood, contract law, and custody. In Canada, there are no laws governing surrogacy, and no answer to the question, "Whose baby is Baby M"?

WHAT IS "SURROGACY"?

As it is popularly used, the terms "surrogacy" and "surrogate mother" are extremely misleading. In the usual "surrogacy" arrangement, a woman is artificially inseminated with the sperm of a man whose wife or partner is infertile, unable, or unwilling to carry a child to term. The woman who is inseminated is in every respect the "natural" mother of the child. She has contributed genetically, in that it is her egg that unites with the father's sperm, and gestationally, in that she carries the pregnancy in her uterus. It is probably more appropriate to call her a "surrogate wife", while the biological father's partner or wife should be called the "social" or "adoptive" mother. Because the term "surrogacy" is commonly used and understood, we'll use it in this discussion. However, it will appear in quotation marks, as a reminder that it is not really accurate and can be very misleading. It is also worth noting that there are no special terms for the man who provides the sperm in a surrogacy arrangement. He is not called—or thought of—as a "surrogate father", even though his role in the conception is no more "natural" than the woman's.

It is difficult to unravel the tangle of relationships that are being created as reproductive technologies become more common. For example, with the advent of in vitro fertilization (IVF) and embryo transfer, it is possible for a child to have five "parents":

- a biological mother (who contributes the egg);
- a uterine mother (who carries the pregnancy);
- a social mother (who rears the child);
- a biological father (who contributes the sperm); and
- a social father (who rears the child).

And this doesn't begin to address the issue of social and biological siblings and half-siblings. In the interests of simplicity, in this discussion we will refer to the woman who contracts to bear a child for another couple to raise as the "uterine mother."

HOW DOES "SURROGACY" WORK?

Commercial "surrogacy" arrangements originated in the United States where there are more than 15 private agencies, some of which are franchised. There are no agencies in Canada, but "surrogacy" arrangements have been conducted across the border, with Canadian couples hiring American women and Canadian women bearing babies for American couples.

Lawyers and agencies which handle "surrogacy" arrangements keep catalogues containing photographs and information about potential uterine mothers. Couples wishing to hire a woman to bear a child choose from the catalogues, and after meeting with one or several women, make a choice. The fee is usually $25,000 (US), $10,000 of which the uterine mother receives when she has produced a healthy baby.

WHAT'S IN THE CONTRACT?

Jeremy Rifkin, president of The Foundation for Economic Trends, speaking at the 57th Annual Couchiching Conference, described a standard "surrogacy" contract this way:

> "I'm going to read to you the standard contract that Mary Beth Whitehead-Gould and other women signed...Here's the contract: By contract, as the client I control your body from the neck down for nine entire months. (There is a clause in the contract that says that you cannot attempt to develop a maternal bond during pregnancy—where did these lawyers come from !? So women, you can't have a maternal bond because it's in the contract, you see.)
>
> "Now there's another provision in the contract. If I want to check the product, I can make you come into the clinic and have an amniocentesis probe put into your belly. I control that belly. It's in the contract. You can't

> "The most victimized character in the courtroom dramas is unquestionably the surrogate mother. Most of the public censure is directed toward her for accepting a fee, while everyone expects doctors and lawyers to charge for their services. "We want to avoid the money-hungry types," said the attorney who is holding up the book he wrote in every photo I saw. Women who list money as the only motive on their application forms are not selected. They must be able to provide reasons more compatible with public opinion: they truly enjoy pregnancy, they want to "give life"; they want to share their happiness with total strangers."

WHO BENEFITS FROM "SURROGACY" ARRANGEMENTS?

The most obvious beneficiaries are the lawyers and agencies who make the arangements. The uterine mother, remember, gets only $10,000 of the $25,000 (US) fee paid by the couple seeking a child—less than half the fee and less than minimum wage.

People seeking children also benefit, but only those who can afford the fees. Some agencies have proposed importing women from Third World Countries in order to make "surrogacy" available to more people by lowering the price. Should this be allowed?

But what if poor women or Third World women want children of their own? Women's Health Interaction reports that in parts of Africa, the rates of childlessness may be as high as 40%. Is the desire for children any less real or less valid for these women? Is there benefit in allowing "surrogacy" between friends or relatives when no money is exchanged and no third party involved?

No one knows whether the children involved benefit from "surrogacy" arrangements. How will it affect these children to know that they have been "bought"? How will it affect the other children of uterine mothers who watch their siblings being "sold"?

FOOD FOR THOUGHT

"Surrogacy" is based on the idea that women are passive vesels whose childbearing abilities can be bought and that children are commodities that can be sold. It also assumes that a man's desire for a child that is genetically "his" is more important than a woman's desire to keep a child that is genetically "hers" and which she bears in her womb. To quote Somer Brodribb once again:

> "The literature reviewed argues that male genetic narcissism is what the new technologies afford, rather than a re-evaluation of the responsibilities of social or biological paternity, or men's relationships to women."

What you should know about...

IN VITRO FERTILIZATION

On the surface, the process of in vitro fertilization (IVF) seems simple: An infertile woman is given fertility drugs which stimulate her ovaries to produce many eggs. The eggs are removed from her ovary in an operating room. The eggs are then fertilized in a laboratory with sperm from her husband or a donor. If these eggs begin to divide and become a "pre-embryo", they are placed in the woman's uterus by means of a tube inserted through her cervix. Nine months later, the woman has a baby, and the newspapers report the "miracle birth" of another "test tube baby."

But IVF is not really simple at all and the success stories reported in the news hide a great deal of information that every woman and couple should have before deciding to undergo this drastic procedure.

WHAT DOES IVF INVOLVE?

Step 1: Selecting Patients

Who gets IVF? Each IVF program sets its own screening procedures. In order to qualify for most programs, a woman must be under 40 years old (under 35 in some programs), heterosexual, and either married or in a long-term relationship which the program considers to be "stable."

IVF was originally developed to allow women whose fallopian tubes were blocked to bear children. Over time, the criteria have expanded to include women with many other kinds of infertility.

About 16% of the women who undergo IVF have no fertility problems themselves. They accept the risks and pain of IVF because of a problem with their husband's or partner's sperm.

Another selection factor is affluence. If you live in Ontario, OHIP will cover some of the costs of IVF in registered hospitals. Elsewhere, you can expect to pay from $1,500 (Calgary) to $5,200 (Quebec). The average fee is $3,000 for each attempt at IVF. Most couples try three times, although some couples have made as many as nine attempts.

The final criterion is patience. Many women have had to wait as long as 2 1/2 years to be accepted into a program.

Step 2: Inducing Ovulation:

One egg is not enough for IVF, so beginning about the fifth day of your cycle, you are given a fertility drug—usually Clomid, every day. This is to encourage your ovaries to produce many eggs at a predictable time.

Around the ninth day of your cycle, you begin daily injections of Pergonal, a fertility drug that induces ovulation.

At this point, you must undergo daily blood and urine tests to check on the levels of hormones in your body, and daily ultrasound scans to check the size of the egg follicles on your ovaries.

When your largest egg follicle is 18mm in diameter, you're given an injection of hCG (human chorionic gonadotropin), a hormone that triggers ovulation.

All of these hormones have side effects and risks. Clomid produces hot and cold flashes and mood swings. It is chemically similar to DES (di-ethyl stilbestrol), a drug that has been linked to higher rates of problems like breast cancer and cervical and ovarian cancer in the daughters of women who were given it. **There have been no animal studies or good clinical analyses of the long-term effects of clomid.** Pergonal can produce severe abdominal pain and headaches.

Women who are given these hormones may also have irregular and painful menstrual cycles for some time afterward. Helen Bequaert Holmes (BIRTH, Sept. 1988) noted that "It is also reasonable to speculate that women treated with these drugs, especially repeatedly, may be at risk for endometrial, cervical, ovarian and breast cancer for two or three decades."

About 10% to 35% of IVF procedures fail at this point. Either the eggs leave their follicles too soon, or too few eggs ripen to make egg collection, the next step in IVF, worthwhile.

Step 3: Collecting Eggs

After you've been injected with hCG, you'll be admitted to hospital, and within the next 24 to 48 hours the eggs that have been developing in your ovaries will be suctioned from the follicles.

Several different methods can be used for egg retrieval, all of which require some form of anesthesia, either general or local, and all of which carry some risk to the woman. Risks include pain and mild to moderate bleeding, hemorrhage, puncture of internal organs, recurrence of pelvic inflammatory disease and infection of the vagina or bladder.

Step 4: Collecting Semen

Your husband or partner will be asked to masturbate to produce a semen sample. This may be done either after your eggs have been collected, or in advance. If your husband's or partner's sperm is unsuitable, donor sperm may be used. The semen is washed and separated, and the most active sperm are collected to use in fertilizing your eggs.

Step 5: Fertilizing the Eggs

Your eggs are placed in a culture medium and are combined with the collected sperm. Not all of your eggs will be fertilized, but those that are will be allowed to develop until they have at least four cells.

Step 6: Transferring the Embryos

Between 24 and 48 hours after your eggs have been fertilized, the embryos which have developed will be placed in your uterus. This is done through your vagina and cervix, using a thin, stiff catheter. Usually, several embryos are transferred.

There are two issues to consider here: how many embryos to transfer and what to do with the extras. Transferring more than one embryo increases the chances that at least one will implant and develop, but it also increases the chance of a multiple pregnancy. Multiple pregnancy is more risky for both mother and child.

In most cases, the extra embryos are frozen and stored for future use. The storage of human embryos raises many ethical, legal and social questions. Who "owns" them? What happens to them if the parents die? What happens if the parents disagree about what to do with them? Can someone else use them? Can they be used for research? Can they be bought and sold?

Step 7: Confirming a Pregnancy

After the embryos have been transferred to your uterus, all you can do is wait. The chances that an embryo will implant and that you will become pregnant vary from program to program. On the whole, an embryo implants less than 20% of the time, and not all pregnancies will result in the birth of a live baby.

If you are one of the more than 80% of women who do not become pregnant, you must now decide whether or not to undergo the procedure again. This decision may not be entirely your own, since every clinic has its own rules governing who they will allow to repeat the procedure.

HOW WELL DOES IVF WORK?

Most women would consider IVF a "success" if it resulted in the birth of a baby. If this measure is used, IVF success rates are very low.

Most clinics greatly exaggerate their success rates. It is difficult to determine exactly what the success rates are because they vary widely from clinic to clinic and because each clinic has a different definition of what it considers to be a "success." For example, some clinics include ectopic pregnancies and miscarriages among their "successes."

In **The Globe and Mail** (Feb. 6 & 8, 1988), Ann Pappert reported that Foothills Hospital in Calgary reports a success rate of 22% to 27%. The actual success rate—babies born—is 8%. Shaugnessy Hospital in Vancouver reports a 20% success rate. The actual rate is 8%. The Toronto Fertility and Sterility Institute reports a success rate of 20 to 25%. The actual success rate is zero—as of February 1988, no babies had been **born** as a result of their procedures.

A recent survey of 164 IVF clinics in the US by the House Sub-Committee on Regulation, Business Opportunities and Energy showed that overall, the success rate of IVF programs was 9%.

WHAT ABOUT THE BABIES?

IVF babies are more likely to be stillborn, to have a birth defect, to die soon after birth, to have a low birth weight, or to be part of a multiple pregnancy than babies conceived in the "natural" way. To date, no follow-up has been done on IVF babies, so there is no way of knowing if they have any long-term effects from the ultrasound, drugs and hormones that they were exposed to before their births.

WHAT ABOUT THE MOTHERS?

Most women are not told that the process of IVF could be hazardous to their physical health. The more often you try IVF, the more likely it becomes that you will experience some of the dangerous side effects of the drugs and hormones used. Other risks include the formation of ovarian cysts and an increased risk of cancer. IVF also carries a greater risk of ectopic pregnancy: 5% to 10% compared to 1% to 5% for unassisted pregnancies.

Most women are also not told that the procedure can be emotionally hazardous as well. Women who undergo IVF are on an emotional "roller coaster." They have tremendous emotional highs as each step is successfully completed, and deep depressions when a step fails. For some, the stress, anxiety and depression are worse than the physical pain of the procedure. Psychological support and counselling are not a part of most IVF programs. The 85% to 90% of women who fail to achieve a pregnancy through IVF, and the even greater number who don't give birth to a live baby, are left to come to terms with this on their own.

Another concern is that almost every woman who undergoes IVF is part of a research study. Women have very little real choice in this, since it would be very difficult for a woman desperate for a child to refuse to participate.

IS IVF WORTH IT?

Think about this:

- At Dalhousie University Fertility Center, 61% of 437 pregnancies in 1145 infertile couples occurred without any treatment.

- At McMaster University, out of 12 patients who had **not** become pregnant through IVF, 3 had conceived naturally 10 to 12 months later. As far as we know, these pregnancies were not linked to the IVF process.

- At Ohio State University, among infertile women whose tubes were not blocked, 13.9% became pregnant through IVF, while 11.3% became pregnant without it.

These figures suggest that doing nothing at all may be as likely to result in having a baby as undergoing IVF.

And this leads to another question: Why is so much effort and money being spent on developing IVF which only offers couples a way around infertility? IVF does not, after all, **cure** infertility.

And why is so little spent on preventing the infertility that makes women desperate enough to try anything—even painful procedures that offer little hope of success—that might help them to have a baby?

What you should know about...

SEX SELECTION

In September of 1987, Dr. Allan Abramovitch opened Canada's first sex selection centre in Toronto. For a fee of $600 for the first insemination, and $500 for each additional insemination, parents can purchase an 80% to 85% chance of conceiving a boy, or if they prefer, a 75% chance of conceiving a girl. It usually takes three tries before a woman conceives. The procedure is not covered by provincial medical insurance.

Sex selection is the most commonly used form of pre-birth "quality control." Technologies like in vitro fertilization (IVF) have made other kinds of pre-natal interventions possible, including genetic manipulation through which new characteristerics can be introduced to an embryo and undesirable characteristics removed. At this point, these technologies are experimental, but work on their development is continuing.

Sex selection, though, is not experimental. It's happening now and its implications are worth thinking about.

HOW IT'S DONE:

The sex of a fetus can be selected either before or after conception. **In pre-conception sex selection**—the kind performed in the clinic described above—sperm washing or separation techniques are used to separate sperm bearing the Y (male) chromosome from sperm bearing the X (female) chromosome. The woman is then artificially inseminated with sperm bearing only or predominantly the desired sex chromosome. As noted above, this method is not 100% effective.

After conception, prenatal screening techniques—amniocentesis, ultrasound, chorionic villi sampling—can be used to detect the sex of the fetus. If the fetus is not of the desired sex, it can then be aborted. This method **is** effective, and is widely used, especially in cultures where sons are highly preferred.

WHY IT'S DONE:

Several reasons are given for the development and use of sex selection technologies. Not all of them stand up to close examination.

1. **Sex-related genetic diseases could be eliminated.**
   Some hereditary diseases are sex-linked: that is they show up only in one sex. If there is known to be a family history of this kind of sex-linked disease, then the high-risk sex could be identified and aborted or not selected.

2. **Population could be controlled.**
   In developing countries, like India, male children are much preferred and sex selection through amniocentesis and abortion is being increasingly practiced in an effort to produce sons. It has been suggested that if there were fewer females in developing countries, the population explosion which threatens the world's food supplies could be controlled.

   This is a frightening and extreme "solution" to a problem which already has an answer. Demographic studies which compare birth rates between countries show that population growth is effectively controlled by increases in income level, education, employment opportunities, health care and the status of women.

3. **People would have more choice.**
   When it comes to the sex of a human being, there are really only two choices; male and female. What this argument comes down to is that sex selection allows those who can afford it to indulge their society's overwhelming preference for male children, especially male firstborn children.

   The technology which makes it possible to indulge these preferences is already available and in use. In India and China, chorionic villi sampling followed by the abortion of female fetuses is a common practice. One follow-up study of an abortion clinic in India showed that of 8000 abortions following amniocentesis, 7997 of the aborted fetuses were girls. Three were boys.

   In many places, debates are occurring within the medical profession about whether information on the sex of the fetus should be revealed to pregnant women, given the apparent willingness of some to seek an abortion if the fetus is not the "right" sex. However, at the moment, many doctors are quite willing to perform an abortion for sex selection under certain circumstances. According to a recent poll of medical geneticists, 47% of these Canadian doctors and 62% of Americans would agree to abort a female fetus if a couple with four girls and a last pregnancy came to them for amniocentesis.

Once again, the question is "Who decides?" Can being famale be considered to be a "undesirable" fetal characteristic? Is a fetus of the "wrong" sex sufficient reason for ending a pregnancy? Many people would agree that every child should be wanted by his or her parents, but what if the parents want only boys? Or only girls? Should we be able to abort until we get our own personal version of the "perfect" baby?

What you should know about...

GENETIC MANIPULATION

At the 57th Annual Couchiching Conference, Jeremy Rifkin, president of the Foundation for Economic Trends, spoke on "Efforts To Improve the Human Race". Discussing gene splicing and genetic engineering he said:

> "Scientists several years ago took human growth hormone genes—human genes. They placed these genes into the permanent genetic code of mice—into a mouse embryo, then they put the embryo into a surrogate. She gave birth.
>
> "These weren't like any mice you ever saw. They had human genes in their genetic code. And those were functioning human genes, allowing those mice to grow to sexual maturity twice as quick as any mice in history and they grew twice as big....Supermouse. Very big mouse—and those mice pass on those human genes into their offspring. It's a phenomenal experiment! Every generation of this strain of mice has human genes in their code.
>
> "Let me give you another example. Scientists have taken a cell of a sheep and a cell of a goat. Now these are unrelated species—they can't get it together in the barnyard, no matter how much they would like to. And they created a "geep", half sheep and half goat....
>
> "Finally, my friends, do you have fireflies up here? Remember the little, beautiful firefly? They have taken the gene that emits light in a firefly, injected that gene into the code of tobacco plants, and the leaves on those plants glow and light up 24 hours a day.
>
> "The fact is we now have a technology—gene splicing—that allows us to eliminate biological boundaries..."

Genetic manipulation is not something that might happen, maybe, someday. It has happened and it will continue to happen. The question is, should it happen to human embryos?

In the US, a $3 billion, 15 year project to map the chromosomes and decipher the genetic instructions that make up a human being is underway. This knowledge will enable scientists, eventually, to read and understand an embryo's genetic code—the specific set of instructions that makes up each individual person.

In vitro fertilization already allows for genetic screening and manipulation of embryos, and some practitioners are advocating that IVF be the preferred method of conception so that only "good" embryos are implanted. Research continues into techniques like embryo biopsy, in which a small bit of embryonic tissue is removed and analyzed. These techniques allow the potential for sorting embryos before they are implanted in a uterus—only "good" embryos would be implanted. A scientist in London has recently performed a biopsy on marmoset embryos to analyze their DNA, and he suggests that we now have the technology to sample human embryos through such biopsies, without damaging them. The next step in this research is gene therapy, which involves the introduction of new characteristics into an organism by recombining or splicing together genetic material, as Rifkin described above in the experiment with mice.

Many disabled people are worried about this focus on the detection and elimination of fetuses with genetic abnormalities. They believe it devalues them as individuals and could lead to the perception that there is little reason to spend public funds to provide services for disabled people, when the disablility could be eliminated simply by discarding the "imperfect" embryo. They fear that someday, only "perfect" babies will be allowed to be born.

At the present time (Spring 1989), in Canada there are no laws that specifically regulate the use of embryos and fetuses in research. The Ontario Law Reform Commission (1985) has recommended that human embryo research be allowed.

WHAT DOES ALL THIS MEAN?

Genetic manipulation has enormous potential for both good and evil. It is already possible to determine whether an embryo will be a boy or a girl, have certain physical or mental disabilities, or be affected by, or be the carrier of a genetic disorder.

The question is, what do we do with this information? What rules should govern its use? Will women be forced to undergo genetic testing? Can a woman be required to abort a fetus which carries a hereditary disease?

What are "undesirable" fetal characteristics? Which fetuses are "fit" to be born? If the fetus is found to be "defective" can a woman be forced to abort? Do only "perfect" babies have the right to be born?

The most important questions though, may be these: Who will answer these questions? Who will make these decisions? In whose interests will decisions be made? Doctors? Scientists? Politicians? Women? Men? Religious leaders? Business people?

Who do you trust?

Whose Womb Is It Anyway?

Barbara Pasternak

Maggie Thompson

On September 3, 1987 a British Columbia family court judge ruled that the apprehension of a Vancouver woman's unborn child and the subsequent coerced cesarean section were entirely proper. The Baby R case, as it has become known, is a precedent-setting one. For the first time the B.C. Family and Child Services Act has been successfully used to seize a fetus and thereby force its mother into surgery she did not want. Further, the case relied on a prenatal apprehension as the basis for state custody of the child born. It is a dangerous precedent that will affect all pregnant women because the rights of the mother have been considered secondary to the rights of the fetus.

Events as described in the hearing clearly illustrate that the woman involved was treated as little more than a baby container. Along with other members of the Vancouver Women's Health Collective, Maggie Thompson attended the hearings.

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In strutted family court judge Brian Davis. He hurridly seated himself on a high backed leather chair, examined the court room gallery over the upper rim of his half glasses and began to tap his pen impatiently. It seemed he was looking for someone. I immediately felt tense.

"Is Ms. R in the court room?" Davis asked. "Yes, your honour," responded legal-aid-appointed lawyer Jim Thompson. Thompson turned in the direction of Ms. R. nodding his head. Every gaze in the court room turned to her, a small 37-year-old woman we'll call Rose. The sudden rush of attention seemed to take Rose by surprise. Her eyes turned downwards, her long brown hair shielded her, deflecting glances.

From that moment on the looks, the whispers, the notes passed from person to person all said that people

were already making their judgements. Rose was on trial.

Ministry of Social Services and Housing (MSSH) lawyer Tom Gove, a red-faced, stocky little man, announced he had 10 people waiting to give testimony. He estimated it would take him three days to complete his evidence. Rose's lawyer, Jim Thompson, said he had no witnesses to call and that he was unsure of whether to ask his client, Rose, to take the stand. Rose's prospects looked poor. The testimony that follows recounts the events on the day of Rose's son's birth.

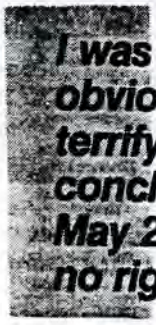
At 3 p.m. on May 20, 1987 Rose entered a Vancouver maternity hospital, in labour. It was her fifth birth, the previous four resulted in healthy babies, all born vaginally. Her fetus was in a footling breach position (its feet rather than its head appearing first), the cervix already quite dilated. In the absence of her own doctor, attending physician Christos Zouves examined Rose and quickly concluded that "the baby would die or would be seriously or permanently injured" without a cesarean section. Rose didn't agree with his assessment. She refused to give consent for the cesarean.

Zouves then phoned the Ministry of Social Services and Housing in order to find a way to force Rose to have the cesarean. He attempted to have her temporarily committed under the Canadian Mental Health Act, but a hospital psychiatrist and MSSH's emergency health team found that there were not sufficient grounds to take such extreme action. They assessed Rose to be competent and able to make her own decisions.

It then became apparent to Zouves that in order to proceed with the cesarean, apprehension of the fetus, declaring the child in need of protection, was his only option. He contacted a ministry social worker, Ivan Bulic, who had never met Rose, to ask how an apprehension could take place.

In virtually every instance, the State is only given the authority to seize or apprehend a child once it has evidence that the child has suffered abuse or neglect. Once apprehended, responsibility for the well-being of the child is transferred, temporarily or permanently, from the parent(s) to the State. The State then has the authority to decide what is in the best interests of the child.

In the testimony that continues, Zouves' held that if the fetus was found to be in need of protection, then the ministry was responsible for the fetus, and he could perform a cesarean section without Rose's consent. He went on to say that the fetus needed medical attention to survive, yet the only medical attention he mentioned was the cesarean section.



For a moment I was stunned. Could this fetus be pregnant, I asked myself?

Continuing testimony, Bulic understood Zouve's plan and recognized its irregularity. He checked with the superintendent of Family and Child Services and was told to ask Zouves whether he was dealing with a child or a fetus. Zouves responded "In my opinion this is a child." Within an hour Bulic had made all the necessary arrangements. He'd had absolutely no contact with Rose. He didn't even leave his office. Everything was done over the phone.

While Zouves and Bulic were discussing their plans, hospital support staff tried to convince Rose to have the cesarean section. After viewing ultrasound images, and hearing news that the apprehension had occurred, she succumbed to the pressure around her, saying "Go ahead, cut me open."

At 10:50 p.m. a healthy baby boy was pried out of her. He required no special postnatal medical attention, showed no signs of distress and was described by the doctor as "vigorous at birth."

The State-approved abuse of Rose which began in the hospital, continued over the five long days of the hearing in New Westminster. MSSH lawyer Tom Gove carefully planned an attack on Rose, her friends and lover. His case was nothing less than a character assassination designed to make Rose look so bad that the impropriety of events on May 20 would be overlooked.

Day after day, Gove prompted recollections and glib editorial comments from social workers and doctors. Testimony throughout was full of harsh, judgemental, uncorroborated comments about the most minute and insignificant details of Rose's life. Because the courts failed to distinguish between the apprehension of her fetus prior to birth and State intervention in the case of her children, we heard lots of testimony about alleged problems of a mother caring for her children. We heard that on one occasion the cereal Rose fed her first child was not appropriate, that her friends were not suitable, and that, while she displayed love and affection for her children, she could not provide for them. One social worker referred to her behaviour as schizoid. Another remarked that her breath smelled like she'd had two beers. Yet another claimed her friends used hard drugs.

The well-dressed, articulate social workers could remember the most microscopic details, yet they were forgetting one thing, for me a fundamental factor. Nowhere in the hours of testimony, or in Rose's lawyer's flimsy cross-examination, did it appear that her rights as a pregnant woman were being considered or defended. I sat there screaming inside myself "What about her right to protect herself from the wounds a cesarean would inflict? What about her right to liberty and security of the person? What about her right to say *no*?"

I was left with the obvious and terrifying conclusion that on May 20 Rose had no rights.

For five days Rose and her partner came and went from the New Westminster court room. Each day she made her way through the throngs of the hostile, the curious and the supportive, encountered in the hallways, in the courtroom, even in the bathroom. All the good intentions, the sympathetic glances, all the authority and rancor, the huddles of lawyers, social workers and advo-

cates whispering about her and her chances. Outside, the swarms of cameramen readied themselves for the attack. Once out in the open they rammed their weapons where they could: her mouth, her crotch, anywhere, the closer the better.

By the last day of the hearing, tensions were high, the MSSH's case was reaching its crescendo. Rose tapped her fingers nervously. Glances darted all around the court room. The glances were briefer, sharper and more critical than before.

"This woman is not on trial," said Tom Gove in his summation. The court room broke into sarcastic, nervous laughter. Judge Davis was offended. Unauthorized laughter in his court room was unacceptable. He gave a belligerent lecture about respect and boorish behaviour, and ordered the room to be cleared for a 30-minute break.

While the outcome of the trial seemed to be a foregone conclusion — considering the mood — Davis delayed his decision for six weeks. On September 3 he ruled that events on the evening of May 20 were entirely proper, and awarded permanent custody of Rose's baby boy to the Ministry of Social Services and Housing.

Davis's decision is clearly outlined in this quote:

"The evidence is that the birth was" imminent and it in fact occurred within three hours of the superintendent making the apprehension. The purpose of the apprehension was to ensure proper medical attention for the baby. This is not a case of women's rights, Mrs. R. consented without coercion or threat to the operation . . . This is simply a case to determine what is best for the safety and well-being of this child. It is clear that this child was in the process of being born and the intervention and redirection of its birth were required for its survival. It was at or near term. It required no life support: it was "vigorous" at birth and indeed he was born healthy. . . .

"Under those circumstances, namely where the baby is at or so near term and birth is imminent, the failure to provide necessary medical attention to prevent death or serious injury is sufficient to allow the superintendent to invoke the procedure of apprehension. I am satisfied that the apprehension was entirely proper."

Yet it was Rose who received the controversial medical attention, not her son. In essence, Davis contends that the medical rights of a pregnant

woman are secondary to the rights of her unborn child or fetus. By implication Davis' ruling concludes that Zouves had the right to pressure Rose, cut her open and take her child.

I fiercely disagree. The right of anyone to refuse treatment was, I thought, firmly grounded in Canadian law. What still stands is the obligation of caregivers to seek free, full and informed consent for medical treatments they deem necessary. Rose was denied her right to refuse treatment. The so-called consent she gave was clearly forced, not free, full and informed.

I agree that during birth the needs of the mother and her fetus have to be carefully weighed. However, the needs of both are far better served when the woman's concerns are fully addressed, when she is fully informed and when she is treated with care and respect. Ultimately, I believe that the woman has the final say.

Indications are that we will encounter more instances of forced obstetrical interventions such as the one Rose experienced. We may see that women are presented with the threat of complying with medical intervention, rather than have the State apprehend before birth.

In Belleville, Ontario in March 1987, a woman who was eight months pregnant, and who seemed to be behaving erratically was committed to a hospital so that her unborn child could be monitored. The Children's Aid Society of Belleville

In that case, presiding Judge Kirkland included in his decision a passage from a previous decision which read:

> a local psychiatrist was quoted recently as saying every child should have certain basic rights such as: the right to be wanted, the right to be born healthy, the right to live in a healthy environment, the right to such basic needs as food, housing and education and the right to continuous loving care.

This second hand opinion was used to justify the forceful detention of a woman so that tests assuring her baby's health could be done. The woman's rights were suspended so that the right of the fetus to be born healthy could be upheld.

This case and Rose's case together provide evidence of the increasing attack on women's reproductive rights and of the growing confidence of the State to launch these attacks.

A study quoted extensively in an article entitled "Court Ordered Obstetrical Interventions" by Veronica Kolder, Janet Gallagher and Michael Parsons, printed in the *New England Journal of Medicine* on May 7, 1987, reveals that like Judge Davis and Dr. Zouves, many physicians are prepared to disregard the rights of women during pregnancy and birth. In the study, the heads of fellowship programs in maternal-fetal medicine were asked to agree or disagree with a number of statements. Twenty-six of 57 (46 per cent) thought that mothers who refused medical advice and thereby increased the risk of danger to the fetus should be detained in hospitals or other facilities so that compliance could be ensured. Fifteen of 58(26 per cent) advocated State surveillance of women in the third trimester of pregnancy who stay outside the hospital system. The U.S. survey reported court ordered cesarean sections in eleven states, hospital detentions in two states and intra-uterine transfusions in one state.

Yet doctors' opinions are not foolproof. The study states that "uncertainty is intrinsic to medical judgements. The prediction of harm to the fetus was inaccurate in six (out of 15) cases in which court orders were sought for cesarean section."

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"It's Going to Work for Me." Responses to Failures of IVF

Linda S. Williams, Ph.D.

ABSTRACT: *Although most in vitro fertilization (IVF) attempts end in failure, most women who try IVF once try again one or more times. This paper is based on an interview study of twenty Canadian women who underwent at least one IVF procedure, and it describes the way in which failure affected their decision to try IVF again. Since undergoing IVF increases awareness of each step in the biological process of becoming pregnant, it allows a woman to think of herself as "getting closer" to becoming pregnant, depending on the number of steps she successfully completes in the process, even if her attempt ultimately fails. Since a subsequent attempt might progress even further, perhaps to pregnancy, it therefore becomes difficult to stop trying. Women must be informed of this aspect of IVF if they are to make informed decisions concerning its use.* (BIRTH *15:3, September 1988)*

Despite the fact that in vitro fertilization (IVF) fails the majority of the time, most women who try it once make a second attempt, and many make several tries. A nurse at one of the hospitals where some of the subjects in this study underwent IVF estimated that 80 percent of the couples at that hospital who did not achieve a pregnancy on their first try came back for another attempt. This paper focuses on women's experience of the failure of IVF in a Canadian sample, and the way in which failure affected their decision to try again. It is based on an interview study of twenty women who underwent at least one IVF procedure in the province of Ontario from 1984 to 1987, and their husbands. Ten of these women made one attempt, two made two attempts, and eight made three or more (see Table 1 for outcomes). For most couples, the decision to try a second time was usually simple and straightforward. For those in which the woman had undergone two or more attempts, however, husbands' enthusiasm generally decreased as the number of failures increased, while the wives generally wished to continue. The major reason for this difference was quite simple—husbands were worried and even fearful about the effect that IVF was having on their wives. They were often deeply affected by seeing their wives go through IVF, and their concern focused on three main areas: 1) the emotional stress of IVF, which these husbands perceived to be exacerbated or even caused by the fertility drugs used in the procedure, 2) the physical pain and discomfort of IVF, and 3) the potential long-term risks posed by the fertility drugs used in the procedure. The wives were more likely than the husbands to cling to the hope that "next time" would produce the pregnancy they so ardently desired, and were consequently much less willing to discontinue IVF.

The strong desire of these women to have a child was obviously a major factor in their decision to keep trying IVF, but I believe that another factor that played an extremely important role is the hopefulness that is produced by the very nature of the procedure. To understand this it is necessary to examine one of the major differences between IVF and normal pregnancy, and the way in which this difference affects women psychologically.

Becoming pregnant is not, of course, a one-step procedure, but a biologic continuum made up of many discrete steps. A woman who is trying to become pregnant through intercourse knows that the process begins with the sex act and ends with the implantation of a fertilized ovum in her uterus; however, since these processes occur inside her body, she is not aware of the failure or success of

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Presented at the Third International Interdisciplinary Congress on Women, Dublin, Ireland, July 1987.

Table 1. Results of All IVF Attempts (N = 50)

Outcome of Each Woman's Attempts	*Number of Attempts per Woman*																			
	1	*1*	*1*	*5*	*2*	*2*	*3*	*3*	*3*	*1*	*1*	*1*	*1*	*6*	*1*	*1*	*6*	*6*	*4*	*1*
Cancellation		1	1	2			2	1	3					2			1	1	2	
Egg collection, but no fertilization											1						1			
Embryo transfer completed, but no pregnancy	1			3	2	2	1	2					1	4		1	3	3	2	1
Miscarriage following diagnosed pregnancy																		2		
Pregnancy expressed in no. of live births/pregnancy										1		3*			1		1			

* *This woman had triplets.*

each step as it occurs. She only becomes aware of her failure to conceive at the onset of her next menstrual period. She cannot be aware of the stage at which her attempt at pregnancy "broke down."

In vitro fertilization not only separates reproduction from sex, it also makes visible the series of biologic steps that lead to pregnancy, since all of these steps, whether they occur inside the woman's body or outside of it, are constantly being monitored by doctors and technicians. Unlike women who become pregnant normally, those who attempt IVF are aware of each stage of the process that leads to pregnancy and they are able to learn *at exactly what point the process breaks down*. Thus becoming pregnant normally and becoming pregnant through IVF both involve a continuous series of biological processes; however, the way in which women experience the processes is vastly different. Pregnancy through IVF is a conscious, continuous process. This fact has enormous psychologic significance because the women are able to think of themselves as "getting closer" to becoming pregnant depending on the number of steps they successfully complete.

The intense psychologic features of the IVF experience and the way in which they act to encourage women to keep trying is perhaps best described by examining one woman's experience and her reactions to each attempt. When I interviewed Marilyn she had been through four IVF attempts in one year. At that time the doctors at the hospital she attended were advising women to wait three months after a failed attempt that had proceeded to the egg-collection stage before trying IVF again. This waiting period was recommended in order to recover from the effects of the egg-collection surgery and the fertility drugs. Consequently, Marilyn's first four tries were the maximum possible number that a woman in this particular program could undertake in one year. In order to be fully recovered for another attempt, she then waited seven months before trying a fifth time. She was planning to make a sixth attempt within a few months of our interview.

Marilyn's Story

Marilyn's first attempt at IVF was unremarkable. Four eggs were collected, only one fertilized, and it was returned to her uterus. Marilyn did not conceive, and as is the case with most women, the decision to make a second attempt was not difficult: "There was no question," she said. "We were definitely going to do it again." For her second attempt, her doctors decided to increase her Pergonal dosage to increase egg production. This treatment did indeed produce the desired effect, as Marilyn vividly describes. "I became, as Dr. F. put it, a regular baby factory. I was producing more follicles than you could believe. I had enough to support an army. I must have had 12 follicles on one side and at least 9 and counting on the other side." Before these eggs could be surgically removed, however, Marilyn ovulated and had to be "cancelled."

> I was really disappointed. I was really upset. Andrew took me out for dinner, and I don't drink, but I had a drink because I was really upset. And he didn't know what to do for me and I didn't know what to do for me. I think it was more of a rude awakening because it had gone so well on the last attempt and I went through the whole program, how the hell did I get cancelled? So you go through a lot of, "What did I do wrong?" I didn't do anything. Every period is different and your body reacts differently each time.

In spite of the tremendous upset, Marilyn decided to try IVF a third time.

> No question again. I'm a glutton for punishment. Here I'm cancelled and I don't want to be cancelled, and I'm going to do it, and dammit, I'm not even going to consider stopping the program because if I came this close . . . look how many eggs I produced. If they can get this more

under control . . . I mean, you are really a guinea pig for the next person, but it's a good kind of guinea pig because you can gain something at the same time.

When her third try began, Marilyn was extremely anxious. "I was very nervous," she said. "I prayed to get to the surgery stage." Five eggs were collected, and three fertilized. "They implanted them and I swore I was pregnant." However, three weeks later Marilyn bled profusely, and her doctors felt that she had actually had an early miscarriage. Although this outcome was traumatic, it had the effect of renewing her hope in the whole process. When I asked her if it was difficult to decide to try IVF for a fourth time, she emphatically replied, "No! Now more than ever, because if I was this close obviously I was just a step away." Marilyn's fourth attempt, however, was no more successful than her previous three.

I had one follicle that decided it was going to be king pin, and every time I got a shot of Pergonal this one little follicle ate it all. I had a follicle the size of New Jersey, and the rest didn't have a chance. The doctors waited longer too [before deciding to cancel her]. They kept trying with more Pergonal to see if it would make a difference. It didn't.

Since the chances of becoming pregnant when only one egg is removed are very small, Marilyn's doctors advised her not to go through surgery to try and recover the egg within her one enormous follicle. For the second time, Marilyn was cancelled.

I was, again, very upset, because it's sort of going on a roller coaster. You had the first try, the second try, *the third try* [she emphasized this because this was the time she thought she miscarried], and the fourth try. And again it's sort of like the thing with lottery tickets. It's so close to my numbers. It must be next week that they'll probably draw mine. Plus the fact that I still strongly believe in the program and I believe they're excellent doctors and they've got a very well-organized program. It's going to work, and it's going to work for me.

Despite Marilyn's obvious desire to continue with IVF, she and her husband decided that it would be prudent to wait a while before trying for a fifth time. "The drugs make you put on weight, and I thought I'd better get my body in shape to begin with. And let my head get in shape." Marilyn's fifth try, seven months after the fourth, also ended in failure. Eight eggs were recovered and four fertilized, but they very quickly stopped developing.

I went through a very, very traumatic time. Dr. C. came in and I've never seen him so emotional. He was crying, he was really upset. He said, "I don't know what to tell you," and I said, "Well, what do I do?" He said it would be a miracle if anything happened. I said, "Well, I'll pack now and leave." Really, really upset. I was quite certain that here I was with eight and four had fertilized and they would implant four and this would be it. This would be the time. And Dr. C. said, "Why don't we wait and see. Stranger things have happened." I said I really didn't see any point.

I stayed in the hospital trying to help other patients, very very upset. Dr. C. came in the next morning, a big grin on his face, and I wanted to throw something at him because I hated him for being in that kind of mood, and he said, "Miracle of miracles, one took off." Couldn't believe it. It had stopped, but then, not only did it start again, from the 1-cell stage to 2, it went right to the 10-cell stage. So we said, we have a fighter on our hands. So I was firmly convinced that this little bugger [would make it]. We knew of people who got pregnant with one, and I was now convinced. In fact I saw it. I went into the lab and took a look at it. It looked like a giant grape with all these little cell structures around it. And the lab doctor said to me, "What do you think?" and I said, "It looks just like me."

After the implant, part of me was so firmly convinced that it was working because it was meant to be. It stopped and it started and it was strong and it was tough. I was tough and it would work.

In spite of her abundant faith, Marilyn's pregnancy test was negative. "Then I made up my mind that I still would not give up on the program but that I would wait until I felt I was ready to do it again."

Marilyn's story clearly demonstrates how IVF makes it extremely difficult psychologically for women to discontinue attempts even after a series of failures. Generally speaking, I believe it is correct to say that most of the women in this sample did not see each attempt as a discrete, independent event. Since they were aware of the outcome of each step, positive outcomes such as the collection of a large number of eggs or their subsequent fertilization were interpreted by these women as signs that they were getting closer to becoming pregnant and would probably be pregnant next time. Consequently, they were very reluctant to stop trying.

Paradoxically, even cancellation of an attempt in the earliest stages had the same effect as the successful completion of a number of critical steps on the women's decision to try again. Women who were cancelled often interpreted this to mean that they had not had a "real try," and they were also very keen to try again.* This was especially true for

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* *Most hospitals in Ontario have a limit on the maximum number of times a woman can attempt IVF, but cancelled attempts are generally not counted toward this maximum. For instance, if a hospital allows a maximum of four tries, and a woman has two cancellations in her first three attempts, she is still considered to have three tries left. Since the doctors who run IVF programs do not count cancellations as real attempts, it is not surprising that women do not either.*

women who were cancelled on their first try. When I asked one of these women if she would try again she said, "Absolutely. It's nonnegotiable. I'm doing it again. Why? Because I didn't get to first base. Also, I don't think I could live with myself. I'm not ready to shut down."

Conclusion

While many factors affect a woman's decision to undergo IVF initially, and continue to motivate her subsequent attempts, the way in which the procedure affects the decision to continue trying has not, I believe, been fully recognized. Since in vitro fertilization makes visible each step in the biologic process of becoming pregnant, it allows a woman to learn at exactly what point her attempt breaks down. It therefore becomes possible for a woman to think of herself as getting closer to becoming pregnant if she successfully completes a number of steps in the procedure, even if the attempt ultimately fails. Her next attempt might progress even further, perhaps all the way to pregnancy, and it becomes very difficult to stop trying.

While several attempts at IVF are not necessarily more likely to lead to pregnancy, they do help to ensure that a constant supply of experimental subjects (i.e. women) will be available for this controversial and largely unsuccessful technology. The way in which the procedure itself affects the decision to try IVF again must be recognized and publicized if women are to make informed decisions concerning its use.

Prenatal Screening and Discriminatory Attitudes Towards Disabled People

Marsha Saxton*

Résumé

Plusieurs mythes entourent la problématique du handicap et du diagnostic prénatal. La notion, par exemple, que le DPN accroît la qualité de la vie, prévient l'incidence du handicap ou que l'avortement est la réponse automatique au foetus handicapé doit être remise en question. Dans notre culture, les déficiences physiques et mentales soulèvent beaucoup d'appréhension et les personnes atteintes souffrent davantage de la discrimination exercée envers elles que de leur handicap.

D'autres idées préconçues affectent plus particulièrement les parents qui doivent prendre une décision à la suite d'un diagnostic positif. On croit généralement que les personnes handicapées représentent un poids pour la société sans voir que c'est la société elle-même qui est en cause en ne réussissant pas à répondre aux besoins de ce groupe de personnes. De plus, on tend à exagérer la souffrance physique et mentale des handicapé-e-s. Malgré cette souffrance, ces personnes sont tout à fait aptes, comme toutes les autres, à jouir de l'existence et à mener une vie productive. La question du degré de sévérité du handicap n'est pas non plus pertinente dans ce débat, car qui peut s'arroger le droit de décider quelle vie vaut la peine d'être vécue? Enfin, on soulève fréquemment le problème du conflit entre les droits du foetus et ceux de la mère. Il n'y a là que contradiction apparente résultant du sexisme et de l'oppression sociale dont sont victimes les personnes handicapées.

Ne faudrait-il pas fournir aux femmes qui se trouvent en situation de décision, une occasion de rencontrer des adultes ou des enfants affectés d'un handicap? Elles pourraient découvrir, lors de ces échanges, l'intérêt du défi que peut présenter la tâche d'élever un enfant handicapé.

* Marsha Saxton est une militante de longue date de toute la question des droits des personnes handicapées. Elle a été consultante auprès d'institutions de santé, d'employeurs et de maisons d'enseignement sur ce sujet et en tant que directrice d'un centre pour personnes handicapées, elle a eu l'occasion de connaître et d'étudier les problèmes qu'ils vivent. Elle dirige actuellement un projet portant sur les femmes et le handicap pour le compte du Massachussets Office on Handicapped Affairs. Elle a écrit de nombreux articles sur des questions touchant à la condition féminine, à la santé mentale, aux attitudes discriminatoires vis-à-vis les personnes handicapées. Parmi tous les aspects des nouvelles technologies de la reproduction, elle s'est intéressée particulièrement au diagnostic prénatal et aux conséquences que cette technique entraîne tant sur le plan des attitudes sociales que des pratiques médicales. Madame Saxton vient de terminer un ouvrage qu'elle a co-édité avec Florence Howe: *With Wings: An Anthology of Literature By and About Women with Disabilities* publié par Feminist Press.

Ce texte a été fait à partir de l'enregistrement.

I speak as a disability rights activist, as a feminist and as a person who has to live with a disability.

My disability is called spina bifida. It is a form of neural tube defect and it is one of the major target of the prenatal screening.

I have been doing, speaking and writing on the issue for the last three years. And very often, when I approach audiences of parents, medical, care-takers and students, the most common reaction is: "I have never thought of that issue, in terms of the relationship between attitudes about disability and the culture, and prenatal screening."

The most common assumption about prenatal screening is that it raises the quality of life, for everyone, that it can prevent or reduce the incidence of disability in the society, and if the woman has the information that the fetus she is carrying is affected, that of course, she would have an abortion.

The assumptions that I would like to challenge include that a quality of life for disabled people is necessarily less than for people without disabilities. Also that having a disabled children is a wholly undesirable thing, and thirdly, that we, as a culture, have the means to rationaly decide who is better of living and who is better of dead. Disability in our culture triggers much fear. Disabled peoples are the targets of behaviors and attitudes that restrict our access to the mainstream life of the community.

People with mobility impairments because of architectural barriers, have limited access to restaurants, to movie theatres, court rooms, the post office, sometimes hospitals. People with hearing impairments are restricted in their access to media, television, radio, conversation, sometimes communication with their physicians, the shopkeepers, etc. People with visual impairments are restricted in their access to media, to materials in tape and in Braille.

In fact, it is and it can be difficult to have a disability. It can be physically painful, it can be extremely inconvenient but I contend that what is disabling about disability is discrimination. Discrimination and oppression are what makes it difficult to have a disability. What I would like to discuss is how attitudes in our culture affect a perspective parent in the choice of wheter to abort a fetus identified as having a disability.

I think that there are two major assumptions about disabled people that affects parents in this decision-making process. One is about the burden of the disabled on society. I read a story in a women's magazine about it called: "The Young Mother Story", a parent of disabled child, severely disabled child and the child's non-disabled sibling.

This woman described her life in her suburban home. Her husband was working all the time, away from the home, and in this story, she described no support from the neighbours, from extended family, from support organizations for disabled children. She described the only resource as the family physician. This woman described her life as overwhelming, she felt isolated. She didn't feel burdened indeed by the child's needs. What has striken me in the article was that any woman, alone in her suburban home, raising a non-disabled child would feel overwhelmed and isolated. That it was the failure of the nuclear family to address the needs of a unique situation, that we typically interpret this woman's difficulties as caused by the child's disabilities rather than by the social factors that affect her isolation.

Another assumption is about the suffering of people with disabilities. In my work as a counselor, I have had exposure to the lives of hundreds of peoples with disabilities, many people who are seeking services for the difficulties they face, in relation to having a disability, for depression, for emotional reactions that people with disabilities face. But I feel very strongly that people with disabilities don't necessarily suffer any more than any other group of people who are the target of oppression. Some people with disabilities may choose to end their own life because of the physical pain, the isolation, the difficulties they face. But this is also true for non-disabled people who may choose to end their own life because of emotional distress, because of poverty, because of oppression.

The vast majority of people with disabilities enjoy their lives, live productive lives, have a good time, just like people without disabilities. Sometimes, the issue of severity is raised, the severity of disability, in relation to prenatal screening. Sometimes, feminists will approach me after I have spoken and done training around the issues of disability in relation with prenatal screening and the reaction will be: "I hadn't realized that spina bifida could be so mild. I didn't realize that somebody with that disability could live such a productive life as you. Maybe, we should reevaluate our attitudes about prenatal screening, and be more careful to allow people with mild disabilities to survive."

My reaction is: You didn't get it yet.

If I were sitting up here speaking, with a severe disability, if I was drooling and spactic, with an extreme disability that prevented the easy articulation of my needs, would that mean that I had less right to survive, to live a productive life, to enjoy myself, to articulate my own needs. Supposing I was a disabled person who was unable to advocate for myself, a person with mental retardation, a person with severe profound retardation, does that mean necessarily that I should have less right to survive, to live and to experience existence as I would?

People with disabilities are oppressed in our society. I want to mention, in relation to the issue of the society, that I recently had the experience of meeting with German women at the Congress of People with Disabilities, from around the world, to get together in Bremen. It was sponsored by an organization called Crippled Movement, at the Independent Living Center. What I was struck by, in relation to the disabled German women, is that they had a much better accurate grasp of the extremes of the oppression than women that I have met in North America, including disabled women activists. That people born in Germany have a much more graphic sense of the extremes of the oppression having been born in a generation during and immediately after the Nazi Holocaust.

We were allowed to view a video that the organization had created on the last ten years of the disability rights movement and it included some Nazi's newsreel films, propaganda films, about the quality of life for people with disabilities. The message being that disabled life is worthless, that disabled people are a burden to society and interfere with the quality of life of anyone else. And therefore, people with disability should be eliminated.

I feel very strongly that our goal should be to eliminate oppression, that our attempts to eliminate an oppressed population is not a workable goal for our society. How would I counsel a woman who is considering prenatal diagnosis, with intent to abord on the basis of a diagnosis of disability. I would ask: has she had the opportunity to meet with children and adults with disability, has she had the chance to examine her own values about disability, to look at the values that were taught her, as a child, in relation to imperfection, to physical vulnerability, to disability. Has she had a chance to talk with her husband, with her family members, with her close friends, and resources about the opportunities that might be presented to her in relation to raising a child with differences?

The issue is often raised that there is an apparent conflict between the rights of the mother and the rights of the fetus, in relation with disability. And I would like to point out that this apparent conflict is only the result of oppression, of sexism, and of the oppression of people with disabilities. I don't believe that there is a rational human conflict between the needs of a mother and her child.

Source:Collectif, Sortir la maternité du laboratoire, Actes du forum international sur les nouvelles technologies de reproduction, Gouvernement du Québec, Conseil du statut de la femme, 1988, 423p.

$3.95

DILEMMAS

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Québec

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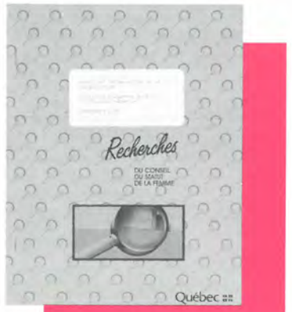

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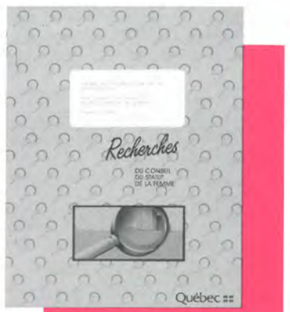

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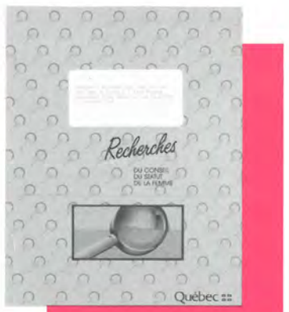

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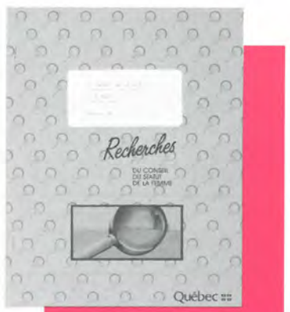

Les enfants que je veux... si je peux... by Françoise-Romaine Ouellette

750 pages, six documents on new reproductive technologies: one topic explored from different angles. *Dilemmas* is a synthesis of this research carried out by the Conseil du statut de la femme. For additional information, documents may be consulted at the Documentation Centre of the CSF or at any regional office of Consult-Action.

Dilemmas
is a joint publication of
the Conseil du statut de la femme
and Les Publications du Québec.

Editing:
Francine Gagnon, CSF

Graphic design:
Louise Bernatchez, CSF

Translation:
Edward Bantey

Legal deposit: 2nd quarter 1987
Bibliothèque nationale du Québec
ISBN 2-551-08579-9

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Crumbling motherhood

Francine C. McKenzie, president of the Conseil du statut de la femme (CSF).

The scientific child is born and the media herald the coming. He is the shiniest product of high technology. Not for him the primitive dependence on sexual intercourse. He has bypassed nature, leapfrogged ethics and law. And he has lent respectability to the "logic of desire" — ask and it will be given. A new page has been turned in the history of humanity: henceforth the human being can intervene in his own origins, deliberately blur his identity, indeed modify himself. The potential is there. For human wisdom, it is five minutes to midnight.

Science responds to our doubts with the word performance. Technique claims it fulfills a need. Need that has become desire, desire that has turned into obsession: we must have a child **regardless of the cost**. **Right now**. And the child must be **perfect**. We promise there won't be any traumatic effects.

Why is infertility no longer tolerated? Is it because of the decline in the birth rate? Having become a rarity, the child must make it happen. Is it part of our productivist approach? Meaning the need to produce more ought to include that of reproducing ourselves: I have a child, hence I am. Or is it part of our conformist way of looking at things (I'm typical because I have two children)?

How can one explain that **only 5% of couples are actually sterile, but 20% consult specialist about their sterility?**[1] That one third of the women surveyed in our research on those resorting to in vitro fertilization (IVF) already have a child?

How can we blindly accept that failure to conceive after only a year of sexual relations is deemed sufficient to qualify for treatment of infertility? And even less than a year if the woman can provide graphs of her body temperature variations. Perhaps the fear of pregnancy during their youth and insistence on contraception led women to assume it was easy to conceive[2].

Is technique responding to a couple's drama or to its impatience? The 12-month period of non-conception is all too brief. We ought to allow nature to take its course, acting instead where it is breaking down, such as in the case of young people who are losing their capacity to reproduce because of the epidemic of sexually-transmitted diseases. Unless we want Québec to become a procreation laboratory. Nor can it be overemphasized that medically-assisted reproduction practices are **not a cure but a palliative**. **Infertility is not being treated**. It is being circumvented by achieving conception otherwise.

Let's level with the women tempted to venture into the mine field of in vitro fertilization. Let's tell them the truth about the risks involved, about the real chances of success. In an article in Les Temps modernes[3], "*Pourquoi faire simple quand on peut faire compliqué?*" (Why simplify matters when they can be complicated?), Joachim Marcus-Steiff demystifies the question, raising ethical considerations regarding the information disseminated about such techniques. He lists six methods used to inflate the IVF success rate and 12 different ways to calculate it. He concludes that the probability of giving birth to a living child may not be 20% as practitioners claim, not even 10 or 15% as is often reported (the figure indicates the perfomance rate of better clinics, not an average), **but more likely in the neighborhood of 5%**. Various authors suggest **that so-called infertile couples having sexual relations are likely to experience the same rate of success as those who turn to IVF**.

As for risks inherent in IVF, it need only be noted that the rate of extra-uterine pregnancies is higher than in the case of natural pregnancy, that reimplantation of several embryos in the uterus results in a multiple birth rate of 12 to 30% as opposed to 10% for natural fertilization, that 27% of births are premature, that 33% of the children are born hypotrophic, that perinatal mortality is higher, that flexed breech deliveries are 15 times more frequent and that one out of two children conceived in vitro must be delivered by caesarean[4]. Not to mention the side effects of drugs and hormones used for homonal stimulation, the risks involved in extraction of ovules, the dangers of general anesthesia required for embryo reimplantation and, finally, the patience women must have and the difficulties the couple will experience.

In the chess game of test-tube babies, the perfomance is hardly up to Karpov's standards. Knowing that wonderment can give way to horror helps one gain a better perspective on scientific boastfulness.

There are dark clouds on the horizon: sex selection, eugenics, genetic manipulation, egg fusion, feminine self-insemination, cloning, artificial creation of twins, banks of substitute material, male pregnancy, human gestation in animals, development of human-animal chimera[5] and unscrupulous application of veterinary discoveries to human reproduction ends, as Jacques Dufresne points out in *La reproduction humaine industrialisée.*

The tailored-to-measure baby already exists: on August 9, 1986, the *London Daily Express* reported the birth of Justin Spencer, a made-to-order male. Dr. Jack Glatt of London let it be known his clinic is being swamped with requests for boys. What's more, sex selection can be independent of artificial fertilization: "I am absolutely certain that sex choice will soon be widely available in this country and that it will not be restricted to couples having test-tube babies!".

Prenatal diagnosis also makes sex selection possible. A Danish woman recently demanded an abortion when she learned she was carrying a girl. Since Denmark provides abortion on demand up to the 12th week of pregnancy, doctors there are now forbidden to disclose the sex of a fetus less than 12 weeks old.

So means do exist to slow down the transition from the naturally-made to the prefab baby, to throw a monkey-wrench into the "medicine of desire" — designer medicine — and the runaway machine of progress.

An IVF practitioner has the gall to ask why we presume the matter concerns us. Well, doctor, it does affect the mother and the child. We believe the technique ought to be used with great caution, that a notion of limits should be introduced to safeguard the inherent sense of being human. Our research takes a **humanist** perspective. Not because we are nostalgic and reject progress (after all, women do make use of technique in contraception and abortion) but because women must have free choice in the matter. In that way, we can say "no" to the technology of the possible and opt instead for other ways that reconcile us with nature. The research also takes a **feminist** perspective. We must rid ourselves of the double polarization that has dominated recent feminist thought on maternity: on the one hand, glorification; on the other, rejection.

The abortion debate as well as the preoccupation with birth control that has become an obsession for some[6] may have created the impression that women reject maternity.

As Hubert Doucet has written[7]: "For sexuality without reproduction, technology has now substituted reproduction without sexuality."

Similarly, as a substitute for meticulous choice of the right moment to have a child, the medical profession proposes induced childbirth. Now more and more babies are born on weekdays and during normal working hours... Surely wagering on nature is something that concerns women and couples as much as it does medicine. We think the medical profession ought to change its tune, that which has traditionally implied domination of women patients. Along with us, it should strive to curb the "logic of desire".

It's also a matter that concerns children, fast becoming products. And that puts the focus on the crucial question of anonymity, the question basic to artificial insemination involving a donor and also to so-called combined artificial insemination, widespread in the United States, the practice whereby donor sperm is mixed with that of the father to create a doubt. This is done after having carefully chosen the sperm of a man who resembles the future social father and after having exacted a promise from the parents to hide the truth from the child. Why concoct and organize a deliberate lie regarding the identity of a human being? Have we forgotten that loss of identity can lead to insanity, that the child who discovers the truth could be ruined for life.

"The lifting of anonymity has the effect of a bomb," a French magistrate said recently. Indeed it has. Up to the present, only Sweden has had the courage to legislate in this area by passing a law on artificial insemination. The CSF believes the Québec Government should do likewise.

Would that put an end to the use

of donors? The Swedish Minister of Immigration and Women's rights, Ms Gradin, points out that sperm banks in Sweden are in no danger of running dry. The new law, however, has reduced the use of donors by 30%. Donors have changed, too, since those who now offer their sperm know they may be identified one day, although they are protected against possible legal recourse with repect to obligations of paternity.

That is the path we ought to envisage in Québec. We ought to recognize the right of every child who is technically conceived or subject to future adoption to know the identity of this biological father and mother. He should also have access to such information in a State register so that he is in a position to exercise that right. That would end the use of unidentified sperm, "made in the USA" or elsewhere. The rule would apply to future adoptions, to AID and IVF, to frozen embryos and to substitute motherhood.

As to the danger of in-breeding, a strict ceiling ought to be set on use of sperm from a given donor and limits clearly defined if we are to avoid the scenario of Dr. Skroda[8].

Legislation is required with respect to frozen embryos, to banks of genetic materials and embryos and to surrogate mother agencies. That is the way to prevent any form of commercialization.

As to the complex problem of surrogate mothers which has received so much attention in the media, we are inclined to share the view of Jurist Catherine Labrusse-Riou who maintains it would be an attack on the social consensus to revamp common law merely to deal with a few problem cases. To legislate in this area, indeed, could violate the fundamental principle that persons may not be the object of contract, proprietorship or barter[9].

Since it is manifest that law flows from community ethics, it is urgent we provide an opportunity for that ethic to surface. That, in turn, means discussion, a debate based on rigorous fact.

By publishing **Dilemmas**, the CSF hopes to further stimulate the debate it has launched in Québec. It also hopes to establish the notion of limit as a key parameter in the development of new reproductive technologies. At the same time, it seeks to challenge notions regarding the ineluctable nature of "progress", to safeguard motherhood and to preserve society from what Elisabeth Badinter, in a Radio-Québec interview, described as "the greatest denial of nature (male pregnancy)".

Free choice, yes. But within the limits of human nature and social conscience, limits that take into account the staggering paradoxes, the dilemmas of mind-boggling proportions and the explosion of our system of values that cloud the issues:

- overpopulation in the South, declining birth rate in the North;
- humanization of childbirth, fore, crumbling motherhood, aft;
- voluntary and premature sterility, then second thoughts and recourse to IVF;
- abortion at street-level, child manufacturing one floor up;
- desperate efforts to discover one's origins and simultaneous attempts to deliberately conceal the origins of artificially-conceived children;
- on the one hand, Pro-Life activist, on the other, supernumerary embryos whose fate is uncertain;
- recognition of paternity in the case of the natural child, deliberate creation of monoparental families (single women resorting to AID or IVF);
- the increasing emancipation of women and, on the horizon, the possibility of "gynocide" (via sex selection);
- impressive charters of human rights alongside biology that can modify the human being and erase the identity so basic to that same being.

Reading **Dilemmas** could inspire you to add to the list.

What's there to lose? What's there to gain in the procration sweepstakes? Judge for yourself. What is certain is that we can't afford to avoid the debate any more than we can seek refuge in ambient pluralism. Human reproduction is too important a matter to be left to technicians alone. In other words, we'll end up with the ethics we deserve.

Francine C. McKenzie
President

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1 The question is raised by Bernard Fonty, a French obstetrician and gynecologist, in *Origines. D'où viens-tu?*, Stock, 1985, p. 171 (*Les cahiers du nouveau-né*, No 7).
2 AFP article, *La Presse*, October 17, 1986.
3 *Les Temps modernes*, September, 1986, No 482.
4 Idem, pp. 8-9.
5 *Le Monde*, September 11, 1986, "*Le non de professeur Testart*".
6 In the sense indicated by Betty Friedan, in *Femmes: le second souffle*, Paris, Hachette, 1982, p. 318.
7 Article in the magazine *Fermières*, October 1985, Vol. 11, No 5.
8 The character Kundera (*La valse aux adieux*), who inseminates all of the women of the city with his own sperm.
9 *Des motifs d'espérer? La procréation artificielle*, p. 148.

Infertility

They want a child.
She seeks fulfillment as a women,
he hopes for continuity.
They want to strengthen
their relationship as a couple.
The desire to have a child is there,
deep-rooted, pervasive,
but elusive.
For various reasons,
like so many other couples,
they find the flesh
and perhaps even the spirit
won't cooperate.
At least for now,
maybe forever.
Infertility?
One has to be certain, discover why,
endeavor to overcome it.
That means taking steps
that are both personal and medical,
constraining and exacting,
steps that, just perhaps,
may lead to achievement of fertility.

The will... but no way

Infertility is hard to live with, hard to understand, hard to deal with. Identified with women more than men, hardly a stranger to sexual behavior and lifestyles, subject to a battery of tests and hormonal treatment, infertility is perceived as an obstacle that must be overcome regardless of cost.

When the dream is unfulfilled

There are 32 of them, varying in age from 21 to 39. Most are married and gainfully employed. Most live in the Montréal and Québec City areas.

Interviewed in the course of a research project, they are asked why they want a child. They reply that they consider motherhood essential to their fulfillment as women. Motherhood is seen as the most rewarding of all forms of self-achievement. "Having children," says one of them, "is sort of a social accomplishment."

For many of these women, the desire to have a child stems from a wish for pregnancy, the physiological symbol of feminity. For others, satisfaction of the husband's desire to have a child may become a personal priority; in such cases, no persuasion is needed.

The notion of maternity is a natural part of the marital relationship and women have no difficulty accepting it since it is coherent with their own desire.

Some regard the arrival of a child as a means of strengthening the emotional bond with their spouse. Others view it as an opportunity to transform the couple into a family.

The child assures continuity. Through the child, values are transmitted and the name of the father or the mother or both perpetuated. The child is someone to love and be loved by.

But the reasons advanced in the survey are not the only ones that make women want children. Nor can they be applied in a general way and without distinction to all women. Elsewhere and in different circumstances, women and couples are likely to express their desire in other ways.

Yet the deep-rooted motivations defined by Québec women largely coincide with feminist analysis of the social and cultural context that surrounds maternity: the close association with the notion of feminity; the intrinsic value of the femal with the notion of feminity; the intrinsic value of the female body that fulfillment of its sexual and reproductive functions implies; the importance of the genetic link with one's descendants. Some women authors suggest the desire to have a child has acquired new significance in the present economic context. The child is increasingly perceived as a consumer product whose acquisition can be planned, programmed to suit parental expectations. The child thus becomes a success symbol, rendered precious by the likelihood couples will have only one.

The will... but no way

Like hundreds of Québec women, the 32 in the survey wanted to have a child or even two, but were unable to do so. They saw it as a personal failure, a defeat. Many thought of themselves as active, determined, persevering — women who roll up their sleeves and get things done. They resented the feeling of impotence that infertility inspired. Others, on the contrary, wanted to become pregnant to prove they could be "successful" at something.

Infertility suggests failure on the part of one's body. It implies failure to enrich one's life, to create a family, to ensure continuity, to enjoy an affective bond with a child.

It also inspires a powerful guilt complex. Use of contraception may be identified as the cause. Or the woman may feel her fear of child-bearing is responsible. Or, as so many claim, that she thinks about it too much. Or too little. It may be a feeling of guilt about the suffering caused to one's spouse, even though he may be the one who's infertile.

Whatever the reason, these women finally decided to undertake and pursue the necessary steps to regain fertility. The survey indicates all frequent specialized clinics where they have been treated for periods ranging from a month to 12 years. Thirteen of them have been seeking help for four years or more. As one put it, "Going to a fertility clinic may not be ideal, but waiting there helplessly is hardly more ideal." ■

Involutary infertility, the one that's hard to take

Some women and some men deliberately choose infertility by undergoing ligatures and vasectomies.

However, as sterility indicates, infertility isn't always a matter of choice. In such cases, hope seems to knock at a door that is tightly locked. Either the woman or the man lacks the necessary reproductive cells and is unable to conceive on his or her own.

For certain cases of infertility, there's a ray of hope: when only one of the partners is infertile, the situation can be rectified if the cause of the incapacity is identified and treated.

Doctors define infertility as failure to achieve pregnancy after 12 months of sexual intercourse. The definition is used to establish that approximately 15% of couples within the reproductive age group have fertility problems.

The definition does not cover the actual capacity to conceive, but rather what is regarded as the "normal" period in which conception should occur. In Europe, the period generally accepted is two years. In fact, demographic studies indicate pregnancy does occur within a period exceeding a year in the case of 20% of couples who wish to conceive. The probability is even higher in the case of women who previously resorted to anovulants.*

Many causes account for infertility.

* ROCHON, Madeleine, *Stérilité et problèmes de fertilité*, Études de santé, Ministère de la Santé et des Services sociaux, January, 1986, 16 pages (unpublished text).

Marc Lajoie, ministère des Communications

Some women suffering from infertility seem to regard it as their responsability to undergo investigational and medical treatment.

In women

Infertility factors are more prevalent in women (60%):

- ovulatory factors: anovulation, glandular troubles (thyroidal, hypophysis, adrenalitis);
- tubular factors: absence or obstruction of one or both tubes accounts for 30 to 40% of infertility cases. Sexually-transmitted diseases are particularly damaging: gonorrhea, chlamydia causing Fallopian salpingitis. Endometriosis is another cause: the presence outside the uterus of endometrium, the mucus from the inside wall;
- uterine factors: anomalies of the uterus;
- cervical factors: inflammation of the cervix; rejection of spermatozoa by the cervical phlegm (the secretion produced by the cervix).

In men

Forty per cent of infertility cases are attributed to men. Causes are:

- diseases of a genetic nature;
- testicular diseases;
- troubles of the endocrine glands;
- varicocele: dilation of spermatic cord vessels that impedes production and mobility of spermatozoa;
- ejaculation difficulties or impotence, frequently due to environmental problems or drugs;
- regressive ejaculation: when the sperm is emitted into the bladder instead of outward;
- absence or blockage of vas deferens due to venereal infection. ■

Knowing why

The couple consulting a fertility clinic must undergo different tests designed to pinpoint the biological factors that prevent conception. Such tests are known as the investigational phase. The couple must also provide the doctor with all relevant facts: background, diseases, personal habits, work environment, sex life.

Complexity of the tests varies with men and women.

The man must furnish a sample of his sperm so that the number, the mobility and the quality of the spermatozoa can be checked in a laboratory.

The woman must submit to more numerous and more exacting tests:

- temperature curve: basal temperature must be recorded each morning and a curve established for each menstrual cycle. The curve makes it possible to determine if the cycle is long enough, if ovulation is normal and when it occurs. Sexual intercourse must take place on days appropriate for fertilization. A key control tool, the temperature curve also serves to fix appointments at the clinic

for tests that must occur at a specific point during the cycle;

- Radiographies of the uterus and Fallopian tubes: injection of a coloured liquid makes it possible to determine if circulation is normal in the tubes through which ovule and spermatozoa must pass. The test is known as hysterosalpingograms.
- uterotubal insufflation: a stethoscope is used to ascertain if air circulates freely in the Fallopian tubes, thus detecting possible blockage;
- post-coital test: several hours after sexual intercourse, cervical viscosity is checked to evaluate the survival rate of spermatozoa and detect possible presence of antibodies;
- an endometrial swab (from the inside wall of the uterus) is analyzed to determine if a fertilized egg is likely to implant itself. The procedure is known as endometrial biopsy;
- a laparoscopy, which requires general anesthesia, involves insertion in the abdomen of a long tube with a fibre-optic telescope for examination of the uterus, the Fallopian tubes and the ovaries and diagnosis of possible endometriosis. ■

The treatment: on the wings of faith and hope

Either by chance or as a result of the stimulation induced by certain examinations, some couples achieve the desired pregnancy during the investigational phase. For the others who decide to go on, the treatment will vary, depending on the cause of infertility detected in either partner.

For the men, antibiotics and surgery

Sometimes it is impossible to identify the causes of infertility in men; in other cases, no medical treatment is available. Such individuals make up 50% of men who, in the light of present knowledge, have almost no hope of becoming fertile again.

Antibiotics will be prescribed when venereal disease is identified as the source of the problem. Surgery may be suggested in other cases to correct varicocele (success rate: 50%) or to unblock the vas deferens.

For women, hormones and surgery

Hormonal treatment can resolve or reduce certain causes of infertility in women, such as anovulation and endometriosis. The five types of hormonal treatment designed to stimulate ovulation necessitate methodical control. Resumption of ovulation is frequent and there is a possibility of multiple pregnancy.

Surgery of the Fallopian tubes is designed to increase permeability reduced by ligature, inflammation or endometriosis. (The success rate varies from 10 to 90%, depending on the case and the technique used). Surgery is also used to correct malformation of the uterus. ■

"They don't call us patients for nothing"

She has undergone 17 endometrial biopsies in eight years. So she knows what it's all about when she refers to the pain involved (in tubal insufflation and laparoscopy) and to the patience required by the women.

Not all women have chalked up such records, but many do undergo certain tests more than once. That means being available. "I'm always in the doctor's office," said one of them. To be available, some quit a full-time job and take on part-time work; others forego sick leave to compensate for the time spent in clinics.

Keep the thermometer handy

When the thermometer is the first thing you see when you wake up every morning for six months, a year, even two, you soon think of chucking it out the window.

When you must have sexual relations whether or not you're in the mood, satisfaction tends to take a back seat. At the clinic, it will be noted that you made love and at what time you did so. It will also be decided if you did so efficiently. Result: stripped of all intimacy, sexual relations become trite.

It's just like the temperature-taking. You have to motivate yourself day after day.

The highs and lows of wanting a child

The testimony of the 32 women indicates that the desire to have a child is stable or more intense at the start of the testing period, when treatment actually begins and even throughout the process if treatment lasts only a limited time.

On the other hand, desire recedes, sometimes giving way to second thoughts, when the diagnosis is pronounced, during periods of routine or prolonged examination or treatment, or following a particularly painful operation.

Claire Dufour

The thermometer and a temperature graph, there to greet you every morning during the investigational phase.

Whether desire increases or diminishes, the treatment becomes a part of daily life. How can one forget it with all those appointments, the programmed lovemaking, the nausea and headaches produced by the hormones? With the stress that precedes the operation and the pain that follows? Not to mention moments of discouragement one's partner may not always understand. Yet, in spite of it all, hope persists.

The changes in social life and professional life

Women who participated in the CSF survey agree that the problem of infertility substantially alters one's social life.

Some women isolate themselves. Others avoid visiting friends who have young children, pregnant women, a brother-in-law with a warped sense of humor, a mother-in-law who is either over-protective or gossipy.

Some women do the opposite. They endeavor to strengthen ties with in-laws, a sister or others whose help they find comforting.

In a word, the survey indicates social relationships are called into question during the infertility crisis. Friendships can be broken up or efforts made to preserve or strengthen them or perhaps to establish new ones.

The professional lives of infertile women also undergo change: renewed interest in a career as a means of self-achievement may appear as a fallback solution to infertility. Studies or jobs may be abandoned or employment changed and schedules reorganized.

Life is never quite the same when infertility gets in the way. ■

The situation in Québec

Québec has a total of 11 infertility clinics (A), nine birth control clinics in hospitals (B) and 26 in CLSCs (C) which also offer infertility services. Following are the resources available according to region:

Bas-Saint-Laurent—Gaspésie

B- Centre hospitalier Saint-Joseph, Rimouski
Hôtel-Dieu, Gaspé
Centre de santé de l'Archipel, Îles-de-la-Madeleine

C- Centre local de services communautaires (CLSC) des Chaleurs, Paspébiac
CLSC de la Saline, Chandler
CLSC de Matane, Matane

Saguenay—Lac-St-Jean

A- Hôpital de Chicoutimi

C- CLSC Saguenay-Nord, Chicoutimi-Nord
CLSC des Prés-Bleus, Saint-Félicien
CLSC des Grands-Bois, Chapais

Québec

A- Centre hospitalier de l'Université Laval, Québec
Hôpital Saint-François d'Assise, Québec

C- CLSC Saint-Marc, Saint-Marc-des-Carrières
CLSC Basse-Ville, Québec
CLSC des Frontières, Saint-Eleuthère district, Pohénégamook

Mauricie—Bois-Francs

B- Centre hospitalier Sainte-Marie, Trois-Rivières
Centre hospitalier régional de la Mauricie, Shawinigan

Estrie

A- Centre hospitalier de l'Université de Sherbrooke, Sherbrooke

Montréal

A- Hôpital Saint-Luc, Montréal
Hôpital Sainte-Justine, Montréal
Hôpital Maisonneuve-Rosemont, Montréal
Royal Victoria Hospital, Montréal
Hôpital Sacré-Coeur, Montréal
Hôpital Notre-Dame, Montréal
Queen Elizabeth Hospital, Montréal

B- Hôpital général Lasalle, Montréal
Cité de la Santé, Laval

C- CLSC Montréal-Nord, Montréal
CLSC Centre-ville, Montréal
CLSC du Marigot, Pont-Viau
CLSC Métro, Montréal
CLSC Pierrefonds, Pierrefonds
CLSC Sainte-Rose, Laval
CLSC Lamater, Terrebonne
CLSC Sainte-Thérèse, Sainte-Thérèse
CLSC Saint-Hubert, Saint-Hubert
CLSC Richelieu, Richelieu
CLSC Longueuil-Est, Longueuil

Outaouais

C- CLSC de Hull, Hull
CLSC des Draveurs, Pointe-Gatineau
CLSC Petite-Nation, Saint-André Avellin
CLSC Vallée de la Lièvre, Buckingham
CLSC La Désert, Maniwaki

Marc Lajoie, ministère des Communications Concept: Diane Dubé

The RAMQ pays for diagnostic and surgical acts related to infertility, but the infertile woman must assume the cost of prescribed hormonal treatment.

Abitibi—Témiscamingue

B- Centre hospitalier Saint-Sauveur, Val d'Or
Centre hospitalier Rouyn-Noranda, Rouyn

Côte-Nord

B- Hôpital de Sept-Îles

C- CLSC Basse Côte-Nord, Blanc Sablon

Services available

Infertility clinics generally have the personnel and the equipment needed for all tests designed to identify the cause of infertility and to provide the various types of treatment.

Birth control clinics in hospitals offer basic examinations and certain types of treatment: hormones, antibiotherapy, homologous insemination (with the sperm of the spouse). When surgery is required, men are directed to the urology department, women to the gynecology and obstetrics department.

CLSC services are limited to information and physical examination. Treatment then is carried out in an infertility clinic.

Diagnostic acts

In 1981, the Régie de l'assurance-maladie du Québec (RAMQ) recorded many thousands of diagnostic acts related to infertility:

- 5 341 hysterosalpingograms[1]
- 12 144 laparoscopies[2]
- 9 859 endometrial biopsies[3]
- 6 753 post-coital tests[4]
- 5 130 spermiograms

Surgical acts

In the year 1983-84, 890 men and 1 807 women afflicted with infertility underwent different surgical procedures in Québec. In both cases, the majority of operations involved persons ranging from 25 to 34.

Costs of surgery are assumed entirely by the Government. The Régie de l'assurance-maladie paid $600 000 in medical fees in 1983-84. Women accounted for 75% of such costs.

Hormonal therapy

A prescription is required for hormonal treatment. The woman seeking such treatment assumes the cost. Treatment with clomiphene, the least expensive hormone, costs $25 to $125 per cycle. It may be required for three or four cycles. ■

1 Although hysterosalpingograms are used to diagnose other health problems as well, cases of infertility are believed to account for their use 90% of the time.

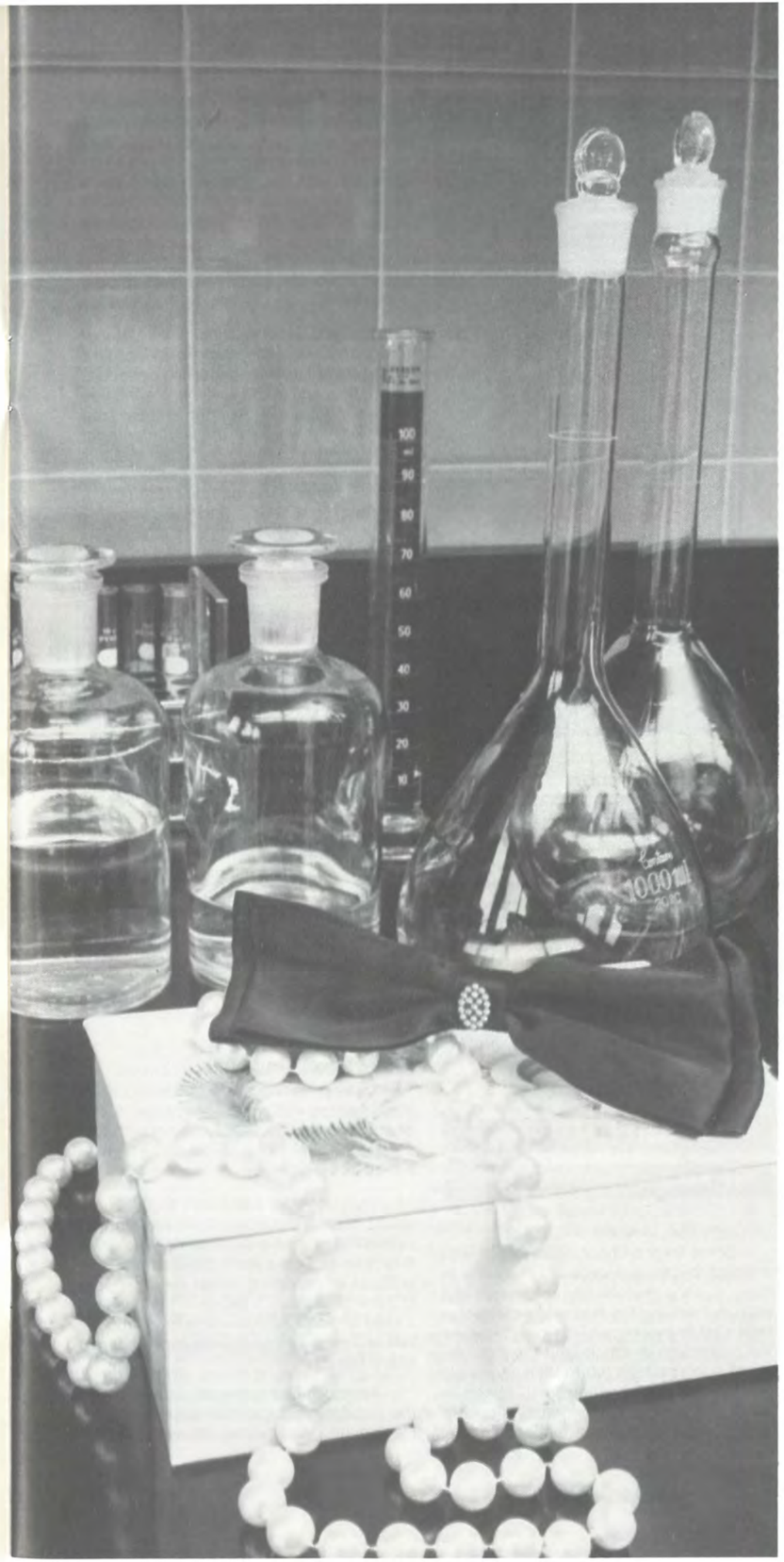
2 Laparoscopy also is used in diagnosis of other pathologies.

3 Endometrial biopsies are practised both on women suffering from infertility or experiencing menopause.

4 The post-coital test is used only in cases related to problems of fertility. A couple may have to undergo the test several times.

Marc Lajoie, ministère des Communication Concept: Diane Dubé

"In the final analysis, I want a child because I want to experience pregnancy."



New reproductive technologies

**Examinations,
surgery and hormones,
hope... then disapointement.
It's a long road
that leads to the child.
How far should a couple go
when unable
to achieve the objective
on its own, naturally?
Science has a solution:
for the ovule and the sperm,
a new sort of blind date,
a high-tech rendez-vous
in a glass décor
where the anonymous father
or a temporary female guest
can be on hand
for the birth
of the desired child.
What if there's no child?
Well, you can say
you tried to the bitter end.
At no little cost
to your heart
and your body.**

Artificial insemination, more complex than it seems

Technically speaking, artificial insemination is simple, whether the husband's sperm or that of a donor is used. But a closer look at the technique raises a number of questions.

When it's due to him

Artificial insemination, the method used to offset male infertility, calls for the deposit of good-quality sperm in a woman during her fertile period. In Québec, only doctors are allowed to practise it.

The husband's sperm can be used if, for one reason or another, his spermatozoa fail to reach the egg in the course of sexual relations. It may be there are insufficient spermatozoa or they lack the required mobility. The malformation count may be too high. Or it may be due to precocious ejaculation or poor volume, to anatomical or congenital anomalies. Or the man may be impotent. In such cases, either through masturbation or withdrawal from the urine (in regressive ejaculation), a sufficient quantity of spermatozoa is collected and deposited in the cervix or in the uterus itself. Artificial insemination with the husband's sperm or that of a donor apparently produces no side effects.

Recourse to a donor

If the husband is sterile or suffers from a congenital disease likely to be transmitted to the child, the couple may have recourse to a third person who donates his sperm for insemination.

Given the widespread impression that fertility symbolizes virility, recourse to a donor may present problems for the spouse. It's a consolation to know, however, the child will have a genetic link with the mother (''We're better off having one that has your half rather than a complete stranger'') and may resemble the social father. In fact, when circumstances permit, efforts are made to find a donor with similar physical characteristics.

Portrait of a donor

The donor is usually rigorously selected by the doctor. Most donors are recruited among medical students or the staff of health establishments. A donor must meet a number of medical requirements: a genetic history without blemish, absence of venereal disease, etc. He must also undergo psychological evaluation, furnish all available information on his state of health. Participation is on a voluntary basis and he can withdraw from the program whenever he chooses. His expenses are reinbursed when his services are required. ■

For? Against? Yes, but...

Some favor artificial insemination with a donor because it allows the couple to have a child biologically related to the woman, because the husband's consent is regarded as evidence of his love, because the procedure is simple and the probability of success high (60 to 90% in the six consecutive cycles when fresh sperm is used), because the experience is said to strengthen the couple's relationship.

Arguments against artificial insemination are numerous, too: third-person involvement may jeopardize a supposedly exclusive relationship; absence of a biological link with the husband; the donor's anonymity, perceived as his refusal to accept parental responsibility and a violation of the rights of the child conceived with his sperm; finally, subordination of the child's interest to the parents' wish to have a child.

Artificial insemination with a donor (AID) has been the subject of studies, analyses and recommendations by specialists and many committees in Canada as well as in Australia, Sweden and Switzerland. Having weighed the arguments for and against AID, they concluded that it is morally acceptable within certain limits which safeguard the interests of the child. the donor, the couple and the doctor.

Is Lucie really Robert's daughter?

Lucie is born during the marriage of Robert and Michelle or within 300 days of dissolution or annulment of their marriage. Legally it is presumed that Robert, as Michelle's husband, is the child's father. However, he can always disavow the child before the courts or Michelle can contest his paternity. Yet, since Lucie was conceived by artificial insemination, the Québec legislator considers either recourse unacceptable on the grounds Robert and Michelle had given their consent for the treatment. The presumption, therefore, is that Robert is Lucie's father, whether his sperm or that of a donor was used for conception. That's how the Québec Civil Code sees it.

Elsewhere, however...

To resolve case similar to Lucie's, study groups in England, Australia, Sweden and certain Canadian provinces have called for legislation which would recognize the child's legitimacy.

They consider it aberrant that the law would make a distinction between a child conceived naturally by parents who give their love and care and a child born out of artificial insemination. What society does to cement the family group in the case of a child artificially conceived is more important in their view than the defence of hereditary lineage.

American law generally is based on the principle that the child born of AID is illegitimate. Many states, however, have legislated to give formal recognition to the child's legitimacy in cases where the husband has consented to the treatment. ■

Access to AID: a matter for the couple

The technique of artificial insemination with a donor theroretically enables divorcees as well as single heterosexual and homosexual women to carry a child.

In practice, however, the single woman has little access to AID. In Australia, for example, it has been suggested that recourse to AID be restricted to married women or to women living in a stable common law union with a man who has consented to artificial insemination with a donor. In Sweden, psychosocial examinations are recommended for prospective parents, whether married or in a common-law relationship. A report published in British Colombia refers to the recipient ''couple''. In Ontario, while single women deemed stable have access to AID, the study group which looked into the matter agreed with other national committees that the child's best interest is served by a two-parent family.

For the time being, therefore, AID generally is available only to stable heterosexual couples. Two Québec centres, however, do not require the presence of a spouse. ■

The question mark in the family tree

The man suffering from infertility in a couple desirous of a child becomes the legitimate and social father when there has been due consent in the case of a child born out of heterological artificial insemination.

The biological father is the fertile man who agreed to donate his sperm to a woman who is unknown to him, allowing her to conceive a child.

As matters now stand, however, the donor is father only by definition. He has donated his sperm and passed on his genetic stock anonymously. The infant conceived with his sperm is unknown to him and he is unknown to the infant whose mother was able to conceive because of the man's donation.

Marc Lajoie, ministère des Communications Concept: Diane Dubé

Anonymity is sometimes seen as expressing the donor's refusal to accept parental responsibility and as a violation of the rights of the child conceived with his sperm.

Anonymity is the rule in Québec and donors frequently make it a condition of participation, limited to conception of a maximum of 10 children.

The right to know one's origins

The requirement of confidentiality as to the donor's identity negates the child's right to be aware of his origins.

The Conseil du statut de la femme (CSF) contends that such right exists and the child should be able to exercise it upon attainment of majority. In a brief presented to an interministerial committee on research concerning socio-biological origins, the CSF proposed legislation to this effect which would apply to AID and to future adoptions.

Sweden has already taken such steps. Since 1985, individuals conceived be heterological artificial insemination enjoy the right, once they become adults, to know the name of their biological father. Studies show adopted children experience a strong need to know their origins and the possibility of obtaining such information is an important factor in their development. Swedish legislators decided children conceived by artificial insemination have similar needs. ■

Sperm banks: the cold detour[1]

Does the husband want to ensure that, even after his death, his sperm can be used to conceive a child by artificial insemination? Would he like to preserve his capacity to procreate in the event its's threatened by treatment for cancer of the testicles? And, in order to avoid transmission of sexually-related diseases such as haemophilia which strikes only male children, should one not be allowed to select from among the spermatozoa?

Science has come up with the answer: frozen sperm. Kept in a bank specially set up for that purpose, the frozen sperm can be used whenever needed.

The first sperm banks were established in France in 1973. Today the *Centre d'étude et de conservation du sperme humain* is a network of 15 establishements. It has acquired a vast experience in the management of frozen sperm banks and in the distribution of sperm samples to French doctors.

In 1975, the Ontario Law Reform Commission recommended that establishment of sperm banks be authorized and that they be allowed to operate on a commercial basis under license and strict regulations. The same commission recommended that importation of human sperm be allowed.

In British Colombia, the report of a consulative committee on the stockage and use of human sperm made known its opposition to such imports, but expressed the hope federal norms be established for Canadian sperm banks which would set a ceiling, among other things, on the freezing period.

In Québec, there are sperm banks at the Maisonneuve-Rosemont and Sacré-Coeur hospitals. ■

Artificial insemination in Québec

Insemination with donor sperm is available at:

1 Postel-Vinay, Olivier, *Les enfants du froid, Science et vie*, No 805, 1984.

- infertility clinics listed previously;
- two birth control clinics, the Centre hospitalier de Rouyn-Noranda and the Cité de la Santé in Laval

According to these clinics, donors receive from $25. to $50. each time their services are required. The total cost, assumed by the couple requiring such assistance, usually amounts to $200.

Recruiting of French-speaking donors appears to be more difficult than that of English-speaking ones.

Homologous insemination

In Québec, insemination with the spouse's sperm is available at:

- infertility clinics;
- birth-control clinics;
- doctors' offices.

78% increase in five years

From 1979 to 1984, the Régie de l'assurance-maladie du Québec paid for 34 505 cases of artificial insemination throughout Québec. The figure does not indicate the number of women who resorted to the technique, but the number of inseminations actually carried out. The average number per woman is 8 or 10. ■

In vitro fertilization: the test-tube relay

In 1978, Louise Brown, the first baby ever conceived in vitro, was born in England. The Americans "produced" their first infant in 1981, the French in 1982. The same year, twins were born in Canada. And Québec made it in 1985. Now there are almost 2 000 children in the world who were conceived that way. It's precious little, considering the research, the time, the money and the hope invested. But it's a lot as well, considering society still hasn't weighed the pros and cons.

Alpha Diffusion

Amandine, the first French baby born via in vitro fertilization and embryo transfer.

Surprise!

An American sued his ex-wife and the University of Pennsylvania Hospital, alleging that sperm samples funished before the divorce were used subsequently without his consent for the artificial conception of a girl, now one year old. His suit also called for lifting of a court order that makes him provide financial support for the child he apparently didn't desire. Toronto Star, *July 5, 1986.*

Help in conceiving

When a woman's body resists natural fertilization, either because of irreparable blockage of the Fallopian tubes or sterility of undetermined origin, the mating of ovum and sperm can be stimulated artificially outside the natural fertilization environment.

The high-tech rendez-vous takes place in a test tube under the watchful eyes of gynecologists, biologists and specialized technicians.

In vitro fertilization (IVF) involves five steps:

1. **Hormonal treatment** — to ensure an adequate production of eggs by the ovary, intensive hormonal treatment is effected daily.

2. **Extraction of eggs** — a needle is inserted in the ovarian follicle through the abdominal lining to recover the required eggs. Until recently, laparascopy was used for the extraction, necessitating general anesthesia.

3. **Sperm recovery** — the spouse provides a sperm sample whose fertilizing capacity is maximized in the laboratory.

4. **Mixture of eggs and sperm** — the reproductive cells are placed together in an environment suitable for fertilization.

5. **Embryo implantation** — if fertilization has occurred and the embryos are healthy, they are introduced into the womb through a catheter. To improve chances of success, more than one embryo is implanted. This may result in multiple births.

At one stage or another, the treatment may have to be abondoned by the couple, usually the woman. When hormonal stimulation proves unsuccessful, fertilization fails to take place or the embryo does not implant itself, there is no hope — unless the couple is prepared to start all over again.

Other scenarios

In vitro fertilization can also take place with reproductive cells other than those of the woman who wants a child. When she is unable to produce the ova or when she is fertile but stricken with a genetic disease, the eggs of another woman may be used in one of the following scenarios:

- the donor's eggs are extracted, fertilized in vitro with the sperm of the man seeking paternity, then implanted in the womb of the infertile woman. If the spouse is himself infertile, sperm of a donor can be used.
- the woman donor is inseminated with the sperm of the spouse or that of a donor. When fertilization occurs, the embryo is transferred a few days later to the womb of the infertile woman so that it can implant itself.
- the egg of the fertile woman it transferred to the sterile woman, then fertilized by the sperm of the spouse or that of a donor.

Not a painless process

In vitro fertilization involves a complex series of operations which may have to be repeated if they fail the first time. In her book, *The Mother Machine — Reproductive Technologies from Artificial Insemination to Artificial Wombs,* the American author Genoveffa Corea describes the following risks, based on studies and the experiences of recognized specialists:

- hyper-stimulation of the ovaries can produce cysts;
- the dangers of general anesthesia (used in laparascopy) and the possibility of ovarian trauma;
- a higher rate of miscarriages and multiple births; the danger of ectopic pregnancies (outside the womb), of abortions provoked by examinations (ultrasound and aminocensis carried out during pregnancy);
- the possibility of anomalies in the chromosomic makeup resulting from hormonal stimulation or manipulation of the egg and embryo. ■

From one technique to another

In the upheaval engendered by new technologies of human reproduction, the questions raised by the practice of in vitro fertilization and the arguments put forward by opponents and advocates alike strongly resemble those frequently associated with discussions on artificial insemination.

Alpha Diffusion

In vitro encounter of sperm and egg.

For example, like artificial insemination with a donor, recourse to in vitro fertilization is usually proposed to married couples only. But the College of Obstetricians and Gynecologists in Britain goes a step further: it recommends that single women be given access to IVF, but only in exceptional circumstances to be determined by a doctor.

Religious groups tend to regard both techniques as immoral since they are seen as upsetting the natural order, endangering the family and separating the procreative and conjugal aspects of marriage.

The arguments for and against the donation of sperm can be applied to a large extent to egg donation as well. The latter is justified on the grounds that, notwithstanding the intrusion of a third person, the spouses contribute directly to the birth of the child, the man by providing the sperm, the woman by carrying the fetus. Arguments against egg donation stress the risks extraction involves for the woman.

Questions dealing with the selection of female donors, anonymity and consent are equally relevant with respect to in vitro fertilization. The need for legislation to safeguard the child's status appears evident.

But here analytical comparisons end between artificial insemination and in vitro fertilization. The latter technique raises a number of specific questions rarely mentioned in media reaction to IVF births. ■

Success story

For the Jacobssen couple, fertilization in vitro worked so well there are now seven in the family: their five sons were born prematurely be caesarean March 26, 1986. La Presse, *March 30, 1986.*

Somewhere in bank lies a waiting embryo

Several embryos are produced by in vitro fertilization of ova. Some find their way into a womb where they will become a fetus. Then there are the others... What should be done with embryos that aren't reimplanted? Should they be frozen for implantation later in the same woman or in another woman? Ought they be used for experimentation? To ask such questions is to beg another, the most basic of all: when does human life begin?

Wanted: a status

Scientific, religious and philosophical opinions regarding IVF differ from those expressed in the debate on abortion. Some argue the embryo is a human being or potentially so, not raw material. Others maintain the embryo is neither a person nor a potential person but rather a mass of cells which, unless implanted in a human uterine environment, has no potential for development.

The law offers a certain degree of protection for the embryo and the fetus. In Québec, the infant who is conceived but not yet born is considered a person when his interest is at stake — on the condition he is born alive and capable of living.

Thus the fetus enjoys a legal existence conditional on birth and viability. Our legal system, however, makes no provision for the juridical and ethical questions raised by new technologies. The Commision des droits de la personne du Québec has recommended that the Québec legislator amend the Civil Code to include provisions covering the prenatal condition.

The status of the embryo is a sensitive issue. Yet it will have to be dealt with some day because science which moves along so swiftly has made time of the essence.

For embryos-in-waiting, a cold country indeed

Freezing of embryos "produced" during in vitro fertilization is now a reality. When a first IVF attempt fails, technique makes it possible to avoid laparascopy and proceed with a new implantation during a more favorable cycle.

But suppose the woman or the couple refuses to try again. The embryo created by their cells will wait there, frozen, in a specialized bank. Who owns an embryo abandoned by the parents or one whose parents die? Should it be destroyed? Should it be given up for adoption to other parents or kept for research? Does it have any right to the legacy of the biological parents? The freezing of embryos can modify generations: notions of age, of parental links, of birthright can all lose their present meaning.

The unknown effects of long-term freezing and the difficulty of resolving the related moral and legal issues underscore the need to set a limit as to the time embryos can be kept frozen. In Australia, the National Health and Medical Research Council has recommended a limit of 10 years and means to respect the wishes of the donors of gametes. In Ontario, it has been suggested conservation be reviewed every five years. In Great Britain, a limit of 12 months is favored by the British Medical Association while the College of Obstetricians and Gynecologists, without suggesting a specific period, believes a limit ought to be established and a specific objective set, say a second pregnancy for the same couple.

Alpha Diffusion

Embryo implantation in the womb of an infertile woman.

Experts insist on the power of decision-making as to the fate of supernumerary embryos must rest with the couple which provided the gametes. Should one of the two die, the survivor would decide; should the two die or in the event of disagreement, the decision would be made by the institution or the attending physician.

Discovering the embryo's secrets

Utilization of the human embryo for research purposes would help to improve IVF effeciency and contribute to a better understanding of infertility, embryonic development, and fertilization and implantation procedures. It would certainly prove useful to researchers and couples afflicted with infertility, but the fundamental question concerning the status of the embryo would remain unanswered. Depending on the nature of the safeguards provided, should research be allowed or not? Generally speaking, study groups throughout the world believe general prohibition of research on the human embryo would not be justified. They suggest it be allowed under certain conditions, including consent of donors and establishment of limits to embryonic development.

Somewhere in a bank, a frozen embryo is waiting. ■

Getting a head start

In Australia, a new method of in vitro fertilization enabled a 29-year-old woman to give birth to twins. Dr. Christopher Chen explained that three eggs had been extracted from the mother, frozen, later unfrozen for fertilization and reimplanted. Two of the fertilized eggs survived. Dr. Chen believes the new technique resolves ethical problems created by the freezing of embryos. La Presse, *July 5, 1986.*

An opportunity and new risks

The very existence of the IVF technique puts implicit pressure on women who might otherwise have to abandon the search for fertility.

Of the 32 women interviewed in the survey of the Conseil du statut de la femme, those who had recourse to in vitro fertilization said they had made up their minds about it a long time ago. Their doctors didn't have to persuade them since they saw the treatment as a marvellous opportunity. Some had reluctantly accepted their condition of infertility, by found their guilt feelings rekindled by development of the IVF technique.

"I was afraid of feeling badly afterwards, of having to start all over again, but the feeling that 'maybe...' proved stronger... I wanted to try, but I was afraid... It was as if I had lost 2 000 pounds. I never felt lighter in my life. I had gone as far as I could... I did everything humanly possible."

Regardless of the low rate of success, it appears difficult not to imagine that one might be the exception for whom IVF will achieve the desired pregnancy.

"I was convinced it would work for me. And I'm stubborn. I said to myself, 'It works for one out of 20 women in Québec. I'm going to be that one'."

They wanted the treatment so deeply doctors did not have to pressure or even encourage them. Such acceptance obviously facilitates the task of the medical team. Is that why certain "good" candidates were accepted for second, third and even fourth attempts without the least suggestion that take the time to think about it?.

"He didn't have to ask, 'Would you like to try again?' Not even that. It was I who told him I wanted to start all over again the following month. He merely said, 'Fine. You're not on a waiting list. Just drop in three days before and we'll give you a prescription'."

Yet the woman had found the IVF experience trying.

"I was sure it would work. When he told us it hadn't worked, the roof caved in... I found it extremely difficult to pull myself together."

No one seemed concerned about the physical and emotional condition of another woman who, when IVF treatment failed at the hormonal stage, tried once again right after her menstrual period. During the new attempt, four fertilized eggs rather than three were reimplanted with her consent.

"We signed the papers agreeing to take the risk. They said it would improve the chances of success considerably. We were pretty confident it would work, but again it failed."

At the time of the survey, she had made up her mind to try once more. They had told her again the probabilities would be better than ever.

Tails, you lose

So the "marvellous opportunity" that IVF is seen to represent is not bereft of risk or difficulty: side effects, the possibility of multiple births, the need to be available during treatment, the costs involved, the hope at each suspenseful stage.

IVF is almost at the end of the road. Before it, the futile sexual relations, the many examinations, other treatments that have led nowhere. During IVF, either the desired pregnancy or failure. After it, the fetus that must be carried until birth or the difficult acceptance of the reality one will never conceive a child, either on one's own or with the help of others, however specialized they may be. ■

Alpha Diffusion

The embryo is progressively withdrawn from the azote in which it was frozen. The status of remaining embryos raises many questions.

It beats hypophysis

During a meeting of French ovulation specialists, it was explained that use of the hormone DRTP6 makes it unnecessary for IVF teams to wait until hypophysis sets off ovulation naturally. Now it can be programmed regardless of the woman's normal cycle: extraction of eggs at the beginning of the week, fertilization in a test tube, implantation of the embryo at week's end. "The result: better planning, reduced operating costs. (It is possible to close down on Saturday and Sunday, leaving only one doctor on duty)." Unfortunately, however, the alphanumeric hormone still costs a lot of money. Parents, *August, 1986*

In vitro fertilization in Québec

Four specialized hospital clinics provide in vitro fertilization as a palliative for infertility:

In Montréal

The Queen Elizabeth Hospital
L'hôpital Maisonneuve-Rosemont
L'hôpital Saint-Luc

In Québec city

Le Centre hospitalier de l'Université Laval (CHUL)

The CHUL infertility clinic is the most important in Québec in terms of IVF services. There the first pregancies were achieved and there, too, the first test-tube baby was born in 1985 after six years of research on humans.

IVF, a matter of money

Access to the treatment is generally limited to married couples who can afford it. In one clinic, the treatment costs $1,000. and hormones cost another $500. Travel and bed and board for two or three weeks make it more costly for women who live outside Québec city and Montréal. Couples assume only direct costs. Other operations related to IVF such as laparascopy are billed to the RAMQ.

Regulation

The practice of fertilization outside the woman's body is subject to no specific legal restrictions or control mechanism. Ethics committees in hospitals are consulted only when called upon to review research projects for the purpose of grants. ■

Surrogate mother: for the duration... of the pregnancy

It's quite a favor asking another woman to carry the child one can't or chooses not to carry. It's also quite a commitment for her to make. And it's likely to be quite a task for the child to accept the very special circumstances of his conception and birth.

Alpha Diffusion

Paris, July 22, 1985 — Left to right, Mireille, the adoptive mother; Dominique, the surrogate mother; and the latter's husband, Jean-Luc, during labor. The young woman had been inseminated with the sperm of Mireille's husband.

The third person

Many reasons prompt couples to ask another woman to help them achieve the pregnancy they desire. A woman may want a child, but is physiologically unable to carry one and give birth. She may be fearful of transmitting a hereditary disease or too impatient to accept the long adoption process. Or it may be that, for personal reasons, she's unwilling to carry the child.

Once formal agreement is reached, the surrogate mother will be artificially inseminated with the sperm of the woman's husband, carry the baby and, at birth, hand him over to the couple. Her contribution is important: not only does she participate in conception, but she also goes through the pregnancy and labor.

She may be required at times to agree to implantation in her uterus of the embryo resulting from the natural or artificial mixture of the couple's gametes (in cases where the infertile woman is nonetheless able to produce the egg). Here, again, she will be called upon to assume the pregnancy, give birth to the child and hand him over to the couple who wanted and paid for him.

Recourse to a substitute mother is perceived by the couple as having a marked advantage over adoption since either the man or the woman, or both, will have a genetic link with the child.

Who are these surrogate mothers?

In the United States, Dr. Philip J. Parker carried out a study in 1983 among 125 candidates for surrogate motherhood. It revealed that most were married, had experienced at least one previous pregnancy, minimized their genetic contribution as substitute mothers and wanted payment of at least $5 000. For 89% of the women, receiving payment was essential, but it wasn't everything. The psychological motivation was also important. Some wanted to fulfil the couple's wish for a child. For others, consciously or otherwise, it helped overcome regret over an earlier abortion or perhaps over abandonment of an infant.

Once recruited by an agency or a lawyer, future surrogate mothers, similarly to sperm donors, must undergo various examinations and physical, psychological and intellectual tests designed to evaluate their motivations. Unlike sperm donors, however, that is when their real commitment is made.

Surrogate mothers in Québec?

Little information is available on the incidence of substitute motherhood in Québec. It is known there are infertile couples anxious to have recourse to surrogate mothers, women prepared to accommodate them, individuals willing to serve as intermediaries, but as yet no specialized agencies. ■

Motherhood in the market-place

The commercial aspect is probably the most controversial question raised by this new form of maternity.

Is the sum of $5 000, $8 000 or even $25 000 the sales price of the child or the price to purchase her consent to adoption? Is it payment for services rendered and reimbursement of her expenses?

A new market has come into existence. In several countries, agencies specialize in the recruiting of potential substitute mothers and act as intermediaries between them and the couple seeking a child. In Paris, it's the Association nationale pour l'insémination artificielle par substitution; in Marseille, Mères d'accueil; in London, Miracle Program Incorporated. Some lawyers individually also offer such services.

Complicated contracts spell out conditions of the agreement between the substitute mother and one or both members of the couple. After all the negotiations, analysis, sharing and payment, what remains of motherhood?

And what remains of certain value when the child, notwithstanding good intentions all around, becomes a commercial object? ■

Just sign here

to become father and mothers*

On the contract that details rights and obligations of the parties, there may be two signatures (that of the husband in the child-seeking couple and that of the surrogate mother) or perhaps three (that of the future social mother if she furnished the egg).

The signature of the substitute mother means she has agreed to a long list of conditions:

- to submit to medical examinations before and during pregnancy;
- to be inseminated with the sperm of the spouse (or that of a donor, which hardly simplifies matters) or to receive the fertilized egg;
- to forego sexual intercourse during the period of artificial insemination;
- to behave in a manner that will ensure healthy development of the child (proper nutrition, exercise) and to give up her right to abortion unless required for health reasons;
- to accept any operation deemned necessary by the medical team, including a caesarean;
- to give birth, to recognize as the father the man who has signed the contract and to consent to adopton by the social mother.

If the surrogate mother is married, her husband will have to agree not to claim paternity rights. He will also have to agree to examinations after the child is born to avoid ambiguity as to the paternity.

The couple commits itself to take the child and to pay the agreed amount.

And what if someone has second thoughts?

The surrogate mother may change her mind before insemination, during pregnancy or after the child is born. In such cases, the father may have no recourse other than to demand reimbursement of expenses or whatever compensation has been provided for in the agreement.

The father could refuse to honor the contract, rejecting the child because of a handicap. He could deny paternity, refuse to pay the agreed amount.

The contract may have been well prepared, but its implementation can give rise to serious problems. The validity of such agreements has yet to be established.

Null and void?

There exists no law at present bearing directly on agreements of this nature and existing legislation is quite inadequate to settle possible problems.

Legally, a person cannot be the object of commerce. Moreover, an agreement with a surrogate mother, if interpreted as remuneration for abandoning her parental rights, constitutes a violation of public order since such rights are inalienable. Most laws governing adoption make any payment of money a criminal offense. In other words, were financial compensation to the substitute mother interpreted as purchase price of the child, the agreement would be deemed in violation of adoption laws prohibiting such payment. Consequently it would be null and void. ■

The bond the contract

didn't provide for

The pregnancy went well, the child is born, the parents have completed adoption, the surrogate mother has returned to her studies, the contract has been honored. The file is closed. Or is it? In appearance, yes, but not necessarily in fact.

Carrying a baby nine months obviously creates a bond: for the sake of the child, one has eaten differently, set aside that pack of cigarettes, put away the skis. Because of the child, one has experienced morning sickness. Because of the child's presence, one's body felt life inside.

Bringing a child into the world leaves traces in the body and in the heart.

It can be heartbreaking to tear oneself away from a child one has hardly seen and hand him over to the genetic father and his spouse. Particularly when the infant bears one's imprint.

Bonds, traces, marks, an attachment no contract can either provide for or prohibit. ■

How the world views it

Experts in many countries have expressed opinions on the matter. Most reject the practice of substitute motherhood. In England, the Warnock Report is clearly unfavorable to such agreements. From an ethical viewpoint, surrogate gestation has been described as totally unacceptable when a woman is physically able to carry a child but finds it inconvenient to do so. Even when justified by medical circumstances, surrogate motherhood is rejected on the grounds that the danger of human exploitation outweighs possible benefits that may be derived. The report goes so far as to recommend that it be made a criminal offense to establish or operate an agency for the purpose of recruiting and negotiating agreements with substitute mothers. The British College of Obstetricians and Gynecologists, the British Medical Association and the Victoria Report (Australia) also reject the practice of surrogate motherhood in connection with in vitro fertilization.

A committee in Ontario is the only group not to oppose it. That committee has recommended passage of regulations to govern such contracts, suggesting provisions as to the form and content. Contracts would be subject to prior approval by the courts.

Seven American states have introduced bills on surrogate motherhood. The legislation frequently includes a clause to the effect that any agreement with a surrogate mother must be in conformity with existing provisions of the law. Thus excluded are agreements that violate existing laws, but that does not solve the problem of illegal agreements. In such cases, unfortunately, it's the child who must accept the consequences. ■

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* • the biological mother: provides the egg and carries the child, assuming the function of maternity in its entirety.
• the genetic mother: provides the egg.
• the womb mother: carries the child.
• the social mother: adopts the child conceived and carried by another woman.

Qualitative birth control

Now, in order to be born,
must babies
be of the sex
their parents and society want?
Show no trace,
now or later,
of a defect?
Have a genetic makeup
that ensures
superior intelligence?
Now that science and medicine
know how to make it so,
will babies
have to be born perfect?
Since we know
so much is possible,
it's time we decide
just how far
we want and ought to go
to safeguard
the quality of our lives

Genetic manipulation: useful and worrisome

Sperm, embryos and ova don't have an easy time of it nowadays. In laboratories everywhere, they're being observed, isolated, separated, selected, modified, stimulated. But to what and whose benefit? And how far do researchers intend to go? Before the French biologist Jacques Testart set his own limits, he was prepared to go far indeed.

Genes bare their secret

Genetic manipulation consists of a series of operations that are at different stages of development. These operations make it possible, prior to conception, to choose the sex and other genetic characteristics of the future child, to eliminate certain diseases and to reproduce from a single cell.

In the case of sperm...

Research efforts have focused on the penetration capacity of sperm and development of techniques to split the X and Y chromosomes in spermatozoa.

Evaluation of the quality of sperm for in vitro fertilization and artificial insemination and of its penetration capacity is made by injecting it in hamsters, rats, mice and monkeys. The council of the European Medical Association approved such experiments, although it recommended that the resulting embryos not be allowed to go beyond a certain stage of development.

A technique developed by a California researcher makes it possible to separate male Y and female X chromosomes in spermatozoa to increase the odds of having a child of the desires sex. The sperm, either with a concentration of X or Y chromosomes, can then be used for artificial insemination. Dr. Ericson says the technique facilitates removal of immature and abnormal sperm, reducing the dangers of miscarriages and of giving birth to physically or mentally handicapped children.

Alpha Diffusion

Through cloning, Professor Peter Hoppe was able to create three little mice that were "genetic doubles" of the basic embryo.

As to the embryo...

Leaving to theologians, philosophers and jurists the difficult task of defining the status of the human embryo, scientists use various techniques to pursue studies enabling them to learn more about the mechanics of the creation of human life.

- embryo freezing: before the embryo reaches the stage of cellular differentiation, it is placed in a protective solution which is slowly frozen. It can then be preserved for a number of years.
- separation of blastema: the embryo is split in two, four or eight parts, each of which can produce an individual. At a given stage of development, one of the parts is frozen to be used, in the event of malformation, as a backup of healthy cells for other parts that have been implanted. Blastema separation research is being actively pursued by Dr. Edwards, a pioneer in IVF.
- filtering embryos: in vitro fertilization makes it possible to choose from among the embryos while searching for genetic anomalies.
- modification of the genetic code: an anomaly can be corrected or a new genetic characteristic introduced in an embryo or a fetus. The technique is also known as genetic therapy or genetic manipulation in the strict sense of the term.
- inter-species fertilization: an attempt has already been made to mix the cells of embryos of two different breeds of the same spe-

cies, specifically mice. It produced mice of two colours. Eventually it may be possible to introduce genes from one species to another, say from humans to animals or vice-versa.

One cell is enough

Researchers around the world are experimenting with ways of reproducing animals from a single cell.

The fact that all the cells of an individual contain the totality of his genetic information constitutes the basis of the technique of reproduction by cloning since the cells from a single individual could be used to create others genetically identical. Until now the experiment apparently has never succeeded in humans. Two reasons have been put forward for eventual use of the human clone: on the one hand, the desire to have offspring with the same genetic makeup; on the other, the possibility of reproducing individuals with great intellectual or athletic capacities or with certain specific characteristics.

Nuclear transplantation can have the same effect on genetic identity, but that technique necessitates use of a specialized cell.

With parthenogenesis, embryonic development can be triggered by chemical or mechanical stimulation of the egg alone, eliminating the need for the male gamete. In Edinburgh, biologists have brought cellular separation of a single unfertilized egg up to the eighth cell. ■

Children à la carte

A family of boys who were planned, a fatherless girl, twins of different ages, offspring with a special talent for mathematics, children without a single defect — the stuff of fiction?

Behind locked doors, genetic science is making giant strides. Its techniques are being refined, its horizons broadened. It has achieved success upon success and actual application of the techniques being developed appears both useful and worrisome. We may benefit from its discoveries, but we are in the dark as to its real objectives.

Just how far can science go? As far as the family of planned boys or the fatherless girl? As far as the commercialization of embryos of famous origin or the blind rejection of the disabled?

Genetic manipulation raises as many questions as it resolves. ■

A biologist sets his own limits

Alpha Diffusion

Jacques Testart, renowned biologist

Professor Jacques Testart, a leader in the field of artificial reproduction, has decided not to push forward with research on certain aspects of genetic manipulation. The evolution of such research has him deeply worried and he believes that there are limits beyond which research must not venture. The French biologist, a world-renowned expert in both in vitro fertilization and the freezing of human embryos, is the author of ***De l'éprouvette au bébé spectacle****, in which he reveals exciting perspectives for science that could be worrisome for humanity. He has now called a halt to his own ambitions. In his latest book,* ***L'oeuf transparent****, he calls for an international moratorium on such research. "I am well aware," he says, "that my decision is a form of professional suicide."* ***Le Devoir****, Sept. 15, 1986.*

An open letter to Jacques Testart

Following Dr. Testart's announcement, Francine C. McKenzie, president of the Conseil du statut de la femme, sent the following message to the scientist and the media:

It is good to hear from accross the sea that a French scientist has decide to limit his research in the field of artificial procreation.

The ethical choice not to cross the frontier of "research bearing on the identity of the human egg" will go down in history. By refusing to produce made-to-measure children, you have bridled the medicine of desire and thrown a monkey-wrench into the machine of "progress". As a result, people need no longer feel like dinosaurs because they want to give the matter some thought. Only one voice of dissent was needed to create a doubt. Thanks for providing that voice.

Some of your peers here have already taken note of your decision. Your plea for common sense has been heard. We can only hope your suggestion regarding a world-wide moratorium elicits wide support.

The Conseil du statut de la femme which I head is conscious of the abuses and dangers you refer to. That is why, for the past two years, the fait accompli *attitude on the question has concerned us. That is why we have challenged the annoying doctrine that would have us believe the development of new techniques is inescapable.*

Nor is pride in our species likely to be fostered by the perspective of C.V.I. (congelation of sperm, vasectomy and insemination) as a solution to the problem of birth control.

Stimulated by your view that ethical choices must precede discovery, we are more than ever resolved to wager on the power of thought and enlightened public opinion.

You have achieved what a hundred ethicists cannot accomplish. You have made ethics fashionable. Congratulations.

Prenatal diagnosis: tell me what you are, I'll tell you what will become of you

Rapid progress in genetic research and its applications in the field of reproduction have provided clinicians with new tools for qualitative birth control. It's no longer a matter of determining if one can have a child, but rather of knowing what the unborn child is and will become. Knowing beforehand is not necessarily a blessing.

The fetus analyzed

Various examinations carried out during pregnancy make it possible to gather information on the fetus and to detect malformations or diseases.

Access to prenatal examination

Apart from ultrasound, such examinations are not automatically part of medical supervision of pregnancy as practised at the present time.

Alpha Diffusion

Most pregnant women undergo at least one ultrasound test.

Such examinations are justified in specific circumstances:

- mothers over 35 years of age;
- after repeated miscarriages;
- where a parent suffers from hereditary disease;
- when a first child was stillborn or abnormal.

Prenatal investigation and diagnosis

- ultrasound: in obstetrics, ultrasonography through the abdominal lining provides an image of the fetus in the womb. The age and size of the fetus, its position and its sex can be determined. During prenatal diagnosis, the ultrasound can detect certain anatomical malformations (brain, organs, limbs);

- amniocentesis: guided by the ultrasound, a fine needle is inserted in the abdomen to withdraw a small quantity of fetal fluid. Laboratory analysis of the amniotic fluid and the cells provides information on the sex and blood group of the fetus and indications of genetic anomalies that may be clues to potential disease or malformation;

- chorionic biopsy: through the cervix, a sampling is taken of the chorion, the membrane surrounding the embryo, where the placenta and ombilical chord meet. Direct access to cells of fetal origin makes results of the analysis available more rapidly; sex of the fetus, metabolic diseases, chromosomic anomalies. The Montréal Children's Hospital now uses the technique on an experimental basis;

- fetoscopy: with a fine fiber-optic telescope inserted in the amniotic cavity, various parts of the fetus can be observed and samples of fetal blood or tissue extracted to detect certain diseases. Since there is a risk of abortion (5 to 10%), the technique is rarely used.

Risks and effects

Risk of injury to the fetus or of spontaneous abortion is only minimal in amiocentesis. A shortcoming of the technique, however, is that it can only be used when pregnancy is advanced. The extraction cannot take place before the 16th week because the amniotic cavity does not contain sufficient fluid. Then two to four weeks are required for cell culture. If positive diagnosis denotes need for an abortion, physical and psychological effects are greater in the 18th or 20th week of pregnancy.

The ultrasound and the chorionic biopsy can also produce miscarriages.

What's on the horizon

Prenatal diagnostic techniques are developing rapidly. In addition to indicating malformations and diseases in the fetus, the examinations will make it possible in the future to detect any tendency towards diabetes or cardiovascular troubles that may appear in adulthood.

Tell me what you are, I'll tell you what will become of you. ■

Condemned to be born perfect

Annie has just undergone a prenatal examination because she has had repeated miscarriages. The amniocentesis brings bad news: the fetus is afflicted with spinal bifidity, a defect of the neural tube the seriousness of which varies from one individual to another.

Now that she knows, Annie must decide quickly. Should she have an abortion or go ahead with the pregnancy and wait until the child is born to decide whether to choose treatment, give the child up for adoption or have him placed in an institution?

Like most couples confronted with a diagnosis of fetal anomaly, Annie and her husband probably will opt for the abortion. It's a decision that involves basic questions for her doctor, for herself and for society.

Marc Lajoie, ministère des Communications

Is it right to give birth to infants bound to become a social burden or shouldn't we do more for those who have less?

Abortion under medical pressure

Before performing a prenatal diagnosis, some doctors want the woman to agree beforehand to an abortion in the event the diagnosis is positive. They maintain the examination is futile if the woman is determined to go ahead with the pregnancy regardless of the results.

Not everyone is in agreement with that approach. But is does focus on the question of the real objective of prenatal diagnosis. It suggests we look more closely at the role doctors play as counsellors on birth and childhood. When parents have to make a decision, the information gathered by these specialists as to the nature of the disease detected, its gravity and the possibility of treatment is indispensable. And the way they provide such information can make all the difference, the difference between medical power that is imposed and that which takes into account the freedom and values of the couple.

When abortion is freely chosen

Annie has a gynecologist who doesn't lay down the law. Should she decide to interrupt the pregnancy after being made aware of the consequences of the fetal anomaly and the alternatives that exist, she will be making a free choice rather than reacting to medical pressure. She really wants the child, but she cannot and will not accept the idea of giving birth to one who is or will become handicapped. So she accepts responsibility for rejection of the abnormal fetus.

Selective abortion as a societal choice

Is the progress of prenatal diagnosis likely to result in more abortions? Further diminish the birth rate? By progressively eliminating individuals deemed undesirable, shall we foster eugenic policies to improve the human species? Will abortion remain a personal matter for women when techniques such as automated prenatal diagnosis, getting inexpensive and popular, make it possible to detect genetic anomalies in the first weeks of pregnancy? Shall we all become intolerant of any disease, serious or not, ranging from daltonism to the absence of a brain? Is it right to give birth to infants bound to become a social burden or, on the contrary, shouldn't we do more for those who have less but who, in their way, enrich society? Can we really expect to take the risk out of being born and out of living?

These questions must be answered by Annie and by the women like her, by the men who share their lives, by the gynecologists and by the politicians.

Made to order

The couples in question wanted girls... and girls they got. Once their choice had been made, they could leave the rest to the doctors. The latter separated the X from the Y chromosomes in the sperm and artificially inseminated the future mothers. Results: at least six "made-to-order" girls were born in Japan between September 1985 and January 1986. Now sixty Japanese doctors reportedly have mastered the technique which could be used to control certain hereditary diseases. Le Soleil, May 31, 1986.

In United States, a woman was also able to select the sex of her child but fertilization in vitro was used to mate the X-chromosomes-rich sperm and the ovule. The Globe and Mail, September 30, 1986.

Marc Lajoie, ministère des Communications Concept: Diane Dubé

A boy?... A girl?

No more need for surprises when a child is born! Now we know, long before the happy event, if it's a girl or a boy. That's one of the results of prenatal diagnosis.

Knowing the sex of the child is necessary if there is any indication of congenital malformation, say hemophelia in a male fetus. Then prenatal diagnosis is a meaningul medical procedure.

But it isn't always so. Is prenatal diagnosis morally and socially acceptable when it serves such non-medical needs as sex selection or parental curiosity?

In the first case, prenatal diagnosis seeks to determine the sex of the fetus so the pregnancy can be interrupted if the parents are not satisfied. Sociological studies in many countries prove most couples prefer a boy as first-born.

In the second case, the motive is mere curiosity. The parents just want to know if it's a boy or a girl. Thus the real purpose of ultrasound is sidetracked with the procedure being used to obtain information of secondary importance (sex, size, position) rather than to detect the malformations or diseases for which the technique was designed.

Many reasons are advanced to refuse prenatal diagnosis that is not dictated by medical necessity. In *Reproductive Ethics*, Michael D. Bayles defines the chief reasons as the risk of spontaneous abortion, the financial burden on the State and the lack of resources.

In its 1984 report, the National Institute of Health in the U.S. said it did not favor prenatal diagnosis in cases where the patient derives no medical benefit and it is solely intented to satisfy the couple's wish to know the sex of the child, to see the fetus or to obtain a photo for commercial or educational purposes. On the other hand, while it rejects the tendency to make sex identification and selective abortion a normal medical practice and an instrument of birth control, the Genetic Research Group of the Hastings Center neverthless maintains that legal constraints would violate the principle of non-interference in parental decision-making (as reported by Powledge and Fletcher in *Cahier de Bioéthique 2*).

Here, too, there exists a need for norms. ■

The fetus' turn to become the patient

To speak of open-womb fetal surgery seems perhaps more farfetched than open-heart surgery in the fifties. Yet that avenue is being explored and medical treatments and surgical procedures have been successfully tested.

A medical team at the University of Colorado placed a drainage tube in the cerebral cavity of a 24-week-old fetus to extract surplus cephalin fluid.

At the San Francisco University Hospital, a urinary malformation in one of the twins conceived by a 41-year-old woman was corrected after detection in an ultrasound.

A team from the medical faculty at Mount Sinai in New York was able to select between twins, one normal, the other afflicted with an anomaly. During an ultrasound in the 21st week of pregnancy, a long needle was inserted in the thorax down to the heart of the abnormal twin in order to withdraw half of the blood supply. That brought about cardiac

Even before birth

When a surgical team in California spotted a blockage in the urinary tract of the fetus, it opened the mother's uterus, pulled out the legs and lower trunk (the rest was attached to the placenta), opened the abdomen, made an incision in the bladder and put the patient back in his "natural environment" for the final three months of gestation.

Announcement of the successful operation was delayed until the child's first birthday. "Two similar operations were attempted previously," the announcement said, "but Mitchell is the first to have survived so long." Le Soleil, *December 9, 1986.*

arrest and ended movements of the fetus. The normal twin was then born without difficulty and the dead fetus expelled.

A few weeks later, a similar operation was attempted in Virginia. It provoked a premature birth and the death of a healthy child.

With time and further research, doctors will be able to correct more and more fetal anomalies. It remains to be seen who stands to benefit. Who is the patient, the fetus or the mother? Has the fetus the right to treatment? If so, how can it be reconciled with the mother's right to have an abortion and to consent freely to medical procedures? Many more questions of the kind can be added to what is already a long list.

When prenatal diagnosis brings bad news, fetal surgery can offer the woman a choice other than a handicapped child or an abortion. But the uncertain results and the physical and psychological pain that go with it can be a high price to pay. In the end, will a woman always have the choice? ■

Curbing genetic manipulation

The Parliamentary Assembly of the European Council has laid down a code of ethics for artificial procreation, prohibiting all experimentation with living embryo, viable or not. The Assembly, composed of national representatives from 21 countries, also ruled out any manipulation or deviation made possible by present medical techniques with a view to "creation of identical human beings through cloning, creation of identical twins, implantation of a human embryo in another species or vice-versa, creation of embryos with the sperm of different individuals, creation of children by persons of the same sex, sex selection through genetic manipulation for non-therapeutic reasons and production of human embryos for research purposes." Journal de Québec, *September 25, 1986.*

Prenatal diagnosis practices in Québec

Ultrasound

Between 1979 and 1984, ultrasound tests carried out throughout Québec totalled 728 896. The number has been increasing annually.

It is not known how many ultrasound tests were carried out for prenatal diagnostic needs as such, but use of the technique apparently has become routine. It can be said that, during the course of pregnancy, women undergo at least one ultrasound and frequently two.

Amniocentesis

Amniocentesis is practised at the Montréal Children's Hospital, at Sainte-Justine, at the Centre hospitalier de l'Université Laval and at the Hôpital de Chicoutimi. All four establishments are part of the *Réseau de médecine génétique du Québec*. Amniocentesis is also practised at the Hôpital Sainte-François-d'Assise and at the Royal Victoria Hospital.

In the first three hospitals mentioned above, doctors performed more than 10,000 amniocentesis in the course of prenatal diagnosis during pregnancy and of blood tests designed to avoid post-partum problems in the latter stages of pregnancy. Most women who underwent the operation were over 35 years of age.

Amniocentesis research is centered on the information it can provide rather than on the technique itself. New tests are being made available almost monthly to prenatal diagnostic teams. Three hundred of the 3,000 known genetic diseases can now be detected and present research is designed to increase the number.

The cost

Medical costs related to prenatal diagnosis are billed to the Régie de l'assurance-maladie du Québec. Between 1979 and 1984, the cost of ultrasound tests was $12 000 000 and that of amniocentesis $385 000.

The techniques of prenatal diagnosis are being introduced and developed in Québec at about the same rate as elsewhere. The tendency is towards earlier, faster tests that would substantially increase investigative potential. ■

Marc Lajoie, ministère des Communications

While favoring greater access to prenatal diagnosis, activists for the rights of handicapped persons also want more information and assitance for women who must choose between abortion and the responsibility of raising a handicapped child. Not everyone shares their point of view.

Medicine's solution

Medical resources frequently offer the only solution when couples want a child and can't or when they face psychological obstacles. Feminists contend that solution is too technology-oriented, largely indifferent to women's real needs, geared to cure rather than prevention, control rather than free choice. And theorists are not the only ones who see it that way.

Controlled reproduction

Several women authors perceive current medical research and practice as an attempt to exercice psychological control over a woman's reproductive system rather than relieve suffering and satisfy her desire for maternity and autonomy.

Medical practice relies increasingly on high-tech methods entailing violent and costly means controlled by health specialists and not the women concerned.

The woman machine

The process of human reproduction has begun to resemble the industrial production model. It is split up into several operations and efforts are made to control each one of them, whether they occur inside or outside the woman's body. The objective: best results at the lowest possible cost.

The model progressively reduces the role of women to that of a reproductive machine. Each woman is assigned a specific function on the "assembly line". Some are chosen for the quality of their eggs, others for their ability to bear children. The case of the woman who had been dead 61 days but was kept functioning artificially so the fetus could reach maturity is perhaps symbolic of the tendency to treat women as matter.

The woman's health and the man's role

Solutions favored by science and medicine to cope with problems of fertility, contraception and sterility subject women to most of the risks and disadvantages. The pain that's part of certain tests, the side effects of general anesthesia, the exhaustion and tension of the long investigational phase, the risk of spontaneous abortion, the anguish of waiting for results — all are part of the reality the media and medical literature rarely mention, the reality women experience. The technique seeks to resolve a problem of fertility, but it's the woman much more than the man who must suffer most of the consequences, even to the point of endangering her health.

Techniques seen as a challenge to the man's role, such as artifical insemination with a donor, appear to elicit a more reserved response than those which offer the man the certainty of biological paternity, such as in vitro fertilization which as won rapid acceptance. ■

Marc Lajoie, ministère des Communications Accessoires: gracieuseté de Jacmédic Ltée

When a couple is afflicted with infertility, medical resources frequently offer the only solution.

How medical power limits free choice

Development of new reproductive technologies is in perfect continuity with the evolution of medical power ever since the specializations of gynecology and obstetrics came into being, eliminating midwives in the past century.

Centralization of deliveries in hospitals, frequent recourse to examinations and a tendency to assume labor will involve complications have cost women a major part of their power and autonomy in maternity. They have become more and more dependent on medical knowhow and technology.

For the time being, artificial reproduction and prenatal diagnosis are practised on a selective basis. But such techniques could be applied in future to a growing number of pregnancies, becoming tools of reproduction management rather than instruments of prevention and therapy. Little by little, certain operations may be viewed as a necessity. Infertile couples and women may discover they have no other choice.

At the outset of pregnancy

The advent of prenatal diagnostic techniques, fetal therapies and genetic manipulation has increased and rendered more complex the decisions that have to be made. In the future, when pregnancy occurs, the decision as to whether to go through with it may no longer be based on the desire to have a child, but on the desire to have a child of a certain sex, a certain appearance and a certain genetic type.

The risk is that choice will be strongly influenced, not to say controlled, by doctors. Genetic counselling is being presented nowadays as the new expertise of the medical profession. It could provide another means to challenge or restrain the pregnant woman's freedom of choice. According to Genoveffa Corea, embryo selection could be imposed eventually on some or even all pregnant women. It is an area of medicine that is rapidly developing. ■

While inadequate budgets are allotted for prevention of infertility or research into its causes, for birth control, improved perinatal services and assistance to pregnant women, impressive sums are being spent for development of artificial reproduction.

Certain women authors suggest the little interest shown for prevention may provide a clue to the motivations of those who favor new reproductive technologies. Some problems could be avoided, they say, if efforts were made to improve the quality of the environment and reduce the progression of sexually-transmitted diseases. Yet governments and the medical world pay little attention to the causes. That indicates, say these authors, that the desire to combat infertility may not be the principal reason for development of new reproductive technologies.

Claire Dufour

Prevention: what medicine fails to do

...and what it does foster

Other female authors point out some fertility problems are associated with the use of drugs and oral contraceptives, but health professionals either fail to mention the risks or minimize them.

Abusive recourse to caesareans, inadequate precautions during abortions and insertion of intra-uterine devices are frequently identified as factors which contribute to the increase in pelvic infections and damage the reproductive system. ■

As those who tried see it

Who but the woman who sought help to have a child would be better qualified to express her feelings on the solution of the medical profession and on the relationship with her doctor? Thirty-two women were asked to tell their story in their own words.

Somewhere between faith and criticism

These women see medical treatment in a fertility clinic as the only possible solution.

"I think we knocked at the right door. And I still feel no one could do more."

They may be highly critical of the medical system, but they are also convinced it's the only source of possible help.

"I didn't see it as hope, but as help. I couldn't have done it alone, I said to myself, 'if spiritual, medical or any other assistance can do the trick, so much the better'."

They are conscious of the fact they have no choice. They can either forget about pregnancy or check into a fertility clinic.

"We have to depend on doctors for a solution. We don't have any choice. If it's rest I need, then I'm going to rest. If I have to stay in bed, then that's what I'll do. I'm always waiting for the doctor to come up with a solution. I have no choice. I try to keep informed. I read, but I don't have any answers other than theirs."

Some place all their trust in doctors or in medical science generally, particularly women who have just begun the treatment or those who cannot imagine life without a child. The specific causes of their infertility have been identified. They are relieved that someone is taking matters in hand, that they won't have to carry the entire burden.

It can be reassuring when treatment is suggested.

"It's like a light at the end of the tunnel... When he told me there was a solution, I was very confident. It was good to hear that pills would take care of everything. I'm encouraged because they've found an answer to my problem."

> « I didn't see it as hope, but as help. I couldn't have done it alone"

As treatment gets under way, a woman may say, "There's nothing they can't do." Another, who has been under treatment for some time, may add:

"They always find a solution. I'm the one who let myself get discouraged."

One woman who tried IVF says it's not a matter of leaving it up to the doctors, but rather of having confidence in medical science and perhaps of hoping to make a contribution.

When infertility is in the picture, life — that of the couple as well as social and professional life — seems to change.

"I said to myself, 'we're in 1986, not in 1950'. You can't say no to the telephone. You can't say no to science, to what's going forward... And I have the feeling I can be useful, that I can contribute something. That's important to me. I have a sister-in-law who's infertile and a sister... It's rough on me, perhaps it will be less complicated for them if other people lend themselves to the experience."

Not all are strong supporters of what the medical system proposes. A woman who has had a child as a result of the treatment obviously has every reason to believe in medicine. But even such women have reservations, particularly with respect to the unpleasant treatments and the exacting nature of the medical process.

"I'd never encourage anyone to go to the clinic. I'd tell them about it, but that's all... I wouldn't send my worst enemy there... You have to be tough on yourself."

Five of the 32 women refused to submit to certain examinations or operations.

"They wanted to do another laparoscopy. I said, 'No, it's too rough'."

"In my opinion, they make you take too many drugs."

Three women were particularly critical of the services proposed or given at the clinic. They would have liked to have a say in orientation of the treatment.

"I say, we're our best doctors. It's our responsibility, too. But they do all the talking and we do all the listening."

They want to exercise more control over the process.

"I want to call the shots as I see it. I haven't taken my temperature curve for months now... I tell you, I want to be the skipper. Two skippers aboard is one too many."

Fertility clinics don't have a monopoly on knowledge, some women say, adding clinics tend frequently to forget their expertise is limited.

"As far as I'm concerned, it's important to remain critical. After all, a clinic is a research centre."

In the case of a minority, criticism of the medical system goes beyond condemnation of objectionable practices. These women want more research into the causes of infertility, such as sexually-transmitted diseases and certain methods of contraception. They emphasize the need for studies in areas that affect health and possibly fertility: nutrition, lifestyles, psychological conditions, etc. They think more attention ought to be paid to alternative medicine, that simple techniques like insemination with the husband's sperm should not be strictly medical procedures. In a word, when women criticize the medical system, it's because they are aware of its limitations. ■

The missing contact

Judging by the opinions of these women, medical assistance given in fertility clinics is an extension of the traditional inequality in doctor-patient relationships. Some women are highly critical of doctors' attitudes.

"It's a relationship in which you're dominated. I don't feel he allows me free choice."

Most of the women mentioned aspects of their experience at the clinic which illustrate their dependence on and their submissiveness towards a system of care that is basically indifferent to their needs and to the effect the treatment might have on them.

Of course some had a good relationship with their doctor and were grateful for the treatment dispensed at the clinic. Generally, however, such comments concerned a specific doctor or nurse who had been willing to listen, who had shown empathy and had been accessible. The general climate at the clinic never prompted favorable comment. When women submit to the painful process of medical assistance, it is certainly not because they find the environment at the clinic particularly agreeable.

An impersonal matter

Many women felt they were treated as mere numbers at the fertility clinic. In the first place, it's difficult to develop a continuous and personalized relationship with the attending doctor. As one woman said, "When you're being treated for infertility, you'd better be prepared to see several doctors." At the clinic, staff doctors succeed one another for consultation. Often consultations are handled by residents or interns.

"It's always the residents you see... Sometimes months go by and you don't see the doctor who's in charge of your case... And since they don't know you, they keep asking the same questions over and over again."

When women do see their doctor, he's in a hurry, pressed for time, and they hardly have the time to talk with him.

"You see him for two or three minutes. If you have something to say, you'd better say it quickly."

Doctors who manage to communicate, even though interviews may be brief, are highly regarded by patients. Some women get into the habit of refusing to consult a doctor other than their own — even if that means waiting longer for an appointment.

"When I go there, I always ask for the same doctor and only him. I don't want to see the others. I don't like them. He's sensitive."

> « It's a relationship in which you're dominated. I don't feel he allows me free choice"

Even in an IVF program, a special case in that the woman is the object of much attention during the intensive fortnight of treatment, the relationship with the doctor apparently leaves much to be desired.

"What disturbs me is that doctors are always in a hurry. Like Dr. X this morning: 'Hello, hello. I'm the one who'll be operating on you tomorrow' (extraction of follicles). Then he was gone. There's really no contact between the doctor and the woman."

"It's never the same one. In my case, C measured my uterus, Y extracted the follicles and the next one may have been Q or Z, I don't know which."

Once her follicles were extracted, one woman couldn't reach her doctor for several days. Finally she was told by the nurse during a telephone conversation that the operation had been unsuccessful. But that is all she learned. Since the news was likely to be such a disappointment to her and her spouse, it seems incredible so little effort was made to communicate with her.

At the clinic, it was ultimately with the nurses the woman had a real contact. It probably explains why comments on nurses generally are more favorable.

Some women feel the way the waiting room is laid out is a clue to little importance they have. They are critical of the fact they have to wait for hours alongside pregnant women or women about to give birth, often with the nursery close by, when they're at the clinic precisely because they are unable to have children. However, it doesn't seem to bother all women; some like the idea of seeing newborns.

> « I'm nervous inside. I sit there, glued to the chair, and wait. If he doesn't have much to say, I keep mum"

The lack of information

Women are also critical of the fact that the information they would like to have is hard to come by.

"They won't ask, 'Is there something you'd like to know?, is there something bothering you? . But if you ask a question, they'll answer you, usually in a nice way."

But unless a woman is insistent, lack of information can be a real problem.

Marc Lajoie, ministère des Communications

Many women say communication is difficult and information inadequate at the fertility clinics.

"I'm nervous inside. I sit there, glued to the chair, and wait. If he doesn't have much to say, I keep mum."

Things are done, prescriptions given without anyone bothering to tell the women what it's all about.

"The other day, when I was there to undergo a second biopsy, the nurse called out my name. She gave me two pills, told me to take them in the bathroom. But she didn't tell me what they were. We're not animals, we want to know what they're giving us."

Accessories: Jacmédic Ltée

Women often have the impression they had better check their emotions in the cloakroom when they enter hospital.

« They used every-day language. We understood a lot better"

In IVF cases, a greater effort is made to supply information. Patients get long explanations about the how of procedure, "but they never tell you why".

Yet so little is required to make women understand.

"There's a graph on the wall... 1st day, 2nd day, you know, something you can follow. It's interesting."

Some women claim they obtain more information on IVF from women who have had the treatment than from the staff at the clinic.

"They used every-day language. We understood a lot better."

Some women not only consider the information inadequate, but have the impression the clinic isn't really interested in making it available. Apparently it's not unusual for women to experience the typical situation in which the doctor refuses to explain on the grounds the patient won't understand, such information might have psychosomatic effects or might encourage erroneous selfdiagnosis.

"They're running the show and they know it all. It's as if we know nothing. The way I see it, it's more like veterinary medicine than anything else..."

"I had the feeling they were giving me the information so I'd do what I was told rather than suggesting, 'Here are the facts, you decide'. I had to find out for myself." ■

Check your emotions in the cloakroom

Except for those women whose doctor listened and was available, the others felt that, when they were admitted to hospital, they were expected to check their emotions in the cloakroom.

"In a hospital, you may get all the care you need, but no psychological support. They don't ask, 'Does it hurt?'. At first, I used to hate them."

The fact that the doctor rarely sees his patient and hardly knows her probably accounts to a large extent for the lack of interest in the psychological aspects of the search for fertility.

"In any case, we're only numbers. They don't remember who you are even if they pretend to. They have so many patients. The place is always full."

Despite the fact they get more attention than others, the women undergoing IVF treatment feel the same way.

"It was as if my feelings had no importance. What mattered was the result..."

Assembly-line IVF (several women going through the procedure simultaneously) underscores the impersonal nature of the doctor-patient relationship. Each woman is just one of many and interest isn't centered on the individual case but on the group because the objective is to achieve a certain rate of success.

What women would like to discuss with their doctors are the things that bother them. Both women who decide to seek medical assistance and those who are ambivalent about it have a need to discuss their situation, get advice on the advantages and disadvantages of possible solutions. Most doctors fail to perceive that need and concentrate solely on the objective of bringing about the pregnancy.

There are exceptions. Some women referred to an individual doctor who showed he cared.

"I've rarely seen a doctor who's as sensitive... He was like a psychologist. You find yourself developing a bond."

"There was something else I asked of the doctor: support from others. You have the impression you're all alone. I know I'm not alone, but I don't like telling my life story to everyone."

It would be helpful if clinics and hospitals could assign a specific person to that function.

"...there must be a way. Perhaps they could find a clue by asking a few questions. Then they could set you straight. Of course the nurse who's doing post-coital or blood tests can't get involved in psychological extrapolation. But they could provide us with some help, give some direction... If there had been someone like that, I might have learned about guilt feelings. In spite of everything I had read, I knew nothing about such feelings. It's stupid."

The lack of thoughtfulness

Not only do doctors fail to provide psychological support, some are downright tactless.

« He said, 'Buy a lottery ticket, you're more likely to win the lottery than become pregnant'. I found that pretty rough on the phone."

"They behave as if it doesn't matter either way... I wonder if they realize how important it is to us. I wonder if they ever put themselves in our shoes."

Some women have learned, whenever possible, to avoid consulting a doctor who's thoughtless, but not all dare express their reticence openly. The thoughtlessness is reflected at times in the physical contact — for example, the disregard for the anxiety and pain experienced by women during certain procedures.

What women really want from the clinic staff is a more humane attitude. Given the distressing nature of the experience, that doesn't seem too much to ask for. ■

The powers that be

Powers as ancient as the world itself have already moved in on the field of artificial reproduction. Through the interplay of economic and political interests, notions of commerce, profit and social control have become part of the vocabulary of infertility and birth control.

Economic interests: a new health industry

Little by little ovules have become precious, highly valued resources. Doctors have long had a tendency to proceed all too quickly with ablation of the uterus and healthy ovaries. But now ovules for research purposes or for artificial reproduction are in such demand that licit and illicit markets have come into being. Some doctors even resort to abusive practices, removing ovules without the full consent of the woman. Incidents of the sort were reported even when the initial teams were created to carry out IVF research in England and the United States.

On a long-term basis, growth of such industries could result in women's bodies being regarded as "natural resources" to be exploited and managed like so many others.

The embryo commerce

Commercialization of animal embryos has been a reality for years. Commercialization of human embryos and fetal tissues began in the seventies. Women authors are convinced the objective of maximum production at the lowest possible cost will soon influence development in this area. They predict sterilization, now widely resorted to and often abused, will be increasingly practised among more young women because of the availability of embryos and the development of the technique of embryo transfer. For women who work in a toxic or dangerous environment, for example, sterilization could become a condition of employment.

Marc Lajoie, ministère des Communications Concept: Diane Dubé

A lot of money is devoted to development of new reproductive technologies while insufficient amounts are spent on prevention of infertility and the study of its causes, improvement of perinatal services and assistance for pregnant women.

Payment for donations of ovules and sperm

In an effort to determine if the principle of remuneration is acceptable, a parallel is sometimes drawn between the donation of ovules and that of sperm. Some women authors maintain the donation of ovules, which implies a painful procedure that could endanger a woman's health, is more demanding and consequently of greater value. Yet they wonder if payment won't pave the way for exploitation of women in need.

Surrogate mothers

The commerce of substitute mothers is another that has emerged with artificial reproduction: recruiting agencies, contracts, fee scales. Some authors believe underprivileged women are likely to be recruited in larger numbers for this type of "work" while the buyers will be middle-class and well-off couples.

American promoters reportedly have considered establishment of international networks so that women from poorer countries can be recruited at a lower cost, an arrangement that would "serve the interests" of both the women in question and couples from wealthier countries.

Prenatal diagnosis could be profitable

Economic arguments could carry a lot of weight with governments when calculating the cost of prenatal diagnosis. Elimination of a genetic anomaly or, more likely, abortion of the abnormal fetus at the stage of prenatal diagnosis could save society the cost of caring for physically and mentally handicapped persons. Cost-benefit studies have been made to determine the viability of systematic screening programs. ■

Political interests: NRT in government service

Several feminist authors believe non-medical factors may come to influence the practice of new reproductive technologies. The decision to resort to such techniques could depend on one's status: a white woman who is privileged, enjoys a "normal" family situation and shares the religious affiliation, nationality and sexual orientation of the majority would fare otherwise than a woman from a marginal, impoverished environment.

Were NRT practices governed by laws, regulations and codes of ethics, the latter would inevitably come to reflect political interests. NRT could be used to reinforce demographic control over a country. Governments could use NRT as an instrument of nationalism or as a means of curbing demographic growth. Research shows several countries have already adopted laws on abortion, sterilization and contraception. Penalties are imposed and incentives used to influence population growth. Countries could employ similar methods to "improve the genetic stock of the nation."

Science's interests

Poor and coloured women have frequently served as guinea pigs for the testing of new contraceptives. One suspects the same phenomenon could occur with NRT, although mainly the more privileged stand to benefit from these techniques. Few governments have yet established policies or adopted legislation concerning such research. In countries like England and Australia, the political climate would seem favorable to development of NRT; in the U.S., researchers are being more discreet so as not to alert public opinion. Several feminist thinkers question the rights of scientists to pursue their search for knowledge as they themselves see it without impediment and without consideration of the social consequences. These authors point out that most scientists happen to be men. ■

Alpha Diffusion

In India, systematic abortion of fetuses of the female sex has already affected the demographic balance.

Claire Dufour

The dilemmas of NRT: keeping on top of the situation

The dilemmas created by NRT are profound, the stakes high. Some suggest artificial reproduction can free woman from a cumbersome biological function. Others believe just as strongly women must maintain and insist on control of a function that is theirs alone. Views of both schools, broadly outlined here, can contribute to fuller analysis. The school to which one relates will condition one's outlook on infertility and the desire to have a child. The phenomenon of surrogate mothers will be viewed differently as will the advantages and disadvantages of NRT. But, beyond differences or agreement, the dilemmas identified by feminist authors clearly constitute a call to society to keep on top of a situation that is rapidly evolving. Women ought to insist not only on less violent solutions, but on the right to influence development of such solutions.

Alpha Diffusion

Pressures concerning the right to abortion

The question of women's right to free choice with respect to abortion has acquired a new dimension. Society in future could deny all responsibility in the case of a woman who, having been informed of a fetal anomaly during prenatal diagnosis, nevertheless decides to go ahead with the pregnancy and gives birth to a handicapped child. That could introduce an important new element of pressure on her. Yet the idea of selective abortion of abnormal fetuses has also been challenged. Handicapped activists believe the struggle for recognition of the rights of handicapped persons cannot be divorced from the larger struggle for the right to abortion. While some favor prenatal diagnosis, they stress the need for more information and greater support for women who must decide whether to have an abortion or assume responsibility for a handicapped child. They also believe dissemination of unbiased information on the subject of the handicapped would calm fears rooted in ignorance. Their viewpoint has not elicited unanimous approval.

The threat to physical integrity

A number of women authors contend the multiplicity of diagnostic and therapeutic procedures may lead to more numerous violations of the physical integrity of pregnant women. Their rights, as opposed to the rights of the fetus, including that of refusing to undergo an examination or a medical procedure, could be called into question on the basis of the assumption that the fetus is a distinct being rather than an integral part of a woman's body.

The threat to the reproductive function

Since recourse to artificial reproduction has become less difficult, it could serve as an argument for sterilization of women, even at a young age, as a drastic alternative method of contraception, a condition of employment in a dangerous industrial environment or a means of controlling costs related to the fertility of certain social groups (welfare recipients, the physically or mentally handicapped, ethnic minorities). Some authors raise the spectre of massive recourse to sterilization.

Splintered motherhood

Human reproduction is in a state of profound transformation. With the advent of new technologies, maternity is now viewed as a series of distinctive functions (genetic mother, uterine mother, social mother), each of which medicine seeks to control in order to counter shortcomings of the "human machine" and achieve the best possible results at the lowest cost. That would further undermine maternal power and reduce the mother-child bond. In the process, the child would become a "product", a programmed consumer object, "normalized" and assembled "to measure", having a tenuous link with one or several mothers.

Disturbing commercialization

The commercial aspect of reproduction (sale of ovules and embryos, rental of wombs), say women authors, invites abuse, particularly that of underprivileged women. Substitute mothers, they add, are subjected to excessive controls and are relatively poorly paid. They enjoy little protection.

Stated simply, the "working conditions" are unacceptable, but many women in difficulty will have to accept such conditions just as they now accept underpaid jobs. Other authors see substitute motherhood as a threat to human dignity that goes beyond economic exploitation. They predict that commerce will evolve like sexual prostitution and give rise to an international traffic in embryos, women and children from Third World countries.

Male power over reproduction

Development of artificial reproduction technologies is seen by some women as evidence of a male ambition to discover the secrets of the uterus and reach beyond the imperfect mechanism of human reproduction. In vitro fertilization specialists already assume part of the credit for the resulting births. Pessimistic women are convinced that, once complete artificial reproduction becomes possible, women will be reduced to mere sexual objects, at the limit even unnecessary.

Such projections may appear farfetched in the light of present reality. Yet threats to women's survival have already appeared on the horizon: methods used in the selection and predetermination of sex could lead, in the view of certain authors, to a substantial reduction in women's numbers, creating dismal conditions of life.

In India, systematic abortion of female fetuses is being practised on a large scale. It has already had an impact on the demographic balance, an effect some women authors define as "gynocide". ■

Other avenues worth exploring

The dilemmas created by development of new reproductive technologies have inspired feminist authors to suggest exploration of other avenues:

- concentration of research on the causes of infertility;
- research and development of contraceptive methods that are less harmful, more efficent, reversible and inexpensive;
- adoption of social policies on reproduction which would enable women to recover control over that aspect of their lives and to exercise free choice concerning the use of new types of reproductive services;
- promotion of healthy pregnancy and births under optimal conditions, maternal leaves, assistance for parents and others providing care for children;
- recognition of abortion as a service rendered to women at their request and not because of pressure;
- withdrawal of all support for research that encourages or renders possible the choice of male offspring;
- a change of attitude in our relationship with children.

Women authors are demanding the right to unbiased information on NRT, respect for the physical integrity of women and reinforcement of women's right to use of their genetic potential. Some say specific areas of research in keeping with women's interests should be given priority. ■

NRT is news

Scientific people, philosophers, feminists, journalists have all publicly expressed opinions and convictions on different aspects of the new reproductive technologies. Some books worth reading:

La reproduction humaine industrialisée, Jacques Dufresne, Québec, Éditions Diagnostic, Institut québécois de recherche sur la culture, 1986, 125 p.

The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs, Genoveffa Corea, New York, Harper and Row, 1985, 374 p.

Maternité en mouvement — Les femmes, la reproduction et les Hommes de science, a collective effort under the direction of Anne-Marie Vilaine, Laurence Gavarini and Michelle le Coadic, Grenoble, Presses universitaires, Montréal, Éditions Saint-Martin, 1986, 244 p.

Test-Tube Women: What Future for Motherhood?, Rita Arditti, Renate Duelli Klein and Shelley Minden, Boston, Pandora Press, 1984, 482 p.

Des motifs d'espérer? La procréation artificielle, major interviews by Emmanuel Hirsh, Paris, Les Éditions du Cerf, 1986, 159 p.

L'un est l'autre: des relations entre hommes et femmes, Élisabeth Badinter, Paris, Éditions Odile Jacob, 1986, 361 p.

De l'éprouvette au bébé spectacle, Jacques Testart, Bruxelles, Édtions Complexe, 1984, 126 p.

L'Oeuf transparent, Jacques Testart, Paris, Flammarion, 1986, 203 p.

L'enfant à tout prix — Essai sur la médicalisation du lien de filiation, Geneviève Delaisi de Parceval, Paris, Éditions du Seuil, 1983, 282 p.

L'enfant derrière la vitre, Dominique Grange, Paris, Encre, 1985, 234 p.

Les enfants de la science, Robert Clarke, Paris, Stock, 1984, 275 p.

Un acte d'amour — Nous avons fait porter notre enfant, Guy and Monique Libaudière, Paris, Éditions de la Table Ronde, 1984, 319 p.

L'insémination artificielle humaine: un nouveau mode de filiation, Didier David and al., Paris, Éditions ESF, 1984, 151 p.

L'insémination artificielle thérapeutique: aspects cliniques, psychologiques, juridiques, éthiques et philosophiques, Jacques E. Rioux and al, Québec, Presses de l'Université Laval, 1983, 217 p.

La rage de donner la vie, Dr. Roland Dajoux, Paris, Encre, 1985, 228 p.

Fertilisation en laboratoire d'ici à l'an 2000, Simon C. Davis, coordinator, in collaboration with Marcel Melançon, Ronald Hamel, David J. Roy, Montréal, Les Éditions Bellarmin, 1981, 114 p.

Actes du colloque "Génétique, procréation et droit", Paris, Actes Sud, 1985, 569 p.

Droit et science, Monique Ouellet, Montréal, Les Éditions Thémis, 1986, 176 p.

Du contrôle de la fécondité au contrôle des femmes, Fédération du Québec pour le planning des naissances, Montréal, 1986, 7 p.

Moral Dilemmas in Modern Medicine, Michael Lockwood editor, Oxford, Oxford University Press, 1985, 259 p.

The Technological Woman: Interfacing with Tomorrow, Jan Zimmerman, New York, Praeger, 1983, 296 p.

The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood, Barbara Katz Rothman, New York, Viking Penguin Inc., 1986, 274 p.

Test-Tube Babies: A Guide to Moral Questions, Present Techniques and Future Possibilities, edited by William A. W. Walters and Peter Singer, Melbourne, Oxford University Press, 1984, 165 p.

In publishing *Dilemmas*, the Conseil du statut de la femme would like to make an active contribution, that is both humanist and feminist, to the current debate surrounding new reproductive technologies.

In this brochure readers will find:

— a description of artificial reproductive and prenatal diagnosis methods;
— numerous moral, ethical and legal issues ensuing from the application of these methods;
— testimonies of women suffering from infertility;
— an analysis of the question from a feminist standpoint;
— the stakes of these new technologies;
— the paradoxes that they bring to light;
— Québec practice in this field;
— suggested readings on the subject.

In a handy condensed format, *Dilemmas* is an efficient means of learning a great deal in a very short time. *Dilemmas* is a synthesis of the numerous research studies conducted by the Conseil du statut de la femme on this important issue and has been prepared in cooperation with Les Publications du Québec.

Gouvernement du Québec
Conseil du statut de la femme

9 782551 085798

Printed in Québec, Canada.

What you can do about reproductive technology

FACILITATING A DISCUSSION

Once you've begun to think about reproductive technologies, you may begin to wonder if there's anything that you can **do** about them. This information kit contains "How to" sheets for several possible activities. You can do any of them or all of them.

One place to begin "doing something" about reproductive technologies is to find out what other women think and feel about the issue. One way to do that is to have an informal group discussion.

ORGANIZING A DISCUSSION

The fact sheets on Reproductive Technology in this kit provide a good basis for a discussion or a series of discussions. There is no one "right" way to arrange these. This sheet offers some suggestions, but if your group has its own way of doing things, go with what you know works for you.

If you're already part of a women's group or organization, suggest reproductive technology as a topic for a meeting or, if interest is high, for several meetings. The goal is to introduce these issues to your group and to give everyone a chance to think and talk about them. You don't need to bring in an "expert" for these discussions. Ask members of your group to read one sheet each and to facilitate a discussion on that topic. If you can afford it, have copies of the information sheets in this kit sent to the group members to read before the meeting. If this isn't possible, try to have copies for them at the meeting. If you can't afford copies, you can share the sheets you have.

If you're not part of a group, you can organize a discussion on your own. Call you friends, people you know, and people you think might be interested in the topic. Invite them to an informal discussion. Tell them the time, place and topic. If you can afford it, send them copies of the information sheet or sheets you'll be using before the meeting. If you can't afford it, pass your own copies around during the meeting.

Once you've invited people to a discussion, or gotten your group to agree to discuss the issue at a meeting, your next step is to do some planning to help ensure that your discussion is informative and productive.

PLANNING AND FACILITATING A DISCUSSION

Good discussions don't just happen. They require planning and forethought. Think about three things:

- **Your objective**: What do you want to happen at the group discussion?
- **Your plan:** What can you do to help make it happen?
- **Your follow-up:** What next?

"Facilitating" the discussion is the way you put your plan into action.

The goal of a facilitator is to encourage people to talk, not to force them to listen. The idea is to get their ideas out of their heads, not to put your ideas in. **Action on Health Barriers,** a book produced by Opportunities for Advancement, describes a facilitator this way:

> "A good facilitator is someone who can create a learning environment which helps the group draw on its own resources. The facilitator helps the group members to share their own experiences, ideas and questions in a supportive environment, to draw their own conclusions, and come to their own solutions through a process of mutual support.
>
> "In a traditional teaching role, the educator often dispenses information—the latest research or the "expert's" theories. A group facilitator sees the participants as the experts. She does not need to have the right answers, she needs to be able to ask the right questions. Her role involves helping each individual connect with the rest of the group."

Facilitators can acheive this by:

- **Being clear about the topic being discussed and about your role**. For example, "We're here to talk about reproductive technology and how it could affect us as women. I'm certainly no expert on the topic, but we're not here to listen to an expert. We're here to listen to one another. What I'm here to do is to make it as easy as possible for everyone to have her say."

- **Accepting people's feelings.** People won't feel comfortable if they think they are being judged or disapproved of.

- **Recognizing both the value and the limitations of everyone's experience.** What has been true for one person is not necessarily going to be true for all. This in no way reduces the value of individual experiences. It is the variety of experience and response that can point out both the strengths and weaknesses of a system or an idea.

- **Summarizing what people say.** Ask questions to help them clarify what they mean.

- **Keeping the discussion on the topic**. If people start going off on tangents, bring them back to the point by summarizing the direction of the discussion so far and asking a question that will move them back in that direction.

Here is one example of how to get a discussion started:

- State the discussion topic and introduce yourself. Ask everyone to introduce themselves.

- Tell the group the topic of the discussion and describe your role and what you hope will happen.

- Give a brief introduction to the topic, or have someone else do this.

- Turn the discussion over to the group.
  - ✔ For example: "Our first move should be to list issues and ideas that we think are important. I'll write them down as you call them out and then we can discuss them."

- If no one seems ready to talk, ask someone specific to start.

Once your group has defined their issues, told their stories and discussed their ideas, try to get them thinking about what they want to do about it.

WHAT NEXT?

One of the results of your group discussion may be that some of the women want to find out more about the issues or to take some action. This Kit contains materials to help them do so. If you haven't already, share the "What you can do about reproductive technology?" sheets with the group.

Be sure to set a date for another meeting to decide on your next move.

IDEAS FOR FOLLOW-UP DISCUSSIONS

If your group decides that the introductory discussions weren't enough and want to pursue the issues further, you have several options for organizing additional discussions:

- **Show a video or film.** A film and video can be a very useful way to introduce a topic or to start a discussion. If you use a film, be sure to preview it yourself so you'll know what to expect. Some films come with a study guide which can give you ideas for effective ways to use the material. If there is no study guide, make notes when you preview the film, and use these to suggest some questions or key points your group might look for as they watch the film.

  When you introduce the film, tell your group what it's about and suggest that they think about specific things while they watch. For example, you might say something like: "This film is called **In Fertile Ground**. It deals with issues related to reproductive freedom among women in third world countries. Although these women's lives are very different from ours, some of their concerns are the same. As you watch, try to see the things we have in common and the how the treatment they receive is rooted in some of the same attitudes toward women that we face here in Canada."

- **Use a book, article or clipping as the basis for a discussion**. This kit contains reprints of several articles that expand on the ideas raised in the information sheets. You could also base a discussion on a book—fiction or non-fiction—that deals with one or more issues related to reproductive technology. If a particular issue has been receiving media coverage, clippings can also provide a starting point for a dscussion.

- **Invite someone to give a brief talk.** If you do this, recognize that there are different kinds of resource people, and each kind has a different kind of expertise and experience to offer. For example, if your topic is amniocentesis, you will get one kind of information from a woman who has had the experience and can talk about what happened to her and what it meant. You will get something completely different if your speaker is a professional who does amniocentesis and can talk about its technical merits. Each of these viewpoints is valid, and your group may decide it wants to hear both. If this is the case, you can have both speakers at the same meeting, or have them separately, at consecutive meetings.

  Some kinds of speakers can be very intimidating to a group. If you want to encourage people to speak freely, they will be less intimidated if they are not confronted with someone whom they may expect to have all the "right" answers and with whom they might not feel comfortable arguing. One way around this is to arrange the meeting so that there is time for informal discussion after the speaker has left. For example, have the speaker give her/his talk, allowing time for questions. Then break for refreshments. After this, the speaker leaves and informal discussion begins.

- **Organize a panel discussion.** This is an effective way to point out that the same experience or issue can be seen in several different ways.

These are only a few possibilities and you can probably think of others. As your group becomes more familiar and comfortable with the issues, you may want to consider involving more people in the discussion by inviting other groups of women to attend your meetings or by sponsoring a public meeting.

What you can do about reproductive technology ...

FINDING MORE INFORMATION

PLANNING YOUR SEARCH

Looking for information is a step-by-step process. You start with an issue or idea that interests you. These fact sheets are one place to look for an issue. Media reports and clipping files are another.

Once you have an issue, you can focus on whatever aspects interest you the most. For example, you can look at the way it affects women locally, or, if you want to go further, you can look at the national or international aspects of the topic.

The first thing to understand is that you will never know everything or be able to answer every question. The section below contains a long list of questions to ask and a number of suggestions for places to look for answers. *These are only ideas.* Don't feel that you have to answer all the questions. Don't think that you'll be able to. Pick an idea or topic that interests you and follow it as far as you want to.

1. Pick your issue.

You and your group will be spending a lot of time with this issue, so it should be one that you're comfortable with and concerned about. Your own experience and that of other women can, and should, influence your choice. The issue that you choose to pursue will also be influenced by what's happening around you. Think about the issues that have been getting media coverage lately. Are there any particularly "hot" issues in your area? Are there any issues that will have a particular impact on women?

2. Find out what you can locally and nationally.

This is how you begin to define your issue and expand your knowledge. One of your first steps should be to start a clipping file on reproductive technology issues. This will help you to keep track of new developments—locally, nationally and internationally.

You can also begin asking questions and seeking specific information. Some questions to consider:

- ***Local information:*** What kinds of reproductive technologies are in use locally? What policies govern their use and availability at local hospitals and clinics? Do your provincial medical or nursing societies have policies or guidelines on the issue? What about your provincial law associations? What is the legal status of the various reproductive technologies in your province? Does your provincial Department of Health have any policies or directives on the issue? Are any reproductive technologies covered by medical insurance in your province? Is research on reproductive technologies being done at local universities? If so, what is it and who funds it?

- ***National Policies and Guidelines:*** Does the federal government have policies relating to reproductive technology? Are there any laws governing the procedures? Does Health and Welfare Canada have any guidelines or policy statements? What about the Canadian Medical Association or the Canadian Association of Obstetricians and Gynecologists, the Canadian Nurses Association, Planned Parenthood or the Canadian Public Health Association? Do national bodies like the National Science Research Council fund or approve research projects on reproductive technology? If so, what are their guidelines and limitations?

3. Use international sources, policies and precedents, and scientific and technical information to support your points.

What policies or laws exsist in other countries? What research has been done there? How has it been applied? How does this compare with Canadian experience and practice? Look for details on specific techniques and procedures. Check research reports in scientific journals. Look for women's studies sections in libraries and examine feminist literature for new perspectives. Look for background material on the ethical, moral, medical or legal implications of various reproductive technologies.

WHERE TO GET ANSWERS AND INFORMATION

One of the best ways to get information on local and national policies is to ask for it. Write to hospitals, clinics, government agencies, MPs, members of provincial legislatures, science councils, professional associations—particularly the women's caucuses within these professional groups—and anyone else that you think might have information you want.

The reference departments of most public libraries have extensive lists of the addreses of these agencies, associations and government officials. Often they also have the name of the information officer or executive director to whom the letter should be addressed. You will find a local address for your MP in the phone book.

When you write, be brief, direct and clear. State what you want and be sure that your return address is visible and legible.

Don't be too surprised if you don't get the information you're after with a single letter. Knowledge is power. Agencies that have information often have power as well, and they may not be particularly interested in sharing either one of them. If you get no response to your letter, or only an acknowledgement that it was received, write again. Re-state your request, refer to your earlier letter and ask for the information you want or for a written explanation of why they won't give it to you. It may help if you have other people write asking for the same piece of information. One of you may get it.

If after all this you still haven't found what you want to know, then you can give up, go public or go political. Going public means involving the press or the media. Write a letter to the editor of your local newspaper, issue a press release, call reporters or open-line radio shows. Say that you've asked a simple question—why can't you get an answer? If you can create enough public fuss and interest in the issue, you may get your information. Or you may not. Going public is always a risk. You may make the source of the information you want so angry that they just dig in their heels and say "No! You can't make me!" If it's a publicly funded or government supported agency, your chances of success are better.

Going political means involving politicians. Write your MP or member of your provincial legislature or the Minister of the relevant government department. Reproductive technology is a health issue, a legal issue and a women's issue. Write to Justice Ministers, Health Ministers and Ministers responsible for women's issues. Write to Advisory Councils on the Status of Women. Ask why you can't get the information you want. Ask them to try to get it for you.

FINDING SCIENTIFIC INFORMATION

Finding scientific or theoretical information involves reading and library research. Start with the Suggested Reading List in this kit. CRIAW has also published an extensive bibliography of research on reproductive technology entitled **New Reproductive Technologies: Research Information for Women.** It contains an introduction to reproductive technology issues and brief summaries of many current books and articles. Information on obtaining a copy is available on the Resource and Information Sheet in this kit.

If you live near a university, the collections on medicine, law, philosophy, ethics, and particularly women's studies, should be very helpful. Ask for help from reference librarians. University libraries have access to many indexes—both in print and computerized—that can save you a lot of time and effort if you ask how to use them.

Your local public library will also have some useful source material. Again, reference librarians can be very helpful in showing you how to get the most out of their collections. Many libraries also have Inter-Library Loan services which will allow you to borrow a book that your local library doesn't have.

FINDING INFORMAL INFORMATION

Libraries are a source of a particular kind of information—published knowledge, the kind of information and analysis you find in books, journals, and research reports.

Informal information is altogether different, but equally valid and useful. It's the kind of information you can only get from other people—reports of action research projects, stories about women's experiences, briefs other groups have written, names of other people interested in your issues. Women's groups are a valuable source of this kind of information.

Make as many contacts as you can among women's groups, professionals and politicians. Finding information is exciting, but looking for it can be exhausting. If other groups have already done some of the groundwork, why do it over again? Co-operate and share as much as you can.

What you can do about reproductive technology ...

ACTION RESEARCH

WHAT IS "ACTION RESEARCH"?

"Action Research" is gathering information for social change. Action research attempts to understand and describe the ways that policies, events and procedures affect all kinds of women. For example, a good policy on artificial insemination would be one that benefitted all women and didn't discriminate against any particular group of women. Some hospitals have artificial insemination programs that work well for white, married, middle-class women but effectively exclude unmarried women or minority groups. An action research project would examine the policy, look at the way in which it is carried out, and if the policy is unfair, use the information to try to change it.

HOW DO I GATHER INFORMATION FOR ACTION RESEARCH?

One way to do this is to gather information in the ways that are described on Sheet #2. For example, finding out what kinds of reproductive technologies are available in your area, what policies regulate them, how this affects women and using this information to decide what needs to be done about it, could be an action research project.

Another way of gathering information is through what we call "experienced-based research." Experience-based research is a way of learning about and expressing women's practical experience. It is based on the understanding that women's personal experience is a valid form of knowledge, and that this knowledge can and should be considered as decisions are made about reproductive technology. Experience-based research involves:

- Contacting women who have used, or are thinking about trying, various reproductive technologies;
- Bringing these women together for mutual support and sharing of ideas and experiences;
- Collecting their stories and experiences—either on tape or in writing;
- Compiling this information into a package or presentation.

Experience-based research offers a way to make women's experiences visible. It provides a description of the way in which an issue is understood and experienced by women. For example, childbirth is experienced very differently by a labouring woman and a male obstetrician. And though the woman's view is important and central to an understanding of the event, it is seldom given the kind of serious consideration and acceptance that the viewpoint of a male professional automatically receives. Until we begin to recognize the value and validity of our own experiences and to give them the attention and consideration they deserve, no one else is going to.

Experience-based research can take many different forms. Each group decides on an issue or topic that meets its needs and interests. Each group decides what it needs to know and how it can best go about finding information—through informal interviews, conversations, libraries, archives, workshops, questionnaires or meetings. Each group decides on the presentation format that will work best for them—a brochure, a fact sheet, a workshop, a report, a play, a lobbying brief, a brief to a royal commission or a committee, a press release, a journal or magazine article, a poster, an information kit, a grant proposal.

An important aspect of experience-based research is the way in which it strengthens and empowers the women who participate. An experience-based research project would not, for example, start with the idea that "We are going to test the hypothesis that 80% of the women in this community who have undergone artificial insemination found it to be emotionally unsatisfying." It would start with something like, "How do the women in this community who have undergone artificial insemination feel about their experience?" Because you are not using women's experience to try to prove or disprove your own ideas, the women involved can participate and even direct the study. Their experiences determine what the study becomes. The women being researched see themselves as becoming the researchers. They share the responsibility for, and control over, defining the problem and finding the best way to answer questions and interpret their experiences.

What you can do about reproductive technology…
LETTING PEOPLE KNOW ABOUT THE ISSUE

This kit suggests several ways to let people know about reproductive technology: offering it as a topic for discussion at a regular meeting of an existing women's group; organizing a discussion on your own; and contacting other groups, especially women's groups. But once you've talked about the issue, found out more about it and perhaps even done some action research, you may be looking for a way to make your ideas and information available to a wider audience. The most efficient way to do this is through the media.

WORKING WITH THE MEDIA

Learning how to work with the media is the key to getting your ideas to the widest possible audience. In fact, if you should decide to organize a public meeting or a workshop, the amount of pre-event publicity and coverage you get from the media will have a lot to do with how successful you are.

A good place to start is to ask for advice from other groups who have worked with the media in your area. Their experience can save you time and keep you from making mistakes.

Dealing with the media can be frustrating if you don't understand that it has its own needs and interests. Often, editors and reporters seem to be totally uninterested in issues that you see as vitally important. One way to handle this is to recognize the points that make a story or an issue "newsworthy" and to present your issue in a way that focuses on these points.

What you can do about reproductive technology ...

LOBBYING

Lobbying is a process of convincing. When you lobby, you are trying to convince an individual or an institution that it is to their advantage to see an issue your way.

Lobbying is also an on-going process. Convincing people to listen to you takes time. Convincing them to agree with you takes more time. Convincing them to do what you want done can take even longer.

Lobbying has five basic steps:

- **Choosing your issue or goal**
  What exactly do you want? How realistic is it? Should you divide your ultimate goals into a series of smaller objectives?
- **Finding allies**
  Who will help? To what extent?
- **Deciding who to lobby**
  Who is in a position to do what you want done?
- **Working out your strategy**
  What strategy or tactics will work for you in this situation, on these people?
- **Implementing your strategy**
  Putting your plan into action.

STEP 1: CHOOSING YOUR ISSUE

Often we become interested in an issue because it affects us personally. In order for that issue to be appropriate for a lobbying effort, we have to define it in a way that makes it a public issue. For example, the founders of DES Action had to move from "I have vaginal cancer because my mother took an untested drug" to "Inadequate drug testing standards and prescription practices have put thousands of women at risk". Your issue has to be defined in a way that makes political action (lobbying) possible.

Research is essential at this stage. You need to find out what other people in other places might have tried and you need to clarify your own understanding of the issue. You need to know as much as possible. Information will help you focus your efforts and define your goals.

Decide exactly what it is that you want. Be very specific. For example, "Consumer participation in health care planning" is too vague. "Consumer participation in all levels and stages of the planning and operation of health care programs and faciltities" is better. "Three consumer representatives, appointed by a process to be jointly determined by community groups, community and professional health organizations, and the Department of Health, with terms of reference and accountability also jointly determined, to be appointed to all boards, commissions and committees, at all levels and stages of the planning and operation of health care facilities and programs" is very specific indeed. It would be good as an overall, long-term goal, which could be broken down into smaller, short-term objectives.

STEP 2: FINDING YOUR ALLIES

Lobbying is a labour-intensive activity. In some ways it's like a group of people with shovels trying to move a mountain. The more shovels you have, the bigger the dent you can make. But even if you're all alone, don't give up. If you manage to shift even a single shovelful, you've changed the shape of the mountain forever.

Lobbying is easier if you have help. Think about:

- Who else might be involved?
- What are their resources?
- What stake do they have in the issue?

Some possible allies are:

- Local people who share your concern
- Other groups (local, regional and national, as appropriate)
- Researchers or professionals working in your area of concern
- Media allies (for example, reporters doing stories relevant to your issue)

You needn't confine your search for allies to people who are interested in your issue in the same way that you are. For example, some people working for DES Action are interested in the topic of drug testing in general, not DES specifically. In Halifax, a conference on reproductive technology was co-sponsored by five groups who all came at the issue from different perspectives: Canadian Research Institute for the Advancement of Women (CRIAW Nova Scotia), a group interested in women's issues in general; Nova Scotia Women and the Law, a group of lawyers and law students; Women, Health and Medicine, a group of medical students and health professionals; The Prepared Childbirth Association of Nova Scotia, a consumer group interested in pregnancy and birth-related issues; and The Women's Health Education Network, a organization which makes health information available to women throughout Nova Scotia.

As you go about making contacts in the community, in the media, in the bureaucracy, and among politicians, it pays to remember that lobbying is rarely a one-shot action. It can go on for quite a while, so it's a good idea to nurture your contacts. Be fair, be friendly, be reasonable. Thank people who help you. Offer information to people who have kept you informed. If you have someone's good will, it's easier to get their help.

STEP 3: DECIDING WHO TO APPROACH

This is a crucial step in the lobbying process. Lobbying the wrong people is worse than useless—it's discouraging. You're wasting your valuable time and your limited resources. You're also wasting the time of whoever you are lobbying. If you lobby the wrong people, you can't succeed for the simple reason that the people you're lobbying can't give you what you want.

So try to find out:

- Who has jurisdiction or control over whatever it is you are concerned about? What sorts of people have a stake in the existing system and what sorts of people can initiate a change? Is it a federal matter? Provincial? Municipal? A single hospital? A Medical Society?
- When you've isolated the level at which the problem should be addressed, who within that level is the best person to work on? Who's in charge of the particular issue you're concerned with? What is the chain of command? Who does the decision maker listen to? Where does s/he go for advice?

STEP 4: WORKING OUT YOUR STRATEGY

At this point, you've defined your issue, found your allies, and decided who to lobby. Now you need to decide what to do. This is your strategy, and it has two parts: Deciding on positive actions and anticipating problems.

- **POSITIVE ACTIONS**
  This is where you decide what you plan to do. While you may be unyielding in your definition of your long-term goals, you will most likely have to be prepared to be flexible in the way you plan to go about getting them. To quote Penny Kome: "Successful campaigns change all the time, because changing people's minds is usually the objective."

Think about what you'll need to do :

- To achieve short term goals
- To achieve long-term goals
- In what order should you do things? What comes first?

Another thing to consider is how to implement your strategy. What tactics will be most effective in each situation? Keep in mind that lobbying is a process of convincing, and different kinds of people respond to different approaches. For example, an elected politician may respond to an approach that involves publicity, political pressure and petitions and emphasizes the numbers of people who agree with you. A politician wants to know whether doing what you ask will help him/her get re-elected.

A bureaucrat, civil servant, or administrator, on the other hand, is not likely to respond positively to these kinds of tactics. A bureaucrat appreciates a calm, professional approach. She/he wants you to state what you want done, what you expect him/her to do, and why. Politicians come and go, sometimes quite quickly. Bureaucrats don't. When you lobby a bureaucrat you are establishing what may turn out to be a long-term relationship. It is much pleasanter and enormously more productive if that relationship is pleasant and based on mutual respect. If you come up against a bureaucrat who is unyielding and completely unreceptive, then you may have to go over her/him and take a political approach, but give him/her a fair chance first.

- **ANTICIPATING AND DEALING WITH BARRIERS**

This is problem-solving in advance. When you lobby to change something or make something happen, you are trying to make yourself and your group a part of a decision-making process. As well as lobbying for a particular cause, you are also becoming a participant in a planning or decision making process, either formally or informally. A new player in any game changes things, and will result in resistance from those already involved. As a newcomer, you are a threat to the status quo. It is important to realize this, because some of the resistance (maybe most of it) will come from the **fact that you are lobbying**, rather than to the content of whatever you are lobbying about.

Some barriers that you might find yourself facing are:

✔ **Intruder Status:**
You are the newcomers—if not to the issue, then certainly to the process—and as such likely to be viewed with suspicion and resentment. Accept this as part of the process. Don't work so hard at being likeable that you forget why you're there. Remember that it matters more that these people respect you and become willing to work with you, than that they like you.

- **Different Goals:**
  Your goal is likely to be different from that of the people you are lobbying—you will be looking at the problem from a different perspective. For example, in hospital planning, consumers are concerned with the effect that the hospital will have on patients—that is, will what is being planned improve health care. From the administrator/politicians' point of view, most hospital planning is an exercise in rationalizing, streamlining and reducing the cost of operating exisiting facilities. They assume that a newer, bigger hospital will naturally result in better health care. They never ask if a hospital is the best solution to the problem. They are there to plan a hospital, not to plan for patient good. Their assumption is that these two are the same thing. You may not be willing to accept that assumption.

- **Anti-Participation Ideology—The "What do *you* know?" Syndrome:**
  This is the reluctance to admit or acknowledge that you, as an outsider and non-professional, can have a valid viewpoint or make a valuable contribution. It is a reflection of the "establishment's" resistance to you as an unknown force.

- **Use of Authority and Control:**
  Those in power have the ability to make rules governing the decision making process. This power can be used to neutralize participation by outsiders by:

  - Not making changes that would make it easier for you to participate.
  - Controlling the timing of the process. "There's plenty of time for your input, don't worry." "You're too late. We don't have enough time for this." "It's too early. We'll ask for your input later when we have more information."
  - Controlling rules and access to information. Those in charge of a decision-making process are the ones who set agendas for meetings; select the topics that will be discussed; decide what information to release and what to keep to themselves; and design the structures and select the members of the committees which contribute to the process.

Besides these external barriers, we also face barriers from our circumstances—the lack of time, money, energy, childcare, and confidence are all very real barriers.

STEP 5: IMPLEMENTING YOUR STRATEGY

At this point you've thought about what you want, you've found your allies, you've picked a target, and you've planned a strategy. Now you put your plans into action.

To do this, you may need to learn some new skills. Putting a lobbying strategy into action may involve:

- Issuing press releases
- Arranging for public meetings
- Arranging and preparing for face-to-face meetings with politicians or "authority figures"
- Writing letters—letters to MPs don't need stamps
- Organizing phone campaigns
- Writing briefs
- Circulating petitions

Information about some of these are contained in other parts of this kit. Advice and information on lobbying can also be obtained from the Canadian Advisory Council on the Status of Women, provincial Status of Women Councils, and The National Action Committee on the Status of Women.

As you implement your strategy, remember to do things in stages. Give whoever you are approaching a chance to respond to your initiative before you apply public pressure. For example, a letter writing campaign is carried out in two stages. The first letter should go to your target. Give her/him a chance to respond. If you don't get a response, or you don't like the response you get, then write again, and this time send carbons to anyone you can think of who could put pressure on your original target.

Another aspect of implementing your strategy is keeping your allies informed. The groups and individuals who are helping and supporting you need to know what's happening. They can't help you if they don't know what you're doing.

And finally, keep records of your activities. Some issues can last for a long time. You may have periods of intense activity followed by periods during which nothing much happens. A record of what's already been done can be invaluable when the issue heats up again.

What you can do about reproductive technology ...

WRITING AND PRESENTING A BRIEF

The federal government has announced the formation of a Royal Commission on Reproductive Technology and has selected the commissioners . (They're listed at the end of this sheet.) The Royal Commission will travel across the country to hear briefs from groups and individuals. These submissions will form the basis for the report and recommendations that the Royal Commission will present to parliament.

The appointment of this Royal Commission gives women across Canada the opportunity to let parliament know what they think about reproductive technology, what they want done about it and how they want to be involved in the process. You do this by writing and presenting a brief to the Royal Commission.

WHAT DOES A BRIEF DO?

According to the Canadian Advisory Council on the Status of Women, the purpose of a brief is to:

- Criticize existing conditions
- Suggest ways to remedy a situation
- Initiate action on an issue or project
- Inform or persuade

WHAT'S IN A BRIEF?

A brief has three basic parts:

1. **The Introduction.**
   This is a statement of who your group is, why you're interested in the issue and what points you're going to cover.

2. **The Issue.**
   This is the heart of your brief. You state the problem and describe who it concerns and why. State your issues one by one and back each of them up with your research—facts, statistics, personal stories, information from community-based research your group has done, or whatever kind of information seems appropriate. As you conclude each issue, make a recommendation—say what you think should be done about it.

   Be as clear, brief and to the point as possible. You don't have to be dry and cold. You don't have to pretend to be objective. You wouldn't be going to the trouble of writing a brief if you didn't have an opinion and didn't care deeply about the issue. It's perfectly legitimate to let your care and concern show through. It's quite possible to be passionate and coherent at the same time.

3. **A Summary of Your Recommendations.**
   A short statement of the issues you've covered and a list all the recommendations you've made.

HOW DO WE GO ABOUT PREPARING OUR BRIEF?

1. **Get a copy of the terms of reference of the Royal Commission.**
   This will tell you what kinds of submissions the Royal Commission is looking for. The Terms of Reference for the Royal Commission on Reproductive Technology are attached to this sheet.

   Additional copies of are available from: Status of Women Canada, 151 Sparks Street, 10th Floor, Ottawa, Ontario, K1A 1C3. Phone: (613) 995-3901.

2. **Decide on a group to prepare the brief.**
   You can work through an existing group, you can create a new one, or several groups can work together on a joint presentation. It is possible to present a brief as an individual, but commissions seem to give more weight to submissions from groups, on the assumption that a group represents the views of more people.

3. **Decide what points your brief will cover.**
   Get your group together and list all the topics you'd like to address in your brief. Pick the two or three that you all agree are most important. Make these issues the basis of your brief.

4. **Contact the Royal Commission.**
   Tell them you would like to present a brief and ask for a presentation date and time. The address will probably be included with the terms of reference. Royal Commissions also place ads in newspapers inviting submissions and stating how to arrange to present a brief.

5. **Pick two or three people to research and write your brief.**
   This core group should be able to call on other group members for whatever assistance—for example, with child care or typing—they might need. Give these people as much time as possible. Keep in mind that Royal Commissions often require briefs to be submitted several weeks before the formal public hearing.

6. **Have a meeting of your group to formally review and approve the brief.**
   Attach a sheet to the brief which states that the brief has been approved. This provides your group with a chance to talk about the issues and lets the Royal Commission know that your brief really does represent your group.

7. **Decide who will present your brief.**
   Pick one or two of your best public speakers. This should be someone who reads well, speaks well, and doesn't get flustered in public situations. Your best speaker may not be your most knowledgeable member. If this is the case, have one or two resource people accompany the presenter to answer questions and provide additional information if it is required.

8. **Have a dress rehearsal.**
   Pick several people to play the commissioners. Have your speaker and resource people present your brief. Encourage your "commissioners" to ask hard questions so that your presenters can role-play their responses.

9. **Write a press release covering the main points of your presentation and describing your group.**
   You can circulate this before your presentation and/or have it with you to give to any reporters who are covering the hearings.

10. **Make copies of your brief.**
    Make sure it is clearly and accurately typed. Make sure that your group's contact person, mailing address and phone number are on the first and last pages of your brief. If it hasn't been sent to the Royal Commission in advance, have enough copies to give one to each commissioner. Have extras to give to any reporters who want one. Be sure that your group has several copies of the brief to keep for future reference and to share with other groups.

WHEN YOU PRESENT YOUR BRIEF

- **Be on time. Dress appropriately. Be prepared**.
  If possible, attend other presentations before your own. This will give you some idea of what the atmosphere is like and what kinds of questions you're likely to be asked.

- **Have the presenter introduce herself and any resource people accompanying her.**

- **Present your brief.**
  Be calm. Be confident. Be concise. If your brief is short, you can read it. If it is longer than a page or two, give a short summary and read your recommendations.

- **Thank the commissioners for listening.**
  Ask for a copy of their final report.

- **Say you'll be happy to answer questions.**

ROYAL COMMISSION ON REPRODUCTIVE TECHNOLOGY

Chair:

- Dr. Patricia Baird; Department of Medical Genetics, University of British Columbia

Members:

- Dr. Bruce Hatfield; University of Calgary Medical School
- Martin Hebert; Lawyer, Specialist in Medical Law and Bioethics, Montreal
- Grace Jantzen; Lecturer in the Philosophy of Religion, University of London, U.K.
- Maureen McTeer; Lawyer, Ottawa
- Suzanne Scorsone; Director, Office of Catholic Family Life, Toronto
- Dr. Louise Vandelac; Sociologist, Member of the National Bioethics Council on Research on Human Subjects, Montreal

MANDATE

The Commission 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 transfers, prenatal screening and diagnostic techniques, genetic manipulation and theraputic interventions to correct genetic anomalies, sex selection techniques, embryo experimentation and fetal tissue transplants;

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

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

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

WORDS you should know about...
THE NEW REPRODUCTIVE TECHNOLOGIES

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 the fluid in the amniotic sac is removed and the cells in it are checked for abnormalities. 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 to 20th week. Amniocentesis has a small—less than one percent—chance of causing a miscarriage.

ARTIFICIAL INSEMINATION: A way of becoming pregnant without having sexual intercourse. Sperm is placed in a woman's vagina when she is ovulating. There are three kinds of artificial insemination:

- AID (artificial insemination/donor), in which the sperm comes from a donor;
- AIH (artificial insemination/husband), in which the sperm comes from the woman's husband; and
- AIC (artificial insemination/combination), in which a combination of husband and donor sperm is used.

Most artificial insemination in North America is done with sperm from paid, anonymous donors. Because the identities of these donors are unknown to the children, it is nearly impossible for them to trace their biological father.

Despite routine screening of donors, the risk of being infected with HIV (the virus which causes AIDS) is higher during artificial insemination than during intercourse with a known partner.

CHORIONIC BIOPSY or CHORIONIC VILLI SAMPLING (CVS): A test in which a catheter (small tube) is inserted through the mother's vagina and cervix, and a sample of the membrane surrounding the fetus 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 eighth or ninth week of pregnancy and the results are usually known within a week. CVS has about a one percent chance of causing a miscarriage.

CHROMOSOMES, DNA, GENES and GENOME: Genome is the word used to describe the complete set of instructions for making a human being. These instructions are contained in the 46 **chromosomes** which human beings normally have. Twenty-three chromosomes come from a mother's egg, 23 from a father's sperm. Contained in each of these chromosomes is a long, twisted ribbon of **DNA** (deoxyribonucleic acid). **Genes**—the basic biological units of heredity—are located at specific points along this ribbon of DNA. Each gene contributes a specific bit of the information that makes each human being different. The human genome contains about 100,000 genes.

CLOMID: A drug used to induce ovulation so that eggs can be collected for use during in vitro fertilization. Clomid is chemically similar to DES (di-ethyl stilbestrol), a drug that has been linked to higher rates of some kinds of cancer in the daughters and sons of women who were given it. To date, there have been no animal studies or good clinical analyses of the long-term effects of clomid.

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.

CONCEPTUS, EMBRYO and FETUS: After the egg has been fertilized, the cells begin to divide. Some of these cells will become the "embryo", the term applied to the first eight weeks of development. Other cells will become part of the membranes that nourish the developing embryo. "Conceptus" is the term used to describe the product of conception and includes both the embryo and the membranes. After eight weeks, the "embryo" is referred to as the "fetus."

ECTOGENESIS: Describes the production of a real "test-tube baby." Ectogenesis means developing a human fetus completely outside the womb, using an artificial womb or life support technology. So far, this has not been done and is still only a theoretical possibility.

ECTOPIC PREGNANCY: A pregnancy that develops outside the uterus, for example in the fallopian tubes. Ectopic pregnancy occurs in one of four in vitro fertilization pregnancies, compared to 1 in 100 to 300 naturally occurring pregnancies. Most ectopic pregnancies end in miscarriage because tissues other than the uterus cannot support a fetus. A medical emergency, like bleeding, can result when an ectopic pregnancy ruptures.

EMBRYO TRANSFER: A surgical procedure in which a fertilized egg is removed from one woman's uterus and placed in another woman's uterus.

EUGENICS: The term applied to efforts to "improve" the human race, either through selective breeding or genetic manipulation.

FETAL HEART MONITORING: Used during labour to detect fetal stress so that, if needed, a rapid delivery can be performed. Fetal monitoring can be done externally, by placing electrodes on the mother's abdomen, or internally, by attaching electrodes to the fetus.

GENETIC MANIPULATION: Making changes in the genetic code to correct imperfections or introduce a new genetic characteristic.

GENETIC OR BIOLOGICAL FATHER: The man whose sperm fertilizes an egg.

GENETIC OR BIOLOGICAL MOTHER: The woman whose egg is fertilized.

GESTATIONAL OR UTERINE MOTHER: The woman who carries the pregnancy to term.

INFERTILITY: Inability to become pregnant as readily as most women or couples. In North America, a couple that has been having intercourse for one year, isn't using any form of birth control, and hasn't conceived, is considered by medical experts to be infertile.

IN VITRO FERTILIZATION: 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.

PARTHENOGENESIS: A type of asexual reproduction in which the female egg is duplicated without being fertilized by sperm. Parthenogenesis produces only female offspring. The process has been used in laboratory experiments, but has not been done with humans.

PELVIC INFLAMMATORY DISEASE (PID): An infection of the uterus and fallopian tubes. PID is often caused by untreated sexually transmitted diseases like chlamydia and gonorrhea. PID can cause scarring and blocking of the fallopian tubes, and can lead to infertility, ectopic pregnancy or pelvic pain.

PRE-CONCEPTION CONTRACTS: The contract a woman signs when she agrees to act as a "surrogate mother" and 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.

SEX SELECTION: Choosing the sex of a child before birth. Sex selection can be done before conception, by separating male and female sperm. The woman is then artificially inseminated with sperm that are 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.

STERILITY: Inability to conceive. Sterility may be primary, meaning that no conception has ever been possible, or secondary, which means that the sterility has been caused by surgery or disease.

SURROGATE MOTHER: A term used to describe a woman who is artificially inseminated with the sperm of a man whose wife is unable or unwilling to bear a child, and who has agreed to give the baby to the couple after it is born. She is usually paid for this service. The term "surrogate mother" is misleading in this case, because the "surrogate" is in fact the true biological mother of the child.

ULTRASOUND: Sends high frequency sound 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.

Resources and Information on
THE NEW REPRODUCTIVE TECHNOLOGIES

ORGANIZATIONS

The organizations listed here are national and international. Keep in mind that there may also be groups working on these issues in your own community.

- **Canadian Advisory Council on the Status of Women/Conseil consultatif canadien sur la situation de la femme**, 110 O'Connor Street, PO Box 1541, Station B, Ottawa, Ontario K1P 5R5

- **Canadian Research Institute for the Advancement of Women/Institut canadien de recherches sur les femmes,** 151 Slater, Suite 408, Ottawa, Ontario K1P 5H3

- **Conseil du statut de la femme,** Centre de documentation, 8, rue Cook, 3rd Floor, Quebec City, Quebec

- **FINRRAGE** (Feminist International Network Resisting Reproductive and Genetic Engineering). Canadian contact:
  - Somer Brodribb, Department of Sociology, O.I.S.E., 252 Bloor Street West, Toronto, Ontario

- **National Action Committee on the Status of Women (NAC)**, 344 Bloor Street West, Suite 505, Toronto, Ontario M5S 1W9

- **Women's Health Interaction**, 58 Arthur Street, Ottawa, Ontario K1R 7B9

PRINTED RESOURCES ON REPRODUCTIVE TECHNOLOGY

- **But What Will they Mean for Women? Feminist Concerns About the New Reproductive Technologies.** Linda S. Williams. No. 6 in the series "Feminist Perspectives". Available for $3.00 from: Canadian Research Institute for the Advancement of Women, 151 Slater, Suite 408, Ottawa, Ontario K1P 5H3.
- **The Custom-Made Child? Woman Centered Perspectives.** Helen B. Holmes, Betty B. Hoskins, and Michael Gross, editors. New Jersey, Humana Press, 1981.
- **Man-Made Women: How New Reproductive Technologies Affect Women.** Gena Corea. Indiana University Press, 1987.
- **The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs.** Gena Corea. New York, Harper and Row, 1985.
- **The New Our Bodies, Ourselves.** The Boston Women's Health Collective. New York, Simon and Schuster, 1985.
- **New. Reproductive Technologies: Research Information for Women.** 1988. Available from: Canadian Research Institute for the Advancement of Women, 151 Slater, Suite 408, Ottawa, Ontario K1P 5H3.
- **Sortie La Maternité du Laboratoirie.** Proceedings from the International Conference on New Reproductive Technologies, October 29-31, 1987. Gouvernment du Quebec, Conseil du Statut de la Femme. 1988. (Fifteen of the 37 articles are in English.)
- **Sterilité et infertilité: deux concepts, deux realities.** Madeline Rochon. Services des etudes socio-sanitaires, Ministre de la Sante et des Services Sociaux, 1989.
- **The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood.** Barbara Katz Rothman. New York, Viking Penguin Inc., 1986.
- **Test-Tube Women: What Future for Motherhood?** Rita Arditti, Renate Duelli Klein and Shelly Minden. Boston, Pandora Press, 1984.
- **Women and Reproductive Technologies: Report Prepared for Status of Women Canada.** Somer Brodribb. 1988.
  Available from: Status of Women Canada, 151 Sparks Street, Ottawa K1A 1C3.

VIDEO RESOURCES ON REPRODUCTIVE TECHNOLOGY

- **In the Light of the Womb/ Au clair de l'ovule.** 1987 (French and English). Distributed by: Quebec, Service de la distribution de documents.
  An exploration of the political, social, economic, psychological and ethical repercussions of the new reproductive technologies on the lives of women. Prenatal diagnosis, in vitro fertilization and artificial insemination are discussed.

- **La cigogne technologique.** 1987 (French). Distributed by: Office national du film (NFB).
  An examination of two infertile couples, one who accepts childlessness and another who chooses to register in an in vitro program.

- **In Fertile Ground.** 1987 (English). Distributed by: Women's Health Interaction (WHI), 58 Arthur Street, Ottawa K1R 7B9.
  Presents a feminist examination of population control, family planning and the new reproductive technologies, focusing on their impact on the lives of women in developing countries.

- **One, Two, Three—Zero.** 1979 (English). Distributed by: CBC Enterprises.
  From the TV series, The Nature of Things. The film looks at medicine's role in the treatment of infertility and sterility.

PRINTED RESOURCES ON POLITICAL ACTION AND LOBBYING

- **Action Research for Women's Groups.** Jan Barnsley and Diana Ellis. Vancouver: Women's Research Centre, 1987.
  Available for $3.00 from: Women's Research Centre, #101-2245 W. Broadway, Vancouver, BC V6J 1X6.

- **Every Voice Counts: A Guide to Personal and Political Action.** Penney Kome. Ottawa: Canadian Advisory Council on the Status of Women, 1989. Publication # 89-L-156.
  Available from: Canadian Advisory Council on the Status of Women, 110 O'Connor Street, 9th Floor, Box 1541, Station B, Ottawa, Ontario K1P 5R5.

- **Women Using Media to Effect Change.** (The Tribune: Women and Development Quarterly, Newsletter 41, March 1989).
  Available from: International Women's Tribune Centre, 777 United Nations Plaza, New York, NY 10017 USA.

WHAT DO YOU THINK OF "OUR BODIES. . . OUR BABIES?"

Your feedback on this community resource kit is most welcomed and is in fact essential to our future efforts in communicating information in this format. It is hoped that this kit will be used by a wide range of Canadians many of whom will be encouraged to participate in the Royal Commission. A few minutes of your time to answer the questions below would be most appreciated.

1. Was the kit used by an individual or group?
   Individual ____ Group____

2. If used by a group, please describe the group-- its objectives, how many people are involved?

3. For what purpose was the kit used?

4. Before using the kit were you or the group familiar with the issues surrounding new reproductive technologies?

5. After using the kit do you feel that the information is sufficient or do you need further information before the kit's contribution can be useful to you?

6. Was the background material (articles, Dilemmas) useful?

7. Did your group do any of the activities suggested in the sheets on 'What you can do about new reproductive technologies'. If so which ones? Were they successful?

8. Which parts of the kit were most useful and which were least useful? Why?

9. Please feel free to add any additional comments on the back side of this sheet.

Thank you for your time. Please return to CRIAW at 151 Slater St., Suite 408, Ottawa, Ontario, K1P 5H3.