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Diana Majury\*

Is Care Enough? *Proceed with* Care: Final Report of the Royal Commission on New Reproductive Technologies

Having just finished reading *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies*, <sup>1</sup> I find that the questions I am left with pertain less to the technologies themselves, although I certainly do have those, and more to the role and effectiveness of royal commissions generally, and this Royal Commission specifically. <sup>2</sup> I am left wondering, Was it worth it? What really was the point of it all? How could we expect any group of seven—or was it nine? well,

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<sup>1.</sup> Royal Commission on New Reproductive Technologies, *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies*, vols. 1–2 (Ottawa: Minister of Government Services Canada, 1993) [hereinafter *Report*].

<sup>2.</sup> I should confess, at the outset, that my critical reaction to the Report was probably fairly predictable. I write as one who has serious concerns about reproductive technologies and the rapid and unchecked pace of their development and as one who was sceptical of the usefulness of a royal commission on this subject. Back in 1988, mine was among the few feminist voices arguing against the call for a Royal Commission on Reproductive Technologies. We were concerned then that, at best, the Commission would take a "safe middle-of-the-road position"; that it was both too little too late and too much too soon (see C. Clement & D. Majury, "A Question of Strategy" (1988) 9:2 Healthsharing 19). Connie Clement and I made an oral presentation to the Commission in which we supported others' calls for a general moratorium on reproductive technologies during the time that the Commission conducted its work. In addition, for me the credibility of the Report was irredeemably undermined, regardless of its content, by a number of factors. These include the serious delays in the Commission's reporting dates (originally scheduled for October 31, 1991, then October 1992, then July 1993 and finally November 15, 1993. See 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 Technologies, vol. 1 (Hull: Voyageur, 1993) [hereinafter Misconceptions] 196); the controversies relating to the processes of the Commission and the Commissioners themselves (see infra note 3); the secrecy surrounding the research conducted by the Commission, giving rise to criticisms from both the Social Science Federation of Canada and the Canadian Association of University Teachers (Eichler, ibid. at 211); and the stories of intolerance and control told by researchers and other staff hired by the Commission (see Anonymous, "Inside the Royal Commission" in Misconceptions, ibid., 223).

ultimately five people<sup>3</sup>—to respond with depth and substance to a mandate that required them to "inquire into and report on current and potential medical and scientific developments related to new reproductive technologies, considering in particular their social, ethical, health, research, legal and economic implications and the public interest, recommending what polices and safeguards should be applied"?<sup>4</sup> At bottom, this was somewhat akin to asking the Commissioners to report back on the meaning of life. The technologies under examination involve assisted conception, prenatal diagnosis, embryo research and genetic technologies. These technologies deal with the creation of life. The values, ideologies and interests involved flow from our definitions of "life," from what we see as important in and about "life."

Even though, at one level, the mandate was impossible and overwhelming, at another level, it was limited and too narrowly focused. Criticisms directed against the Commission can be traced back to the limitations imposed by the mandate. The Commission has been accused of failing to look behind the existing technologies to assess their appropriateness and at least to question the trajectory that these technologies have put us on. This apparently was one of the tensions that arose among the original seven commissioners. According to Louise Vandelac:

there has not been adequate questioning of [reproductive technologies'] nature, validity and relevance, of their impact and profound meaning. In this vacuum, the debate on these technologies has drifted, focusing mostly on the modes to manage them. This has helped to insure the social legitimization of their development. And, while the mandate and interdisciplinary composition of the Commission should theoretically have al-

<sup>3.</sup> The Government originally appointed seven people to serve on the Royal Commission: Patricia Baird as Chair, and Bruce Hatfield, Martin Hébert, Grace Jantzen, Maureen McTeer, Suzanne Scorsone and Loiuse Vandelac as Commissioners. Disagreements arose among the Commissioners over how the Commission was being run and the research process undertaken. Four of the Commissioners (Hatfield, Hébert, McTeer and Vandelac) tried to discuss their concerns internally and then with the Clerk of the Privy Council, at which point they were told that the government cannot interfere in the workings of a commission. However, three weeks later, the government appointed two new members to the Commission (Bartha Knoppers and Susan McCutcheon) and issued a second Order-in-Council, revising the Commission's procedures so as to strengthen the authority of the Chair. On December 6, 1991, the four "dissident" Commissioners brought an action against the federal government and Patricia Baird in which they sought to have the second Order-in-Council declared invalid. Ten days later, the four commissioners were fired from the Commission, leaving the three original appointees plus the two recent additions. See M. Eichler, ibid.; "Appendix: Statement of Claim" in Misconceptions, ibid., 273; R. Howard, "Commission Dispute Breaks out in Lawsuit" The Globe and Mail (7 December 1991) A6; and G. York & R. Howard, "Dissidents Fired from Commission on Reproduction" The Globe and Mail (17 December 1991) A6. 4. Report, supra note 1 at 3.

lowed it to fill the vacuum meaningfully, the process and structure imposed by Dr. Baird compromised this potential.<sup>5</sup>

While I would agree with Vandelac that this lack of fundamental questioning is indeed a shortcoming, I think that the fault lies, at least in part, with the mandate given to the Commission. The mandate wording has a fait accompli air to it, an air that permeates the *Report* itself. The mandate and the *Report* seem to assume that, given the current existence of the technologies and the developments to date, the focus now can only be on policies and safeguards; we are past the point of fundamental (re)thinking. The Commissioners dismissed the calls for a general moratorium, arguing that it was neither desirable nor feasible. The approach of the *Report* is one of containment, management and monitoring. Having been asked to explore the meaning of life, the Commission was limited to examining life as we know it, not how it might be, if different choices were made—not as if those choices could still be considered open.

The title of the *Report*, "Proceed with Care," reflects this same assumption of inevitability. The implication is that these technologies are, will be, and should be, ongoing and that for the most part as long as this is done with "care," it is a good thing. The care in the title is presumably intended to have two meanings. First, the title invokes the "proceed with caution" traffic signs that warn drivers of potential dangers ahead that require their strict attention and prudence. This bothers me for a couple of reasons. The implied allusion seems too "cute" for the very serious subject matter at hand, thereby tending to trivialize the whole report. I am one who enjoys word plays, frequently using them in my own writing. However, this title served as a reminder that one can sometimes get carried away and undermine one's content in the pursuit of one's own cleverness.

The other, and even more troubling reason I am uncomfortable with this allusion—given my own mistrust of most of these technologies,

<sup>5.</sup> L. Vandelac, "The Baird Commission: From 'Access' to 'Reproductive Technologies' to the 'Excesses' of Practitioners or the Art of Diversion and Relentless Pursuit" in *Misconceptions*, *supra* note 2, 253 at 269–70.

<sup>6.</sup> Supra note 1 at 15.

reenforced by some of the alarming information compiled in the *Report*<sup>1</sup>— is that the standard being promoted is less than that advocated under adverse road conditions, that is, the Commission advises "care" rather than "caution." While the difference between care and caution is only one of degree, using caution as the backdrop to the chosen term, "care," serves to down play any sense of urgency or risk. The title depicts the technologies as less dangerous and uncertain than even the information in the *Report* and its own recommendations would suggest.

The second meaning of care conjured by the title of the *Report* relates to care as caring. In this sense of the word, care becomes mantra-like in its invocation throughout the *Report*. Chapter Three of the report outlines the ethical framework employed by the Commissioners. They adopted what they describe as an "ethic of care" in conjunction with eight guiding principles designed to "give concrete expression to the ideal of care." This ethic of care, said to be found "in secular mainstream ethics, in feminist theory, and in religious thinking," is described in the following terms:

moral wisdom and sensitivity consist, in the first instance, in focussing on how our interests are often interdependent. And moral reasoning involves trying to find creative solutions that can remove or reduce conflict, rather than simply subordinating one person's interests to another. The priority, therefore, is on helping human relationships to flourish by seeking to foster the dignity of the individual and the welfare of the community.

Where intervention is necessary, its aim should be creative empowerment so that, as far as possible, everyone is served and adversarial situations do not arise. At the very least, intervention must, in this view, avoid causing harm to human relationships.... The concept of non-maleficence goes beyond simply avoiding actions that might cause harm,

<sup>7.</sup> This includes, for example, information on the use of sperm in assisted insemination without proper testing for HIV and other sexually transmitted diseases (*ibid.* at 449); on the use of IVF, not only in circumstances for which there is as of yet insufficient evidence to categorize the procedure as either effective or ineffective, but also in circumstances for which the Commission actually categorizes IVF as ineffective (*ibid.* at 519); on the pressures exerted on some women to have prenatal diagnoses and then to abort a fetus with a disability (*ibid.* at 754, 770); and on the level of education required to understand some of the consent forms used with respect to these technologies—IVF forms rated as requiring one graduate degree to understand (*ibid.* at 549) and assisted insemination forms requiring up to four years of post-secondary education (*ibid.* at 461).

<sup>8.</sup> Ibid. at 52.

<sup>9.</sup> *Ibid.* at 51. While the Commission prides itself on the use of these diverse sources, I am quite sceptical. These different schools of thought may all employ the concept of care but I would expect that their approaches to and understandings of the meaning of care differ considerably. Rather than explore these differences, the Commission glosses over them in the hope of establishing some unchallengeable common ground. It is, after all, difficult to argue against an ethic of care.

to taking steps to prevent harm and create conditions in which harm is less likely to occur and beneficial results are the more likely outcome. 10

While it all sounds nice and "caring," the overall impression that I am left with from this discussion and the Report itself is that of a desperate attempt to avoid conflict. The goal seems to be to find some middle position that mediates between the dangers and risks of reproductive technologies on the one hand and the benefits and desires for them on the other. But these reproductive technologies are highly controversial; attitudes toward them are characterized by heated debates and passionately held positions. These disagreements are acknowledged in the Report but are usually understated. The approach throughout is to present the 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. These are issues that require some tough and firm decision-making, in the absence of which it is likely to be reproductive business as usual. The burdens imposed by the recommended licensing, monitoring and reporting requirements<sup>11</sup> may mean that only big business will be able to provide the services. I am not sure that these burdens will do much to change or curtail current practices.

The eight guiding principles enlisted to ground the application of the ethic of care are "individual autonomy, equality, respect for human life and dignity, protection of the vulnerable, non-commercialization of reproduction, appropriate use of resources, accountability, and balancing of individual and collective interests."12 There is nothing wrong with these principles. In fact, they seem most laudable. The problem is, How does one operationalize these lofty ideals? It is a critical, but perhaps impossible task to fully integrate these concepts; it is possibly an unrealistic expectation to impose on the Commission. However, I cannot help but wonder what if, in pursuing, for example, the guidelines of autonomy, equality, respect, and protection of the vulnerable, the Commissioners had put people with disabilities, or aboriginal women, or some other oppressed group at the centre of its analysis and allowed that group's concerns and perceptions to direct and guide the discussion. From such focal points, the issues posed by the technologies and their ramifications might look very different. In the end, we would have had, I think, a fuller and more complex understanding of reproductive tech-

<sup>10.</sup> Ibid. at 52.

<sup>11.</sup> See Part Three: Overview of Recommendations, *ibid.* at 1019–50, especially 1023–33, on the proposed National Reproductive Technologies Commission.

<sup>12.</sup> Ibid. at 53.

nologies. However, rather than using the principles to reconceptualize the analysis, they are used simply as guidelines. As a result, while the principles clearly have some effect, their impact is limited.

As discussed and applied in the *Report*, these principles frequently lack depth and substance. Take equality for example. The appropriate groups are all named; consultations were held; the current buzz words—diversity, empowerment, choice, access, and so forth—are liberally sprinkled throughout the *Report*. But the attention to these issues seems largely superficial: there is little evidence of the integration of issues relating to race, disability, income status and sexual identity into the substantive discussions in the *Report*. With the exception of gender, which has a much more prominent place throughout the discussions, equality issues are raised more as an addendum than as a central concern. The focus is on the individual, and issues of systemic discrimination are largely ignored.

The chapter on assisted insemination provides some good examples of the shortcomings of the equality analysis as it is applied to lesbians. The Commissioners begin quite well, having eschewed the heterosexist and pejorative term "artificial insemination" for the more current "assisted insemination," although it too has its problems. However, the good news does not last long. In the first paragraph of the chapter, they refer to the fact that "the woman [seeking insemination] can be married, single, or a lesbian."13 It does not take a very sophisticated equality analysis to recognize that being a lesbian is not a (non)marital status. Lesbian denotes one's sexual identity, not whether or not one is in a sexual relationship. Lesbians can be single or in a relationship; many are married.<sup>14</sup> The listing of lesbian as a relationship status, distinct from single or married, is the listing of lesbian as "other." "Normal," that is heterosexual, women can be in a sexual relationship or not, their sexual identity is not collapsed into their relationship status. "Other women." that is lesbians, are included only as a relationship status, implying one of two things: either that they are only lesbian if they are sexually involved with another woman, otherwise they are to be considered (heterosexual) single or married; or that, for lesbians, whether or not they

<sup>13.</sup> *Ibid.* at 425. The wording also presents problems for heterosexual women for whom the only two relationship options recognized by the *Report* are single and married.

<sup>14.</sup> Lesbians enter or remain in heterosexual marriages for a variety of reasons, most of which derive from discrimination. While not an absolute protection, marriage provides a fairly strong safeguard of heterosexual privilege. The loss of heterosexual privilege may mean, among other things, the loss of one's children, loss of one's job, exile from cultural and social communities, and loss of family and friends.

are involved in a sexual relationship is irrelevant to their relationship status.

The Report then goes on to discuss the "views of Canadians" as gleaned through the Commission process of surveys and consultations. Not surprisingly, they found that the majority of Canadians do not support the use of donor insemination by single heterosexual women or lesbians. The Commissioners go through a rather lengthy discussion of the dilemma presented by this apparent conflict between the views of Canadians and the equality principle. This is not very reassuring on the equality front.

Discrimination is tolerated, endorsed and promoted by the dominant groups; that is why it is so entrenched and so difficult to overcome. To accord the discriminatory views of the majority the power to create a dilemma is to concede too much, to fall prey to a simplistic notion of pluralism in which issues of power and domination are invisible. With one dissenting opinion, the Commissioners work their way through the dilemma to come to the conclusion that their recommendations must ensure that "services provided and funded by provinces' health budgets are not offered in a discriminatory way." They rely upon the *Charter* to rationalize their divergence from the views of Canadians:

the Commission believes that society's approach to new reproductive technologies should be governed by the social values of Canadians. We are also aware, however, of the difference between social values and individual opinions. We believe that the social values held by Canadians are reflected in the *Canadian Charter of Rights and Freedoms* and the prohibitions on discrimination it contains must be our guide in this matter.<sup>16</sup>

This reflects what I would describe as a Pollyanna approach to equality and "Canadian values." Racism, sexism, lesbian hatred, oppression based on class or disability are not simply matters of "individual opinion"; they are very much about deeply engrained values and institutionalized practices. An approach that dismisses discrimination as "individual opinion" ignores, even denies, systemic discrimination. Equality issues relating to access and service delivery can not be meaningfully addressed in the absence of the recognition of the much more fundamental nature and source of the problems and a willingness to take a strong stand against "Canadian values" when they reflect and promote discrimination.

<sup>15.</sup> Ibid. at 456.

<sup>16.</sup> Ibid.

The dissent on this and five other issues in the Report is in keeping with the muted and conciliatory tone of the Report. Commissioner Scorsone is the only one of the Commissioners to write a dissent and she does so on six subjects: Educational Strategies for STD Prevention; Access to New Reproductive Technologies; Embryo Research; Aspects of Prenatal Diagnosis; the Genetic Link in Gamete Donation; and Judicial Intervention in Pregnancy. 17 These dissents are unobtrusively noted in the body of the Report with an asterisk and a footnote indicating "See Annex for dissenting opinion." This "annex" is buried at the end of the Report, with the glossary and appendices. While I disagree with Commissioner Scorsone's views on these issues, I find the low level of attention and significance they are accorded in the Report troubling. It is another instance where the Report downplays and masks what are, in fact, fundamental differences, an approach to which Scorsone herself contributes. She introduces her discussion on the access issue almost apologetically:

The vast majority of the recommendations of this Commission maintain a fine and humane balance of the complex medical, ethical, social, and legal factors which form their context. On very few points do I feel obliged to object that this balance has not been maintained. <sup>18</sup>

In the context of the chapter on assisted insemination, she objects to the requirement that publicly funded services be made available on a non-discriminatory basis, that is, she does not agree that single heterosexual women and lesbians should be given equal access to assisted insemination. Commissioner Scorsone is of the view that:

there should be no absolute requirement of provision without regard to "factors such as marital status, sexual orientation or social and economic status".... Those who consider them relevant, particularly but not only because of their impact on the best interests of a child and/or for reasons of conscience or religious belief, must not have the contrary view imposed upon them with no possibility of legitimate diversity.<sup>19</sup>

The fact that this dissent, that undermines fundamental equality rights of lesbians (among others), is put forward without direct challenge and with such an air of gentleness and support suggests to me a lack of commitment to these equality issues in the body of the *Report*. It seems that neither side is pushing these issues, nor pushed on them, for fear that the fragile "balance" will fall apart. But these are not minor differences

<sup>17.</sup> Ibid. at Annex (outlined at 1053-65, with detailed reasoning at 1067-1146).

<sup>18.</sup> Ibid. at 1056.

<sup>19.</sup> Ibid.

and the "balance" we are left with does not have the depth and rigour needed to support it.

The conciliatory nature of Scorsone's dissents rekindles my questions about the fate of the four outspoken dissenting Commissioners who were fired from the Commission.<sup>20</sup> The *Report* makes no mention of them or of what happened, as if they were never appointed. While I recognize that the final *Report* is probably not an appropriate place to discuss the internal conflicts and maelstroms within the Commission, it seems a bit heartless and misleading not to acknowledge them in any way. It seems to me that the "ethic of care" and the eight guiding principles might have required something more on this matter.

While most of the recommendations reflect a policy of containment and management, the Commission does take a strong and unequivocal stand on a few issues. In four areas the Commission recommends outright prohibition under the Criminal Code. For-profit activities in relation to reproductive materials (sperm, eggs, etc.) would be prohibited, as would profit based activities, by any party except the birth mother,<sup>21</sup> in connection with preconception arrangements. "[R]esearch involving human zygotes or embryos directed toward development of ectogenesis, cloning, the creation of human/animal hybrids, and the maturing and fertilization of eggs from fetuses"22 is recommended to be subjected to criminal sanction. Finally, unwanted interferences, or threats thereof, with the physical autonomy of pregnant women are also recommended for prohibition. I find the Commission's recommendations on all of these issues most interesting, in part because it is not clear why or how the ethic of care led to these more extreme recommendations with respect to these, and only these, specific issues.

The singling out of the use of human reproductive materials and preconception arrangements as the areas in which to sanction the profit motive is not unusual. This generally accords with public perceptions and recommendations from other jurisdictions.<sup>23</sup> The prohibition focus is limited to fairly individualized profit-making; it begs the much larger question of the commercial and profit driven nature of much (if not all) of this technology and the impact that this has on priorities in terms of issues like prevention versus "treatment." The Commissioners offer good insights on many of these economic issues. They are the subject of a

<sup>20.</sup> Supra note 3.

<sup>21.</sup> The birth mother is exempt from criminal sanction in order to avoid compounding her vulnerability (*supra* note 1 at 689).

<sup>22.</sup> Ibid. at 108.

<sup>23.</sup> See discussion in the Report, ibid. at 1001–03, 668–82.

chapter on commercial interests and new reproductive technologies. In the context of their discussion of in vitro fertilization, I think that the Commissioners do a particularly good job in outlining the potential for the creation of a two-tier health care system and the dangers that inhere in such a model.<sup>24</sup>

These larger discussions of the economic implications of reproductive technologies raise questions about the effectiveness or appropriateness of hiving off only the more individualistic and publicly visible manifestations of the profit motive and invoking the extreme measure of criminal sanction. The Commission might instead, or in addition, have examined the possibilities for more fundamental change in the economics of reproductive technologies and even health care more generally. There is really no discussion of whether or not criminal law is the appropriate forum for the enforcement of these kinds of social policies. I would want to explore much more fully the potential ramifications, in this context, of invoking the criminal law, which is the harshest incarnation of the state, and the attendant protections for accused. I fear, for example, that a prohibition of the commercial aspects of "preconception arrangements" will only force participants to hide their financial arrangements and serve to render birth mothers vulnerable to increased coercion and exploitation.<sup>25</sup>

The Commission makes some interesting concessions even within the prohibitions it does recommend. For example, the Commission supports the continued payment of a \$75 fee, to be increased only to accommodate inflation, to sperm donors in order to compensate them for their time and inconvenience. Their rationale for this exception is that "[t]his is unlikely to act as a financial inducement, given the inconvenience involved." While this may be true for many people, there are certainly lots of people for whom \$75 would constitute a fairly major incentive. The Commission is either promoting the idea that only those for whom \$75 is relatively insignificant should be sperm donors, or it is willing to tolerate profit motive at this minor level. The questions become more complicated with respect to the "compensation" of birth mothers under preconception arrangements. Where does one draw the line between "compensation" and "profit" for a woman who has carried a fetus for nine months with all of the attendant risks and limitations? Is the restriction to "compensation"

<sup>24.</sup> Ibid. at 561-64.

<sup>25.</sup> See D. Majury, "Pre-conception Contracts: Giving the Mother the Option" in S. Rosenblum & P. Findlay, eds., Debating Canada's Future: Views from the Left (Toronto: James Lorimer

<sup>&</sup>amp; Company, 1991) 197.

<sup>26.</sup> Supra note 1 at 448.

simply a means of ensuring the exploitation of women who agree to bear a child for someone else?

The research prohibitions present even more interesting questions about how and why the Commission chooses to draw the lines where it does. Cloning, parthenogenesis (creation of a zygote from the female gamete alone) and ectogenesis (development of a fetus to viability outside the uterus) are among the kinds of research that the Commission finds "would contravene the Commission's stated ethical principles and be contrary to the values of Canadians." The Commission says of ectogenesis:

The idea that human zygotes could develop and grow into infants in an artificial womb is seen as quite inappropriate by most Canadians. Such research, if pursued, would dehumanize motherhood; some have even envisaged it as opening the way to "baby farms" and femicide. Commissioners regard such research as ethically reprehensible, and we have recommended that it be prohibited.<sup>28</sup>

These are among the strongest words emanating from the Commission on any topic, one of the few areas in which the recommendation is for prohibition. Yet these are the same types of arguments that have been, and continue to be, levelled against in vitro fertilization and genetic technology more generally.<sup>29</sup> The Commissioners adopt their position with very little discussion, almost as if it were self-evident. But I think that there are lots of questions and I am left wondering, Is there is a fundamental difference between in vitro fertilization and ectogenesis, or is it simply a matter of time and familiarity? Why is the line drawn here? Why are only these areas of research considered dehumanizing? Why is motherhood singled out for concern, rather than persons with disabilities for whom the consequences may be even more dire and more immediate?<sup>30</sup>

Furthermore, the *Report* tends to be very doctor- and science-focused and engages only with a traditional medical model of health care. This is quite surprising and disappointing at a time when health care in Canada seems to be becoming more inclusive of other health care practitioners and of other cultural approaches to, and understandings of, health care. The limited approach of the *Report* may have been in part a consequence

<sup>27.</sup> Ibid. at 618.

<sup>28.</sup> Ibid. at 744.

<sup>29.</sup> See, for example, G. Corea, *The Mother Machine* (New York: Harper & Row, 1985); R. Arditti, R. Klein & S. Minden, eds., *Test-Tube Women* (Boston: Pandora Press, 1984); P. Spallone, *Beyond Conception* (London: MacMillan Education, 1989); C. Overall, ed., *The Future of Human Reproduction* (Toronto: Women's Press, 1989); *Misconceptions, supra* note?

<sup>30.</sup> See discussions in the Report, for example, ibid. at 796-802.

of the limited range of submissions received by the Commission and the research undertaken by it. The problem may have been that a focus on "technology" by definition excluded those with a more holistic, non-allopathic approach.

This same allopathic focus is evident in the Commissioners' emphasis on "[e]vidence-based medicine," defined as "[m]edical practice based on data and assessment of whether procedures or treatments are of benefit for their intended purpose." In conjunction with the ethic of care and the eight guiding principles,

evidence-based medicine shaped the Commission's approach to assessing the various forms of infertility treatment. It too provided a prism through which to view the technologies and to determine whether their provision within the health care system was ethically acceptable and constituted an appropriate use of resources.<sup>32</sup>

The definition contains the seeds of a problem that is exemplified in the Commissioners' application of the concept. The reference to "intended purpose" ignores the critical question of overall and long term effects. In keeping with this approach, and with the traditional medical model, the Commissioners, throughout the *Report*, refer to "side effects." This terminology has been criticized because it treats the "intended purpose" as if it is severable from the "unintended effects." Such an approach not only tends to de-emphasize the significance of these effects but its focus on intended purpose can delay the discovery of harmful or damaging impacts. Effectiveness can not be assessed solely, or even primarily, on the basis of "intended purpose."

However, the need for data implicit in the evidence-based medicine approach accords with the perceptions of those who initially called for the establishment of a royal commission. It was hoped that the Commission would initiate some of the much-needed research on these new technologies. The Commission did produce a huge quantity of research, fifteen volumes in all. This vast quantity of material will, undoubtedly, be of great assistance to future regulators, policy makers and researchers. It is a valuable resource. However, the research seems to have been directed more toward compiling existing information than to generating new data or analysis.

<sup>31.</sup> Ibid. at 72.

<sup>32.</sup> Ibia

<sup>33. &</sup>quot;Side Effects" was the title of a satirical play produced by Women's Health Interaction in Ottawa and performed across Canada in 1986. The play, dealing with women and pharmaceuticals, was premised upon the irony of the term side effects when those effects can be so devastating, even deadly. See Women's Health Interaction, "Side Effects: A Dramatic Prescription" (1986) 7:4 Healthsharing 13.

I have not read, nor even looked at, the research compiled. I am responding here based on the list of the contents of the research volumes provided as an appendix to the Report.<sup>34</sup> From this it would appear that a primary research focus was on literature reviews, overviews and annotated bibliographies. A second focus was on surveys and attitudinal studies. The Commission initiated or participated in three major surveys of "representative samples" of Canadians and one "survey of 100 key representatives from ethnospecific and ethnocultural women's communities."35 The information from these various surveys is referred to frequently throughout the *Report* and seems to have been relied upon extensively in the Commission's assessment of Canadian values and responses to reproductive technologies. This kind of research seems rather limited and ineffectual to me. Reproductive technologies are a disparate and complex subject about which, I fear, the general public is ill-informed, largely through media sensationalizations. One of the recurring themes in discussion of reproductive technologies, including the Royal Commission Report itself, is the need for public education and the difficulties encountered in trying to address that need. Consequently, I am concerned about the level of the knowledge and the accuracy of the information upon which these "representative samples of Canadians" based their opinions. I am nervous, in this context, about attaching much weight to public opinion.

In addition to the compilations and the surveys, the work of the Commission provided some new information relating to usage and practice with the new technologies. It is incredibly important to know what is happening "out there" and I wish that there had been more research of this nature, and that it had been more of a focus within the *Report* itself. However, there seems to have been little else in the way of primary research undertaken by the Commission; frequently their recommendations point to the need for further tests or scientific data. There is a desperate need for critical research in so many of these areas, to assist in determining and assessing the risks involved and the potential benefits to be derived. I fear that, in practical terms, the effect of the Commission has been to delay this research and consume research funds that might otherwise have been available.

There are even larger questions about resource allocation to be asked. A frequent criticism of the current focus of research and finances on reproductive technologies is the lack of attention that this has meant with

<sup>34.</sup> Supra note 1 at Appendix E, Research Studies, 1253-71.

<sup>35.</sup> Ibid. at 25.

respect to the causes and prevention of infertility.<sup>36</sup> The Commissioners do direct a significant amount of attention to these issues which, in itself, is an important statement. However, as with so much of the *Report*, the discussion of the causes of infertility is highly individualistic. It begins with an examination of causes related first to sexually transmitted diseases, followed by smoking, and then age.<sup>37</sup> According to the Report, little can be said about workplace and environmental causes because so little is known about them. 38 The last chapter on causes includes eating disorders, endometriosis, substance use and abuse, stress and finally medical intervention.<sup>39</sup> The impression is that infertility is largely due to the actions of the individual woman or man and this is where there is hope for change. The systemic issues are, by implication, secondary and, while the Report certainly indicates that they need to be addressed, the task is depicted as totally overwhelming. The prevention focus is on individual responsibility and public education. The rationale for this focus is the lack of knowledge and information on systemic factors, but there is no analysis or commentary on this lack of information. The tension between prevention and treatment is discussed, but resource allocation questions are never tackled in terms of priorities between the two.

The primary recommendation of the Commissioners is the creation of a national regulatory and licensing commission, with jurisdiction over five areas of reproductive technologies: the handling of sperm and assisted insemination services; assisted conception services; prenatal diagnosis; research involving human zygotes; and the provision of human fetal tissue for research or other purposes. This recommendation was, perhaps, almost a foregone conclusion. Similar suggestions have been put forward in other countries and it has much to commend it. The technologies are too diverse, complex and rapidly expanding for a small, limited term Royal Commission to be able to come to definitive long term solutions. There is clearly a need for further study and deliberation, as well as for ongoing control and enforcement mechanisms. However, the proposal for the creation of a permanent regulatory body is a bureaucratic response, accompanied by all of the attendant bureaucratic problems, including delay, added costs, red tape, and representativeness of the

<sup>36.</sup> Supra note 27.

<sup>37.</sup> Supra note 1 at 199-268 (chapters 10-12).

Ibid. at 270.

<sup>39.</sup> Ibid. at 303-38 (chapter 14, "Other Risk Factors and Infertility").

<sup>40.</sup> Ibid. at 116-17.

appointees.<sup>41</sup> In addition, it is a very expensive proposal, which makes its acceptance unlikely in these economic times. Having put virtually all of their recommendations for control of reproductive technologies in this single regulatory basket, the Commissioners may have effectively delayed regulation.

The Royal Commission on New Reproductive Technologies was a massive undertaking. The completion of the work of the Commission and the distribution of its report are significant events. Some good and important work was produced. By and large, the recommendations are thoughtful and, from my perspective, relatively positive. But overall, I am disappointed. While the Report is a valuable resource, reading it added little to my knowledge or understanding of the issues. The Report presents a muted synthesis of the debates rather than itself making a major contribution to those debates. And so I am left with the question, What was the point? To me, it just was not worth it. We did not, perhaps could not, get enough from this process to make it worth the time, energy and resources that went into it, not to mention the suspension of other activities and the syphoning of funds. While the technologies have continued to advance unabated, I am not sure that we are really any further ahead in knowing how to handle them or in implementing any regulatory action than we were in 1987 when the calls for a royal commission first went out.

<sup>41.</sup> The experiences of the Commission itself with respect to these matters would not auger well for the effectiveness of an ongoing body.

# Dalhousie Law Journal

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