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Rachel Ariss
University of Toronto

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Rachel Ariss*

The Form and Substance of
Ethics: Prenatal Diagnosis in the
Baird Report

This article analyses the employment of textual tactics in the Final Report of the Royal Commission on New Reproductive Technologies. The author argues that the Commission uses these tactics to persuade several different audiences that its stance is correct, and simultaneously to manage dissent over new reproductive technologies. Analysis of textual tactics opens the ethical position of the Commission to substantive questioning. The author focuses on the Commission's discussion of prenatal diagnosis for genetic anomalies and concludes that the Commission fails to engage with ethical arguments put forward by persons with disabilities and their advocates. The conclusion also encourages the development of an ethics of disability.

Cet article fait l'analyse de l'emploi de tactiques textuelles dans le rapport final de la Commission extra-parlementaire sur les nouvelles technologies de reproduction. L'auteur argumente que la Commission utilise ces tactiques à la fois pour convaincre plusieurs différentes audiences que leur position est correcte et pour gérer les opinions divergentes sur les nouvelles technologies de reproduction. L'analyse de ces tactiques textuelles soulève une interrogation quant à la position éthique de la Commission. L'auteur se concentre surtout sur les discussions de la Commission qui portent sur le diagnostic prénatal pour les anomalies génétiques. Elle conclut que la Commission néglige de répondre aux arguments avancés par les personnes handicapées et leurs partisans, et elle termine en encourageant le développement d'une éthique d'incapacité.

* R. Ariss is a doctoral candidate at the Faculty of Law, University of Toronto. I would like to thank Prof. S. Noonan, Faculty of Law, Queen's University for her comments on an earlier version of this article. I am also grateful to the anonymous reviewers at Dalhousie Law Journal for their constructive criticisms.

Introduction

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Introduction

The mandate of the *Royal Commission on New Reproductive Technologies* was to “inquire into and report upon” the current and future state of new reproductive technologies. It was to consider specifically the technologies’ “social, ethical, health, research, legal and economic implications and the public interests. . . .”¹ The *Baird Report* is, perhaps not surprisingly, lengthy, factual, technical and dense. It presents itself as thoughtful, yet it is stolidly conclusive on the ethics of current uses of new reproductive technologies. It strives to attain prescriptive authority, and to reflect the values and views of the Canadian public, all the while remaining grounded in a beneficent medical science. The Commission engages in a number of textual tactics through which it attempts to maintain these various positions; importantly, a further effect is the exclusion, or at least, management, of dissent. The Commission marginalizes voices, particularly feminist voices, that radically question the subtexts and power implications of new reproductive technologies.

In this article, I consider both the form and substance of the Commission’s discussion of prenatal diagnosis for genetic anomalies. The manifestation of the Commission’s ethical approach in its arguments justifying its recommendations is especially interesting. The Commis-

1. Canada, *Proceed With Care: Final Report of the Royal Commission on New Reproductive Technologies* (Ottawa: Minister of Government Services Canada, 1993) (Chairperson: P. Baird) at forepages [hereinafter *Baird Report* or *Report*].

sion uses its version of the ethic of care both to argue the merits of prenatal diagnosis, and as a textual tactic to support its claimed position as the properly ethical, the truly “caring” voice in debates over new reproductive technologies.² The participants in the Commission’s public hearings presented arguments, perceptions and opinions that intertwined principles, experience, emotion and spirituality. The Commission refused to accept this layered sensibility as ethics, in favour of an impartial and neutralizing stance in which it portrays itself as the authoritative ethical voice in the debate.

Centred as it is on the technology of prenatal diagnosis, the Commission cannot engage with the substantive ethical questions inherent in determining fetal dis/ability. I have approached the task of deconstructing the Commission’s arguments (for both form and substance) from an understanding of the ethic of care as a complex approach to moral decision-making. The ethic of care, as presented by Carol Gilligan, is not without problems.³ Nor is it, however, as simply reflective of medical beneficence as the Commission portrays it. At the end of its brief discussion on the ethic of care, the Commission states, “Of course, promoting the ethic of care is not entirely new—to a degree it has been reflected over the centuries in various formulations of medical ethics and

2. The Commission claims the ethic of care and a number of guiding principles (individual autonomy, equality, protection of the vulnerable, non-commercialization of reproduction, appropriate use of resources, accountability and balance of individual and collective interests) as its evaluative tools for the use of new reproductive technologies. The Commission understands the ethic of care as “concerned with how to build relationships and prevent conflict,” and as a “perspective that fosters care and community. . . .” (*Baird Report* at 50). This simple explanation of the ethic of care is in direct contrast to that developed by C. Gilligan in *In A Different Voice: Psychological Theory and Women’s Development* (Cambridge, Mass.: Harvard University Press, 1993). Gilligan illustrates the stages of development in the ethic of care through her chapter on women making abortion decisions. While Gilligan’s exposition of the ethic of care is more complex and frankly, more attractive to me than that espoused in the *Baird Report*, it is not without serious flaws. For an explanation and critique of Gilligan’s ethic of care and a detailed exploration of its use in the *Baird Report*, see R. Ariss, “The Ethic of Care in the Final Report of the Royal Commission on New Reproductive Technologies” (1996) 22 *Queen’s L.J.* 1.

3. For an example of the debate which sprang up around the ethic of care in feminist legal theory, see I. Marcus *et al.*, “Feminist Discourse, Moral Values, and the Law - A Conversation” (1985) 34 *Buff. L. Rev.* 11.

For critiques of the ethic of care, arguing that it can be used to justify colonialism and restrict women’s abortion rights, see U. Narayan, “Colonialism and Its Others: Considerations on Rights and Care Discourses” (1995) 10 *Hypatia* 133, and P.S. Karlan & D.R. Ortiz, “In a Diffident Voice: Relational Feminism, Abortion Rights and Feminist Legal Agenda” (1993) 87 *N. Ill. U. L. Rev.* 858, respectively. For an example of applying the ethic of care to the Canadian justice system, see P. Peppin, “Justice and Care: Mental Disability and Sterilization Decisions” (1989-1990) 6 *Can. Hum. Rts. Y.B.* 65.

the duty of physicians.”⁴ Looking at the rhetorical use of the ethic of care in justifying prenatal diagnosis helps open this technology, as well as the rest of the *Report*, to substantive ethical questioning.

This article is divided into two main sections, “Textual Tactics,” and “The Rhetoric of Care and the Ethics of Disability.” The first part broadly canvasses the nature of rhetorical analysis and some of the rhetorical devices which the *Report* uses to assert itself as the authoritative ethical voice in debates over new reproductive technologies. I am not engaging in a classical analysis of rhetorical devices, such as metonymy, metaphor and synecdoche. I use the term “rhetoric” to show that I am engaging in an analysis of the form of the Commission’s discourse, and that through examining form, something of the substance can be understood as well.⁵

I begin “The Rhetoric of Care and the Ethics of Disability” by providing the contexts of my argument. I then engage in a discussion of the physical layout (the form) of the text of the *Baird Report*, focusing on its use of sidebars. I analyse both the substantive and formulaic use of “information” and “reassurance” within the *Report*’s discussion of prenatal diagnosis. I emphasize the rhetorical uses of “care.” This is followed by a brief analysis of the substantive challenge to the Commission’s construction of “care” by an ethics of disability.

Although I focus on the management of dissent within the text itself, there are two issues involving dissent and the Commission which should be mentioned. After internal struggles over the Commission’s research goals, access to information, confidentiality, and the release of interim reports, four of the original seven Commissioners filed a suit against the Chair of the Commission and the federal government.⁶ Martin Hebert, Louise Vandelac, Bruce Hatfield and Maureen McTeer claimed that changes to the Commission’s original Order-in-Council, giving exclusive decision-making authority to the Chair and appointing two new Commissioners violated the *Public Inquiries Act*.⁷ These four Commis-

4. *Supra* note 1 at 51.

5. A rhetorical analysis, quite simply, analyzes the use of language in a given text or discourse. Specifically, it is an analysis of the various ways of persuading an audience toward a certain course of action, usually presented as good for the community. P. Goodrich, *Reading the Law: A Critical Introduction to Legal Method and Techniques* (Oxford: Basil Blackwell, 1986) at 20 [hereinafter *Reading the Law*].

6. M. Eichler, “Frankenstein Meets Kafka: The Royal Commission on New Reproductive Technologies” in G. Basen, M. Eichler & A. Lippman, eds., *Misconceptions: The Social Construction of Choice and the New Reproductive and Genetic Technologies* vol. 1 (Hull, Quebec: Voyageur Publishing, 1993) 196 at 203.

7. *Ibid.* at 200. See Statement of Claim in Basen, *supra* note 6 at 273.

sioners were fired ten days after filing their statement of claim, thus losing standing before the Court and dropping their claim.⁸ In this instance, dissenting opinions were eliminated by excluding the people who held them.

It is also important to note that the *Report* does include "Six Dissenting Opinions" by Commissioner Suzanne Scorsone,⁹ although their inclusion is not as open as it could be. They are tucked into Part Four, entitled "Annex, Glossary, Appendices," requiring the reader to look closely to find that the Annex is a dissenting opinion. Each issue in Scorsone's text could have been included at the end of the appropriate chapter. This would have made it clear to readers that the ethical issues surrounding new reproductive technologies are not as easily resolved, even by the experts, as it appears in the *Report*.¹⁰

I. *Textual Tactics*

The textual tactics used in the *Baird Report* are important because "the rhetorical process at any given historical instance [can] shape and alter public discourse about particular issues in ways that make it, in its own right, a creative contributor to the distribution of power through law, institutions and social practices."¹¹

Whether or not the Canadian government ever implements the recommendations of the *Report*, its style emphasizes some approaches and arguments within the new reproductive technologies debate over others. This emphasis may powerfully shape subsequent public discourse surrounding these issues, determining which ones become controversial and which are overlooked.

James Boyd White argues that law can be seen as a "constitutive rhetoric," or, "the central art by which community and culture are

8. *Ibid.* at 203.

9. *Supra* note 1 at 1053.

10. An example of a different textual structure which includes dissent can be found in the Law Reform Commission of Canada's Working Paper 58, entitled *Crimes Against the Foetus* (Ottawa: The Commission, 1989). At pages 41-45, two approaches to abortion law are outlined. The minority position permitted abortion for whatever reason up to twelve weeks gestation, and from twelve to twenty-two weeks only on medical grounds to protect the physical and psychological health of the woman. The majority position permitted abortion up to twenty-two weeks gestation, only to protect the health of the woman. Both positions are included in the main text and both positions are reflected in two examples of statutory language for the *Criminal Code*. As Ms. Scorsone dissents on only six issues within the Baird Report, this approach could have worked for that text. Another dissent is added at the end of *Crimes Against the Foetus*, which is openly titled "Dissent."

11. C.M. Condit, *Decoding Abortion Rhetoric: Communicating Social Change* (Chicago: University of Illinois Press, 1990) at 7.

established, maintained, and transformed.”¹² He argues that instead of seeing rhetoric (only) as the “ignoble art of persuasion,” it should be seen as “the knowledge of who we make ourselves, as individuals and as communities, through the ways we speak to each other.”¹³ I examine the *Baird Report*’s rhetorical tactics in order to see what kind of ethical approach to new reproductive technologies would be shaped should the Commission’s recommendations become the basis of law. White argues that rhetorical analysis “directs our attention to the most significant questions of shared existence, which are wholly outside the self-determined bounds of science.”¹⁴ This is how an examination of the form of an argument can lead to its substance: asking questions about how and why language is used in a specific discussion can reveal substantive assumptions within and difficulties of the argument.

The creation of community through rhetoric relies on “its continuity with ordinary discourse and hence with real communities, real values and real politics.”¹⁵ White states that rhetoric enables discussion about fundamental values by providing questions to ask of a text: how does the language establish and classify facts? What does it claim as reason? What does it include and exclude? How does the writer reshape this language? Is the text internally and externally coherent and why? White’s most important questions for my analysis of the *Baird Report*’s recommendations on prenatal diagnosis are:

What is the voice here and what kind of response does it invite or allow? What place is there for me, and for others, in the universe defined by this discourse, in the community created by this text? What world does it assume? What world does it create?¹⁶

The Commission creates a community around the proper use of new reproductive technologies by adopting rhetorical devices from both legal and scientific medical discourses. These are institutional discourses with authoritative weight in public debate. It is assumed that law and medicine are neutral or disinterested, particularly when placed beside a social discourse (such as feminism) which is understood as an ideological perspective.¹⁷ Using rhetorical tactics from both law and medicine gives the *Report* a certain disinterested authority. This tactic is also, in part, an

12. J.B. White, “Law as Rhetoric, Rhetoric as Law: The Arts of Cultural and Communal Life” (1985) 52 U. Chi. L. Rev. 684.

13. *Ibid.* at 700.

14. *Ibid.*

15. *Ibid.* at 701.

16. *Ibid.* at 702.

17. J. van Dijk, *Manufacturing Babies and Public Consent: Debating the New Reproductive Technologies* (London: MacMillan Press, 1995) at 20.

example of the use of “borrowed rhetorics.” Borrowing rhetorical tactics makes it easier for texts to inhabit different discursive domains and thus, convince, persuade and manage different audiences at the same time.¹⁸

I will consider the styles of both legal and scientific/medical discourse in order to see where the *Baird Report* obtains its rhetorical tactics. The appearance of authority is central to legal and medical discourse, as it is to several coercive, disciplinary, normalizing discourses at work in society such as psychiatry and religion.¹⁹ As a discourse, law constructs its own “analytic space” within which it assigns roles and functions, and defines and approves certain issues and speakers as properly legal according to highly technical rules.²⁰ Legal discourse is used to convince an audience that it is “the best available means of regulating human conduct [forming] a complete order of rules that are to be distinguished from mere coercion or brute force by their legal quality, namely the unity and rationality of the order (and mechanisms of application) to which they belong.”²¹ From legal rhetorics, the Commission borrows the monologue style, which minimizes the existence of a dialogue and thus manages dissent. Judicial writing uses this style to present “an image of incontestable authority.”²² Peter Goodrich explains that “[s]uch a task is essentially a rhetorical one: the monologue is the language-usage of authority, it precludes dialogue or any questioning of the meanings given, and it closes legal discourse by privileging the voice of the judicial author as the supreme arbiter of meanings.”²³

Textual moves that distance the author from the text, thus making its conclusions appear necessary and logical, are characteristic of the appearance of authority in legal discourse.²⁴ For example, the first seventeen pages of the embryo research chapter of the *Report* explain the views of Canadians on embryo research, the general aims of embryo research,

18. John Lyne, “Bio-Rhetorics: Moralizing the Life Sciences” in Herbert W. Simons, ed., *The Rhetorical Turn: Invention and Persuasion in the Conduct of Inquiry* (Chicago: University of Chicago Press, 1990) at 49. Lyne applies borrowed rhetorics to sociobiology. He states that sociobiologists use the reality/appearance pair as a rhetorical strategy to support their arguments: “Sociobiologists use it to relegate a culture’s preferred understanding of a social behavior to the status of a surface appearance and to present the inferred genetic strategy as the deeper, truer explanation (reality).”

19. *Reading the Law*, *supra* note 5 at 16.

20. *Ibid.*

21. *Ibid.* at 7.

22. *Ibid.* at 188.

23. *Ibid.* at 189.

24. *Ibid.* In order to make conclusions appear necessary, words such as “therefore” or “consequently” are used (at 189). Legal texts are rarely made in the language of personal opinion, rather they emphasize the “shared language of objectivity” (at 189). Another distancing and excluding strategy is to define the issue by saying what it is not about (at 192-3).

specific projects, future directions for research and how eggs and embryos are currently handled in Canada. Finally, the Commission, under the heading “Alternatives to Research on Human Zygotes,” states that

Although animal models can provide insights for application to basic human embryo research, animal research alone is not enough; human embryo research is also needed to safeguard the health and well-being of women and the resulting children. Similarly, the use of human cell lines can provide insights into certain questions, but it cannot eliminate the need for human embryo research.²⁵

The technical explanations of embryo research projects, speculations on the benefits of such research and how it is currently conducted in Canada, have shaped embryo research into a “need.” The Report recommends safeguards to protect women from undue exploitation in the quest for consent to use embryos from this “necessary” research.²⁶ Nowhere in the chapter, however, is there analysis of the thought process that led to the establishment of freezing human eggs and studying human embryonic development as “needs,” rather than for example, technological imperative and scientific curiosity. These goals are accepted as inherently “good.” Only after the conclusion that embryo research is necessary, does the Commission discuss the ethical uses of human zygotes in research, briefly examining debates over the moral status of the embryo, and then permitting research up to 14 days based on biological steps in zygote development.²⁷

25. *Supra* note 1 at 625.

26. Recommendation 186 of the *Baird Report* reads, “Clinics and researchers be permitted to use human zygotes for research only with the fully informed consent of the persons who have donated the gametes used to create the zygote” (at 639); recommendation 187 states that “[a] woman’s or couple’s consent to donate zygotes generated but not used during infertility treatment for research never be a condition, explicit or implicit, of fertility treatment. Potential donors must be informed that refusal to consent does not jeopardize or affect their continuing treatment in any way” (at 640); and recommendation 188 states that “[z]ygotes be created for research purposes only if gametes for this purpose are available without conducting any additional invasive procedures” (at 640).

27. The Commission begins its section “The Ethical Uses of Human Zygotes in Research” after twenty pages of discussion of embryo research. The moral status of the embryo is discussed on pages 631 and 632 and then the *Report* states that “Commissioners recognize that no amount of deliberation on our part will definitively answer the question of the moral status of the embryo” and continues, “[w]e believe that the moral status of the embryo before day 14 after fertilization does not preclude research under certain defined conditions We recommend the 14-day limit on research for several reasons: it recognizes the developmental stage at which the primitive streak appears, establishing the start of one or more distinct entities; it is also the point at which the zygote has normally completed its implantation in the uterine wall; and it is the most widely accepted international standard for embryo research” (*Baird Report* at 632).

As well as creating a community and positively assigning meaning, rhetorical devices can be used to close a text, to avoid an issue, to deflect questions and to manage dissent. These uses of rhetoric are subsumed in the technique of “antirrhetic,” which is, as Goodrich states, “denunciation directed at outsiders, heretics, iconoclasts.”²⁸ The Commission avoids a dialogue when it names the presentations at the public hearings as “opinions and concerns,”²⁹ thereby placing those presentations on a different level than the Commission’s self-proclaimed analytic and ethical approach.

The *Baird Report* uses antirrhetic tactics to establish its authority throughout the Report. The Commission’s primary goal was “[t]o provide direction for public policy by making sound, practical, principled recommendations to help Canadians and our social institutions deal with the technologies now and to put in place mechanisms to ensure a continuing capacity to deal with them.”³⁰ It seeks recognition as the best source for policy to develop the regulation of new reproductive technologies. Rather than emulating traditional legal claims of separation from morals and politics³¹ as legitimating its authority to make “correct” decisions, it claims the moral high ground. The Commission embeds itself in a self-styled “ethic of care” and in “principles” that reflect the “moral point of view,” and gains its authority through its assertion that its analysis is principled.

The ethic of care is very simplistically constructed in the *Baird Report*. The Commission adopts the ethic of care as its basic ethical framework, meanwhile reducing it to the traditional medical ethic of beneficence. The Commission defines and reduces the ethic of care as follows:

Finally, overarching ethical frameworks like utilitarianism or social contract theory often are premised, in one way or another, on an understanding of human nature that sees people as individuals first and foremost, protecting their interests against the encroachment of others. Yet human beings are connected to one another in families, communities and social bonds of all sorts The ethic of care means that a large part of ethical deliberation is concerned with how to build relationships and prevent conflict, rather than being concerned only with resolving conflicts that have already occurred.³²

28. P. Goodrich, “The Continuance of the Antirrhetic” (1992) 4 *Cardozo Studies in Law & Literature* 207 at 207.

29. *Supra* note 1 at 135.

30. *Ibid.* at 8.

31. *Reading the Law*, *supra* note 5 at 191.

32. *Supra* note 1 at 50.

The Commission does not elaborate the ethic of care much beyond the above statement, continuing mainly to focus on the ethic of care as a “perspective that fosters care and community.”³³ The Commission sees the “moral point of view” as distinct from the self-interest of economics and explains that “all people matter in and of themselves . . . and if our decisions affect their well-being, then we must take that into account.”³⁴ This is where the Commission’s construction of care is used as a rhetorical device: simplification of the ethic of care means a reassuring word like “care” can be used throughout the *Report*, emphasizing that the Commission’s purpose is to “care” for everyone involved with new reproductive technologies. “Care” itself has been said to have a “mantra-like”³⁵ occurrence in the *Report*. Goodrich comments that:

The more numerous the figures of repetition, the greater the probability that the point being repeated is contentious or without any immediately obvious justification . . . [I]ts sole function is to persuade its audience, to make the audience identify with or agree to the themes presented to it on the grounds of its verbal presentation rather than upon any explicit account of its contents or effects.³⁶

In the repetition of “care” as the ethical reason to pursue various new reproductive technologies, what becomes suspect is whether the Commission’s assessment of these technologies truly reflects any ethical position.

The authoritative style of writing, along with its claim to the moral high ground, enables the Commission to tell its readers what kind of reproductive technological community is good for them. This paternalism reflects the beneficent approach of traditional medical practice. Beneficence ranges from preventing evil or harm to promoting good.³⁷ The decision as to what is “good” and which “good” is to be promoted is made, with some consultation, by the authority of the Commission. There is little place for dissent because the Commission has also styled itself as reflecting consensus and/or the views of Canadians, thus masking the controversy over new reproductive technologies that exists in Canada. However, when one examines the Commission’s form of argument, the hidden dissent becomes visible.

33. *Ibid.*

34. *Ibid.* at 51.

35. D. Majury, “Is Care Enough? *Proceed With Care: The Final Report of the Royal Commission on New Reproductive Technologies*” (1994) 17 Dal. L. J. 279 at 282.

36. *Reading the Law*, *supra* note 5 at 199.

37. T.L. Beauchamp & L. Walters, eds. *Contemporary Issues in Bioethics*, 3rd ed. (Belmont, Calif.: Wadsworth Publishing, 1989) at 28.

The Commission's reduction of the ethic of care to medical beneficence is complementary with its use of medical discourse to assert its authority. Medical discourse relies on science as proper authority and sees information as a neutral good. The Commission's ethical decisions too, as much as they are claimed to be based on its principles, are always well-supported with information:

Intelligent decisions require knowledge. The individual and societal choices surrounding new reproductive technologies must be founded on information and analysis about the capabilities, limitations and implications of these technologies. This involves not only medical and scientific information, but also analysis of the values and the social, political and economic forces shaping the development of new reproductive technologies³⁸

As the provider, evaluator and analyst of information, the Commission becomes knowledgeable. This fulfills another of the Commission's goals: "to leave a legacy of increased knowledge in the field of Canadian and international experience with new reproductive technologies," as well as establishing the Commission as authoritative and expert. In particular, the Commission invokes "information" as a corrective to disagreements about ethical use of certain technologies, such as fetal tissue use and prenatal diagnosis. Provision of information renders the Commission the sole informed, and, due to the ownership of information, the sole ethical voice in any disagreement. The ethical dimensions of disagreements over certain technologies are thus smothered: "the notion that knowledge in itself contains no moral lesson represses understanding of the ways that the discoverers of knowledge harbor moral and aesthetic "vision" of all sorts."³⁹

The *Baird Report* provides its information to the reader through studies and statistics. Statistics are used liberally throughout, from comparing the cost-effectiveness of surgery to unblock women's fallopian tubes with in vitro fertilization,⁴⁰ to assessing Canadian opinions about the pace of medical technological development, to the meanings of manipulating birth processes.⁴¹ For example, the Commission conducted surveys asking people to agree or disagree with statements such as: "I worry that medical science is moving too fast for our society to maintain control over its use" and "I believe that even though there are some processes of human life, such as birth, that we increasingly know

38. *Ibid.* at 8-9.

39. Lyne, *supra* note 18 at 35.

40. *Supra* note 1 at 524-526.

41. *Ibid.* at 26.

more about, we are not meant to alter these processes."⁴² Responses to these statements are then reduced to numbers. Economic analysis as well as spiritual or ethical matters are both subsumed in statistics. When the Commission states that "[t]here is simply not enough evidence to determine whether IVF [in vitro fertilization] or its variants are effective or ineffective when diagnoses other than fallopian tube blockage are present, such as ovulatory defects, partial tube blockage, tubal adhesions, seminal defects, or unexplained fertility,"⁴³ the reader is meant to take it as an objective statement (and probably can). In contrast, when the Commission continually invokes numerical data to explain material and socio-spiritual matters, it is using this form to enhance its general status as an objective, scientific authority, even on issues that are primarily about values, rather than medical techniques.

Scientific discourse is conventionally framed in terms of rationality and objectivity.⁴⁴ The Commission's use of this authority is central because of the importance of scientific rationality in Western society: it is "the" way of knowing, and "the" source of knowledge.⁴⁵ According to this world view, expressions of ethics, morality, spirituality, and even perspective, become suspect. Information expressed in numbers rings reassuringly of truth, in part, because it reflects scientific methodological emphasis on the measurement and quantification of nature.⁴⁶ Emphasis on the "discovery" of facts makes them appear rational and immutable. No attention is given to the decontextualization and making of facts.⁴⁷ Scientific method sees itself as a moral good.⁴⁸ The depersonalized authority of scientific observation is created by ignoring the person engaged in the act of observing: "we are left with the scientific observation as a thing in itself, which can be treated as though it were as real as nature and comparable to it."⁴⁹

Scientific writing is most effective as neutral authority when it purports to explain scientific theories or "facts" in the most objective, dry, non-metaphorical language:⁵⁰

42. *Ibid.*

43. *Supra* note 1 at 520.

44. R. Hubbard, *The Politics of Women's Biology* (New Brunswick: Rutgers University Press, 1990) at 8.

45. S.G. Harding, *Whose Science? Whose Knowledge?: Thinking From Women's Lives* (Ithaca, New York: Cornell University Press, 1991) at 42.

46. Hubbard, *supra* note 44 at 15.

47. *Ibid.* at 13-14.

48. Harding, *supra* note 45 at 3.

49. *Ibid.* at 12.

50. *Reading the Law*, *supra* note 5 at 175.

[S]cientific speech should appear to instruct, to inform and to prove but if it performs the other offices of rhetoric connected with persuasion, with “moving” or “bending” (Cicero) the audience, this ought to appear to be on the strength of its rational content and not because of the persuasive power of the particular speaker.⁵¹

Speaking (or writing) so as to appear objective, rational and impartial is a rhetorical device. When this device (used outside of science) invokes science, its authority is doubled: the writer appears to be objectively discussing a further, inherently objective scientific fact. Science is still often understood as perfect knowledge.⁵² Yet covering a discussion of values with a claim that the discussion is about information, or that an approach is purely scientific leads to false communication. Political and value-based differences are relegated to the status of givens, and thus, cannot be openly discussed.⁵³

The textual tactics used in the *Baird Report* are disparate. Some reflect scientific discourse, while others employ legal discourse. With its many audiences to persuade, the *Baird Report* is not an easily classified text. It commissioned research studies and thus performs as a research document while it simultaneously stands as a political text recommending a specific course of action. In terms of regulating, and therefore, normalizing, the use of and access to new reproductive technologies, the *Baird Report* is exemplary of “a discourse which should ideally be read in terms of control—of dominance and subordination—and of social power-relations.”⁵⁴ Reading the *Baird Report* for both the form and substance of its

51. *Ibid.* Despite the importance of “objectivity” in science, the pursuit of scientific knowledge is often described in gendered terms. For example, science uncovers and therefore, can dominate nature (almost always “her”). See Harding, *supra* note 45 at 46. Within feminist writing, there is much recognition of the use of rhetoric (specifically metaphor) to describe scientific pursuit of knowledge as well as women’s psychology, reproductivity and sexuality. The latter are generally explained or described in terms of negative value, often to justify medical interference in women’s bodies as well as their exclusion from different aspects of “public” life. See E.F. Keller, *Reflections on Gender and Science* (New Haven, Conn.: Yale University Press, 1985). See also S.L. Gilman, “Black Bodies, White Bodies: Toward an Iconography of Female Sexuality in Late Nineteenth-Century Art, Medicine and Literature” (1985) 12 *Critical Inquiry* 204; Hubbard, *supra* note 44; T.W. Laqueur, *Making Sex: Body and Gender from the Greeks to Freud* (Cambridge, Mass.: Harvard University Press, 1990) and E. Martin, *The Woman In the Body: A Cultural Analysis of Women and Reproduction* (Boston: Beacon Press, 1987).

52. White, *supra* note 12 at 688.

53. *Ibid.* White uses the example of the discipline of economics. Many economists claim that it is a perfect science. Economists with political differences often merely assert that the “other” economist is not a “true economist” and the discussion about political values informing economic analysis or decisions rarely occurs.

54. *Reading the Law*, *supra* note 5 at 20.

arguments reveals the social power-relations which underlie some of the assumptions of the *Report*, as well as those which are reinforced by the substance of some of its recommendations.

The following short example shows how the Commission uses several textual tactics at the same time. The Commission begins its discussion of fetal tissue use by quoting statistics about Canadians' approval or disapproval of various uses of fetal tissue. It states that disagreements about fetal tissue use "stem from a shortage of information about this research, about the feasible sources of fetal tissue and its alternative, and about the mechanisms for regulating research."⁵⁵ It then provides more information about how fetal tissue is used,⁵⁶ its unique properties,⁵⁷ and its possible applications,⁵⁸ explaining particularly how fetal and placental tissue is currently employed in Canada⁵⁹ and other countries.⁶⁰ It offers alternatives to present fetal tissue applications⁶¹ and notes that the availability of fetal tissue exceeds demand for it.⁶² It further presents regulations and hospital practice related to fetal tissue use in Canada and the United States.⁶³

All this information is meant to calm fears, but at the same time it suppresses ethical dissent. Under the heading, "The Ethical Uses of Fetal Tissue," the Commission states in the first paragraph that:

Most Canadians accept that organ transplantation and research on human cadaver tissues for valid scientific purposes are consistent with respect for human life; by analogy we conclude that research on human fetal tissue is acceptable under controlled conditions. *Indeed, attending to the ethic of care would suggest this research not only should be permissible but should be pursued if it appears to hold the best likelihood of leading to effective treatment.*⁶⁴

After advancing this preliminary conclusion that fetal tissue research is ethical, the Commission examines potential abuses and makes several recommendations. Consent for use of tissue should be separated from consent for an abortion,⁶⁵ protection of women's health and interests should be the sole criteria for choosing the method and timing of

55. *Supra* note 1 at 972-973.

56. *Ibid.* at 973.

57. *Ibid.* at 975.

58. *Ibid.* at 977.

59. *Ibid.* at 978.

60. *Ibid.* at 983.

61. *Ibid.* at 987.

62. *Ibid.* at 989.

63. *Ibid.* at 990 and 992.

64. *Ibid.* at 995 [emphasis added].

65. *Ibid.* at 998.

abortion,⁶⁶ and commercial exchange of fetuses and fetal tissue ought to be prohibited specifically in provincial legislation, and extended to import of fetal tissue from other countries.⁶⁷ While I do not want to denigrate the importance of the safeguards offered to protect women from exploitation, I do not think that merely providing safeguards makes a specific action ethical. Providing safeguards is not a substitute for a thorough discussion of the ethics of fetal tissue use, or for a detailed application of a principle such as the ethic of care to the issue. Without safeguards, fetal tissue use would be unethical, but the converse, that with such safeguards fetal tissue use is ethical, is not necessarily correct. The Commission's discussion is notable for its technicality: the current status of and scientific reasons for fetal tissue research are thoroughly addressed. The provision of this information is not without merit. The Commission, however, does not ask the harder question of *what it means* to broadly accept fetal tissue use and research as ethical in our society.

The Commission then repeats its conclusion that fetal tissue use is ethical in a slightly different context. It states that funding for fetal tissue research is justified because "the potential benefits [of fetal tissue research] are substantial, particularly in terms of reducing the human suffering caused by disease. The ethic of care means we must avoid or prevent this suffering if possible."⁶⁸ In its initial and final conclusions the Commission conflates statistical analysis of public opinion, fetal tissue availability and potentiality, and an ethic of care (reduced to beneficence—one must do good). It thus tries to justify its decision that fetal tissue research "must" be pursued because of our values. This is one example of the rhetorical strategy of making different concepts complementary⁶⁹—in this case facts, ethics, public opinion and policy. Jonathan Lyne states that "[m]aking those alignments is a matter of rhetorical strategy: facts are made to summon a set of values, which are in turn made to summon a policy attitude."⁷⁰

Taking this argument apart opens the issues of fetal tissue use and its ethics to substantive questioning, which the Commission would preclude by its use of "must." I will dissect the form in order to then pursue the substantive questions throughout the next section of the article.

66. *Ibid.* at 999.

67. *Ibid.* at 1002 and 1003.

68. *Ibid.* at 1004.

69. Lyne, *supra* note 18 at 43.

70. *Ibid.* at 44.

II. *Prenatal Diagnosis: The Rhetoric of Care and the Ethics of Disability*

In this section, I am focusing on what it means to seek and dispense information about the disabled status of the foetus through prenatal diagnosis, which is usually followed by the offer of abortion as the most common “treatment.” I do not wish to criticize women who have struggled with these questions personally. I acknowledge that there is some tension between my critique of prenatal diagnosis and full abortion rights for women, which I support.⁷¹ This is not, however, central to my discussion, which focuses on the construction of prenatal diagnosis as “information” and “reassurance” and the structure of the debate over its use. The Commission’s construction of prenatal diagnostic tests for genetic anomalies as informing and reassuring, clouds the ethical questions surrounding them and sends complex messages to and about pregnant women and people with disabilities. The physical construction of the text, divided into a main text and orange sidebars, is central to my analysis. The structure chosen by the Commission supports its authority and subsumes conflict.

My analysis is informed by three main contexts. The first is the medical-scientific construction of women’s reproductive bodies and birth,⁷² particularly the expectation of “biological malfunctioning”⁷³

71. What I find disturbing about abortion for fetal anomaly is that it is seen as more justified or more acceptable than other abortions. While women should be free to make their own decisions, social acceptance of abortion for fetal anomaly represents social fear of disability, rather than acceptance of a woman’s right to decide whether or not to continue a pregnancy. In this I follow Drucilla Cornell, who argues that “we should be extremely suspicious of a system that would utilize intuitions about whose body matters as a basis for allowing exception to an abortion prohibition.” See Cornell, *The Imaginary Domain: Abortion, Pornography and Sexual Harassment* (New York: Routledge, 1995) at 78. See pages 74-80 for Cornell’s further discussion of abortion for fetal anomaly.

72. Until the nineteenth century birth was accomplished at home with the aid of midwives. As doctors began to be involved in childbirth, it became “medicalized,” that is, it moved from the social sphere to the medical sphere. Although there is no doubt that many medical technologies have saved the lives of women and children, overzealous use of these technologies (such as forceps) and early interventions in labour have also resulted in prolonged, difficult labour as well as severe damage and death for women. For detailed discussion of the history of medicalization of childbirth in the U.S. see J.W. Leavitt, *Brought to Bed: Childbearing in America, 1750 to 1950* (New York: Oxford University Press, 1986) and J.B. Litoff, *American Midwives: 1860 to the Present* (Westport, Conn.: Greenwood Press, 1978). For discussion of current childbirth practices as reflecting childbirth as pathological, see E. Martin, *supra* note 51; A. Quéinart, “Risky Business: Medical Definitions of Pregnancy” in D.H. Currie and V. Raoul, *The Anatomy of Gender: Women’s Struggle for the Body* (Ottawa: Carleton University Press, 1992); and P.A. Triechler, “Feminism, Medicine and the Meaning of Childbirth” in M. Jacobus, E.F. Keller & S. Shuttleworth, eds., *Body/Politics: Women in the Discourses of Science* (New York: Routledge, 1990).

73. Hubbard, *supra* note 44 at 168.

which permeates medical outlooks on menstruation, ovulation and birth.⁷⁴ The reproductive functions of women's bodies are often understood as inherently pathological, rather than as an aspect of normalcy.

The second context is the overwhelming devaluation of the bodies of people with disabilities⁷⁵ and a failure to recognize a discriminatory climate. People with disabilities are consigned to a social space in which they are labelled "sick": "The sick person is expected to . . . regard his or her condition as undesirable One interesting correlation is that able bodied people are often offended by disabled people who appear satisfied or happy with their condition. A mood of regret and sadness is socially expected."⁷⁶

The third context is the isolationism and reductionism inherent in genetics. Genes are often conceived of as directly causing human traits. The tendency to explain differences between people as genetic in origin is part of a process that has been called "geneticization".⁷⁷ Obviously, genes function in relation to (and interact with) other biological features. However, there is also a vital relationship with environmental conditions, including the social environment, particularly in such complex biological creatures as human beings.⁷⁸ Evelyn Fox Keller finds the description of human beings merely related to their genetic sequence pointless:

All a pot of normal genes can do is to generate a pot of enzymes, and even this requires the preexistence of the requisite machinery for translation and enzyme synthesis It is in this sense that organisms, be they bacteria or humans, are more than and not reducible to their genes⁷⁹

In combination, then, the faultiness of women's reproductive bodies, the fear of disability and the view of genes as directly causing disease and disability as well as other human traits, create a climate in which genetic testing is desirable, calming fear while apparently being precise.

74. Emily Martin finds that descriptions of menstruation in medical texts use negative terms pointing to menstruation only as the failure to conceive, whether or not a woman wished to become pregnant. See Martin, *supra* note 51 at 47-48.

75. S. Wendell, "Toward a Feminist Theory of Disability" (1989) 4 *Hypatia* 104 at 113.

76. R. Amundson, "Disability, Handicap and the Environment" (1992) 23 *J. of Social Philosophy* 1 at 114, 118 as cited in A. Silvers, "Reconciling Equality to Difference: Caring (F)or Justice for People with Disabilities" (1995) 10 *Hypatia* 30 at 39.

77. A. Lippman, "Worrying—and Worrying About—the Geneticization of Reproduction and Health" in Basen, *supra* note 6 at 40.

78. E.F. Keller, "Genetics, Reductionism, and the Normative Uses of Biological Information: Response to Kevles" (1991) 65 *S. Cal. L. Rev.* 285 at 287-288, and n. 5.

79. *Ibid.* at 288.

1. *Sidebars: Structure and Marginalization*

The style of presentation of opposing views in the *Report* allows the Commission to avoid directly addressing conflict about the appropriateness of specific technologies. The Commission uses small, highlighted sidebars to quote from intervenors' statements at the public hearings.⁸¹ In Chapter 25, for example, where prenatal diagnosis and genetic technologies are introduced, the sidebars, sometimes on facing pages, express deeply-held and often conflicting views.⁸² The Commission employs the

80. The Commission also quotes occasionally in the sidebars from research studies it commissioned. The Commission generally holds itself separate from these studies; they are attributed to the author(s) of the study and the Commission's recommendations do not always reflect the conclusions reached in those studies. For instance, in Will Kymlicka's study for the Commission, he recommended a "principlist" approach to ethics, and discounted the ethic of care as an overarching theory. See W. Kymlicka, "Approaches to the Ethical Issues Raised by the Royal Commission's Mandate" in *New Reproductive Technologies: Ethical Aspects*, v. 1 (Ottawa: Minister of Supply and Services Canada, 1993) 1 at 15. The Commission chose to use the ethic of care as an overarching principle, even though it commissioned Kymlicka's study.

In chapter 28 of the *Baird Report* entitled "Sex-Selection for Non-Medical Reasons," the Commission confirms the guideline of the Canadian College of Medical Geneticists/Society of Obstetricians and Gynaecologists of Canada advising against offering prenatal diagnosis to reveal fetal sex. The Commission also recommends that all clinics providing prenatal diagnosis be licensed, and that the guideline be followed as a condition of license (at 900-901). This chapter is the only place I have found quotations from the public hearings of feminist voices directly in the text, rather than in orange sidebars (at 888 and 897). This makes the marginalization of feminist voices and the voices of people with disabilities in the Commission's discussion of prenatal diagnosis (which I discuss *infra*) even more striking.

81. Although I focus on the Report's establishment of its authority through different rhetorical and textual tactics, the fact of holding public hearings helped to put the Commission in the (legally) authoritative position of judge before it even produced a text. The notion of holding public hearings also gives rise to expectations that all sides of an issue will be heard, and that the result will, somehow, be "fair."

It is interesting to contrast the way the Commission brings voices of experience and conviction to its text with C. Gilligan's method. In *In A Different Voice*, *supra* note 2, the voices of women making abortion decisions are quoted within the main text. Gilligan creates her theory, at least in part, with direct reference to these voices.

82. *Baird Report*. See pages 734-735, for deeply conflicting attitudes towards genetic manipulation. At page 734, two sidebars read: "In the meanwhile it appears that every week new so-called advances are being made in the fields of human reproductive technologies and recombinant DNA research. . . . We have reached a stage in a technological development where the unthinkable is already being done and the ability to impose total genetic control seems just beyond our reach." F. Bazos, private citizen, Public Hearings Transcripts, Toronto, Ontario, Nov. 20, 1990; and "The potential for the dehumanization and depersonalization of humankind is very real and very frightening. Scientists who practise genetic manipulation, a term considered by many to be offensive, are in fact tampering with nature." C. Johnson, Federated Women's Institutes of Canada, Public Hearings Transcripts, Winnipeg, Manitoba, Oct. 23, 1990. On page 735, a sidebar reads "Gene therapy must be encouraged to help people with diseases have hope for a treatment in their lifetime. In the next decade, the window on our genetic blueprint is going to open wider and wider, and it is important that we develop the kinds of programs that make this knowledge useful and applicable, so people like myself won't just

sidebars to allow venting of strongly-held views while apparently remaining the reasonable voice mediating between extremes. Diana Majury comments that:

The approach throughout is to present tensions in muted terms, as perspectives, concerns, or fears that, by implication, form the background to the Commission's reasoned discussion and recommendations. The *Report* rarely directly addresses or responds to the substance behind the tensions.⁸³

Conflict is thus contained in the sidebars and suppressed. The sidebars are merely the "perspectives, concerns, or fears"⁸⁴ that led to the Commission's ethical discussion, and, therefore, are not the product of consideration and application of acceptable ethical, moral or principled thought by the speakers themselves. For the Commission, these voices are related to the sidelines of ethical thought, a mere textual decoration. The sidebars are orange and contain "colour commentary," as in sports coverage, commentary which is vivid, lively, personally expressive and, above all, extraneous. This device leaves the Commission with the corner on ethics.

The sidebars are a book designer's vision of how to make speech present. They enliven a text, making it easier to read. The sidebars create the appearance of permitting what is exterior and other to be incorporated into the text while also marking, and confirming, a subordinate status. The contents of the sidebars are excluded from and subsumed by the authoritative body of the text. The sidebars are therefore superfluous and necessary: they provide glimpses of emotional and personal ethical/moral thought, and substitute for something that nonetheless remains missing in the central text. This visual technique is resonant of Jacques Derrida's consideration of the supplement: "whether it adds or substitutes itself, the supplement is *exterior*, outside of the positivity to which it is super-added, alien to that which, in order to be replaced by it, must be other than it."⁸⁵

get the news that they are likely to die of a disease or their children will likely have a disease but will have some options: options for treatments, options for predictive testing and options for family planning." T. Jung, private citizen, Public Hearings Transcript, Vancouver, B.C. Nov. 27, 1990.

83. Majury, *supra* note 35 at 283.

84. *Ibid.*

85. J. Derrida, *Of Grammatology*, trans. G.C. Spivak (Baltimore: Johns Hopkins University Press, 1974) at 145. In his discussion of the supplement, Derrida speaks of writing as an addition to speech and states that "It is the addition of a technique, a sort of artificial and artful ruse to make speech present when it is actually absent" (at 144).

In the context of the *Baird Report*, individual passionate speech is so completely absent in the technical drone of the Commission, that consciously-chosen, edited “quotations” from public hearings are the supplements which at least bring some evidence of speech and human presence back to the text. The sidelining of speech helps to make the Commission’s conclusions broadly palatable, although it creates a cognitive dissonance in the reader who attempts to connect the sidebars to the text.

Nonetheless, the sidebars are interesting in themselves. A wide, conflicting variety of views on new reproductive technologies exists in Canada and the sidebars reflect that. A number are taken from private citizens, individuals who took the time to make presentations on issues of importance to them. There are also quotes from non-governmental organizations, researchers, volunteer and support groups. While these provide a relief from a lengthy text, they are not usually reflective of the text in a way that a reader initially flipping through the *Report* might expect them to be. Whatever the motivation for the provision of the sidebars, their effect is to highlight and separate the broad range of passionate concerns from the Commission’s technical information and authoritative, rational conclusions.

The Commission’s maintenance of a disinterested stance is consistent with one of the authoritative positions it claims. The Commission attempts to “manage” the stories that have been presented to it by emphasizing its impartiality, much like a mediator.⁸⁶ Goodrich comments that “[l]egal texts are historically and rhetorically organized so as to suppress the conflict of differently orientated social meanings. The monologue of the legal text is simply a dialogue aimed at controlling the hearer by means of authority rather than persuasion, coercively rather than dialectically”⁸⁷ The use of sidebars buttresses the authoritative position of the Commission as the best decision-maker. It appears that an open dialogue has taken place, with everyone having had an opportunity to tell their stories, which are now being assessed by the Commission.

I will now turn to the substantive question: what opinions, concerns and ethical positions are found in the marginalized, highlighted text? And how does the sidelining of these particular opinions shape the Commission’s substantive conclusions? The orange sidebars found in chapter 26 (which discusses prenatal diagnosis in further detail)

86. S. Cobb & J. Rifkin, “Neutrality as a Discursive Practice: The Construction and Transformation of Narratives in Community Mediation” (1991) 11 *Studies in Law, Politics and Society* 69 at 86.

87. *Reading the Law*, *supra* note 5 at 193.

marginalize the perspectives of people with disabilities, particularly those who contend that prenatal diagnostic technologies are aimed at eliminating them, and are an expression of the hostility toward people with disabilities in society.⁸⁸ Whereas in other chapters, the Commission seems to mediate between two extremes expressed in the orange sidebars,⁸⁹ in the prenatal diagnosis discussion, the views of people with disabilities are presented as the singular extreme. The Commission's stance of providing prenatal diagnosis with guidelines to prevent abuse is constructed as the preferred ethical and reasonable approach.

The sidebars supporting prenatal diagnosis focus largely on the benefits of information.⁹⁰ One, despite the frequency of abortion as the only solution offered for diagnoses of fetal disabilities, suggests that foreknowledge of a fetal intestinal obstruction can allow arrangements to be

88. The Commission quotes from the Canadian Association for Community Living: "The message that it is not only permissible but preferable to abort any foetus that may be born with a disability resounds loud and clear from the advice given and the approach adopted by many within the medical community. Canadians who have a disability find this message repugnant and totally unacceptable. The implications for them in their day to day lives is to live in an environment of hostile and denigrating attitudes. The primary purpose of prenatal testing is to try to diagnos[e] disabling conditions in advance. The recommended "solution" to that diagnosis is abortion" (*Baird Report* at 774). Other sidebars noting the discriminatory environment in which prenatal diagnosis takes place read as follows: "Just as society is beginning to open the door to people with disabilities, who have been shut out for so long, NRTs are creating new ways of devaluing the disabled by attempting the creation of the perfect child" (J. Rebeck, National Action Committee on the Status of Women, Public Hearings Transcripts, Toronto, ON, Oct. 29, 1990, at 736); "The social status and realities of those with congenital disabilities, and societal attitudes towards them, warrant serious consideration in the face of advancing PND technologies. There is a need for public discussion about the selection aspect in particular, with a focus on society's fear of disability and the reasons why some disabilities are viewed as socially tolerable, while others are not. As well, society's past and current treatment of those with disabilities, the fears that persist around disability and persons with disabilities, and the question of public policies regarding social and economic support for those with special needs, including women in the caregiving role, deserve closer study. This broader view will allow medicine and society to more adequately address the choices generated by PND" (J. Milner, "A Review of Views Critical of Prenatal Diagnosis and Its Impact on Attitudes Toward Persons with Disabilities," in Research Volumes of the Commission, 1993, at 755). For other examples, see *infra* note 102.

89. In its chapter on In Vitro Fertilization, the Commission places in sidebars concerns emphasizing the emotional costs of new reproductive technologies (at 504 and 527), and others emphasizing the emotional stress of infertility as making the technologies worthwhile. The Commission takes a central position between these two extremes acknowledging the stress of treatments, but stating that even if the treatments fail, the "couple" "... felt they had done everything they could to overcome their infertility." (*Baird Report* at 533).

90. *Supra* note 1. These are found at 773 (see *infra* note 97) and 775 (re: fetal intestinal obstruction, see *infra* note 91 and accompanying text).

made for delivery where there are facilities for neonatal surgery.⁹¹ This emphasis on treatment possibilities following prenatal diagnosis where, in the overwhelming majority of cases, there is no curative treatment, is misleading. While the Commission's test focuses on the information that can be provided by prenatal diagnosis, one of the sidebars asks for information about *choosing* whether to even *use* prenatal diagnosis. The Toronto Women's Health Network states "[w]e want to ensure that women are given the information they need to enable them to make a choice around using it, and the necessary support for decisions which they need to make based on the use of that technology".⁹² Such information would reflect the nuances of interpreting the test results, especially where the tests (usually) cannot measure severity, and the risks of the tests themselves.

The Commission largely places the arguments of groups representing people with disabilities outside the main text. The *Report* does include a small section entitled "Disabilities" (nine pages out of a 101-page chapter) within the text to address ethical questions raised in sidebars, none of which are actually situated in that section. Overall, these few pages do not grapple directly with the questions raised, but sidestep them in different ways.

The Commission answers the question of the meaning of the use of prenatal diagnosis with a caveat noting the limits of the technology: not all genetically-based disabling conditions can be discovered prenatally. The Commission adds that "most disabilities are not genetic or congenital in origin. Most disabilities result from other factors, such as accidents, low birth weight, prematurity, viral or bacterial diseases, birth traumas, acts of violence and aging."⁹³ Here, the Commission is saying that since all disabilities cannot actually be eradicated, then their elimination cannot be the goal of prenatal diagnosis. The limits of the technology are used to justify its use as being ethical. The purpose and ethics of its actual use are not dealt with. The use of technological limits as ethical response is ironic when the Commission itself states that "PND [prenatal diagnosis] should [not] be allowed to develop according to a technological imperative or without boundaries The PND system requires monitoring and public input to ensure that PND is used in an ethical, safe, and beneficial

91. *Ibid.* at 775. I do not know how a diagnosis of fetal intestinal obstruction is reached, although it seems unlikely to be determined through amniocentesis, which collects fetal cells floating in amniotic fluid. As far as I know, fetal intestinal blockage is not one of the problems for which pregnant women "at risk" are regularly offered screening.

92. *Ibid.* at 776.

93. *Ibid.* at 797.

manner.”⁹⁴ New technologies for prenatal diagnosis are being tested: preimplantation diagnosis, testing of fetal cells in maternal blood, magnetic resonance imaging and embryoscopy.⁹⁵ It is not unreasonable to expect that additional methods of prenatal diagnosis may eventually be able to detect a wider range of what then may become perceived as “unacceptable” conditions.⁹⁶

Another concern put forward by persons with disabilities is that prenatal diagnosis is being used to “reduce the ‘burden’ on society of providing supports for people with disabilities.”⁹⁷ In this section, the *Report* states that given recognition of the rights of people with disabilities in Canada, it seems unlikely “that funding for PND will affect the funds available for social support for persons with disabilities.”⁹⁸ The Commission states that social supports for people with disabilities are necessary in a just society, as well as to ensure that women can freely choose to keep an affected foetus.⁹⁹ Elsewhere in the *Report*, the Commission states, however, that 16% of physicians believe that “it is socially irresponsible for women at higher risk not to have PND and to give birth to an affected child.”¹⁰⁰ This attitude, especially when ex-

94. *Ibid.* at 810.

95. *Ibid.* at 824.

96. As well as new methods being able to measure and analyze the fetus at different stages, more and more genetic information is becoming available. The goal of the Human Genome Project is to sequence all human genes. Some geneticists claim the purpose of this is to find out what makes us human. See D.J. Kevles, “Vital Essences and Human Wholeness: The Social Readings of Biological Information” (1991) 65 S. Cal. L. Rev. 255 at 257.

Other geneticists claim it will help to diagnose and cure genetic diseases. But diagnostic abilities are outstripping therapies available. As well, in looking for the genetic causes of the disease, too much primacy is given to genes, even to “susceptibility genes” as causative. Other factors in illness are ignored. See S. Tudiver, “Canada and the Global Context of New Reproductive Technologies: A Cautionary Essay” in Basen, *supra* note 6 at 78-79.

97. *Baird Report*, *supra* note 1 at 796. This is how the Commission puts it. One of the sidebars states that “Testing benefits a pregnant woman by providing her with information about the status of her fetus and thus the option to terminate her pregnancy by early abortion or to carry the fetus to term while making necessary preparations for the accommodation of her child’s needs. For those few disorders whose manifestations can be prevented, delayed, or ameliorated by interventions in utero, or by early delivery by Caesarian section, . . . testing provides an opportunity to reduce the magnitude of disability A universal prenatal screening program [without] adequate social supports for disabled individuals threatens to promote the public perception that women are expected to bring only perfect babies into the world. Such a perception hides the fact that it is society’s responsibility to assist disabled children and their families throughout life. A program with a coercive and anti-disability bias would limit reproductive choice and must therefore be avoided. K. Sandercock, Vancouver Women’s Reproductive Technologies Coalition, Public Hearings Transcripts, London, Ontario, November 1, 1990.” (*Baird Report* at 773).

98. *Ibid.* at 800.

99. *Ibid.* at 799.

100. *Ibid.* at 766.

pressed by physicians who care for, and sometimes directly advise pregnant women, belies the assumption of the Commission that because people with disabilities have recognized rights in Canada, they are not seen, by a significant minority, as a “burden.”

The Commission admits that the social environment is often prejudiced and hostile towards those with disabilities and recommends that counselling materials in genetics centres be reviewed, with the assistance of groups representing women and people with disabilities, so that their lives are represented fairly.¹⁰¹ The argument that prenatal diagnosis and termination of fetuses with disabilities is discriminatory,¹⁰² is addressed by saying that the abortion of fetuses with disabilities does not reflect a lack of commitment. For the Commission, when a “couple” already has one child with disabilities, use of prenatal diagnosis for a subsequent pregnancy does not mean that they are not committed to their first child. The Commission states that these couples can separate their attitudes of commitment to their first child from their attitude toward prenatal diagnosis and termination.¹⁰³ This is an example of the Commission using an exceptional circumstance to justify a general ethical conclusion. Only 7.2% of referrals to genetics centres for prenatal diagnosis are due to the existence of previous chromosomal disorders, previous family chromosomal disorder and previous family neural tube defects.¹⁰⁴ The most common reason for referral (77.7% of referrals) is advanced maternal age—considered the main risk factor in bearing a child with chromosomal abnormalities, the best-known of these being Down’s Syndrome.¹⁰⁵

101. *Ibid.* at 801.

102. This argument is presented in sidebars at pages 775 and 785. It is not addressed until page 801. The sidebars read: “Advocacy of termination solely on the basis of race would be met with loud, impassioned cries of protest, but termination on the basis of gender is dreamed of by some, and abortion on the basis of a fetal abnormality is considered the best thing to do. Best for whom? Those of us who are disabled question the criteria. M. Gibson, Spina Bifida and Hydrocephalus Association of Ontario, Public Hearings Transcripts, Toronto, Ontario, November 20, 1990” (*Baird Report* at 775) and “The ultimate consequence of genetic-risk standard and its associated discourse is a denial of abnormality, a fear of difference, and a reinforcement of couples’ and women’s narcissism, that is, the perception of the other as an extension of oneself, leading, ultimately, to an unwillingness to accept otherness. This, then, in short, defines how technology and science make the other into a tool and, as a corollary, how they make abnormality or handicap even more devastating. [Translation] Brief to the Commission from M. De Koninck, Chaire D’Etude sur la Condition des Femmes, and M.-H. Parizeau, Professeure, Faculté de Philosophie, Université Laval, February 1991” (*Baird Report* at 785).

103. *Baird Report*, *supra* note 1 at 801.

104. *Ibid.* at 758.

105. *Ibid.* at 789. Some women in the Commission’s studies reported that they were told that their age (over 35) meant an automatic referral, and some women did not realize that they could refuse prenatal testing.

The Commission's approach to these arguments, which are based on recognition of power differentials in society, is to dismiss them through emphasizing specific exceptions to the patterns. It seems that they are saying that if the exception exists, then the pattern must not be powerful. The dismissal of conflict, and of the underlying question of values, or ethics, is not "caring" as described by Gilligan.¹⁰⁶ Acknowledgement of conflict is central to decisions which are mindful of the ethic of care.

2. Risk, Information, Reassurance and Effectiveness in Prenatal Diagnosis

The word "risk" is repeated throughout the Commission's discussion of prenatal diagnosis in phrases such as "higher risk," "increased risk," and "couples at risk." As Goodrich suggests, such repetition raises suspicion.¹⁰⁷ What does the Commission mean by "risk"? What attitudes toward disability are created by repetition of the chances of it occurring as "risk"?

The first ten pages of Chapter 26 construct the chances of having a child with a genetically-caused disabling condition as a "risk"¹⁰⁸—or "a hazard or dangerous chance."¹⁰⁹ In the emphasis on the danger¹¹⁰ of bearing a child with disabilities, there are echoes of the risks of childbirth that were emphasized during the time that birth was being constructed as

106. Gilligan, *supra* note 2, develops the ethic of care in her chapter on women making abortion decisions. On pages 80 to 93, Gilligan shows that the women see the decision as a resolution of a conflict. It is only in acknowledging the conflict, often between images of women as self-sacrificing and caring, and what they really want to do, that the women can come to a decision with which they feel comfortable. Denying the conflict (see especially 84-85 and 89-90) does not help the women make decisions they can live with.

107. *Reading the Law, supra* note 5 at 199, see quotation at note 36.

108. *Baird Report, supra* note 1. This is done through statements such as: "The risk that a child could be born with a congenital anomaly or genetic disease is inherent in the human condition. This risk is unavoidable, and every couple must face it." (at 746); "The risk of having a child affected by either a congenital anomaly or a genetic disease is not insignificant." (at 747); "some women and couples have different kinds and levels of risk for a congenital anomaly or genetic disease in addition to the general background level of risk." (at 747); "It is also increasingly possible, through carrier screening and screening of pregnant women, to identify adults in the population who are at increased risk of having an affected fetus" (at 749).

109. *The Random House Dictionary of the English Language*, 2nd ed., s.v. "risk."

110. I do not want to minimize the difficulty of raising a child with disabilities in our society, nor minimize the grief, sorrow, frustration and worry that parents experience as they try to raise a child with disabilities. I do not want to minimize the physical and emotional suffering that living with disabilities often involves. But I think that describing all of this as a "danger," while capturing the enormity of the difficulty, also flattens it into an experience that is singularly negative. No variation in or complexity of experience of disability is allowed by constructing the bearing of a child with disabilities as a singular danger.

a pathological event which required hospitalization. Disability is also seen as a danger, both for an eventual child and for the family who would have to cope with the child's disability, often with very little emotional, social or financial support.

Establishment of an element of risk brings a need for reassurance. According to the Commission, 95% of women tested "received reassuring test results."¹¹¹ Carole H. Browner and Nancy Ann Press found that a California state-mandated program offering MSAFP testing was socially and culturally acceptable to pregnant women because the language used to offer and explain the tests focus on the ability to reassure the pregnant women through the test, rather than on its actual purpose.¹¹²

After creating a statistically-based risk, which plays on fears of abnormality, medical geneticists offer prenatal diagnosis for reassurance.¹¹³ Anne Quéinart, in her study of pregnant women, noted a common obsession with the normality of the foetus.¹¹⁴ Reassurance that the foetus is "normal" is valued so much that many pregnant women will take the small but real risks of miscarriage and damage to the foetus involved with amniocentesis and chorionic villus sampling in order to get it.¹¹⁵ Keller argues that the construction of health and disease as genetically caused and located decentres the patient from a cure in favour of "curing" DNA itself. This raises the threat of a new "eugenics of normalcy."¹¹⁶ Unrealistic biological norms and social standards of normality give rise to this new individually-implemented eugenic pressure.

The Commission states that its investigation into the use of prenatal diagnosis and genetic technologies revealed the "worrisome data" that "researchers and practitioners in these fields overall have not managed to convey adequate information to the public about what genetic services in Canada do."¹¹⁷ The Commission takes on that task, and its rational

111. *Baird Report*, *supra* note 1 at 759.

112. C.H. Browner & N.A. Press, "The Normalization of Prenatal Diagnostic Screening" in F.D. Ginsburg & R. Rapp, eds., *Conceiving the New World Order: The Global Politics of Reproduction* (Berkeley: University of California Press, 1995) at 308-309. Browner and Press analyse the booklet explaining the state program and find that the birth defects the test is looking for are not even explained until halfway through the booklet. On the last page, the question "what happens if the tests show the fetus has a birth defect" is answered by "a four-line obscurely written paragraph in which the reader is told that she will be provided with 'information . . . about what treatments are available' and that 'different options will be discussed.' The words 'abortion' or 'pregnancy termination' do not appear at any point" (at 313).

113. Quéinart, *supra* note 72 at 166.

114. *Ibid.* at 166.

115. *Ibid.* at 167.

116. Keller, *supra* note 78 at 290.

117. *Baird Report*, *supra* note 1 at 731.

assessment and application of objective facts supports its position as ethics expert.¹¹⁸ Technical information is presented as if it were the solution to ethical problems.

The Commission explains the counselling and testing procedures offered by genetics centres in Canada, describes the tests (amniocentesis, chorionic villus sampling and targeted ultrasound) and states that 0.86% of abortions in Canada are done due to fetal anomaly.¹¹⁹ It notes wide regional variations in access to prenatal diagnosis and recognizes that some of these variations may be due to the financial difficulties of travel.¹²⁰ It emphasizes, however, that pregnant women are referred to genetics centres by their general practitioners. The Commission then focuses on the role of general practitioners in access to prenatal diagnostic testing.

The basis of prenatal diagnostic testing, according to the Commission, is to “give couples information on which to base reproductive decisions.”¹²¹ The positive value of information, and of the power to decide whether to bear a child with a disability, are unquestioned. The Commission acknowledges the social limits on choices: “For some individual women, economic and social realities make the possible alternative—raising a child with a disability—so formidable that it does not appear to be a genuine choice for them.”¹²² This awareness, however, does not contribute to the Commission’s understanding of how social contexts and the structure of information relates to autonomy and decision-making. The Commission constructs access to information as promoting autonomy without realizing that decisions are affected by the contexts of social inequality, discrimination against persons with disabilities and poverty in which the decision-makers find themselves.¹²³ Further, the

118. This is another example of “borrowed rhetorics” as explained by Lyne, *supra* note 18.

119. *Baird Report*, *supra* note 1 at 760.

120. *Ibid.* at 761. For example, only 15% of women “eligible” for prenatal diagnosis on the basis of advanced age in Newfoundland (where there is no genetics centre) are referred. In Ontario, with several genetics centres (most located in university hospitals), and an outreach program, 56.7% of eligible women are referred.

121. *Ibid.* at 749.

122. *Ibid.* at 788.

123. The National Organization for Albinism and Hypopigmentation states that “genetic counsellors and physicians should be aware that children with ocular albinism can function well despite their visual disabilities if they are provided with appropriate support and services.” See M. Sidarous & E. Lamothe, “Norms and Standards of Practice in Genetic Counselling” (1995) 3 *Health Law Journal* 153 at 167. Evidently, this support organization believes it has to encourage genetic counsellors to provide information about options for living with a disability. This means that the information that is provided by genetic counsellors in some cases to someone with no experience of a specific disease can be quite limiting rather than fully informing.

Commission refuses to acknowledge any suggestion that even the information is structured by these same factors. It is beyond the scope of this article to include much detail on the practice of genetic counselling. Yet because it significantly reflects and affects¹²⁴ social attitudes towards prenatal diagnosis and disability, and thus ethical evaluations of it, I will discuss some of the basic approaches and problems of genetic counselling.

Mona Sidarous and Estelle Lamothe note that there are varying styles of genetic counselling, ranging from providing information and support to acting as moral advisor.¹²⁵ Most Canadian genetic counsellors see their role primarily as information-givers and aim for non-directive and non-judgemental counselling.¹²⁶ One critique of the information-giver model is that some ethical aspects of decision-making may be under-represented; on the other hand, when a genetic counsellor is acting as a moral advisor, the counsellor's moral framework may shape the information provided to the client or may intensely clash with the client's own values, thus weakening the trust aspect of the counselling relationship.¹²⁷ Sidarous and Lamothe continue, however, to state that "since genetic counselling is necessarily value laden, language transmits the values and biases of genetic counsellors. Language can stigmatize a client when genetic terms such as 'mutant' and 'defective' gene are transferred to the person carrying it. Indirectly, a counsellor who spends more time or detail explaining one option rather than another may be seen to be expressing his or her preference in the case."¹²⁸

124. While it is clear that genetic counselling reflects social attitudes (in their breadth) towards disability, it is unlikely that the practice has a strong effect on society because very few people actually undergo a detailed counselling process. A significant number of pregnant women, however, are offered testing by their general practitioners and obstetricians and thus receive at least some information about risk, risk factors and what the tests can show. However, as more tests become available for more conditions, stories about experiences with genetic counselling will circulate and there will likely be some affect on attitudes.

125. Sidarous & Lamothe, *supra* note 123 at 156.

126. *Ibid.* at 157.

127. *Ibid.*

128. *Ibid.* at 158. Sidarous and Lamothe also discuss the professional standards and training requirements of various professional associations involved in genetics counselling. Also see J.T.R. Clarke, "Professional Norms in the Practice of Medical Genetics" (1995) 3 Health Law Journal 131. Clarke explains practice principles such as autonomy and how respect for autonomy requires that counsellors be non-directive. Further, he acknowledges the major role that ideas of economic cost play in our society saying, "[t]he principle of autonomy is threatened when the nature of the disability under discussion is such that it presents a potentially major burden to the health care and social service resources of the community. To what extent should individuals be allowed to define seriousness for themselves? And are there situations in which the societal stake in a decision might be so great that the rights of the individual to choose for themselves might be reasonably truncated? Questions like these touch dangerously on the highly charged issue of eugenics" (at 146).

The Commission makes recommendations that groups representing people with disabilities should have input into the typical information given to clients during genetic counselling.¹²⁹ Overall, however, the Commission structures information on the dis/ability status of the fetus as a desirable, inherent good which promotes reproductive choice.¹³⁰ This eliminates the ethical analysis of the nature of information and the serious potential problems of communication and information in genetic counselling, and suggests that small adjustments to the information provided can solve any ethical problems that might arise.

Ostensibly, then, the Commission's goals in regulating prenatal diagnosis are to prevent discriminatory use and remove obstacles to access.¹³¹ These are valid goals if one has already decided in favour of broad provision of prenatal diagnostic services, but there is no discussion of the "moral nature of information itself"¹³² in the context of prenatal diagnosis. The Commission never asks, as Ruth Hubbard does, "Is it in our interest to *have* to decide not just whether we want to bear a child but what kind of children to bear?"¹³³

It is here that the ethical discussion must take place: what is the moral and ethical value of this knowledge, how is this knowledge constructed to shape values, how does this knowledge shape the role of women as 'reproducers' in society, how does this knowledge shape the meaning of disability in society, and what individual action does this knowledge imply? The refusal of knowledge must be accepted by medical geneticists, counsellors and society as valid. Instead, the knowledge provided by prenatal diagnosis is pushed, even if a particular woman would not terminate her pregnancy, as it "may still help them prepare for the birth

129. *Baird Report*, *supra* note 1 at 801.

130. Janice Raymond discusses the use of the ideals of sexual and reproductive choice in arguments that value women's participation in pornography, surrogacy and prostitution as their independent "choices" without paying serious attention to the constrictions and channels of patriarchy that shape these choices. She states "The choice that radical feminists defend is substantive. We ask what is the actual content or meaning of a choice that grows out of a context of powerlessness? . . . The point is not to deny that women are capable of choosing within contexts of powerlessness, but to question how much real power those 'choices' have . . . [D]efending surrogacy as 'procreative liberty' serve[s] only to further strip the concept and reality of freedom of any real political meaning for women. For they help reinforce the notion that female freedom is having 'the right' to give up our freedom, our control over our bodies." J.G. Raymond, "Sexual and Reproductive Liberalism" in D. Leidholdt & J.G. Raymond, eds., *The Sexual Liberals and the Attack on Feminism* (New York: Pergamon Press, 1990) at 110-11.

131. *Baird Report*, *supra* note 1 at 778.

132. B.K. Rothman, *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood* (New York: Viking Press, 1986) at 83.

133. Hubbard, *supra* note 44 at 196 [emphasis added].

of an affected child and appropriate medical care for the fetus before birth and at delivery.”¹³⁴ Pregnant women and genetic counsellors interviewed by Abby Lippman “regard their concerns about and reluctance towards testing as obstacles to decision-making rather than as valid expressions of the moral malaise the procedures arouse.”¹³⁵

The Commission’s argument that the referrals for prenatal diagnosis should be based on “medical need”¹³⁶ does not promote women’s empowerment in making their own reproductive decisions. The “medical need” to determine whether a fetus has Down’s Syndrome is in reality a value judgement. The decisions to use prenatal diagnosis and abortion due to disabling conditions in the fetus are value-laden decisions that cannot be stripped down to a theoretically neutral, medically-defined necessity.

The Commission defines success in the context of broad-based prenatal diagnostic testing in its assessment of Manitoba’s MSAFP screening program.¹³⁷ It comments that “[t]he Manitoba program has proven effective in detecting neural tube defects—there has been a 50 percent decline in the incidence of liveborn infants with neural tube defects since the program was introduced in 1985.”¹³⁸ The Commission indicated that there were serious problems in the counselling received by and the informed consent obtained from pregnant women being tested in Manitoba’s MSAFP screening program earlier in this chapter. It emphasized that only 30% of physicians provided the written information on MSAFP screening available to pregnant women—54% provided only

134. *Ibid.* at 787. Rothman, *supra* note 132 at 251 states that a baby with Down’s Syndrome may or may not have immediate problems at birth. Foreknowledge of Down’s Syndrome does not specify what care the baby might require shortly after birth. The presence of physical complications and general prognosis cannot be determined until a baby is born and development progresses.

135. Lippman, *supra* note 77 at 49.

136. *Baird Report*, *supra* note 1 at 765.

137. *Ibid.* at 819. At page 752 the Commission explains MSAFP screening. This test measures alpha-fetoprotein in a pregnant woman’s blood. A higher than normal level may mean that there is a neural tube defect (spina bifida). At page 819, the Commission explains the difficulty in interpreting what level is “normal” for a woman dependent on her age, weight, race and age of the fetus. MSAFP test results are not conclusive—a positive test result means that amniocentesis would be recommended to determine whether the fetus is actually affected. Interpreting MSAFP test results is something of an art. If the upper limit of normal MSAFP levels is too low, false positive tests and therefore unnecessary amniocenteses, with the attendant risks of miscarriage, will be performed. As in Down’s Syndrome, amniocentesis cannot determine the severity of spina bifida. The condition ranges from causing difficulty with walking and bladder control to severe paralysis accompanied by hydrocephaly.

138. *Ibid.* at 819.

oral information. A small number of physicians (11.1%) only offered the test to pregnant women for medical reasons indicating a higher risk. The overwhelming majority (79.2%) of physicians offered it to all pregnant women: of these, 37.7% provided it only with the woman's specific consent, 22% without consent and 19.4% provided the test unless the woman asked what it was for and then declined.¹³⁹ The Commission stated that MSAFP screening is "working effectively and being used appropriately in Manitoba's program."¹⁴⁰ To claim that the reduction of numbers of babies born with spina bifida is evidence that prenatal diagnosis is being used "effectively" and "appropriately," despite the significant lack of informed consent and counselling, effaces the value of informed autonomous choice by pregnant women. It reveals the true goal of prenatal diagnosis—not to inform potential parents, as the Commission claims elsewhere,¹⁴¹ but to reduce or eliminate the numbers of babies born with neural tube defects (spina bifida) in Canada. What problem does the reduction of numbers of babies born with spina bifida solve "effectively"? Although the Commission is distant from the actual decisions women made within this screening program, its language recalls the eugenics movement where the elimination of people with disabling conditions (or the elimination of their ability to reproduce), was said to benefit society.¹⁴²

In prenatal diagnostic testing, pregnant women's knowledge of the "health" of their fetus is the benefit provided by geneticists. Information is presented as a good, in and of itself. The question of what to do with that information, what "choice" to make, despite the work of counsellors, is left to individual pregnant women (and their partners) in isolation.

139. *Ibid.* at 767-768.

140. *Ibid.*

141. *Ibid.* at 749.

142. Eugenics can be defined briefly as "[a] scientific and social movement that flourished in many countries after 1900 [and] embraced the cluster of ideas and activities that were aimed at improving the quality of mankind through the manipulation of its biological heredity. Eugenists declared themselves to be concerned with preventing social degeneration." Kevles, *supra*, note 96 at 260. The most thorough and horrible implementation of eugenics was in Nazi Germany. The "euthanasia program" forcefully applied to inmates of psychiatric hospitals and children living in institutions for the mentally and physically disabled, was extended to "undesirables" including Jews, gypsies and homosexuals. See Hubbard, *supra* note 44 at 187-191.

3. *The Ethics of Disability*

The Commission refers to the view held by some members of First Nations that persons with disabilities are closer to the Creator. The brief acknowledgement of this belief reflects the most significant aspect of prenatal diagnosis: not information or access, but perspectives on people with disabilities. The comment is left hanging and becomes another token reflection of the Commission's commitment to diversity.¹⁴³ The Commission seems unable to imagine that ethical positions on the use of prenatal diagnosis may flow from such a belief. This approach is never related to First Nations peoples' attitudes towards or current use of prenatal diagnosis, or to how people with disabilities are cared for in First Nations communities. This failure, among others, prevents the development of an ethical approach that questions the appropriateness of prenatal diagnosis and decisions made on the basis of disability in Canadian society as a whole.

An ethics of disability has to begin with the conception and treatment of the body in bioethics. Bioethical thought sees the body as passive, transparent, and knowable, whether it is conceived of as a machine or tool, an object of natural science, or as a vehicle of expression for an inner (separate) self.¹⁴⁴ These are all traditional concepts of the body found in Western philosophy. The body-object of medicine, and thus, of bioethical thought has inherited this singular body of Western thought: the medical bodily "norm" includes neither pregnancy nor disability. It is based, as well, on a white, male standard. Bioethics cannot "acknowledge the distinctive complexities of organic bodies, the fact that bodies construct and in turn are constructed by an interior, a psychological and signifying viewpoint, a consciousness or perspective."¹⁴⁵ Despite the preoccupation with bodies, bioethics seems to forget about the body. Rather, bioethics regulates "relations between self-present, autonomous, disembodied individuals."¹⁴⁶ Rosalyn Diprose argues, however, for a self which includes the body: the body is not an appendage, but the fabric of the self.¹⁴⁷ The body is the self expressed—not a vehicle of self-expression. It is not separate from the individual. Diprose understands the

143. *Baird Report*, *supra* note 1 at 736.

144. E.A. Grosz, *Volatile Bodies: Towards a Corporeal Feminism* (Bloomington, Ind.: Indiana University Press, 1994) at 8.

145. *Ibid.*

146. R. Diprose, *The Bodies of Women: Ethics, Embodiment and Sexual Difference* (London: Routledge, 1994) at 1.

147. *Ibid.* at 108.

self as incorporating the world through its habit, gestures and conduct. In this engagement with and activity in the world, existence with/in a body is also modified: "This body is not something *I have*, it is what *I am* and its motility is how I have a world."¹⁴⁸ "Having a world" expresses the intersubjectivity of the body.

Diprose explains that the use of motility might be seen as excluding those who are relatively inactive, such as a person who is quadriplegic. She states that inasmuch as this person is involved in a situation and exists in "familiar dwelling with their bodies in their world," then the person is a body-subject, with future possibilities and deliberation.¹⁴⁹ It does not matter what kind of body one lives with, but significantly, before one can have freedom "is the condition that I not be reduced to a thing either by self-objectification or by another's interpretation."¹⁵⁰ The intersubjectivity of the body and the world means that real bodies are affected and constituted by the experiences of prejudice and stereotypes based on race, sex, ability and class that they encounter.

The human body is idealized in various ways across society: the ideals of appearance, however, do not usually coincide with disability. Susan Wendell comments that these are "ideals of strength and energy and proper control of the body" as much as they are about appearance.¹⁵¹ Persons with disabilities become "constant reminders to the able-bodied of the negative body—of what the able-bodied are trying to avoid, forget and ignore."¹⁵² Wendell argues that people living with disabilities in general and pain in particular, represent the failure of heroic Western medicine.¹⁵³ This reflects Mary Douglas' assertion that there is no natural aspect of the body that does not involve social consideration and categories.¹⁵⁴ Medical-scientific discourse treats the body as a natural, knowable object: yet the social meanings attached to illness in general, specific illnesses and disabilities and the work of caregiving are all present in medical encounters. Douglas associates an emphasis on bodily control (the body as something separate to be controlled by the will) with formal social structure and states that: "Bodily control will be . . . most

148. *Ibid.* at 106.

149. *Ibid.* at 137, n. 2.

150. *Ibid.* at 107.

151. Wendell, *supra* note 75 at 112.

152. *Ibid.* at 113.

153. *Ibid.* at 115.

154. M. Douglas, *Natural Symbols: Explorations in Cosmology* (New York: Pantheon Books, 1982) at 65.

appropriate where the valuing of culture above nature is most emphasized.”¹⁵⁵ Given this context, one of the successes of Western medicine becomes the prevention of a life of suffering (much of which is socially defined) through prenatal diagnosis (and usually abortion) of fetuses who would be disabled.

Social perspectives determining which level of suffering should be unbearable and that the inability to live independently makes life less worthwhile dictate responses to prenatal diagnoses of Down’s Syndrome and spina bifida. Living with Down’s Syndrome does not necessarily entail physical pain, although it often entails the emotional pain of rejection from society. “The public world is the world of strength, the positive (valued) body, performance and production, the able-bodied and youth. Weakness, illness, rest and recovery, pain, death and the negative (de-valued) body are private, generally hidden and often neglected.”¹⁵⁶ Thus, social prejudices create much of the disempowerment experienced by people with disabilities. Despite the Commission’s acknowledgement that advocacy groups state that “as much suffering is caused by attitudes toward disability as results from the disability itself,”¹⁵⁷ the Commission cannot connect this hostility to its presentation of prenatal diagnostic information as purely beneficent.

The Commission’s ethical discussion of prenatal diagnosis never engages with the ethics of disability. While the Commission frames prenatal diagnosis in terms of increasing reproductive choice and providing information and reassurance, it does not relate these ideals to the substantive issue. Current prenatal diagnosis is really about reproductive choice surrounding disability, providing information about the dis/abled status of the fetus, and reassurance that there will be no disability. Ominously, the Commission states:

The reforms we have proposed would promote the autonomy of patients and the appropriate use of resources, while also protecting vulnerable interests of individuals and society and ensuring only ethical uses [of prenatal diagnosis]. In general, and in line with our ethic of care, one goal of our recommendations is to foster a spirit of cooperation among all participants.¹⁵⁸

An attempt to foster “spirit of cooperation” where deeply conflicting value systems have remained unacknowledged is not ethical. Here, the Commission uses the ethic of care to smother conflict between two very

155. *Ibid.* at 71.

156. Wendell, *supra* note 75 at 111.

157. *Baird Report*, *supra* note 1 at 800.

158. *Ibid.* at 844.

different value systems. Gilligan states that honesty surrounding conflict is central to her vision of the workings of an ethic of care.¹⁵⁹ While her ethic of care does focus on continuing relationships, it does not centralize cooperation to the extent of denying conflict or subsuming differences.

For Geraldine Finn, doing ethical work is to work beyond politics (seeking, keeping and exercising power),¹⁶⁰ thus vitalizing the space between politics and ethics:

This space between category and experience, representation and reality, language and life, is, I believe, the necessary and indispensable space of judgement; of creativity and value, resistance and change. It is the ground of the critical intentions and originating experiences which enable us to call the status quo into question and challenge the already known universe and its organisation into the predicative and prescriptive categories of practical reason.¹⁶¹

Ethics should inhabit the “space between”; the place from which the ethics of dominant political discourse can be questioned.¹⁶² Perspectives emphasizing care, interdependence, body-subjectivity and power can all challenge the dominant political and cultural norms of pregnancy, independence and bodies as perfectible and separate from selves. In the *Baird Report*, the only echoes of the “space between” are found in the margins of the text, the orange sidebars which are highlighted and simultaneously excluded from the Commission’s conception of ethical analysis. The core of ethics, which is to always call into question the underlying values of political power structures, is studiously avoided.

In the prenatal diagnosis section, the Commission avoids and discounts any ethical encounter with “otherness” (according to Finn, the encounter that questions “me”¹⁶³): whether the “otherness” of women’s pregnancies or the “otherness” of disability. As the Commission institu-

159. Gilligan, *supra* note 2 at 82–83. Gilligan states: “In separating the voice of the self from the voice of others, the woman asks if it is possible to be responsible to herself as well as to others and thus to reconcile the disparity between hurt and care. The exercise of such responsibility requires a new kind of judgement, whose first demand is for honesty. To be responsible for oneself, it is first necessary to acknowledge what one is doing.”

160. G. Finn, “The Space-Between Ethics and Politics: Or, More of the Same” in E.M. Godway and G. Finn, *Who Is This ‘We’: Absence of Community* (Montreal: Black Rose Books, 1994) at 113.

161. *Ibid.* at 107.

162. *Ibid.* at 105. Finn states that “Feminist interventions . . . both practical and theoretical—tend not to challenge the ethical premises of the institutions and practices which are the focus of their concern, but rather to use them to criticise the political praxis which is done in their name.” Although this is fundamental to feminist praxis, Finn argues that this work cannot be called ethical if it stops there (at 106).

163. *Ibid.* at 108.

tionalizes notions of reproductive choice and the positive value of information in its discussion of prenatal diagnosis, it manages the “silent” space between, “suturing . . . this vital ethical space between representation and reality, language and life.”¹⁶⁴

Susan Wendell stresses the importance of developing a feminist ethic of disability.¹⁶⁵ Women make up more than half of the population with disabilities, and do most of the care work for them. Similar cultural attitudes about the body contribute to women’s oppression and the disempowerment experienced by people with physical disabilities. Some issues are shared by the two groups, such as debates over whether to emphasize sameness or difference in reference to the privileged group, and whether to accept or question dominant values.¹⁶⁶

A feminist ethic of disability should be central to ethical discussion of prenatal diagnosis. The Commission’s construction of care as medical beneficence—doing good, preventing harm—cannot provide a basis for such an approach. It results in paternalism. An emphasis on care as listening and exchange would create a pathway for new perspectives on the values of reciprocity and interdependence, which are not recognized as potentially rewarding ways of living in mainstream North American society with its focus on independence.¹⁶⁷ New perspectives on the values of reciprocity and interdependence are just some of the potential contributions that people with disabilities and those who care for them have to offer to an ethics of disability.¹⁶⁸

If pregnant women are being held responsible for the maintenance of “social health” through prenatal diagnostic testing, a feminist approach to an ethics of disability is necessary. This would emphasize both the subtleties and force of power relations as well as relationships between issues and individuals. An analysis of the political role of medicine and traditional bioethics¹⁶⁹ themselves would be a significant part of a

164. *Ibid.* at 109.

165. Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996). At 163 Wendell states: “Feminist ethics needs the insights of people with disabilities, but do people with disabilities need feminist ethics? Yes, I think so, not only because feminist ethics is already involved in developing an ethic of care and questioning the value of autonomy and independence as moral ideals, but also because the methodological approaches of feminist ethics are particularly conducive to addressing the concerns of people with disabilities.”

166. Wendell, *supra* note 75 at 105.

167. *Ibid.* at 118.

168. *Ibid.* at 119.

169. Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press, 1992) at 86.

feminist ethics of disability. The relationship between doctors and patients is inherently one of an imbalance of power—one is seen to have knowledge, and the other as without knowledge. The social construction of disability as well as the contexts of fear of and discrimination against people with disabilities would be central to such an approach.¹⁷⁰

Conclusion

I have attempted to provide a rhetorical analysis of the *Baird Report's* construction of prenatal diagnosis as a “caring” technology: I used this form of analysis to direct me to an ethical analysis of the *Report*.¹⁷¹ The Commission’s use of the exclusionary tactic of orange sidebars, which also supports its general authority as a mediator, has been central to this discussion. The Commission’s employment of objective language, reflecting both legal and scientific authority, combined with its repetition of the “ethic of care,” places it in several authoritative positions: knower, judge and moral thinker.

The *Baird Report's* proposed regulation of new reproductive technologies is technical and political, rather than ethical, because it

do[es] not actually raise or address *ethical* questions about the implicit or explicit values animating and directing the arguments, institutions and practices under their scrutiny and the society which has produced them; but rather technical, pragmatic, *political* questions about professional etiquette, accountability and control, and the policing of the boundaries of competing individual and institutional jurisdictions.¹⁷²

The Commission’s realignment of the dilemmas posed by new reproductive technologies with existing practise shaped by political hierarchies is technical at best. In reality, it merely serves to endorse and legitimate the values of the political status quo in exploring the new issues it is asked to confront.¹⁷³ The recommendations of the Commission emphasize and yet obscure these political questions. Professional etiquette is the focus of the recommendations requiring physicians to provide accurate information

170. A similar approach is reflected in J. Milner, “A Review of Views Critical of Prenatal Diagnosis and Its Impact on Attitudes Toward Persons with Disabilities” in *Prenatal Diagnosis: Background and Impact on Individuals*, vol. 12 (Ottawa: Minister of Supply and Services Canada, 1993) 461.

171. White, *supra* note 12 at 700 states that “[r]hetorical analysis provides a way of addressing the central questions of collective existence in an organized and consistent, but not rule-bound, way. It directs our attention to the most significant questions of shared existence Justice and ethics are its natural subjects, art its natural method.”

172. Finn, *supra* note 160 at 104.

173. *Ibid.*

regarding prenatal diagnostic tests where medically indicated and to provide patients with informed choices.¹⁷⁴ Accountability and control are found in its recommendations of establishing a prenatal diagnosis and genetics subcommittee of the National Reproductive Technologies Commission to license, monitor and develop standards for prenatal diagnostic services.¹⁷⁵ Boundaries are policed by the Commission's recommendations that prenatal diagnosis not be used to determine the sex of a fetus,¹⁷⁶ and that provincial colleges of physicians and surgeons emphasize that failure to discuss the option of prenatal diagnosis with patients is unethical.¹⁷⁷

In this article, I wrote of the cognitive dissonance I experienced when reading the orange sidebars and returning to the Commission's text. Finn argues that

At least radical politics must begin here, as any critical moment must, in the *experience of disjuncture*, of the incommensurability between language and life, between authorised categories of experience and experience itself.¹⁷⁸

The recognition of this dissonance between the ethical questions raised by intervenors (and the Commission's mandate) and the Commission's proposed political solutions is aptly expressed by Finn as the place where radical politics, or asking the question of ethics, begins. It was this dissonance that, for me, required the *Baird Report* to be the subject of an ethical critique.

The *Baird Report* is not an inviting text. Its factual density is meant to show that the Commission knows best. The Commission's attempt to disguise its authority by bringing (sometimes radical) voices to the text, its attempt to exclude and subsume ethical stances, that, in many cases, came from experiences of oppression and searches for meaning, creates a disjuncture between the Commission's text and ethical spaces-between. True, in claiming the ethic of care, which speaks at least of the possibility inherent in listening to women's embodied experiences, the Commission provides an opening to ethical questioning of the political status quo. Unfortunately, the opening is in direct contradiction to the Commission's own support of the disembodied, bioethical-political structures of power in new reproductive technological practice today.

174. *Baird Report*, *supra* note 1 at 791, recommendations 216 and 217.

175. *Ibid.* at 1030-31.

176. *Ibid.* at 906, recommendation 264.

177. *Ibid.* at 809, recommendation 222.

178. Finn, *supra* note 160 at 109.