

Privacy and Assisted Human Reproduction: A Discussion Paper

Jennifer Foster and Barbara Slater

Introduction

The tension between reproductive rights and privacy interests is not a new theme. Some of the greatest legal and political controversies concern matters of reproduction and procreation. Heated debates rage over old familiars such as abortion, as well as relative newcomers, such as embryonic stem cell research and reproductive cloning. However, while the battle between biology and technology has typically been waged on the terrain of the female body, developments in reproductive technologies have brought gender equality to these debates.

The “right to privacy”¹ is an integral component of privacy interests that extend from control of personal information to autonomous decision-making respecting personal space and bodily integrity. Privacy issues within the realm of human reproduction span this entire range and the dimensions of these rights present novel challenges. A woman and a man who wish to conceive a child may require assistance from sperm or egg donors and surrogate or gestational carriers,² and Canadian law and policy dictate that the confidentiality of each individual’s health information must be protected. Furthermore, the freedom to make decisions about one’s reproductive future is a fundamental aspect of the right to privacy, and particularly relevant in the context of assisted conception. Privacy, therefore, becomes essential to the structure and function of any system of assisted reproduction regulation, and the characterization of reproductive legislation as either enabling or prohibitive depends significantly on the level of privacy protection that it provides.

In May 2002, the Canadian federal government introduced Bill C-56, *An act respecting assisted human reproduction*.³ This paper will explore privacy issues inherent in Bill C-13 and the role of these issues in the broader legal and practical debate respecting privacy standards and principles in Canada.

Privacy and Bill C-13

With respect to health information, the bill sets out provisions dealing with the collection, use and disclosure of health information collected and generated within the context of regulated activities under the bill.⁴ These sections outline: information to be collected from individuals donating reproductive material or undergoing reproduction procedures; notification to be given respecting the collection of information; consent requirements with respect to reproductive material, embryos and health reporting information; and use of this information by the regulatory Agency established under the legislation. The bill also sets out, by regulation, the circumstances under which health reporting information must be or may be disclosed and when this information may be destroyed.⁵

While *Bill C-13* purports to regulate the collection, use, disclosure, retention and destruction of health reporting information in various circumstances, the bill lacks many of the broader elements typically found in privacy legislation.⁶ In order to ensure the confidentiality of personal health information, the legislation must embrace the principle of openness that is a fundamental component of fair information practice.⁷ As a first step towards achieving this objective, the legislation must fully and clearly stipulate acceptable information practices rather than leaving these details to future regulation-making endeavours. In this respect, a narrowing of the extensive regulation making power with respect to the creation or maintenance of a record or standards for the collection, use, disclosure, storage and destruction of records would improve the appearance of the legislation from a privacy perspective.⁸

A related issue raised by the bill concerns the lack of general limiting principles on the collection, use and disclosure of health information, contrary to established privacy laws and initiatives. Provisions that permit the collection, use or disclosure of health reporting or otherwise personal information must limit the scope of these activities to that



which is necessary to serve the legislative purpose of the activity. The legislation must also clearly state that wherever possible, non-identifying information must be collected, used or disclosed. These points are especially relevant where health information is used for the purposes of research and law enforcement, as well as the use of health information by the Agency.

Additionally, *Bill C-13* is silent on permissible or non-permissible secondary uses or disclosures of information. Current disclosure provisions address only the initial disclosure of information by licensees⁹ and not subsequent disclosures by recipients of information. Since the bill fails to include a general limiting statement of authority or scope, clearly stated limitations on the disclosure of information linked to permitted activities under the legislation are essential to preserve confidentiality of health information. Furthermore, the bill should also stipulate that wherever possible, information must be collected directly from the individual, and should prescribe limitations on the indirect collection of information.

From a broader perspective, privacy concerns are also raised by the definition of a number of key terms found in the bill. Here are just two examples.

(a) “Assisted reproduction procedure”

Provisions that afford privacy or access rights,¹⁰ prescribe disclosure or consent requirements,¹¹ permit destruction of information,¹² or refer to information in the personal health information registry¹³ address persons who have “undergone,” or who have been “conceived by means of,” an assisted reproduction procedure. “Assisted reproduction procedure” means “any controlled activity referred to in s. 10 performed for the purpose of creating a human being.”¹⁴ However, s. 10 makes no mention whatsoever of persons who have been participants in (in the sense of having undergone or having been conceived of by) an assisted reproductive procedure. Instead, s. 10 is framed in the language of prohibitions as they may apply to a clinician or researcher.

For instance, one “procedure” under the legislation would include “altering, manipulating or treating human reproductive material for the purpose of creating an embryo.”¹⁵ Another “procedure” would involve “altering, manipulating, treating, or making use of an *in vitro* embryo.”¹⁶ In other words, the meaning of “procedure” in respect of assisted human reproduction becomes synonymous with the use or handling of reproductive materials or embryos, rather than with the experience of the individual who has participated in or who has been the subject of any of these activities.

The failure of the definition of “procedure” to identify or incorporate the perspective of the participants in assisted conception procedures generates confusion respecting the intended recipients of rights and protections under the health reporting information provisions of the bill. A definition that clearly incorporates this perspective is crucial for the exercise of these rights.

In addition to creating confusion respecting the application of this definition, and therefore potentially endangering access and privacy rights for individuals using or conceived by assisted reproduction techniques, the currently drafted definition of assisted reproduction procedure disregards basic principles of dignity and autonomy of surrogates. For instance, a gestational carrier would only be captured by the legislation as a person undergoing an assisted reproduction procedure by virtue of being a part of the process of “making use of an *in vitro* embryo.” Apart from contravening the opening principles by commodifying this woman as simply a tool of the process of creating embryos, this may not be the most effective way to protect her health, safety and rights.

Curiously, the definition of assisted reproduction procedure, in conjunction with s. 10, also includes obtaining, storing, transferring, destroying, importing or exporting sperm or ova, except where these activities are not undertaken for the purpose of creating an embryo.¹⁷ It is hard to understand why the storage of sperm constitutes an “assisted reproduction procedure,” while the transfer of an embryo to a female body must be characterized as an alteration, manipulation, treatment or use of a human embryo in order to fall within the definition.

(b) “Donor”

A similar comment is warranted by the definition of “donor.” With respect to human reproductive material, a “donor” is “the individual from whose body it was obtained, whether for consideration or not¹⁸.” In relation to an *in vitro* embryo, a “donor” is “as defined in the regulations¹⁹.” However, these definitions do not address when an embryo is considered donated and by whom. This question may be easily resolved where the donation respects so-called “extra” embryos of an individual or a couple during the process of assisted conception, but the issue becomes more complex where many individuals are involved.

Further, without greater clarity regarding issues of “donation” and in the context of a very broad definition of “human reproductive material,” it is unclear whether a woman inseminated by donor or her partner’s sperm will be considered an ova donor, particularly if she is a surrogate mother. Since the definition of “donor” as it pertains to

reproductive material refers to the individual “from whose body it was obtained,” it is questionable whether ova fertilized within the female body following insemination is “obtained” in any way. However, this exclusion would create an artificial distinction and is obviously contrary to legislative intent. Confidentiality of donor health information, as well as access rights on the part of children conceived using donated reproductive material, will only be ensured where key terms that convey these rights and obligations are precisely defined.

The kaleidoscope of social and biological relationships that often merge with assisted conception, and the emotional, familial and social implications for the resulting child, demands that greater attention be paid to the definitions intrinsic to these processes. However, in failing to define key terms, *Bill C-13* fails to consider the different implications that may arise with various forms of assisted conception.

The resolution of this situation is especially important with respect to the disclosure of health reporting information to children conceived with reproductive technologies. Under the bill, individuals conceiving a child with medical assistance, using their own reproductive material and without surrogacy, would be required to disclose health reporting information to a licensee by virtue of being either donors of reproductive material or individuals who have undergone an assisted reproduction procedure.²⁰ This information would be available to the resulting child under the access provisions of the bill. In this particular situation the child would receive identifying health information about her known biological parents even though the conception involved only these individuals.

Children born from assisted conception in this situation will become a unique class of children with access rights to parental health information in sharp contrast to children conceived without assistance. In this way, the legislation draws a distinction between individuals on the basis of fertility and denies the fundamental right of privacy to those individuals or couples who have experienced infertility and have accessed reproduction techniques in order to create a family.

The Right to Privacy and Reproductive Autonomy

With respect to privacy rights, the distinction between fertile and infertile individuals is worthy of consideration. As

deleterious effects within Western society on human health and well-being interfere with natural fertility rates, and as individuals decide to start families later in life, demand for reproductive assistance rises. In Canada, the right to procreate and the designation of infertility as a disability in the context of assisted conception require greater legislative and judicial attention. In *Cameron v. Nova Scotia (Attorney General)*,²¹ the Nova Scotia Court of Appeal held that the exclusion of *in vitro* fertilisation (IVF) or intra cytoplasmic sperm injection (ICSI) services from the provincial health insurance plan drew a distinction between the fertile, who

receive full coverage for reproduction services, and the infertile, who do not.

The majority found that this distinction was based on physical disability, an enumerated or analogous ground of protection under the *Charter*, and

therefore discriminatory. However, even though the discriminatory policy was ultimately justified under a s. 1 analysis, the court’s characterization of infertility as a physical disability is a significant development. Legislative encroachment of fundamental privacy rights upon individuals seeking assistance with conception, particularly if there is a differential impact on different classes of these individuals, may provide fertile ground for future constitutional challenges.

Support for the privacy rights of infertile individuals may also be found in caselaw that establishes reproductive autonomy as a fundamental human right. Canadian judicial decisions, such as *R. v. Morgentaler*,²² *E. (Mrs.) v. Eve*,²³ and *Winnipeg Child and Family Services v. G. (D.F.)*,²⁴ have addressed the right to reproductive autonomy, which includes the right to make both reproductive decisions and decisions that impact upon reproduction. While Canadian caselaw has yet to establish reproduction as a basic human right,²⁵ in *Eve*, LaForest J. discusses the fallacious reasoning of the eugenics movement and a growing legal recognition in the common law of the fundamental character of the right to procreate.²⁶ Under American caselaw, reproduction has been established as a basic civil right of humans and the right to privacy has been linked to the right to liberty, which includes a right to procreation.

These decisions emphasize the significance of reproduction to human existence, and a right to privacy is implied within a right to reproductive autonomy. Considered in the context of assisted conception, assisted reproduction legislation should ensure that access to reproductive technologies impairs these fundamental human rights as little as possible.

However, in failing to define key terms, Bill C-13 fails to consider the different implications that may arise with various forms of assisted conception.

Donor Anonymity versus Mandatory Disclosure of Identity²⁷

Under *Bill C-13*, a licensee is required to collect health reporting information from donors of human reproductive material before accepting the material.²⁸ However, unless the donor has consented to the disclosure of identifying information, individuals who make use of, or who are conceived by means of, the donation are entitled only to the non-identifying health information of the donor held by the licensee.²⁹ These provisions represent a legislative compromise between the recommendations of the Standing Committee on Health³⁰ and public interest to the contrary. Despite this compromise, the debate addressing donor anonymity still rages within the Standing Committee evidentiary hearings.

The bill itself provides little guidance for the resolution of this inherent tension. In the absence of legislative initiatives that redefine parentage and inheritance rights, mandatory disclosure of donor identity is problematic. While the legislative reach of the bill stops at the transfer of reproductive material or embryo to the female body, principles outlined within s. 2 of the legislation are inconsistent with this interpretation. The first principle declares that “the benefits of assisted human reproductive technologies for individuals and society can be most effectively secured by measures that protect and promote human health, safety, dignity and rights in the *use* [emphasis added] of these technologies and related research.³¹” This principle values the beneficial use of the technology rather than its application to the people involved in the process. The second principle, however, reverses the direction of the first principle and states that “the health and well-being of children born through the application of these technologies must be given priority in all decisions affecting their use.³²” In the absence of further provisions defining the scope of the legislation, these introductory principles provide little guidance and instead create a confusing array of priorities. As a result, it is unclear whether the legislation is intended to serve an enabling or a prohibitive purpose, and a clear understanding of how privacy rights fit in is essential to this determination.

Unless assisted reproduction legislation addresses parental definitions and responsibilities as well as inheritance rights,³³ or legitimizes the use of preconception agreements, anonymity is a vital element of the donation system. Judicial decisions addressing donor anonymity are sparse; however,

a recent case from California is a noteworthy precedent. In *Johnson v. Superior Court*,³⁴ the appeals court ordered the production of sperm donor identity on a motion for discovery where a child conceived using the donor sperm was diagnosed with a rare genetic disorder transmitted by

Considered in the context of assisted conception, assisted reproduction legislation should ensure that access to reproductive technologies impairs these fundamental human rights as little as possible.

the sperm. In this case, Mr. and Mrs. Johnson sued California Cryobank, alleging professional negligence, fraud and breach of contract for its assurances related to the health of the sperm. The facts showed that the donor had fully disclosed his family

medical history to California Cryobank, but that Cryobank failed to convey the relevant information to the Johnsons. During the proceedings, the Johnsons asserted their right to depose the sperm donor and to obtain his identity and all of his medical information in order to make their case against Cryobank. The court ultimately found that the discovery request constituted a serious invasion of privacy. However, the court held that the invasion was justified by compelling state interests: compliance with discovery requests; the search for truth in discovery proceedings; and ensuring that injured plaintiffs receive full redress of their injuries. In this case the balance of interests was tipped against donor privacy and autonomy in reproductive decision-making. The justification of the court for intrusion upon these fundamental human rights sets a relatively low bar for future determinations.

The right to privacy in the context of sperm donation is not particular to the donors themselves. Donor anonymity also protects the child conceived and her parents from unwarranted strain upon the family unit.³⁵ Many parents who have used assisted reproduction technology prefer not to disclose the circumstances of conception to their children. In some cases, religious or social factors may prescribe secrecy in this area. For instance, religious or societal communities may discourage or even prohibit certain reproductive activities despite the desire of an individual or couple to reproduce. These individuals may feel compelled to conceal the methods used to conceive a child to prevent condemnation by their community. Furthermore, these families may not welcome the reappearance of a sperm donor after their child is born, for any number of personal reasons. Proponents of mandatory identity disclosure point out the need for ongoing health information relevant to illness or disease that may manifest itself at some point after birth. While this is certainly a pressing concern, it is possible that a desire for information may come from the donor himself. Legislative and policy initiatives that

advocate ongoing disclosure for the health and well-being of the child must also consider whether a donor is entitled to similar rights. Ongoing disclosure may permit a donor to contact a donor child upon his discovery of a relevant health issue. Ongoing disclosure may also permit a donor to contact a donor child in order to request a blood or tissue match for one of the donor's own naturally conceived children.³⁶ These implications of mandatory identity disclosure should be fully canvassed by any jurisdiction legislating in this area.

The prospect of mandatory disclosure of identity also raises a number of practical concerns. Research studies and surveys have suggested that mandatory disclosure of donor identity creates a reluctance to donate and a corresponding scarcity of donors.³⁷ According to Dr. Clifford Librach,³⁸ the combination of mandatory identity disclosure and the prohibition against payment for reproductive materials under the bill would negatively impact upon the supply of reproductive materials available and the subsequent conception of children through assisted reproduction technologies. Infertile individuals and couples may attempt to access this technology in another country, and those who cannot afford this option may be forced to obtain these services illegally. This prospect potentially threatens individual health and quality of care standards throughout the industry, and prompts a decline in expertise and research opportunities for Canadian fertility specialists with negative consequences for individuals seeking reproductive assistance in respect of service delivery and accessibility.

The threat of a diminished supply of reproductive material, the lack of clarity regarding privacy protection under the bill and the prospect for mandatory disclosure of identity would significantly impact upon the quality of the reproductive products available. In Canada, donated sperm must undergo screening and testing in accordance with Health Canada guidelines, and only three to four percent of all donations are accepted under criteria related to age, medical history or sample quality.³⁹ One estimate suggests that a mandatory identity release policy would reduce the number of available donors in the Xytex program from 45 to 10.⁴⁰ Furthermore, at this time over 80% of all sperm used in Ontario fertility clinics is purchased from American donors, a source that will dry up upon enactment of the prohibitions related to compensation for donor reproductive material.⁴¹ Canadians who are forced to obtain reproductive material outside of the licensed clinics will not benefit from health and safety protections developed within the reproductive services industry.

The deterioration in quality and supply of human reproductive material in Canada would also have an impact on the ability of researchers and scientists to improve

reproductive technologies and to advance the field of human embryonic stem cell research. *Bill C-13* recognizes the importance of research in improving reproductive technologies and educating practitioners in this area. An insufficient supply of reproductive material would therefore hamper all of the development of reproductive sciences to the detriment of those seeking reproductive assistance.

Conclusion

Privacy is an integral component of human reproduction, and protection of privacy is of paramount concern in the context of assisted conception. The nature of this technology challenges typical models of privacy protection as well as fundamental human rights and dignity. Insensitivity to these challenges will have significant repercussions on the availability of reproductive services for individuals in need. In order for science to move forward, legislation must safeguard the privacy of individual participants and protect basic human rights and dignity without curtailing available resources and opportunities.

Jennifer Foster, Barrister & Solicitor and Barbara Slater, Manager, Health Sciences Policy Unit, Ontario Ministry of Health and Long-Term Care. With thanks to Brent Windwick, Health Law Institute, University of Alberta for his perspectives and comments. The authors wish to stipulate that the views and opinions expressed in this paper are their own and do not reflect those of the Ontario Ministry of Health and Long-Term Care, or any other organization, institution or corporation.

1. Although Canadian caselaw supports privacy as a constitutional right, the extent of this protection is presently unclear. *McInerney v. MacDonald*, [1992] 2 S.C.R. 138, *R. v. Mills*, [1999] 3 S.C.R. 668, and *R. v. O'Connor*, [1995] 4 S.C.R. 41,1 addressed, generally, the relationship between disclosure of personal (medical or therapeutic) information and individual autonomy. These cases acknowledge, but do not define the scope of the right to privacy under the *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11 [*Charter*]. For an expansive discussion of this issue, see M. Marshall & B. von Tigerstrom, "Health Information" in J. Downie, T. Caulfield & C. Flood, eds., *Canadian Health Law and Policy*, 2nd ed. (Toronto: Butterworths, 2002) at 160-4.
2. In the course of this discussion, we distinguish between a traditional surrogate mother, who is inseminated with donor sperm and carries the embryo to term, and a gestational carrier, who bears no genetic connection to the embryo that is transferred to her body after fertilization takes place *in vitro*.
3. 1st Sess., 37th Parl., 2002 (1st reading 9 May 2002). After the proroguing of Parliament the bill was re-introduced in October, 2002 as Bill C-13, *An Act respecting assisted human reproduction*, 2d Sess., 37th Parl., 2002 (1st reading

- 9 October 2002) [*Bill C-13*], pursuant to an Order made October 7, 2002, in the same form as *Bill C-56*.
4. *Ibid.*, ss. 14-15, 18.
 5. *Ibid.*, ss. 15-16, 18.
 6. The Canadian Standards Association has drafted a *Model Code for the Protection of Personal Information* (Etobicoke, Ontario: Canadian Standards Association, 1996) [CSA Code]. While this Code was originally drafted as a voluntary code, it is now incorporated as Schedule I to the *Personal Information Protection and Electronic Documents Act, S.C. 2000, c. 5 [PIPEDA]*. *PIPEDA* is a federal act that protects the confidentiality of personal information in Canada and the CSA Code has now become a mandatory reference point for the information practices of any institution, organization or government agency governed by *PIPEDA*. *Bill C-13* provisions should be tightened in accordance with CSA principles.
 7. Principle 8 of the CSA Code, openness, states that “an organization shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.”
 8. See *Bill C-13, supra* note 3, ss. 65(1)(a)-(z) for a full account of the regulation-making power within the purview of the Governor-in-Council.
 9. A “licensee” under the legislation is an individual/facility that has obtained a license issued in respect of a controlled activity or premises under s. 40.
 10. *Bill C-13, supra* note 3, ss. 15(4) and 16.
 11. *Ibid.*, ss. 18 (2) and (3).
 12. *Ibid.*, s. 16(2).
 13. *Ibid.*, s. 17.
 14. *Ibid.*, s. 3.
 15. *Ibid.*, s. 10(1).
 16. *Ibid.*, s. 10(2).
 17. *Ibid.*, s. 10(3).
 18. *Ibid.*, s. 3.
 19. *Ibid.*
 20. Pursuant to the s. 14 requirement that licensees collect this information as a condition of their license to provide these services.
 21. (1999), 177 D.L.R. (4th) 611 (N.S.C.A.) [*Cameron*].
 22. [1988] 1 S.C.R. 30 [*Morgentaler*]. Wilson J. states, at 56-7, that “the right to liberty...guarantees to every individual a degree of personal autonomy over important decisions intimately affecting their private lives.”
 23. [1986] 2 S.C.R. 388 [*Eve*].
 24. [1997] 3 S.C.R. 925.
 25. See *Morgentaler, supra* note 22 at 168-69 for Wilson J.’s discussion of the right to procreate in the context of American caselaw: *Skinner v. Oklahoma*, 316 U.S. 535 (1942); *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Griswold v. Connecticut*, 381 U.S. 479 (1965) and *Roe v. Wade*, 410 U.S. 113 (1973).
 26. *Cameron, supra* note 21 at 419-420.
 27. While the legislation contemplates donations of male and female reproductive materials, considerations relating to the donation of ova require a more thorough analysis and as such are beyond the scope of this discussion. Anonymity and disclosure in this section will focus primarily on the donation of sperm.
 28. *Bill C-13, supra* note 3, s. 14.
 29. *Ibid.*, ss. 15(4), 18(3).
 30. See Standing Committee on Health, “Assisted Human Reproduction: Building Families” (December 2001), online: Parliament of Canada <<http://www.parl.gc.ca/InfoComDoc/37/1/HEAL/Studies/Reports/healrp01/09-rec-e.htm>> (date accessed: 18 November 2002). Recommendation 19 prescribes the release of identifying donor information and ongoing disclosure of health information throughout the life of the donor.
 31. *Bill C-13, supra* note 3, s. 2(a).
 32. *Ibid.*, s. 2(b).
 33. In Canada, issues related to parentage usually arise in the context of family law statutes and generally fall within provincial jurisdiction. A co-ordinated effort among the federal, provincial and territorial levels of government is required to address these issues.
 34. 95 Cal. Rptr. 2d 864 (Ct. App. 2000) [*Johnson*]. Review denied August 23, 2000. In *Johnson*, the court in effect ordered production of the donor’s information to enable the Johnsons to gain the necessary information to build a successful lawsuit against the sperm bank. It is important to note that the suit was brought against the sperm bank itself and not against the donor. *Johnson* is a significant decision because it is the first case in the United States to directly address a donor’s right to privacy in the context of artificial insemination.
 35. L.R. Dollens, “Artificial Insemination: Right of Privacy and the Difficulty in Maintaining Donor Anonymity” (2001) 35 Ind. L. Rev. 213 at 236.
 36. *Ibid.* at 239.
 37. See BBC News Online, “Sperm donors want to keep anonymity” (15 October 2002), online: BBC News Online <<http://news.bbc.co.uk/1/hi/health/2329675.stm>> (date accessed: 18 November 2002) for a discussion about the practical implications of legislated sperm donor identification on the availability and use of donated reproductive material; *Johnson, supra* note 34 at 240.
 38. Fertility Specialist, Department of Obstetrics and Gynaecology, Sunnybrook and Women’s College Hospital Health Sciences Centre, testimony before Standing Committee on Health, 12 June 2002 at 1535, online: Parliament of Canada <<http://www.parl.gc.ca/InfoCom/CommitteeEvidence.asp?Language=E&Parliament=8&Joint=0&CommitteeID=147>> (date accessed: 15 September 2002).
 39. Heather Brooks, Services Co-ordinator, Xytex Canada Inc. (Xytex is a company specialising in reproductive services and products), testimony before Standing Committee on Health, 12 June 2002 *ibid.* at 1655.
 40. *Ibid.*
 41. Personal communications with the Canadian Fertility and Andrology Society of Canada and providers of assisted reproductive technologies, May 21, 2002.

|

