Health Protection for the 21st Century?

A response from the Maritime Centre of Excellence for Women's Health on Health Protection Branch Discussion Papers

Gender and Health Policy Discussion Series Paper No. 2 ❖ October 1998

The Maritime Centre of Excellence for Women's Health (MCEWH) is glad to have the opportunity to participate in the consultation phase of the Health Protection Branch (HPB) Transition. While we are pleased to see that there is significant breadth to the questions that have been identified in HPB discussion papers, we see some worrisome gaps. We also have concerns about how well practice will fit with the ideals described and we worry about the emphasis that will be placed on different issues. In this paper, the MCEWH will identify some of our major concerns regarding the mandate and approach of the transition process for the Health Protection Branch as it has been described in the consultation documents.

The MCEWH has identified eight inter-related areas of concern regarding the Health Protection Branch Transition.

1. Gender Equity Analysis – In order to recognize when products, procedures and policies affect women's health differently from men's, researchers must investigate their effects on both women and men. Unless deliberate efforts are made to identify cases of differential impact, the specific health risks experienced by women are frequently unknown. Such gaps in knowledge are inequitable; hence, justice requires that all research into the safety of products, procedures and policies include specific attention to their possibly differential impact on women and men.

Background

Over the next two to three years, the Health Protection Bureau will go through a process of review, consultation and renewal in order to find new ways to protect the health of Canadians into the next century. This process, known as the HPB Transition, began with the launch of two discussion papers entitled: "Health Protection for the 21st Century: Renewing the Federal Health Protection Program" and "Shared Responsibilities Shared Vision: Renewing the Federal Health Protection Legislation".

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MARITIME CENTRE of EXCELLENCE for WOMEN'S HEALTH

2. Setting the Agenda – Health risks vary from one social group to another. It is important that all social groups, especially those whose members are systematically disadvantaged, have input into setting the priorities of the research agenda of the HPB.

3. Process – HPB must consult widely in the transition process and ensure that community groups concerned with its mandate have the necessary resources to participate fully in this review.

4. Conception of Health – HPB must resist narrow biomedical conceptions of health in favour of approaches that are sensitive to social and economic determinants of health.

5. Risk – The health of people other than the consumers of a product may be threatened by its use. Moreover, communities as well as individuals are at risk from some health-related products and policies. HPB should avoid narrowly individualistic conceptions of risk and attend to ways in which third parties and social groups may be threatened by innovations that may not pose particularly high risks to the primary users.

6. Autonomy – Autonomy is best understood relationally (and contextually). Simple expression of consumer choice may not be evidence of autonomous choice and, hence, it may not be an appropriate determinant of a product's acceptability.

7. Preserving the Social Fabric – HPB should be sensitive to ways in which new technologies may affect cultural values and practices. It should be particularly concerned with technologies (e.g., cloning) that may threaten the fundamental values of most Canadians.

8. Addressing Ethical Questions – When the ethical answers are clear (e.g., the need to promote equity through gender analysis), legislative approaches are reasonable. Where the ethical questions are more ambiguous, HPB must develop fair and open processes to ensure adequately representative community input in its deliberations.

Gender Equity Analysis

Our own mandate is to improve women's health and promote social change through research on women's health. Hence, our primary concern is to ensure that the distinct health needs of women are recognized in the work of the HPB. This will require, for instance, that appropriate gender equity analysis be conducted whenever it is relevant to determining levels of risk associated with products and procedures.[1] It is important that the HPB recognize that even though men and women share many health concerns and face many of the same health risks, there are also differences in the role of both sex and gender as determinants of risk in many situations.[2]

Gender Equity Analysis of Programs and Policy

Gender equity analysis is a process that assesses the differential impact of proposed and/or existing policies, programs and legislation on women and men. It makes it possible for policy to be undertaken with an appreciation of gender differences, of the nature of relationships between women and men and of their different social realities, life expectations and economic circumstances. It is a tool for understanding social processes and for responding with informed and equitable options.

References

1. Gender analysis studies the specific effects of a product, procedure, or policy on women and men and identifies any differences in impact.

2. The term "sex" is usually used to refer to biological differences between males and females; "gender" includes the social differences in roles assigned to males and females within a culture. Men and women face different health risks on both accounts: e.g., biology makes women but not men vulnerable to cervical cancer, but social roles play an important role in making women more vulnerable to sexual assault.

Health policies and practices are generally decided without conducting gender equity analysis to explore the possibility of differential impacts on women and men. It is very common in research to treat men as the representative standard or norm for the species. Women, if considered at all, are either presumed to be "just like men" or else they are treated as a special and non-representative case to be investigated later (if at all). Hence, researchers often limit their samples to male populations (and often to young to middle aged men, at that) and they neglect to explore the relevance of their results for women. Very often, the necessary data by which we might determine the presence of significant sex differences in the effects of the intervention being studied are simply absent. It is quite common, for example, for pharmaceutical companies to limit their pool of subjects to men. Yet, factors such as body weight, body surface, the ratio of lean to adipose tissue, the greater concentration of steroids in men's bodies, the differences in hormones, and the use of artificial hormones by women (for birth control, control of menopausal symptoms, or fertility treatments) can all affect optimal doses. So, too, can differences in eating patterns which tend to be correlated with different social norms for women and men. This means that unless the research population includes a critical mass of women, and unless the study explicitly analyzes the data for gender differences, we may not know the effect of the drug in question on women.

In order to develop health policies that will provide equitable results, it is essential that research into threats to health be conducted in ways that will reveal whether or not there are gender-related risks attached.

The problem of male bias is not restricted to drug research. As Karen Messing has repeatedly shown,[3] occupational health and safety data typically focus on the threats to male workers and ignore the specific risks associated with jobs that are most commonly filled by women; they also ignore distinct risks women face when they enter into traditionally male job categories. Here, too, gender equity analysis is necessary to promote gender equity in the results of health protection research.

In order to develop health policies that will provide equitable results, it is essential that research into threats to health be conducted in ways that will reveal whether or not there are gender-related risks attached. This requires not only that studies include women in sufficient numbers to obtain statistically significant results but also that the data be collected and analyzed in ways that will reveal this information. Moreover, such analysis may also have to consider whether specific groups of women (e.g., elderly, pregnant, or immigrant women) are at particular risk whenever there is reason to suspect relevance of such differences.

Setting the Agenda

It is important, as well, that efforts be made to ensure that deliberations regarding the need to investigate health threats and risks be sensitive to the distinct perspectives of disadvantaged groups. It is frequently the case that the decision makers who set the agenda for safety testing belong to the more privileged groups in society; inevita-

References

[3] See, for example, K. Messing, *Occupational Health and Safety Concerns of Canadian Women: A Review* (Ottawa: Labour Canada, 1991).

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bly, they tend to focus on their own sense of danger and concern. Health risks are correlated with specific social and historical positions, however, and may not be equally shared by all members of society. For example, the cumulative impact of food additives may be more severe for those who lack the resources to obtain a healthy, well-balanced diet with plenty of fresh fruit and vegetables than for those who are able to select nutritional foods without regard to cost. The availability of alternative organic food products for those who "choose" to avoid pesticide and genetically altered food sources is irrelevant to those who are dependent on food banks to feed their children. Decisions involving what sorts of substances are appropriate for HPB review require attending to the distinct perspectives and needs of all segments of society, especially to those of groups that tend not to have much political power. It is essential that those who set the agenda for exploring risks be sensitive to the differing position of different social groups.

Process

The importance of being sensitive to marginalized voices raises questions of process with respect to the work of the HPB and also to the transition process. Although the mandate of this process specifically excludes questions of implementation, we feel it necessary to stress the need to ensure that the administrative structure chosen be one in which there is room for on-going public review about the priorities of the HPB. There must be particular efforts made to ensure that the health needs of the various disadvantaged segments of the population are identified. Without specific effort to consult groups whose marginal political position is associated with distinctive health threats, it is possible the HPB will fail to recognize its responsibility in these areas.

Health Canada is to be congratulated for recognizing the need for wide public consultation in its efforts to redefine the role of the Health Protection Branch. As the discussion documents observe, health protection and promotion is of concern to all Canadians ... to this end, the current consultation should strive to include effective outreach measures.

The place to begin collecting this input is in the transition process now under way. Health Canada is to be congratulated for recognizing the need for wide public consultation in its efforts to redefine the role of the Health Protection Branch. As the discussion documents observe, health protection and promotion is of concern to all Canadians. All citizens have a stake in the effectiveness and comprehensiveness of the legislation and procedures that will be put in place. It is especially important that this process be as widely based as possible; to this end, the current consultation should strive to include effective outreach measures. We are worried that not all "stakeholders" are equally well situated to participate in this process. In particular, community-based organizations that depend heavily on volunteer labour may lack the resources to educate themselves sufficiently to respond effectively to this initiative. Where industries may have significant resources at their disposal to ensure that new regulations shall not impinge on their profits, effected citizens are unlikely to be as well organized. Therefore, we encourage Health Canada to provide the resources and opportunity needed for community-based groups to participate fully in this project in other cities where other consultation meetings are scheduled. In particular, we support efforts to ensure inclusion of communities that face distinct health risks yet often find their specific needs overlooked (e.g., First Nations peoples and disability rights groups).

Conception of Health

Our worries about voice and agenda-setting are intimately connected to our concerns about the conception of health that will guide the work of the HPB. It is now widely recognized that health involves important social determinants as well as traditional bio-medical factors. It would be a serious mistake for HPB to concentrate its attention on the latter without taking into account the significance of the former. The tone of the consultation documents suggests an orientation towards bio-medical factors and away from social considerations (references to "scientific" research seem to be aimed primarily at bio-medical or biochemical research, not social science research).

It is essential that the HPB acknowledge the role of social and economic factors in health matters even if it ultimately determines that addressing such factors is best accomplished through other departments. An adequate tobacco policy, for example, should reflect the ways class and gender affect a person's risk experience of addiction; for example, smoking is often the only "time out" for women, and is inversely correlated with income level and recent studies confirm that teen-age girls are inclined to take up smoking as a means of appetite and weight control. Also, prison policies that prohibit access to condoms and clean needles condemn prison inmates to a high risk of contracting HIV and hepatitis C. Similarly, programs aimed at protecting the health of Canadians should acknowledge that risk of sexual assault is far higher for women than men and is particularly high for disabled women. In our view, health protection policies should make explicit the full range of threats to health so that they may be addressed. Even when solutions to some relevant social conditions fall outside its mandate, it would still be desirable for the HPB to call attention to these types of risks and encourage action by the appropriate departments.

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Risk

Another area of concern for us is the danger of the HPB taking a narrow, individualistic approach to questions of risk and choice. Health protection policy must identify a delicate balance between individual and collective risk and choice. Illness and injury affect individuals (and, thereby, their families, workplaces, and communities) in an immediate, direct way, so a fundamental aim of all health policies must be to promote and protect the health of individuals. Nonetheless, risks are also borne by social groups and by society as a whole. Health policies can have a profound effect on social groups that extends beyond their impact on individuals considered in isolation. For example, policies that require removing pregnant women from their remote communities to give birth in alien urban areas affects the culture of the community as well as the health of the pregnant woman and her child.

Persons or groups other than those who make use of a product or practice may feel its harmful effects. For example, second hand smoke damages the health of non-smokers and, often, alcoholism and drug addiction cause harm to many people besides the addicts themselves. Drugs prescribed to pregnant women (or, potentially to infertile women trying to become pregnant) may cause disease in their offspring decades later as was the case with DES – a drug widely prescribed to pregnant women in the 1950s and now known to cause cancer in women and men who were fetuses at the time. Hence, risks cannot be calculated merely by considering the effects on those who use a product or procedure. We need an analysis of risk that will reach beyond the effects on the individuals who use a product and include all its effects, both physical and social.

This task can become very complicated because others may be harmed by another's use of a product or procedure in quite indirect ways. For example, as prenatal screening for genetic anomalies becomes increasingly accepted as normal obstetrical practice, individual women find it ever more difficult to resist prenatal diagnosis; they rightly fear that they will be judged irresponsible if a preventable condition should be identified after birth. Family, friends, health care providers, and certainly insurance companies are becoming increasingly less supportive of women who give birth to children with genetic anomalies given the availability of prenatal genetic diagnosis and selective abortion. The threat of lawsuits and challenges to their professional competence force physicians to employ this technology, even when there is no statistical reason to support its use in a given case or when the physician considers the anomaly in question insufficient grounds for termination (e.g., Down Syndrome). Prenatal use of ultrasound, for instance, has become so widespread it is difficult for either patients or physicians to refuse use of multiple ultrasounds despite the fact that they have not been shown to improve birth outcomes. The decision of one group of consumers to use a technology can soon make the use of that technology the normalized standard of care; thereafter, other patients will find their options to refuse that technology limited.

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In such ways, individual choice of certain sorts of health care technologies may ultimately constrain the options of others. The direct health risks of prenatal ultrasound to pregnant women and most fetuses are considered to be relatively low (though some questions remain). The risks are very high for fetuses with detectable anomalies, however. Early detection of serious congenital deformities, multiple births, and even undesired sex can result in selective abortions. In a climate of insufficient public resources for raising disabled children, pregnant women carrying affected fetuses will feel a strong pressure to abort even if they highly value the life of their fetuses. At the same time, disabled members of the community may feel themselves devalued as significant quantities of public resources are directed to prevention of the birth of others like them and declining birth rates of infants with disabilities may be cited as license for reducing services to the disabled. Thus, the harm of a particular procedure may be experienced by others far removed from those who actually choose it.

Autonomy

Further, the concept of choice itself must be understood as complicated. It is typically assumed to reflect autonomy, and, therefore, we recognize that it is important to respect the choices of individuals as a means of promoting their autonomy. It is a mistake, however, to believe that expressions of choice always represent expressions of autonomy. Autonomy is best understood as a relational capacity that admits of degrees and reflects the agent's specific social location.[4] The degree to which an agent is autonomous about a matter is determined by the agent's relational experiences on both an interpersonal and a general political level, and also by her particular position at the time. Social pressures to adopt particular habits, values, and hopes may combine with a variety of other social and economic forces to limit an agent's opportunity to develop the necessary skills to make wise choices or they may severely restrict the available options. (For example, those whose livelihood depends on pleasing powerful others may not have formulated their own preferences on certain matters.) Those with little opportunity to exercise autonomy may ultimately lack the competency or the genuine opportunity to do so even when offered the opportunity to "choose." Oppression, in particular, can have a severe impact on an agent's capacity for autonomy with respect to certain matters. For example, within a culture that devalues females so strongly that it punishes women for giving birth to girls, the ability to resist available sex selection technology is likely to be very low.

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It is essential, then, that the HPB not put too heavy a burden of assessing risks on individual consumers but critically assess the motivations for the choices that consumers express. It must recognize the ways in which social forces structure individual choices and be particularly sensitive to the role that oppression may play in supporting certain types of choices. It should strive to select policies that will help to reduce oppression and resist those that promote it.

Preserving the Social Fabric

It is particularly urgent that the HPB be sensitive to the potential for emerging biotechnology practices to threaten the very social fabric and values of Canada. Risk assessments must take such types of dangers into account. Although reproductive technologies currently

References

[4] For development of this concept, see Susan Sherwin, "A Relational Approach to Autonomy in Health Care," in *The Politics of Women's Health: Exploring Agency and Autonomy* by The Feminist Health Care Ethics Research Network, Susan Sherwin Coordinator (Philadelphia: Temple University Press, 1998).

fall outside the mandate of the HPB, they provide an example of ways in which new technologies threaten to alter fundamental values: the trend towards commodification of reproductive materials threatens to have a profound impact on our understanding of children and reproduction. Geneticization represents another example: Abby Lippman has introduced the term geneticization to describe the increasing tendency to distinguish people from one another on the basis of genetics, i.e., to define most disorders, behaviours, and physiological variations as wholly or in part genetic in origin.[5] The ideology of geneticization is changing our understanding of who we are, what is important about ourselves, and how we ought to go about health promotion and protection in our culture. As the Human Genome Project provides us with the basis for testing for an ever-increasing number of genetically-related conditions, we as a society need to stop and ask questions such as: who wants to know this information? what do they plan to do with it? what sorts of conditions should be treated as acceptable grounds for terminating fetal life, for becoming ineligible for certain types of employment, or for denying access to affordable health or life insurance?

In our view, an adequate process is one that is responsive to community concerns and sensitive to the ways different social groups may be affected by particular health policies. Such a process must be broadly inclusive and fairly balanced to ensure that the perspectives of the most marginalized groups are not eclipsed by the well organized voices of more privileged members of society or by the special interests of industry.

We will need an especially broad definition of risk as we contemplate the growing possibilities of being able to clone human beings and of altering the existing genetic code of individuals at will. Such powers pose significant risks to the experimental subjects on whom these technologies are first tried, but they also pose worrisome challenges to our society's conception of the value of human individuality and difference. The HPB must recognize that society's interests are not reducible to the interests of the individuals that constitute it. Although human rights concerns put clear limits on a government's scope for legitimate interference with individual liberties, they do not provide a carte blanche that protects pursuit of any individual preference.

Nevertheless, there is also an ever-present risk that individual rights will be overridden by an over-zealous focus on social interests. It is all too easy for individuals and minorities to find their interests sacrificed to the good of the community, especially when they lack the political power to assert their rights. It is quite common for the majority to neglect or misperceive the particular needs of a minority. In deciding when society's interests should outweigh those of an individual or of a minority group, it is essential that the responsible body be sensitive to questions of balancing individual, group, and society's rights. Because groups that are oppressed are particularly vulnerable to having their interests overridden, it is vital that policies be such that they do not increase the burden of oppression on those who are already systematically disadvantaged. For example, efforts to promote respect for people with disabilities should not be pursued in ways that further contribute to women's oppression by denying them access to abortion; similarly, efforts to protect the poor from the hazards of addictive substances should not involve policies primarily aimed at punishing the vulnerable.

References

5. Abby Lippman, "The Politics of Health: Geneticization versus Health Promotion," in *The Politics of Women's Health*, op. cit.

Addressing Ethical Questions

There are no easy answers to many of these questions. They are inherently ethical in nature. They involve careful attention to values, since they reflect both conflicts of interest and conflicts of values. Risk assessment must involve much more than careful scientific observations. Risk is a measure both of the undesirability of an outcome and of the likelihood that the outcome in question will occur. Evaluations must consider the question “undesirable to whom?” As we have seen, outcomes that are harmful to some may be beneficial to others. Different social positions represent important differences in perspective; these different perspectives will often yield different analyses of what constitutes harm, what constitutes benefit, and what degree of risk is acceptable. Science alone cannot answer these types of questions. Nor can science alone decide which risks are worth examining, what types of harm merit study. These are all value questions that call for serious deliberation in an open process that is inclusive of a widely diverse group of participants.

This is not to say that all value questions are problematic and unsettled. Canadians have already made some clear decisions regarding the operative values for social policy as reflected in our constitution, and, specifically in the Charter of Rights and Freedoms. We have made a strong commitment to promoting equality in our society. This means that the HPB should actively seek to protect and promote the conditions necessary for full equality whenever possible. Hence, for example, it should make it a matter of explicit policy that all research into the safety and efficacy of products include gender equity analysis. If necessary, it should seek legislative authority to implement a policy of gender equality through inclusion of gender-based analysis. This has been the strategy in the United States, where both the National Institute for Health (NIH) and the Federal Drug Agency (FDA) have passed guidelines concerning the inclusion of women and minorities in most clinical research studies. Without such an explicit policy, we fear that researchers will continue to neglect the specific gender equity analysis necessary to guarantee the safety and equitable treatment of Canadian women.

Where ethical matters remain uncertain, however, such as in deciding the priorities for HPB research and the ways of balancing competing interests, it is necessary to pursue a more flexible strategy. Here process must replace a clear substantive directive. In our view, an adequate process is one that is responsive to community concerns and sensitive to the ways different social groups may be affected by particular health policies. Such a process must be broadly inclusive and fairly balanced to ensure that the perspectives of the most marginalized groups are not eclipsed by the well organized voices of more privileged members of society or by the special interests of industry. Ultimately, questions of health require attention to questions of justice. Policy makers must ensure that the processes they rely on are accountable by both standards.

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