

Placing Values at the Centre of Biotechnology Policy: The Canadian Biotechnology Strategy and Women's Health. Opening Remarks

Susan Sherwin

About the Author

Susan Sherwin is Munro Professor of Philosophy and a Professor of Women's Studies at Dalhousie University. Her principal area of research is in feminist health care ethics.

She is the author of *No Longer Patient: Feminist Ethics and Health Care* (Temple University Press 1992). She also served as Coordinator for the Feminist Health Care Ethics Research Network which jointly produced *The Politics of Women's Health: Exploring Agency and Autonomy* (Temple University Press, 1998). Much of her current work is in the area of ethics and biotechnology.

About the Article

In these Opening Comments, Sue Sherwin explains the history of the Working Group on Women, Health and the New Genetics, and the goals of the national Strategic Workshop held on February 11 and 12, 2000 at York University in Toronto. At issue for concerned observers of the federal government's policy agenda for biotechnology, Sherwin suggests, are "basic questions of values." It is precisely the imperative of value definition and judgment which necessitates democratic rather than bureaucratic policy development in this burgeoning field. Yet the government's approach to defining values, Sherwin argues, has been inadequate at best, and incoherent at worst. Drawing on her own work in the field of feminist health care ethics, Sherwin seeks to "clarify and order the values underlying the Canadian Biotechnology Strategy" by investigating different meanings of 'freedom' and 'choice.' She advocates what she calls "relational autonomy" as a way to approach these ideals. Finally, Sherwin considers the structures and processes through which values – other than those advanced by industry – can be brought to bear in the development and deployment of policies. Despite the difficulty of such a task, Sherwin commends the importance of engaging citizens in the development of Canada-specific approaches to the assessment, promotion and restriction of biotechnology. Only in this way, Sherwin argues, can our policies "reflect and help to realize the deepest values of Canadians."

Introduction

Nearly two years ago, a small group calling itself the Working Group on Women and the New Genetics was formed under the auspices of NNEWH (National Network on Environments and Women's Health). As a group of Canadian academics and community activists sharing a concern with issues related to women, health and genetic knowledge, we structured our investigations around feminist principles of social justice. Specifically, we were concerned with the absence of concentrated gender-specific research investigating the impact of the new genetics agenda on women. With some seed money from NNEWH, we began a series of teleconferences around the need for greater research in the realm of women's health and the new genetics. The membership of this working group evolved a bit and soon settled into a core team.¹

The February 2000 workshop was actually the second in a series of two national strategic workshops. Last February (1999), we organized a preliminary workshop in Winnipeg to which we invited a small group of community activists concerned with women's health issues. They were asked to reflect on their

¹ The Working Group for 1999-2000 consists of: Patricia Lee, Fiona Miller, Roxanne Mykitiuk, Yvonne Peters, Sari Tudiver, myself, and our reluctant but fearless and much overworked leader, Lorna Weir, Department of Sociology, York University, Toronto. Though Ann Rochon Ford has had to give up active membership in the group, she was a very important early member who helped to get us going. The activities of the Working Group have been facilitated by continuing support from NNEWH. That support, supplemented with grants from MRC, the Department of Sociology at York, and the Dean of Arts at York, allowed us to hold this workshop. We are very grateful to all our sponsors.

understanding of the implications of new genetics for women's health and their sense of research priorities in this realm. Building on the feedback from that workshop, the Working Group decided to try to focus the 2000 workshop's investigation of the implications of the new technology for women's health around the three core themes of health, wealth, and community. We re-framed our initial agenda beyond genetics to the whole range of biotechnology in the hope of having an impact on the government's current efforts to restructure its approach to the biotechnology industry. Our hope was that the national strategic workshop would provide an opportunity for participants to define and begin to address a series of fundamental, feminist questions about the Canadian Biotechnology Strategy (CBS) in relation to women and health.

It is our view that that there are basic questions of values related to the genetic modifications of humans and other organisms that must be identified and addressed. These questions cannot be resolved internally through state bureaucratic processes, since they involve questions of society's value commitments. Such decisions must be pursued through democratic processes. Indeed, recognition of the importance of public debate was a major factor behind the federal government's 1998 efforts to solicit public input on these matters through a round of policy consultations. Many of us participated in some of those sessions and were confirmed in our sense that the level of critical cultural knowledge and public understanding of biotechnology is weak. The development of socially accountable strategic frameworks for state biotechnology policy suffers from this dilemma. We are particularly troubled by the lack of attention directed at the question of what these policies mean for women. A distinctly feminist perspective

must be brought to bear on the identification and investigation of the values underlying biotech policy.

We use the term 'women and health' quite expansively to refer to three processes: the impact of policy and technology on women's health; women's relationship to medicine and health systems; and women's 'interests' in health – health as women's business – personally, culturally, socially. We asked Workshop participants to focus on the following: What are the key questions to ask so that we might best understand the impact the CBS will have on women and health? What kinds of research and action need to be undertaken to answer these questions?

In deciding on participants for the workshop, we sought out individuals engaged in developing new knowledge or in carrying out advocacy work. We tried to structure the workshop to facilitate the exchange of existing knowledge, and also to produce new questions and to incite the development of new knowledge and advocacy. We intended the workshop to be a forum for the design of future research projects and activities, where resources could be identified and networks formed of individuals and groups committed to taking the issues further. The aim of the workshop was not to produce consensus. We meant to stimulate and facilitate rather than conclude. We hoped to leave with a clearer sense of what questions should be asked, what research undertaken and what advocacy pursued to deal with the Canadian Biotechnology Strategy from the perspectives of women and health. The collection of papers in this *Proceedings* suggests that we accomplished our goals.

I have the privilege of leading things off. Let me do that by situating my own research interests in the context of our agenda. I work in the field of ethics, more specifically feminist health care ethics. It is

very clear that there is need for sustained feminist research directed at clarifying the many vague suggestions found within the government documents about the values that should be guiding Canada's biotechnology strategy. We can begin by documenting the incoherence in the values expressed in the government's own statements of the values that form the basis for policy directions. For example, the expressed commitment to advancing the health and well-being of Canadians is often incompatible with the strongly endorsed value of supporting industry. Just making clear the competing and incommensurate value frameworks that are being proposed allows us to insist that government be explicit about the priorities it attaches to the various value systems at work. Toward this end, it is particularly important that we ask the familiar feminist questions as to who is likely to benefit from the various types of biotechnology and who is likely to suffer from them. Let me try to be a bit more specific.

It is essential that Canadians understand the different forms of freedom and choice that are proposed as a central value for emerging policy. The terminology of freedom and choice is often used to represent quite different value systems. Not surprisingly, industry is particularly enthusiastic about market models in which freedom is reduced to the ideal of unrestricted consumer choice. In this conception, government is assigned a role of regulating trade to ensure accuracy of information and adequate opportunities to acquire the information necessary to make a rational choice. This is especially tricky terrain for feminists for we often hear our own slogans about the importance of "choice" and personal control over decisions regarding our bodies invoked to support industry's right to market any "health" or "reproduction" related product or service directly to consumers.

We must, therefore, be very clear about

the type of personal freedom we understand to be central to feminist values. Specifically, feminists need to insist that the personal control we demand is not a matter of being granted unrestricted access to problematic technologies. Rather, we seek access to opportunities that can support women's overall autonomy, and not increase their oppression. We cannot decide whether any particular consumer option meets this criterion by examining it in isolation and seeing if it meets some particular person's current desires or needs. To determine a technology's impact on personal autonomy we need to investigate it in the context of what opportunities are created or lost by its introduction.

Elsewhere, I have proposed that we try to understand the ideal in question through a concept I call "relational autonomy" (Sherwin, 1998) The idea of relational autonomy is that we must critically examine not only the decision-making capacity of the agent to make rational choices free of direct coercion, but also the nature of the set of options from which she must choose. Emphasis on the relational dimension of autonomy (which literally means self-government) is meant to counter the familiar over-simplification by which autonomy is equated with the exercise of preferences without interference. Relational autonomy demands moral evaluation of the context in which the person is being asked to choose. In particular, agents should be free of the "double binds" of oppression that tend to reduce an individual's options to a set of harmful choices where the best she can do is to select that option most likely to minimize the resulting damage.

Relational autonomy is also distinguished from consumer freedom in its appreciation of the processes that are essential elements of becoming autonomous. It rejects the common assumption that being autonomous is achieved merely by virtue

of reaching adulthood and being free of explicit coercion. Under the consumer choice model of freedom the self is expected to approach important decisions fully formed and self-transparent; but selves are never fully formed, coherent, consistent, and clear. When individuals are faced with difficult personal decisions they often surprise themselves with the decisions they make. Real autonomy comes not from entering such circumstances with our values settled, such that all we need is respect for our well-articulated preferences, but from having the opportunity to discover what our values really are and how they apply to the situation at hand. We need to wrestle with the implications of serious options to know what we stand for and how we want to be treated. Thus, to respect autonomy for individuals it is not sufficient to leave them free to exercise their preferences; rather we must provide them with the resources necessary for discovering what they truly value and what sort of person they wish to be. It is our reflective, considered values that demand respect, not our current inclinations. Self-discovery and self-definition are relational activities that are essential pre-conditions of genuine self-direction.

Therefore, a consumer model of choice with respect to various sorts of biotechnologies cannot be equated with the moral ideal of autonomy. The fact that people are willing, perhaps even eager, to purchase some form of biotechnology is not evidence that this technology should be brought to market. Individuals are often in no position to resist technologies on their own. If some form of technology is normalized, the option of refusing it may disappear. For instance, it is already difficult for many women to resist prenatal testing of their fetuses even if they are committed to carrying the pregnancy to term and the information available from prenatal testing will be of no benefit to them. Similarly, if the crops produced by

genetically modified seeds prove invasive to other crops, or if they allow production at vastly reduced rates for a few years, independent farmers may be unable to continue to plant traditional seeds in an economically viable way. The fact that women choose prenatal testing under the mistaken belief that it will improve the health of their fetus or that farmers choose to buy seeds from the major distributors is not evidence that the individuals concerned are acting autonomously. Only if their decisions reflect their deepest values can we consider their actions fully autonomous.

We need to do more than clarify and order the values underlying the Canadian Biotechnology Strategy, of course. We also need to explore structures that can ensure that the values selected will be reflected in the policies our government adopts. This project is especially challenging, since it is difficult to see how Canadians might actually go about limiting the development of any potentially profitable biotechnology industry. While government is well positioned to foster the development of favoured industries, it is not as well equipped to restrict the undesirable ones. Biotechnology industries are particularly resistant to government restrictions, for the companies involved are typically engaged in a global, not a national, marketplace. In fact, many belong to that most postmodern of phenomena: multi-national corporations that are situated both everywhere and nowhere. Producers effectively resist national regulations on the grounds that local restrictions would put them at an unfair economic disadvantage in a competitive global marketplace. Typically, they are able to make credible threats that they will move production to a different jurisdiction if their interests are ignored. Governments are understandably reluctant to introduce policies that inhibit the growth of industries when the jobs in question can be easily

moved off-shore. Indeed, governments are far more inclined to support than to restrict these new industrial initiatives. For example, Health Canada was very explicit in its recent announcement that it would shorten the waiting time needed before initiating phase one drug trials from 60 days to two days because it hoped such a move would attract more pharmaceutical research to Canada.

Moreover, it is not only the producers who may resist national restrictions. In an era where free trade has become a mantra of politicians and economists, it is difficult for nations to develop policies that effectively protect their citizens from the potential hazards of products originating elsewhere. While consumers may welcome government's role in setting minimal safety standards and promoting truth in advertising, they tend to be rather intolerant of government restrictions on the availability of goods they personally desire. In fact, many Canadians have become quite adept at "cross border shopping." This means that if our government ever does manage to finally introduce its long-promised legislation to regulate reproductive technologies, we can anticipate that some Canadians will side-step restrictions on reproductive services (e.g., sex selection) through travel to U.S. clinics. Similar action will be taken for access to home-testing kits for genetic traits, anti-aging potions, and even organs for transplant if such products are restricted in Canada but available for purchase in other jurisdictions.

Nonetheless, I believe that Canada must develop a national policy on biotechnology. We need to do this in order to protect and promote the personal autonomy of our citizens, because individuals cannot control the social and material conditions that structure the options they face; many of the preconditions for relational autonomy can only be achieved through political action.

In order to make certain that the options facing Canadians in the realm of biotechnology will promote and not limit personal relational autonomy, it is necessary for the government to develop policies that reflect our national autonomy. That is, they must be policies that reflect and help to realize the deepest values of Canadians.²

In order to develop such policies, we must conduct exercises in collective self-discovery and self-definition about the sorts of activities well informed citizens wish to permit and the sorts of threats they wish government to protect them from. It is only through a complex exercise of communication and debate that we can decide what might constitute "Canadian values" in the diverse, multi-cultural, heterogeneous society we inhabit. In fact, the federal government has recognized that potential transformations of fundamental values and understandings are inherent in many forms of biotechnology. It has undertaken efforts to promote the conversations Canadians must undertake in pursuing the activities of self-discovery and self-definition that are essential for genuine autonomy. For example, more than ten years ago it established the Royal Commission on New Reproductive Technologies to advise on policies in the realm of reproduction. The Royal Commission conducted extensive consultations with Canadians and determined that we are united in not wanting to be a society that treats children or women's reproductive capacities as commodities to be bought and sold. By exploring the meaning of this commitment, the Commission learned that Canadians did not think it appropriate to treat reproductive activities, including the contribution of embryos, eggs, and sperm

² I do not believe that oppression of minorities reflects national autonomy at all, but rather the co-optation of ethical language in the service of immoral abuses of local power.

as commodities to be auctioned off to the highest bidder.

In 1998, the federal government initiated conversations central to self-discovery and self-definition in the sphere of biotechnology broadly defined. It held a series of public consultations regarding development of a biotechnology strategy which would "enhance the quality of life of Canadians in terms of health, safety, the environment and social and economic development by positioning Canada as a responsible world leader in biotechnology." (CBS, 1998). Ethical analysis was understood to be a central element of these deliberations. But as several papers noted, the motivation for discussion was couched in language aimed at facilitating the development and promotion of biotechnology industries and did not really leave room for alternative strategies to emerge. It is, therefore, essential that we make clear the inherent contradiction between a commitment to explore Canadian values regarding biotechnology and an assumption that the outcome of such analysis will be a shared commitment to support most biotechnology industries.

Last fall, the federal government took the next step in its biotechnology strategy process and appointed a 20 member Biotechnology Advisory Committee (CBAC). According to the Minister of Industry "CBAC is an expert, arm's-length committee created under the renewed Canadian Biotechnology Strategy (CBS) to advise Ministers, raise public awareness and engage Canadians in an open and transparent dialogue on biotechnology matters. . . . CBAC will advise government on broad policy issues associated with the ethical, social, regulatory, economic, scientific, environmental and health aspects of biotechnology." (CBAC, 1999). Its express purpose is to facilitate continued dialogue of self-direction and self-definition in the

pursuit of national autonomy in the realm of biotechnology. There is, however, plenty of reason to worry about its effectiveness in achieving this task. It is arguable that the advisory panel of distinguished Canadians is not representative of all concerned citizens; certainly, there are many groups that fear their views will not be represented nor their voices heard. Health activists seem to have been deliberately excluded and I know of only one member who is explicitly committed to a woman's health agenda. CBAC will need to find ways to promote trust in its ability to fully engage Canadians in self-discovery and self-definition and to report accurately the outcomes of these conversations if its advice is to carry the necessary authority. One thing we can do, here and in the future, is to begin to formulate a substantive list of questions regarding the impact on women's health that CBAC should attend to in its deliberations. We might also propose procedural ways that can facilitate meaningful input from citizens who are concerned with, and knowledgeable about, women's health.

Of course, self-discovery and self-definition are not the only elements of autonomy. Self-direction is also required. So far, the Canadian government has been unwilling or unable to engage in the final step of exercising national autonomy in the realm of biotechnology. Despite the thoroughness of its public consultations and of its research and analysis, none of the 293 recommendations of the Royal Commission on New Reproductive Technologies has yet been implemented. It is still too early to determine whether CBAC will be able to contribute effectively to self-direction on biotechnology policy. It is clear, however, that there are likely to be structural impediments to its capacity to influence policy, that is, to see its moral analysis translated into national self-direction. The panel reports to an inter-governmental agency in which the

Department of Industry plays a leading role; the principal responsibility of this ministry is to promote industrial development. Such an arrangement does not seem to be particularly conducive to generating policy that may require imposing restrictions or prohibitions on certain industries.

So far, then, the biotechnology strategy espouses interest in identifying and reflecting the values of Canadians but the processes that have been put in place make it difficult for the government to hear, let alone adopt, values other than those of industry. We need to identify strategic ways to demand more accountability from government in:

1. identifying the appropriate values to guide biotech policy; and
2. ensuring that the values agreed upon do in fact structure both national and international policies.

Protecting and promoting women's health must surely be fundamental to that agenda. Our hope for the workshop was that it would help to provide direction to the research and political activities that are essential elements of translating this commitment into practice. Clearly, there is much work for feminists to do in promoting biotechnology policies that truly support women's health. The following papers provide some guidance for how to proceed.

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