

‘Get a Life!’:

An Anthropological Assessment of Public Bioethical Debate

By

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Abstract

Public bioethical debates are dominated by formalized medico-scientific discourses based on normative judgments about health and disease. A chief consequence of this circumstance is that the polar opposition between health and disease, lying at the heart of conventional modern biomedical discursive practices, has also become central to the field of public bioethical debates. However, this thesis argues that the concepts of health and disease have determined the corporeal norm and ideal through which reproductive and genetic technologies are justified. That is to say that the goal of eradicating ‘disease,’ which is the stated goal of medical practice and public health policy, only further reinscribes an idealistic notion of the ‘healthy body’ in the normative sphere. An anthropological analysis of the normative implications of the dominance of biomedical models of health and disease contributes a counter-discourse that highlights the normative and idealistic judgments and the goals of reproductive and genetic technologies. Thus, this thesis argues that the public bioethical field needs to consider becoming more interdisciplinary in its structure when assessing the implications of the use of reproductive and genetic technologies in contemporary society. This might facilitate corrections of the normative myopia that characterizes the public bioethical field today.

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Chapter One

INTRODUCTION:

HEALTH, NORMATIVE JUDGEMENTS AND SOCIAL CONTEXT

'Get a life? Which one? Why "that" one?' The thesis below is a critical interrogation and investigation of how public bioethical debates and the dominance of biomedical discursive practices have attempted to monopolize the answer to the question of 'a life.' In doing so, it has imposed a normative ideal of health as the goal and purpose that ought to be used in rationalizing and justifying decisions about human life, including social life. However, this normative project, and its justifications, has been masked by the way in which bioethics is structured by the formal rationality of biomedical scientific discourse.

In Canada, a human biotechnological revolution is well underway, driven by scientific innovations. A critical anthropology needs to pose questions about these transformations, such as: What are the goals of the medico-scientific institutions with regards to human reproductive and genetic technologies in regard to health and disease? Why do medico-scientific authorities insist that human reproductive and genetic technologies will help humans become healthy and remove biological 'impurities'¹ from our bodies? I contend that the belief in technological innovation is established by the

¹The use of the single quotations here is to emphasize a problem in the concept of an impurity existing within the body, the idea that pure or impure bodies are contextual and flexible concepts, which are rooted in the moralization of health and disease.

desire for 'health,'² and it is this, which fuels the desire to technologize and perfect the human body according to an ideal of health. This paper will demonstrate that it is the ideal of a 'healthy' body, as articulated and envisaged by biomedical discourse that compels and guides public bioethical discourse and the interest in reproductive and genetic technologies. Discourses are systematized ways of understanding, accounting for, and questioning some facet of the world including the social world (Foucault 1972). The application of human reproductive and genetic technologies re-affirms the conceptual polarization of health and disease constitutive of modern medicine and its deployments in modern political projects and programs.

Problematization refers to the process in and through which some facet of existence becomes a 'problem.' That is to say that it becomes a problem thought about by various authorities and experts (it becomes a concern for them for which they attempt to develop solutions). Problematization is a concept that refers to the process in and through which some or other form of existence (human or otherwise) comes to be seen as a problem, for which solutions are developed. Foucault states,

[Problematization] develops the conditions in which possible responses can be given; it defines the elements that will constitute what the different solutions attempt to respond to. This development of a given into a question, this transformation of a group of obstacles and difficulties into problems to which the diverse solutions will attempt to produce a response, this is what constitutes the point of problematization and the specific work of thought (Foucault 2003d: 24).

²The use of single quotations here is to emphasize the conceptual flexibility of the use of the word healthy. This is questioned in the second chapter of this paper.

Both the articulation of the problem and the development of solutions are constructed within the terrain of discursive practices. For instance, in the field of public bioethical debates, the meaning of life, health and disease have become a problem, but a problem posed within the discursive practices of genetic science and medicine. The historical objective of attaining health through reproductive and genetic technologies is a socially complex artifact, embedded in elaborate social networks. Thus, the problematization of medico-scientific projects, such as reproductive and genetic technologies, is informed by, and articulated with, culturally constituted understandings of health and disease.

The primary analytical approach subtending the thesis is found in Georges Canguilhem's work on *The Normal and Pathological* (1978), and I have applied it to public bioethical discourse. In effect, Canguilhem offers a counter-discourse/counter-science, which suggests that the healthy body is both an ideal body and normal body; it is both a goal and a means of making normative judgments, thus producing concrete social effects (Foucault 1980a). Medico-scientific ideas of physical well-being are derived from socially constructed taxonomies of the 'healthy' body versus the 'diseased' body.³ Normalization is a process in which dominant discursive practices shape and standardize ideological models in social and state apparatuses, using those as a basis for political projects.

³The single quotations used for 'health' and 'disease' emphasize the conceptual ambiguities of these terms. The ambiguities are further developed in the second chapter of this paper.

Normalization produces at the same time procedures and effects of exclusion: it constitutes the form of authoritative veridical discourses, thus defining what should be excluded from veridical discourse, including of course certain speaking subjects; and it constitutes the domains of the pathological and the abnormal that are either to be excluded from some social field or are to be targeted by projects of rule interested in making them “normal” (Datta and Pearce 2004: 34).

Thus, normalization processes are governing techniques supported by discourses that establish institutional legitimacy by creating a norm. Canguilhem expands on the concept of the normal by arguing that health and disease are *both* normal states of an individual, dependent on the conditions surrounding their existence and their capacities for environmental adaptability (Canguilhem 1978: 106). Canguilhem argues that health is a concept that is perceived as both normal and ideal because a healthy body is what is medically considered as the standard or normal, and further, a healthy body is idealized because it is considered how the body 'ought' to be (Canguilhem 1978: 69). This merging of health as an ideal and deemed normal is the basis for the argument presented in this thesis. Canguilhem's understanding of the normal and ideal challenges the biomedical model that assumes a polarization of health and disease in public bioethical debates by showing that health is a complex and hence, is irreducible to genetics alone.

The implicit normative framework at work in medical science has justified and rationalized the idealization of the healthy body. This has had two major consequences: 1) public bioethical debates have tended to occlude the implicit normative framework of medical science; and 2) this has led to the rationalization and application of a biopolitics

targeting health and disease in society. It is the goal of this thesis to draw attention to how this circumstance fails to adequately consider the normative and political implications of the project of creating a healthy, disease-free society, and how a critical anthropological reflection on these issues can potentially shift the terrain of debate.

The Goals of Medical Science: Bioethics and the Spectre of Biopolitics

Medical science claims that its goal is the improvement of health. An inherent assumption in medico-scientific discourse and public bioethical debates is the idea that healthy bodies promote socio-physical advantages, such as social productivity and physical strength to combat disease. This raises questions about ‘bodily enhancement’ and its articulation with biopolitics as engaged in various attempts to eradicate disease as a means of enhancing social life (echoes of eugenics projects should be noted here). When one examines technologies used by medical practice, such as reproductive and genetic technologies, one discovers the extent to which social perceptions of body images are intertwined with the ideas of scientific progress and with assumptions of what constitutes the ideal body.

Biopolitics is a concept created by Foucault, used throughout this thesis. Biopolitics is “the endeavour, begun in the eighteenth century, to rationalize the problems presented to governmental practice by the phenomena characteristic of a group of living human beings constituted as a population: health, sanitation, birthrate, longevity, race” (Foucault 2003c: 202). Thus, biopolitics is concerned with the governing of life and its

environment, through various institutional channels. This means that the emergence of biopolitics, as a strategy to govern, targets the body of the individual as both a political and scientific object (Dreyfus and Rabinow 1983:139).

Technological innovations in medico-scientific inquiry tend to be normatively governed by concepts of bodily idealism. These technologies are deployed in order to generate healthy populations and remove disease. However, the ways in which the technologies are created and applied originate in complex networks cross-cut by social strategies and negotiations. And, within these networks, social agents (individual and collective) inhabit perspectives and understandings of how technology should or should not be applied. These normative positions of different collectives create tensions within the negotiating process concerning the creation and application of human biotechnologies. For example, the various definitions of life found in Vatican writings or in Canadian legislation exist because of their different approaches to the concept of life, approaches that are constituted by their respective institutional contexts, their interconnections by that to which they are opposed.

Questioning the normative dimensions and contexts of public bioethical debates and medical discourse, is a major contribution made by contemporary anthropology and I endeavour to continue in this vein. By normative, I am referring to the three dimensions of politics, morality and ethics, and the ways in which these are interconnected. By politics I mean, the directing and purpose of a society (including the role of religious or

state institutions in providing such direction and/or goal-setting); by morality I draw upon the Durkheimian tradition. By morality, I am referring to collectively understood rules meant to guide human action in order to achieve a particular form of society; and by ethics I refer to the individual reflection and approach to moral concerns (Datta 2003).



Figure 1.1: The Normative Field

Contemporary public bioethical debates are grappling with an epistemic transformation in the field of medical judgments. The shift is one from a form of medical practice geared toward the treatment of actual disease in order to return the body to a state of health to a medicine of the possible. That is to say that genetic medicine is not concerned with the actual; its concern is with the possible and hence, attempts to intervene in the present corporeal state in order to eradicate the present potential, determined by present genetic structures, for the development of a future possible presentation of disease. Its focus on the 'possible' produces its political dimension.

Bioethical Debates: Outlining an Anthropological Approach

Only recently have public bioethical debates been of interest to anthropological inquiry.⁴ The increased interest of anthropology in bioethical debates has revealed the potential contribution that anthropological sensibilities can provide to a broadening of these debates. Anthropological methodology and theory offer a cultural perspective on public bioethical debates and their contexts. In particular, anthropology offers a way of examining and questioning the hidden moral judgments within medical science and public bioethical debates.

Traditionally, anthropologists have not been interested in bioethical debates because these debates tended to be ethnocentric, a tendency that runs contrary to the anthropological sensitivity to questions of cultural relativity that refer to the anthropological appreciation of differences between cultures (cf. Muller 1994: 449). Anthropological methods, such as ethnographic research are sensitive to cultural relativity and hence, involve the investigation of personal (or qualitative) understandings of the relationships between health care, morality, and culture. These are necessary to an adequate analysis of revealing the various cultural tensions in the biopolitical landscape of health-care decision-making practices.

⁴Social sciences began to take a prominent position in the field of bioethics around the mid 1990's (Turner 2003: 101).

Much of the bioethical understanding in anthropology is rooted in moral questions. Because bioethical discourse is inherently moral (even if tacitly), anthropological inquiry into bioethics must consider the importance of social, cultural and historical phenomena that shape the moral situations (Marshall 1992: 49). In other words, morality is embedded in the historical and socio-cultural practices surrounding bioethical investigations. Anthropology can examine the structural issues of bioethical debate, issues such as kinship, fertility,⁵ personhood, family and reproduction (Shore 1992: 296). That is, anthropological perspectives are concerned with the broader cultural ideologies⁶ that are embedded in medical practices, discourses and institutions.

Anthropology also offers pluralistic approaches to the multi-cultural settings of medical facilities. The cross-cultural and comparative emphasis in anthropology attends to the place of moral systems inherent in a culture (Muller 1994: 456). Further, cultural pluralism is important in bioethical inquiry because of the cultural heterogeneity of Western populations (Muller 1994: 457). This is in stark contrast to bioethical discourse, given its tendency toward culturally homogenous and ethnocentric assumptions. This is because

mainstream bioethics fails to attend to the particular moral worlds of patients and their family members. A more anthropologically informed understanding of ethical issues that emerge within health care facilities

⁵For further information on how infertility is a cultural experience, refer to Van Balen and Visser (1997).

⁶ I refer to ideology as a general set of ideas, beliefs and values, held consciously or unconsciously about the world, including the social world, that govern social agents in social practices.

will need to better recognize the role of culture and religion in shaping modes of moral deliberation (Turner 2003: 99).

In other words, bioethics overlooks the imbrication of culture and morals within biomedical discursive practices. Bioethical problematics are constrained by the assumption of cultural homogeneity. Again in contrast, anthropology offers the ethnographic method by which to re-examine moral dilemmas that exist in the multi-cultural situations in modern societies that present themselves in health-care facilities and in other institutional contexts. Subsequently, “research on the culturally constituted nature of moral behavior reveals not only how ethical dilemmas are culturally constructed, but also how these constructions influence decisions about ethics in medical settings” (Muller 1994: 459). Muller’s work illustrates how morality and ethics are rooted in cultural constructions and further, how these culturally embedded ideologies inform personal ethical decisions in medical practices. For example, ethnographic research conducted by Lazarus (1997) demonstrates that there are various moral perspectives and consequences of medical residents practicing, or refusing to practice, abortion. Lazarus’ ethnography thus clarifies the institutional problems of access to abortions because some residents refused to perform abortions, even the work-up procedures, due to personal moral convictions (1417). She concludes by criticizing residency requirements and by highlighting the lack of sensitivity and training for residents, due to improper communication and clear residency guidelines (Lazarus 1997: 1423). Thus, Lazarus’

ethnographic approach exposes the inherent moral and cultural influences within medical decision-making practices, in the context of a public medical hospital.

Sacchini and Antico (2000) conduct an ethnographic analysis of the concept of individual autonomy in Italian medical centers.⁷ They claim that autonomy is an anthropological point of interest because

the affirmations of the autonomy of the individual is one of the elements that make a human act a moral act. From the ethical point of view, it should be noted that the individual autonomy can be interpreted in different ways according the importance we confer on it (Sacchini and Antico 2000: 443).

The concept of autonomy is a valid anthropological focus because it acknowledges that humans are moral beings. Morality is then culturally relevant and can be analyzed through different ethnographical approaches. Other examples of cross-cultural ethnographic approaches examining morality and bioethics are conducted by Khanna (1997) who discusses the pre-natal consequences of applying reproductive technologies to determine gender in a North Indian village (171); and Paxson (2003) who discusses the cultural consequences of natural versus technologically induced reproduction in Athens, Greece.

⁷In addition, Sacchini and Antico emphasize that autonomy can be interpreted in different ways. They state four models of autonomy: individualistic, evolutionistic, utilitarian and personalistic (Sacchini and Antico 2000: 441). In addition, Evans (2002) claims that autonomy is the main focus of public bioethical debates.

Palsson and Rabinow (2001) explore the issues of genetic commodification in Iceland and relate them to anthropological understandings of property. They argue that the concept of property is a cultural phenomenon (Palsson and Rabinow 2001: 170). Consequently, they demonstrate that anthropological methods provide a different perception of bioethical debates that highlight issues of genetic commodification by precisely focusing on the cultural production and location of “property” and “commodification.”

Speculative arguments about the future are a point of interest in anthropology as well. Strathern (1995) discusses the effects of reproductive and genetic technologies on ideas of identity and kinship, as well as how anthropology is relevant to the investigation of reproductive and genetic technologies:

For the European anthropologist, the concept of culture is already problematized. It is not at all clear what is or is not an artifact. The point is not that the boundaries between bodies and machines are theoretically troublesome, but that we now live in a world that makes explicit to itself the *ability* to breach the difference. The new reproductive technologies are but one area where the body (that lives) and the machine (that works) are imagined in new conjunctions (emphasis in original, Strathern 1995: 433).

Strathern claims here that not only is the concept of culture an anthropological concern in itself, but that it requires a questioning of what can be defined as an artifact. That is, the body and machine have morphed into each other through the use of reproductive and genetic technologies. Thus, there is anthropological troubling of the object of study (i.e., the artifact versus the individual). This further clarifies another point of anthropological

contention in bioethics: questions of personhood have normative consequences that may remove or decrease the level of personhood, or human-ness, of individuals, when human biotechnologies are applied to individuals.

The concept of personhood is further elaborated by Landsman (2003), who re-evaluates the conceptual constructions of disability and personhood by conducting qualitative ethnographic research in a “hospital-based newborn follow-up program that serves as an evaluation site, determining eligibility for early intervention services for infants and young children with disabilities” (1947). In essence, she argues that the negative attitudes toward people with disabilities diminishes personhood, and establishes how the idea of normalcy, linked with personhood, informs moral decisions in hospitals concerning newborns who are born with disabilities.

These examples of anthropological questioning of bioethics have undoubtedly contributed different perspectives and methods for developing a nuanced understanding of the cultural roots of bioethical discourse. Thus, as mentioned, anthropologists are generally interested in the cultural shaping of morality and moral behaviours that influence and inform medical practices, resulting in a variety of effects (such as diminishing an individual’s claim of personhood). Anthropology offers methodological tools that problematize moral debates in bioethics by placing moral questions in a broader and complex cultural framework. Cross-cultural analysis and cultural relativity are fundamental for developing an account of moral concerns because they broaden the

questions posed and remove ethnocentric and assumptions of homogeneity that generalize about populations, hence limiting the scope of analysis.

Idealism, Medicine and Ethics: A Brief Historical Overview

The pursuit of an ideal underlies technological practices, making less work for people, higher industrial productivity, and in this paper, bodily health. The following analysis investigates the social assumptions and their normative components at work in public bioethical debates about human biotechnologies. In particular, I will discuss the eugenics movement in Canada to substantiate this contention.

Eugenic discourses and practices have been and continue to be crucial factors in the ethical debates surrounding reproductive and genetic technologies. Eugenic ideas were prevalent in Canadian society in the late 19th and early 20th centuries through to the beginning of World War II. Angus McLaren (1990) outlines the motivation, development and application of this movement. He describes the international paranoia surrounding biological deviants⁸ and describes how Canadians were not immune to eugenic thought. He outlines the general mentality of legislative bodies, with their power to implement laws, that forced the sterilization of those who deviated from medical norms, rather than attempting to change the social systems. This attitude was also prevalent amongst intellectuals and other elite groups. However, this movement was opposed by the

⁸ Biological deviants are those that are considered to be diagnosed with a disease, whether or not the disease is considered social, moral or biological. For instance, venereal disease was considered to be a disease generally plaguing individuals who were morally depraved (i.e. prostitutes).

Catholic community. However, McLaren fails to appreciate that there was a wide spectrum of Catholic beliefs and practices, from left liberalism to extreme right-wing conservatism. The research McLaren conducts groups a Catholic voice into one generalized category, without illustrating the different perspectives within that community. Nevertheless, his extensive archival research on Canadian eugenic legislation makes a major contribution to the understanding of the shaping of recent developments in reproductive and genetic technologies. The main data that I use as Canadian examples of eugenics are the Better Baby Contests in the early 20th century, as well as legislation and contextual historical analysis. I explore reproductive and genetic legislation of the 1920s (sterilization legislation) and that from the late 20th century and early 21st century (2002 being the most current manifestation of the legislation that exists for reproductive and genetic technologies).

Daniel J. Kevles' work, *In the Name of Eugenics* (1985), discusses the history of eugenics in the United States and Britain. He does a comparative analysis of international eugenic influences on the two countries from the late 19th century to the early 1960s and describes how sexual and reproductive behaviours were changing and how men and women modified their standards of sexual and reproductive behaviour due to prevalent eugenic attitudes. He emphasizes the German use of Anglo-American eugenic practices that preceded and contributed to Nazism. It is Kevles' analysis that more adequately handles the ways in which bioethical debate has become narrowed by the notion of a post-eugenic world (cf. Evans 2002). Kevles' fundamental assumption is problematic,

however, because current Canadian legislation prohibits many of the strategies of classical eugenic thought, which included creating designer babies⁹ or commercializing reproductive and genetic materials. An argument that is underdeveloped in Kevles' work reveals that maintaining or creating healthy individuals may be perceived as a form of enhancement of an individual. This idea captures the crux of this thesis and my supposition that the concept of health needs to be re-evaluated; Kevles represents a figure in bioethical discourse that overlooks the circumstance that reproductive and genetic technologies attempt to achieve both an ideal and a norm.

Canguilhem makes an important contribution to theorizing 'the normal,' constructing a different way for understanding the concepts of health and disease (1978). Canguilhem states that the normal is a concept applied to both states of health and disease. The normal is characterized as a state of the body dependent on its surrounding environment that requires that one assess the mechanisms through which the body can adapt (Canguilhem 1978).

My thesis applies Canguilhem's ideas to clarify how the assumption of health informs public bioethical debate and human biotechnologies in the pursuit of embodied norms and ideals, drawn from biology and medical science. Importantly, Canguilhem also notes that pathologies are another state of "normal bodies". Thus, his argument questions

⁹ Designer babies are tailor-made babies with characteristics of which are pre-determined by the parents and actualized using reproductive and genetic technologies. Bioethical arguments have been made that criticize using reproductive and genetic technologies to create specific types of individuals, in terms of autonomy,

and provides analytical tools for re-evaluating the conceptual assumptions of health and disease in public bioethical debates, by showing how the 'normal' cannot so readily be separated from the pathological: both are constituted within the same terrain of the life sciences.

John Evans, in his work, *Playing God* (2002), argues that the field of bioethics has become increasingly professionalized because arguments made by individuals who are not professional bioethicists are under-emphasized and insignificant in the publicized bioethical sphere. Further, Evans writes that bioethical debates regarding genetic engineering in humans are “thinning,” or narrowing the scope of the human genetic engineering debate.¹⁰ In other words, Evans shows how bioethical debates have been shifted toward arguments about specified and “thin” issues, rather than the initial, fundamental, and “thicker” issues and arguments, made by theologians, social theorists and philosophers. Although, Evans argues that autonomy is the predominant point of departure for bioethical debates, I claim that the normative dimensions surrounding ‘health’ is unwittingly the central focus.

Finally, Michel Foucault’s *The Birth of the Clinic* (1994) traces the origins of clinical discourse and the increased medicalization of the body. Further, he describes how medical institutions operated, and how the clinic became politically necessary, and

commercialization and genetic reduction. However in Canada, creating designer babies continues to be a prohibited activity.

¹⁰ “Thin” and “thick” arguments are Evans’ terms and concepts.

how clinical practice was influenced by social, political, and legal institutions. Foucault shows how those medico-scientific institutions are not isolated and are intimately linked with the power struggles that legitimize medical knowledge. Foucault's theory regarding knowledge and state governance are central to my analysis of how medical knowledge becomes legitimated in public bioethical debates.

Methodology and Data Analysis

This thesis conducts discourse-analyses of the concepts of health and disease in public bioethical debates, paying particular attention to its cultural and historical contexts. This involves examining the history, applications of controversies surrounding reproductive and genetic technologies that have informed contemporary issues in public bioethical debates. I examine Canadian governmental documents and Canadian society, and the influence of science on them, from the time of enforced sterilization in the early 20th century up to present discussions of reproductive and genetic technologies. Religious attitudes, medico-scientific perspectives and Canadian legislation on contemporary reproductive and genetic technologies in terms of health and disease, all are indicative of the array of discursive input in this debate, thus constituting the tensions within public bioethical debate. I develop a chronology of the development of reproductive and genetic technologies characteristic of various social changes throughout recent Canadian history. I also discuss the four dominant perspectives in the debate: the normative, the discursive strategies of medico-scientific, political, religious (specifically

that of the Vatican) and social communities. Yet, in the midst of this plurality, there is a common thread, namely in the conceptual idealization of the removal of disease from the body and the cultivation of healthy individuals. This idealization has and continues to inform Canadian public bioethical debates.

The legal materials I analyze include Canadian legislation and policy on a variety of reproductive, genetic and eugenic issues. I examine legislation on sterilization, genetic and reproductive technologies (including genetic therapeutic and diagnostic practices). Specifically, I examine the Assisted Human Reproduction Act (Bill C-13) and the Canada Health Act. Although, these laws provide an overview of many ethical aspects of reproductive and genetic technologies and the maintenance of health, they are subtended by an idealization of a healthy human life, i.e., one that is disease-free. This idealism is, in essence, at the center of these discourses. For instance, the concept of health in the Canada Health Act is defined as follows:

In the Canada Health Act, we position the federal responsibilities with respect to national health care insurance legislation with the two following statements: Canadians can achieve further improvements in their well-being through combining individual lifestyles that emphasize fitness, prevention of disease and health promotion with collective action against the social, environmental and occupational causes of disease, and that they desire a system of health services that will promote physical and mental health and protection against disease; and the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers (Canada Health Act, Chapter C-6, Preamble).

The Canada Health Act adopts a holistic definition of health that is defined by the absence of disease. This holistic interpretation is essential to understand health, as a cultural phenomenon. However, because public bioethical debates have largely ignored the cultural dimensions of the meaning of 'health,' bioethicists have limited their scope of argumentation, resulting in the exclusion of diverse perspectives (including anthropology) and various arguments within bioethical debate.

This thesis places legislation regarding reproductive and genetic technologies in a light that allows for a historical critique with a contemporary anthropological sensibility. I employ Georges Canguilhem's ideas concerning the medicalization of the body and politics which build upon his theories of the 'normal.' This leads to an examination that problematizes the deployment of medico-scientific discourses in social debate and governance. In doing so, this dominant strategy of defining health and disease becomes highlighted as a culturally bound construction. Idealistic assumptions within legislation call for an assessment of the expectations of politico-legal institutions, with respect to the way health and disease have been and continue to be identified in Canada.

Outline of Remainder

In the next chapter, I argue that there is an inherent interdisciplinary quality in bioethics which has been de-emphasized because of the professionalization of the field itself. Public bioethical debates are then defined and contextualized in a Foucauldian

framework, thus revealing the power dynamics at play in the mechanisms of professionalization.

In chapter three, the idealization of health is examined by providing historical and contemporary examples of public bioethical debates that have supported and challenged changes in reproductive and genetic sciences. This chapter also demonstrates further the interdisciplinary perspectives constitutive of the contemporary field of public bioethical debates. This is done in order to emphasize the need to increase the significance of multiple perspectives in professional bioethics.

In chapter four, I question the polarization of health and disease. Canguilhem's theory of health and disease informs a counter-discourse of what is defined as normal and ideal. Health and disease are argued to be culturally bound and multi-faceted concepts. This chapter contends that the professionalization of public bioethical debates further constrains the development of broader cultural understanding of health and disease.

I argue in chapter five that genetic health and disease are not simply based on a genetic formula, but rather they are established in normative and idealized cultural contexts. I present examples of reproductive and genetic technologies in the service of idealized pursuits of normative health in order to highlight the importance of including multiple perspectives in public bioethical debates. Chapter six distills the preceding, and concludes the thesis.

Chapter Two

PUBLIC BIOETHICAL DEBATES: THE INTERDISCIPLINARY FIELD

This chapter highlights the significance of reproductive and genetic technologies in social, academic, theological and legal debates. Reviewing the developments in the discourses of bioethics and reproductive and genetic technologies is essential for analyzing the idealistic norms for health and their historical development. This chapter offers a critique of bioethics as an exclusionary professionalized field, and demonstrates the inherent interdisciplinary nature of public bioethical debates, that are in actuality, grounded in a plurality of social networks.

Public bioethical debates are diverse and must be contextualized. Doing so provides a platform from which to critically assess reproductive and genetic technologies on conceptual and practical levels. Public bioethical debates are potential triggers for social change and are socially negotiated and interactive events. But these debates can become overly myopic since bioethicists have claimed authority over the moral issues surrounding human biotechnologies. This also implies that social expectations and consequences (i.e., the political dimension of normative debate) must be examined in order to understand how technologies are applied to social life and how this is justified.

Public Bioethical Debates: An Analytical Definition

Bioethical debates are comprised of three different types: (1) foundational debate “discusses how the debates about issues such as human genetic engineering are related to broader societal concerns;” (2) clinical debate “concerns the ethics of interactions with patients in hospitals or in research studies;” and (3) public debates are

where societal elites – in this case, professionals – debate over what society should do about the problem such as human genetic engineering The purpose of the public bioethical debate among the professionals is to influence the beliefs and values of the public, to come to some modicum of consensus, or in some cases to represent public opinion to policy makers (Evans 2002: 34)

In other words, Evans distinguishes three types of bioethical debates that differentiate ways in which bioethics is perceived in different contexts. This paper focuses on public bioethical debates where bioethical authority has been appropriated by professional bioethicists. Their interpretation of the events concerning reproductive and genetic technologies is considered to be the predominant and the authoritative approach when engaging with reproductive and genetic concerns. Thus, this constraint is an expression of a structure of normative authority in which bioethicists have become dominant. At the same time, bioethics has become increasingly relied upon both in legislation and public opinion, thus shaping the broader politico-legal landscape.



Figure 2.1: Types of Debate in the General Field of Bioethics

The term bioethics is a recent one. It was coined by an American Physicist, Van Rensselaer Potter in his book *Bioethics: Bridge to the Future* (1971), who endeavoured to link moral values and biology (Roy *et al.* 1994: 1-2). Because bioethics is a young profession, there is a tendency within it to overstate its distinctiveness in order to stake out its territory. Bioethics is a profession that excludes, although it may be informed by, morals, professional ethics, theological ethics, feminist ethics, and philosophical ethics (Roy *et al.* 1994: 37-44). Although, bioethics has become a profession in its own right,

there remain the various interdisciplinary approaches that do not receive significant recognition, and suffer a decline in their political authority in the field of bioethics.

Public bioethical debates have been a powerful factor in politico-legal understandings of reproductive and genetic technologies. When professional bioethicists became the predominant influence in biotechnological debate, other experts, such as theologians and academics become less recognized in these debates. Consequently, bioethical debates have narrowed the basis of normative authority and proceeded to marginalize perspectives from other contributing professions. However, the field of this debate is still complex: different strategies and approaches developed by multiple collectives that attempt to either change, maintain or manipulate current social situations, remain integral to bioethical debates.¹¹ Multiple approaches inform bioethics and constitute different ways in which events, materials and ideologies are shaped in the public sphere. An analysis of strategy methods is necessary for understanding the structure of this field. These methods are inherently part of the negotiative strategies needed by different collectives in order to express their concerns when engaging in debate. Consequently,

An issue rooted in conflicts based upon a restricted value-focus can hardly ever be resolved unless each party to the conflict acquires an understanding of, and respect for, the values the other party is trying to protect. That is unlikely to happen without interdisciplinary, interprofessional and intercultural collaboration (emphasis in original; Roy et al. 1994: 32).

¹¹ Examples of social changes would include amendments in the law, changes in social structures, or changes in economic policy.

That is to say that the conflicts that emerge due to different professional, academic or cultural perspectives require negotiation in order to produce collaborative results. However, the way in which collective perspectives are expressed and how their discursive formations are influenced, is directed by the predominant experts. In other words, if bioethical arguments are made in a manner that excludes different approaches, the scope of criticism becomes increasingly narrowed and those who venture to include themselves in public bioethical debates will have to conform to the predominant discourse before they are properly recognized.

Authoritative Institutions and Public Bioethical Debates

Accompanying the dominance of bioethicists is a variety of other institutions dominated by elites that also limit public bioethical debate. These include professional organizations that

participate in public bioethical debate, but they are not bioethicists unless they use the system of argumentation of the bioethics profession . . . Professionals in the [bioethical] debate began to adopt this new form of argumentation [formal rationalization] largely because they thought it was the best way to make ethical decisions *in light of the new decision-makers*, the commissions. People who entered these debates and who adopted this new form of argumentation – or people who converted to it [from substantive rationality] – began calling themselves “bioethicists” and not scientists, theologians, or philosophers. A new profession was born (emphasis in original, Evans 2002: 35, 37).

In other words, formal rationalization is the logic used by professional bioethicists that excludes broader cultural dimensions surrounding the moral issues of public bioethical

debating. Subsequently, the organizations concerned with broader cultural issues end up using formal rationality in order to be heard. More specifically, “formal rationality refers to the calculability of means and procedures, whatever the end pursuit while substantive rationality refers to the assessment of outcomes in terms of a particular value standpoint,” (Hindess 1987: 145). Thus, formal rationality is the dominant discursive model used by the biomedical and bioethical communities, and those that rationalize substantively, like the arguments used by the Vatican, have to adapt their discursive models to align with the formalized environment in order to be considered by scientific institutions. Moreover, since the government has established commissions as the main authority that gives recommendations to the government about bioethics, those who exercised authority as professionals were individuals who had the capacity to control the form through which bioethical debates were shaped. Consequently, bioethical debates shifted from cultural and substantive arguments to a narrower scope of debate with specialized and formalized methods of argumentation.

Even if these commissions do not hold legislative power, they become the dominant institutional form of normative authority. As Evans argues, *a propos* of the USA, which is also applicable to Canada, “the commissions, although they lacked power in themselves, made recommendations to federal agencies, which did have regulatory powers” (Evans 2002: 82). The use of commissions to disclose concerns and make recommendations about controversial issues is employed in Canada. This is apparent because in 1993, the Canadian Royal Commission of reproductive and genetic

technologies published its final report to the government of Canada with 293 recommendations for understanding the consequences of their deployment (Health Canada 1999). Although, as Evan argues, they had no power in themselves, these recommendations became the foremost authoritative statements on reproductive and genetic technologies that informed much of the legislation that exists today in Canada.

The Royal Commission of 1993 introduced the recommendations informing future legislation on reproductive and genetic technologies. However, what is interesting is the background of the commissioners involved. Patricia A. Baird, the chairperson of the commission, is a pediatrician and professor of medical genetics; Grace M. Jantzen is a reader in the philosophy of religion; Bartha Maria Knoppers is a professor of Law; Susan E. M. McCutcheon is a teacher and an active member of the business community; and Suzanne Rozell Scorsone is an anthropologist and who is also the director for the Office of Catholic Family Life (Baird *et al.* 1993:vi). When examining the biographies of the Commissioners, it is evident that substantive and formal perspectives were included in the process of evaluating the social impact of new reproductive and genetic technologies into Canadian health care. The legislation that currently exists, *Assisted Human Reproduction Act* (2004), does not posit religious or theological arguments to support their positions. Further, the theological input from the commissioners had little influence

on the legislation, the impact of which can be seen in the ongoing debates of what constitutes life in religious ideologies, compared to how life is defined in the legislation.¹²

The consensus model of the Royal Commission in 1993 offered economic, political, legal, religious, multi-cultural and social challenges to the dominant formalized discourse of bioethics and questioned the bioethics of reproductive and genetic technologies. However, the impact of their recommendations remains attenuated in the current legislation, which excludes theological and substantive rationalities, and promotes formalized and scientific ways of shaping the social application of reproductive and genetic technologies.

Although formal rationality is the predominant form of bioethical debates, there are under-represented collectives that challenge this form of authoritative argumentation, such as theological rationalizations. The legitimization of bioethical knowledge is structured by its own profession, but competition for bioethical authority remains (Evans 2002: 179). Nevertheless, public bioethical debates have become increasingly narrowed:

The profession of bioethics created a formally rational type of argumentation that became the accepted way to make claims in the HGE [human genetic engineering] debate. The primary competitor to bioethics, theology, could not take advantage of this new environment because of a shift to formal rationality would threaten its own core jurisdictions having to do with transcendent belief, which cannot be expressed in formally rational terms. Thus began the decline of theology in the HGE debate (Evans 2002: 180).

¹²Refer to section 3.3 in this paper for further analysis on input into bioethical debates from the Vatican.

Bioethical professionals have taken over traditionally theological positions in public bioethical debates and shifted their methods of argumentation which makes theological perspectives of transcendent belief increasingly difficult to sustain in the formally rationalized environment. Thus, public bioethical debates remain exclusionary, resulting in the narrowed scope of what constitutes legitimate bioethics. Consequently, many collectives such as the medico-scientific communities, legal communities, and religious communities, have had less of an impact on bioethical debates. However, public bioethical debates remain heterogeneous because of the ways in which various collective thoughts and actions influence bioethicists. However, while bioethicists do not use the same rationales as theologians, theological discourse continues to inform public bioethical debates. This has been accompanied by another shift: theologians have changed from reliance on substantive rationality to reliance on formal rationalities when engaging in bioethical debates.¹³

The Collective Nature of Public Bioethical Debates: Durkheimian Considerations

The establishment of professional bioethics is indeed influenced by diverse collectives and indicates how human biotechnology is not solely a medico-scientific concern. These technologies are elements within broader social processes that socially shape ideas of the body. Drawing on Durkheim, a collective is a group that expresses a

¹³ One example of a theologian specializing in the bioethical profession is Dr. Leon Kass, who is a prominent bioethical scholar with theological concerns. For further reference, refer to Kass (2002).

collective thought based on a consensus developed within the group. Emile Durkheim defined the *conscience collective* constitutive of collective existence as

the totality of beliefs and sentiments common to average members of the same society [which] forms a particular system with a life of its own . . . it is diffused throughout the whole of society; nevertheless, it does have specific characteristics which make it a distinctive reality. In fact, it is independent of the particular conditions in which individuals are situated (Durkheim 1999a: 39).

In other words, the *conscience collective/commune* is a separate reality, distinct from individualized, egoistic interests. This concept of a separate reality is where the assumptions of health remain, i.e., as a collective representation within the *conscience collective*. To be a healthy individual in a healthy society, you must define yourself as an individual lacking disease and having a well-balanced lifestyle¹⁴. In my analysis, this concept shows that collective thought has a social influence in and of itself. The concept demonstrates that the collective consciousness is shared between many individuals and groups, and it is this sharing of ideas and their application, that triggers social change, and in this instance, informs bioethical debate. Thus, the social aspects of reproductive and genetic technologies are indices of the collective consciousness because they are comprised of diverse reactions that generate social concerns and aspirations. To follow

¹⁴ This notion of the *conscience collective* was not a theory that Durkheim used throughout his works. Rather, he abandoned this idea because it was limiting as an analytical tool, due to the limited application to 'advanced' societies (Lukes 1973: 5; cf. Durkheim 1999a: 39). 'Advanced' society, is in single quotations to emphasize that it is a term that is questionable because societies are neither advanced or behind a standard type of society, rather they are different in their own contexts. However, in this context, Durkheim is referring to Western societies that are identified today as first world or developed countries, such as the United Kingdom or the United States or Canada.

this Durkheimian reasoning, cultural understandings of shared beliefs are based on *systems* of thought and tacit culture. Moreover,

the development and behaviour of such systems [complex adaptive systems of living organisms], at any moment, is the expression of a unique history, resulting from the non-predictable interaction of internal and external forces, or an organism and its environment . . . the world in response to which an individual organism develops – these external forces – is also modified and shaped by the activities of the organism itself (Roy *et al.* 1994: 1-2).

In other words, in order for systems of beliefs to exist, they must inevitably involve complex social negotiations between individuals, social collectives and their environments, which create a complex web of people involved in the culture. Thus, these networks of individuals and collectives produce a problem-space that highlights and reflects on diverse approaches, such as those found in the terrain of public bioethical debates.

Durkheim develops the notion of collective representations to specify the make-up of the *conscience collective*. Durkheim's concept of collective representations refers to the constitution of distinct positions within the collective conscience that are wholly different from that of individual consciences (Lukes 1973: 6). Although individual and collective representations of ideas are negotiated, the collective conscience remains external to the individual. Thus, the study of collective representations can and should be applied to the analysis of reproductive and genetic technologies; it allows the anthropologist to account

for the collective roots of normative and epistemological claims. This concept of collective representations

refers both to the mode of thinking, conceiving or perceiving and to that which is thought, conceived or perceived . . . And second, the *représentation* is *collective* both in its origin, determining its mode or form, in its reference or object (it is also, of course, collective in being common to the members of a society or group). Thus, Durkheim wanted to say both that *représentations collectives* are socially generated and that they refer to, and are in some sense 'about,' society (emphasis in original; Lukes 1973: 7).

In other words, collective representations are collective in origin, thus, providing a means of understanding social phenomena. This demonstrates that social ideas are socially made and thus, lead into an object for social study. In addition, collective representations are about society, and those who study collective representations examine an aspect of society that is purely representational and separate from the individuals involved.

Durkheim's separation of the individual and collective is essential to characterizing how public bioethical debates emerge from collective thought to individual thought and then into the public sphere. Specifically, representations and systems of thought are based in collectivity and collective ideas, which influence individuals. This is significant for an understanding of social thought within public bioethical debates. However, those who rely upon predominant collective ideas influence and inform other

perspectives. Consequently, public bioethical debates need to be considered as collective thoughts and actions, and not the result of individual thought and action.

Durkheim's distinction between the collective and individual demonstrates that the social is not to be analyzed by examination of cases of individuals (cf. Durkheim 1999b:95). Furthermore, this shows that social or collective thought can be studied as its own phenomena with its own existence. Subsequently, Durkheim's notions of collective representations are based on independent (or *sui generis*) ideas, beliefs, and values that persist in a society. When this Durkheimian perspective is applied to human reproductive and genetic technologies, one should not examine individual cases, since doing so would obscure their social and collective nature. Rather the focus needs to be shifted to the structural apparatuses that govern and shape collective thought, such as concepts of health and disease. Moreover, collective ideas of health and disease in Canada rest on concepts perpetuated by governing collectives, such as different politico-legal, medical and cultural approaches.

At the same time, it is necessary to appreciate that different realities exist for different collectives and individuals even within a *conscience collective*. In other words, there are multiple ways of perceiving the existence and characteristics of events and groups and thus, the variety of realities tends to obscure the overall or general consciousness of the collective. In complex societies, there is not one collective

consciousness, but there are many. For instance, social narratives, myths and religions are different collective representations and give rise to multiple realities for collectives.

Every myth shows how a reality came into existence, whether it be the total reality, the cosmos, or only a fragment . . . the myth, which narrates this sacred ontophany,¹⁵ this victorious manifestation of a plentitude of being, becomes the paradigmatic model for all human activities. For it alone reveals the *real*, the superabundant, the effectual (Eliade 1959: 97-98).

This quote highlights links between collective consciousness (myth, as one example) and the notion of reality or realities. Myth and reality inform each other in the ways in which many social situations are perceived. As a result, narratives and myths within social structures may shape collective ideologies or may be a point of focus upon which to analyze social phenomena, such as the concepts of health and disease within public bioethical debates. In such an analysis, the focus on the ideal body is a narrative, a myth, a collective thought rooted in notions of health and disease. The concepts of health and disease are different realities for different collectives. Consequently, differing collective consciousnesses form various social narratives that then shape the material realities of the body and simultaneously justify them. In effect, bioethics has become the dominant myth through which the potential of reproductive and technological manipulation is perceived, understood and justified.

¹⁵ Ontophany is defined as the “appearance of Being” (Ross 2003)

Interdisciplinarity and Heterogeneity in Public Bioethical Debates

Interdisciplinarity and heterogeneity are characteristic of public bioethical debates. If there were an absence of diverse perspectives, public bioethical debates would not need to exist. Differing perspectives, produce conflicting positions that trigger rebuttals. This process continues until a possible common perspective or solution, has been decided upon. This section argues that there is an inherent heterogeneity in public bioethical debates in order to demonstrate that the professionalization of public bioethical discourse is misguided due to the interdisciplinary structure and shaping of bioethical discourse and human biotechnologies.

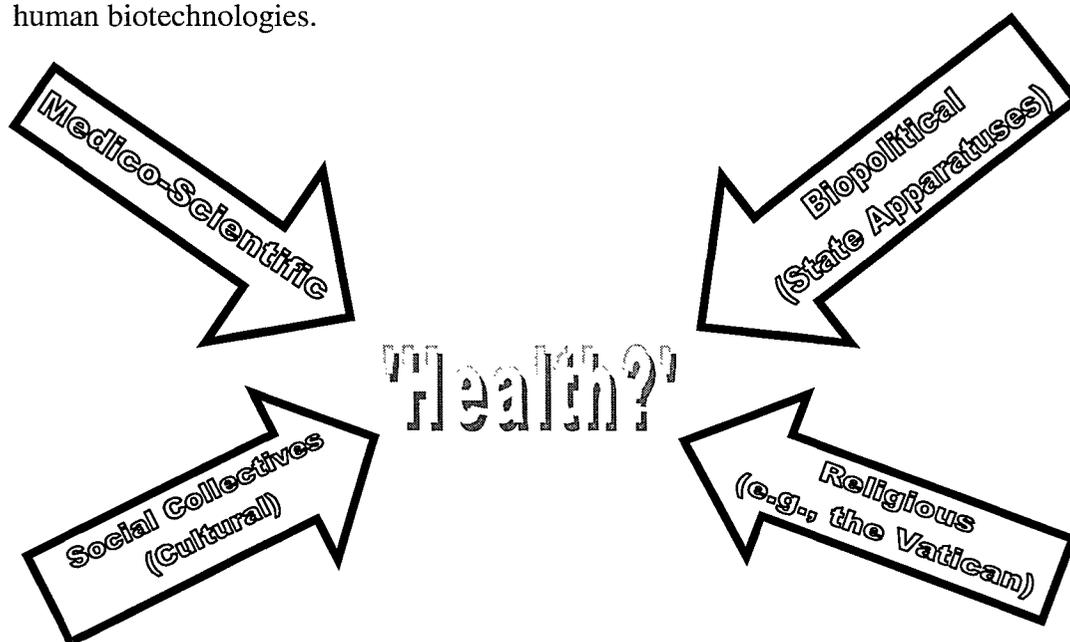


Figure 2.2: Perspectives in the Field of Public Bioethical Debate

Clarke and Fujimura claim that interdisciplinary methods of study are an “ecology of the *conditions of its production* - an ecology of scientific activity/practice/work” (emphasis in original; 1992: 4). This concept of ecology reflects the idea that the analysis of scientific work is a contextual and interdisciplinary endeavour. In addition, the situation, temporal dependency, and wide range of social practices that influence scientific pursuits have roles that inform choices and the production of technologies. Thus recognizing the interdisciplinary character of the field of public bioethical debates is required in order to analyze the methods and choices that are chosen in order to account for technological production. This blurring of academic disciplines requires a broader, overall anthropological analysis in order to determine different extant negotiative strategies that generate conflict in public bioethical debates. This variety of strategies includes political, medical, social, and legal perspectives.

The negotiative strategies discussed here are inherently interdisciplinary, because they represent struggles and challenges brought forth by diverse collectives. For example, there are groups that oppose reproductive and genetic technologies for religious reasons, as opposed to those who agree with these technologies but would like to see changes in its implementation and its application to society. The interdisciplinary nature of bioethical debates allows for different approaches to the understanding of reproductive and genetic research because

interdisciplinary might be termed the practice of disciplinarity observed in the appearance of its breach. *Interdisciplinarity* interests us here only to the very degree it irrupts business as usual, allows new objects of study to

emerge, furnishes new resources for scholarship, and asks new questions not only of practitioners of science, technology and medicine, but also of those researchers who claim to study them (emphasis in original; Reid and Traweek 2000: 7).

Reid and Traweek illustrate the importance of interdisciplinary research in reproductive and genetic technologies, because different perspectives allow increased richness in research and demonstrate that different collectives work on the same or similar issues. With each different approach, however, there are different expectations, different assumptions and different philosophies that mold the social networks of the event at hand: it is not exclusively technology that is being examined, it is the overall shaping of technology that needs to be understood. Thus, public bioethical debates are influential because of their complex history, which continuously renegotiates the normative problematization of reproductive and genetic technologies in society.

Since reproductive and genetic technologies are not purely scientific endeavors, they are negotiated throughout their development. Consequently, “the technological is the social” (Bijker and Law 1992: 4) and further, “it is mistaken to think of technology and society as separate spheres influencing each other: technology and society are mutually constitutive” (MacKenzie and Wajcman 1999: 23). Reproductive and genetic technologies need to be considered as combined social and technical endeavors. “Technologies do not provide their own explanation. If there is no internal technical logic that drives innovation, then technologically determinist explanations will not do” (Bijker and Law 1992: 8). In other words, technological determinism fails to account for

the role of social factors which shape the outcome of technological applications.

Technologies do not have natural trajectories, but “they are the product of heterogeneous contingency” (Bijker and Law 1992: 17). In other words, “a technological system . . . is never merely technical; its real world functioning has technical, economic, organizational, political, and even cultural aspects” (MacKenzie and Wajcman 1999:11). Hence, it is not the product of technology that gives the impetus for other technologies, rather, it is their imbrication in the social, multi-faceted negotiations and contextual bargaining pursued by different social collectives in public bioethical debates that influence the production of reproductive and genetic technologies, and it is the collective conscience that is pre-inscribed and challenged by differentiated ideas of diverse institutional and non-institutional collectives upon every step of technological development.

Public Bioethical Debates and the Question of Power

Foucault offers a micro-analytic perspective on the negotiation strategies that exist in the interdisciplinary terrains that science and technology have facilitated. Foucault helps to demonstrate the power dynamics that exist within public bioethical debates. This is especially the case in modern western societies dominated by “the will to truth,” i.e., the dominance of scientific approaches to understanding and solving social and political problems. The power struggles for authority in bioethical discourse have led to the professionalization of bioethicists and the exclusionary discipline of bioethics. Therefore

demonstrating the decline of theological or substantive input from external social collectives that are outside of the field of professionalized bioethics.

Because Foucault is a pluralist and analyzes the “*individualization* of discourses,” he is exemplary in discussing the processes of institutionalized public bioethical debates through his methods of analysis (emphasis in original; Foucault 1991: 53). As there are negotiative tensions in any social process, Foucault argues, “discourse is not a place into which the subjectivity irrupts; it is a space of differentiated subject - positions and subject formations” (Foucault 1991: 58). Thus, discourse is a focal point in discussing the shaping and understanding of reproductive and genetic technologies because discursive formations demonstrate diverse conditions in and through which subjects shape different thoughts, understandings of reality and means for intervening and transforming that reality. In this case, I am referring specifically to how this process produces different characterizations of health and disease.

The concept of subjectivity reverberates in much of Foucault's work. The formation of the subject is directly related to his notions of power. Subjects are enabled and constrained by power relations, i.e., micro-relations of dominance and subordination (Foucault 1980b: 119). Foucault attempts to “define how, to what extent at what level discourses, particularly scientific discourses, can be objects of a political practice, and what system of dependence they can exist in relation to it” (Foucault 1991: 69). Discursive practices and strategies are then essential to demonstrate the social impact and

political effects of institutions. Discursive practices are interdependent on social structures and social systems, where both supply and nurture the discursive shaping of society. In relation to public bioethical debates, discursive systems constitute specific objects and methods of inquiry that direct social life thus producing social changes. Thus, although discourse is not power, it is an effect of power relations (Foucault 1994b: 135).

By power, Foucault means the following:

The exercise of power is not simply a relationship between “partners,” individual or collective; it is a way in which some act on others . . . Power exists only as exercised by some on others, only when it is put into action, even though, of course, it is inscribed in a field of sparse available possibilities underpinned by permanent structures . . . what defines a relationship of power is that it is a mode of action that does not act directly and immediately on others. Instead, it acts upon their actions: an action upon an action, on possible or actual future or present actions (Foucault 2003b: 137).

This description of power as an object of study stresses the analysis of action. Foucault clearly states that power can only be analyzed through its effects. Thus, in terms of public bioethical debates as forms of social leverage, this does not mean that bioethicists or medical institutions are material versions of power, rather that they are mechanisms of power in action, the effects of which are inscribed in the actual statements produced by various forums of bioethical debates.

The concept of power in action is also linked to Foucault's concept of subjectivity. The subject is central in the analysis of power relations which "have come more and more under state control" (Foucault 2003b: 141). The focus on the subject highlights the location where political power may be exercised, be it in the state¹⁶ or other institutional sites. All of these social apparatuses, in effect, convey power in action. The subject is defined as a

form of power that applies itself to immediate everyday life [and which] categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him that he must recognize and others have to recognize in him, it is a form of power that makes individuals subjects. There are two meanings of the word "subject": subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge (Foucault 2003b: 130).

Subjectivity is a form of power that is defined by the individual's identity, whether that identity is self-made, or one that is socially shaped. Individual and social impositions, however, are at the base of Foucault's theory of subjection. Thus, power, social influences and individuality are ingredients maintaining the subjection of people. In public bioethical debates, this indicates that the subjection of individuals is a necessary condition for collective characterizations of health and disease. Otherwise, there would be no consolidations of populations as targets of biopolitics, no strategic coherence. Rather, there would be constant arguments between individuals instead of social negotiations based in collective conflicts.

¹⁶ I am using state in a broad sense. That is, I am defining state as the governing body that invokes, creates and monitors the social apparatuses and governing institutions that control a population.

Foucault's attempt to show how scientific discourses are inherently linked with political processes and power relations, demonstrates that subjectivity and discourse are inter-related. Discourse is fundamental in understanding subjective perspectives, since it is constitutive of them. "Discourse is not a place into which the subjectivity irrupts; it is a space of differentiated subject - positions and subject functions" (Foucault 1991: 58). So, subjectivity must be analyzed in terms of the intersection of discourse and negotiative pressures that shape perspectives of health and disease in public bioethical debates that then express the dominance of collections and institutional sites. Subjects are negotiated again and again through power-knowledge relations. These social tensions are established through the social apparatuses that use various governing techniques. Consequently, the power dynamics that result are contested events:

The history that bears and determines us has the form of a war rather than that of a language – relations of power, not relations of meaning. History has no "meaning," though this is not to say that it is absurd or incoherent. On the contrary, it is intelligible and should be susceptible of analysis down to the smallest detail – but this in accordance with the intelligibility of struggles, of strategies and tactics (Foucault 2003a: 304).

Public bioethical debates are inclined to be governing strategies of subjection that use various social apparatuses, such as medical and state institutions. An examination of the development of health and disease in reproductive and genetic technologies in Canada shows that there is a contingent historical basis to social ideas that have been maintained to motivate a removal of hereditary illness. Tracing the historical developments in genetic and reproductive technologies illustrates that an understanding of this historicity

is imperative for understanding of the social environment that defines how illness has been characterized, and how social struggles and strategies can lead to social changes negotiated through different perspectives.

Public bioethical debates then, are characterized by a number of factors, such as negotiated strategies and subjectification, but are also linked with the governance of institutional or other public institutions that function as points of pressure in social processes. Thus, power in its complex forms establishes the discursive and social foundation of public bioethical debates.

Social strategies are fundamental within the existence of power relations since they are necessary for the continued subjectification of individuals. This means that,

between a relationship of power and a strategy of struggle there is a reciprocal appeal, a perpetual linking and a perpetual reversal. At every moment, the relationship of power may become a confrontation between two adversaries. Equally, the relationship between adversaries in society may, at every moment, give place to the putting into operation of mechanisms of power (Foucault 2003b: 143).

The mechanisms of power Foucault is referring to are the different struggles, strategies and dominations (and their institutional conditions of existence) that have the capacity to change direction. These social struggles are goal oriented, each social apparatus and dominant group with their own agenda, and each struggle expressing an aspect of power in action. These struggles are illustrative of the torsions within the body politic, relations

that are traced in public bioethical debates. Struggles involve contestations over agendas from religious groups, political parties, governing bodies, medico-scientific institutions and from academia. This strategic field in large part constitutes the negotiations that involve creating a social change, though the deployment of public bioethical debating because these debates are based in a collective attempt to change or clarify a controversial aspect of society, biology, humanity and of course, its direction, purpose and justification. So, public bioethical debates are rooted in negotiations of collective struggles and strategies. To examine public bioethical debates, solely in terms of institutional perspectives, would produce a limited analysis.

As Foucault argued, “where there is power, there is resistance” (Foucault 1994b: 95). In terms of resistance and social pressure one must attend to “resistance against different forms of power as a starting point . . . it consists of analyzing power relations through the antagonism of strategies,” within the terrain of public bioethical debates (Foucault 2003b: 128-129). For example,

The targets of these struggles are power effects as such. For example, the medical profession is criticized not primarily because it is a profit-making concern but because it exercises an uncontrolled power over people's bodies, their health and their life and death (Foucault 2003b: 129).

In other words, the degree of power that medical institutions actually constitute characterizes and scientifically defines physical bodies as ‘healthy’ or ‘diseased.’ This then serves as a basis for political intervention on individual bodies and/or population –

hence the power/knowledge network of biopolitics (Foucault 1994b: 139-145).

Although the examination of power relations, strategies and struggles are necessary, they remain only as one facet of public bioethical debates.

Overall, Foucauldian sensibilities contribute to this analysis of power, the formation of the subject and discursive systems within a social framework. These theoretical models have been applied to public bioethical debates in order to outline the object of analysis. This lays the ground work for examining beyond the immediate common-sense perceptions. Durkheim and Foucault each theorized how conceptions of various realities, collectivities and objects are necessary to social existence. For both, societal ideals (either in collective representations or in discourse) are places to begin analyzing criteria producing judgments about health and disease. Moreover, the ideas of collectives, subjectivity and power demonstrate that collectives are subjective to power relations, hence subjectification. The study of social ideas, like health, must attend to the *sui generis* nature of collective representations and hence are independent of any particular individual. In other words, the subjectification of individuals or individual thoughts create and maintain collectives or collective thoughts which can be examined by analyzing discursive systems. This is a critical technique for exposing power relations, discourses and strategies. Struggles and 'war' are characteristic of power relations and further indicate a political opening for marginalized groups who can intervene and

potentially change political goals and directives, thus destabilizing the strategies of bioethical elites.

Social processes consist of multiple features. They include structural, material, ideological, discursive, bodily and power relationships. Up to this point, I have discussed the importance of collectivity, discursive systems, subjectivity, power relations, struggles and strategies, the object of study and various realities that define public bioethical debates. These are the most significant constituent elements of the field of public bioethical debates, and hence are my direct objects of analysis. In the next chapter, I discuss the applicability of these concepts and models of social processes and networks to reproductive and genetic technologies.

Chapter Three

'HEALTH (?)' CANADA:

THE DEVELOPMENT OF PUBLIC BIOETHICAL DEBATES

The body in biotechnology has not only been medically scrutinized, but the medico-scientific body has also been socialized in a different manner than found in industrial, sexual or women's movements.¹⁷ The body has now become the object of public bioethical debates and has been biologically re-inscribed as a medical takeoff point from which to focus and direct health and disease surveillance. In this chapter, I outline eugenics and the growth of reproductive and genetic technologies in Canada since the early 20th century until the early 21st century. Of course, the Canadian debates did not emerge in a vacuum. To place the international consideration of eugenics in a historical context, an Austrian monk, Gregor Mendel, had outlined the concepts of particle genetics in the mid 19th century and his theories were rediscovered at the turn of the 20th century. I claim that the history of eugenics is an originary point in public bioethical debates, informed by collectives who attempted to create standards of health and disease, by removing and identifying what they considered to be social and physical pathologies. I argue that bioethics is an ongoing debate with a long history in Canada. I demonstrate this by using eugenics as an example of pre-particle genetic discourse and by showing

¹⁷ The industrial revolution changed the body in terms of labour; the sexual revolution changed the notion of a dirty, secretive body, into one that is sexual and open; the women's movement changed the notion of women's rights and women's political and social status. These are general outcomes of these movements, and do not fully characterize the negotiated strategies that encompassed the social changes.

how eugenics developed into a social project rooted in public bioethical arguments and tensions. Thus, the history of eugenics is indicative of the assembling of various motivations for eradicating disease and for identifying healthy individuals, using this as a basis for the development of an ideal healthy body, which in turn is deemed to be the goal of Canadian biopolitics.

The Growth of Genetics and the History of Public Bioethical Debates

Genetics is a biological science that studies, in a scientific manner based on predictive power, the capacity for expressions of some physical and psychological traits postulated by theories of heredity. Although genetics is about predicting chances of future character expressions, the idea of disease and corporality become localized and fragmented: disease was no longer a matter of the individual body, but of various genetic abnormalities. The discovery of the genetic structure of deoxyribonucleic acid (DNA) had a major impact on how the body was perceived and the way disease is treated because disease and corporality could be reduced to the genetic level. So although eugenics was a form of treating genetic diseases, the fundamental scientific basis for genetics was unknown. Once the structure and function of DNA was revealed, the methods by which certain diseases were analyzed were now more concerned with localizing specific genetic factors. The DNA structure of the double helix was published by Francis Crick and James D. Watson in the mid-20th century (Watson and Crick 1953 a, b). This led to a shift of understandings of the body, produced by genetic science and further produced different biochemical and social perceptions of the body.

Mendel's genetic laws were simultaneously rediscovered by three individuals working independently on various biological problems of hybridization: Carl Correns in Germany, Erich Tschermak in Austria and Hugo de Vries in Holland (Kevles 1985: 43). Although, Mendel's theories of a dominant and recessive genetic carry-over had scientific foundations, many scientists remained skeptical because from their observations they recognized that many physical attributes were a product of blending inheritance and Mendel's theories did not theoretically account for blended expressions.

Blending inheritance was the principal theory within genetic discourse during the time of Mendel's experimentations. There was an elaborate, yet inconclusive, understanding of genetics at that time. Offspring could be predicted, to an extent scientists believed, if they examined the parental generation. However, Mendel's particle genetics opposed this common genetic understanding of blending. The theory of blending holds that when an egg is fertilized it takes traits from both parents that are fused together to produce an embryo that has characteristics of both parents, averaged out.¹⁸ Blending inheritance, combined with the 19th century understanding of Lamarck's theory of acquired inheritance, were the theories that Charles Darwin used for his inheritance theory of pangenesis (Paul 1995: 41). The theory of pangenesis

accounts physiologically for how such inheritance might work: minute particles thrown off by various cells circulate through the body and ultimately concentrate in the "germ cells." This process explains how

¹⁸ One example of blending inheritance is when a tall person and a short person have a child together, they will produce a child that has a height that averages between the parents.

changes in parents' bodies could be manifested in their offspring (Paul 1995: 41)

Although, this theory explains observed inheritance of traits from parents to offspring, it still had conflicting arguments, such as Mendel's theory of particle genetics, which states that the chromosomes are separate and it is the dominant genetic trait that will be expressed phenotypically (e.g., eye colour is a common example). In other words, blending inheritance and pangenesis state that genetic traits combine and phenotypically express the mixed genome, as opposed to Mendel who claims that the genes are separate and distinct, and that what is expressed is one trait from one of the parents, not a combination. Thus, Mendel's theory contradicted the common understanding of genetics and was not initially well received in the scientific community.

The understanding of genetics in the late 19th century was sophisticated. Scientists had viable evidence from which to claim that genes are composed of 48 chromosomes and that there are genetic factors in biological evolution, such as deletion and mutation (Osborn 1940: 1-5). Moreover, scientists understood that environmental factors influence many human traits in varying degrees (Osborn 1940: 7). However, the degree to which the environment impacted upon the development of the individual was, and continues today, to be highly debated.¹⁹

¹⁹ For example, the nature versus nurture debate has a long history and continues currently, one instance includes the debates between the schools of biological determinism and social constructivism. For further reference see, Coll *et al.*, (2004).

This transition from blending inheritance to Mendelian genetics demonstrates that the general theoretical field was becoming unstable. The existing dominant school of genetic thought was being challenged by particle genetics thus illustrating that there was a shift in epistemological struggles pertaining to, and a resultant pluralization of, perspectives on genetics. This shift and the attendant social struggles were elements of social changes that affected the general understanding of reproductive predictability and genetic diseases and thus changed ideas of reproductive processes and disease identification. Consequently, this shift in the genetic comprehension of the body is similar to the current shifts that define the genetic body in reproductive and genetic technologies. That is to say that the re-inscription of genetic understanding under Mendel's influence within medico-scientific communities initiated a new beginning from which to study and comprehend reproductive processes and the transmission of genetic diseases, which continue to be fundamental principles in genetic studies of contemporary reproductive and genetic technologies.

This historical analysis of the epistemological shift in genetics is essential to an account of the historical factors that comprise the dominant discursive materials of public bioethical debates today. Historical descriptions allow for the contextual analysis of how reproductive and genetic bodies are represented and integrated in medico-scientific, social, political, religious and legal perspectives. This integration and application of genetic knowledge onto bodies needs to be accounted for when analyzing the ecology of heterogeneous strategies which result in public bioethical debates concerning the

biopolitical social change in the understanding of bodies, reproduction, health and disease.

Eugenics and Public Bioethical Debates

Eugenics is an early example of the modern quest for an ideal body and the belief that science and technology are the right means for attaining this goal. The history and development of genetic discourse provided the ideological materials from which were fashioned eugenic biopolitics in Canada. It was popularized in Canada, even in the face of opposition. The idea that an ideal population could be attained by regulating reproductive and marriage practices gave way to the advocating of eugenic strategies by different collectives. Although, eugenics is not practiced in Canada currently, the eugenic convictions in the early 20th century indicate a significant social side of reproductive and genetic concerns and further suggest that early forms of reproductive regulatory behaviours, problematized through genetics, gave rise to the legal dimensions of stated reproductive and genetic objectives.

The roots of the Canadian eugenics movement can be traced back to the British context.²⁰ The concept of eugenics was coined by the British scientist Sir Francis Galton

²⁰ For further reference on the moral regulation of health, see Hunt (1999). For reference on the biology of social deviations, see Meade and Parkes (1965).

in 1883 (Thomson 2001:7).²¹ The idea of eugenics claimed scientific justification for class distinction and social hierarchies. Galton characterized eugenic analysis,

. . . on what is termed in Greek, *eugenes*, namely, good in stock, hereditarily endowed with noble qualities. This, and the allied words, *eugenia*, etc, are equally applicable to men, brutes, and plants. We greatly want a brief word to express the science of improving stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognisance of all influences that tend in however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had. The word *eugenics* would sufficiently express the idea; it is at least a neater word and a more generalized one than *viriculture*, which I once ventured to use (emphasis in original, Galton 1973:17 footnote).

This application of scientific inquiry in Galton's idea of "improving" human stock, thus supplied a new normative framework for public health policy that targeted race, intellect and class.

Eugenics was founded in notions of maintaining a healthy population with regards to what were considered to be hereditary illnesses. This idea for improving humanity is a useful starting point from which to focus on public bioethical debates because eugenics socialized biology to such an extent, that it began to resonate throughout medical, legal, religious and political institutions. Eugenic perspectives permeated the *conscience collective*, constituting the dream of a biologically improved humanity. This general mentality for human improvement was growing in Britain at this time and the influenced ways in which disease was medically categorized. For example, during the early 20th

²¹ Galton was the cousin of Charles Darwin (Missa 1999: 533).

century, social ills, such as poverty, prostitution, masturbation, immigration and feeble-mindedness, were considered hereditary products (Carlson 2001: 13; cf. Meade and Parkes 1965). Previously, these diseases were seen and treated in terms of morality. There had been a shift from ‘moralization’ to eugenic ‘biologization.’ Furthermore, a prominent British sea captain, Havelock Ellis who became a writer, an unconventional sexual liberator and eugenics supporter stated that²²

Heredity is the chief cause of feeble-mindedness . . . The feeble-minded have no forethought and no self restraint. They are not ordinarily capable of resisting their own impulses or the solicitations of others, and they are unable to understand adequately the motives which guide the conduct of ordinary people . . . Illegitimacy is frequently the result of feeble-mindedness, since feeble-minded women are particularly unable to resist temptation . . . and giving birth to illegitimate children (Ellis 1911: 35-37).

In the early 20th century, eugenics grew in popularity in Canada. Ellis argued that inherited “feeble-mindedness” is a scientific and legal concern for society, thus illustrating that eugenics was not exclusively medico-scientific: it was based on social and hence normative conceptions of health and disease.

Canada was not immune to similar moral and biological claims made by eugenics supporters. One classic eugenic argument claimed that disease would be removed if those that were diseased were not able to reproduce. An example of Canada's involvement in eugenic biopolitical strategies between 1913 and the 1950's, is found in the case of a woman's group, the Vancouver Council of Women in conjunction with the

²² For further reference on Ellis' life, refer to his autobiography, Ellis (1939).

New Westminster Local Council of Women, who held contests to show the notion of what constituted a “better baby” in terms of beauty (Thomson 2001: 5).²³

What constituted a “better baby” was rooted in notions of eugenics, concerned with issues of race, class, and intellect (Thomson 2001: 6). These contests were

linked to the emerging eugenics movement in the early part of the twentieth century as well as to the role of women in furthering the supposed quality of the “race.” During this period the term “race” generally referred to people of Anglo-Saxon origin or the peoples of northern Europe, excluding such social outcasts as the Irish . . . Considering the context of the times, middle-class Anglo-Saxon women and their better baby contests undoubtedly played a central role in furthering the social goals of eugenics for “race” improvement (Thomson 2001: 6-7).

Thomson describes one attitude toward eugenics that included concepts of human improvement and demonstrated its growing international popularity. He further states that the definition of what was considered highest, in a hierarchy of races, were those of Anglo-Saxon descent. Further, “Eugenics helped to popularize such concepts as ‘the quality of the stock’ and ‘a breed fit for the struggle of life’” (Thomson 2001: 7).

The popular locus of eugenics was in the middle-class and those of higher classes. Consequently, eugenics has connected with class struggles social hierarchies. Moreover, the perpetuation of eugenic thought was not solely an elite scientific endeavour. Some

²³ The better baby contests were held in Vancouver from 1913-1919, then it moved to New Westminster (until 1929, due to the venue being burnt down) because it was said that there was a lack of volunteers and the war needed workers, however, “the reason for the abrupt end . . . remains unclear” (Thomson 2001: 23).

men and women of the middle to higher classes were involved in the attempts to improve the population, and used eugenic criteria as a way of establishing and maintaining their place in the social hierarchy.

The “better baby” contests were an attempt by one group that exposes the influence of eugenic projects in Canada in the early 20th century. Scorecards were used to rate the physical and mental “fitness” of babies and were essential for the judges’ comparisons between babies. Many babies were entered and judged for characteristics that were deemed to be ideal, such as weight, height, bodily measurements and intelligence (Thomson 2001: 28).

The contests were originally meant to compare beauty, however after a few years, the judges became more strict on the qualifications and thus, these “better baby” contests became clinics for parents that suggested improvements that were deemed necessary for correcting their flawed children (Thomson 2001: 29). Thus, explicit criteria were developed in order to identify the ideal characteristic of the ideal baby and attaining this ideal was the driving force behind eugenic objectives. If certain defined characteristics were deemed flawed, then by default, those traits that were considered not to be flawed were considered closer to idealized attributes. This illustrates how the ideology of human improvement worked its way through these baby competitions.

These baby contests highlight the eugenic convictions that permeated the Canadian *conscience collective*. The better baby contests defined an ideal of good and

healthy babies, according to stereotypes based on the Anglo-Saxon imaginary of the time. Further, the idea of a “better baby” was a standard that emerged due to eugenic thought, as were the criteria of assessment.

The women who led this competition continued with their eugenic endeavors and lobbied to sterilize those that were considered and categorized as unfit to reproduce, such as prostitutes and feeble-minded individuals. Thus, their collective strategies to change social conditions pertaining to fertility and reproduction, became a part of public bioethical debates in Canada that focused on the reproductive capacities of the population based on their beliefs of who should or should not reproduce.²⁴ Succinctly put, using defined characteristics to identify an ideal baby reflected impressions of who was subjugated to eugenic discourse and expressed the power relations within the Canadian social hierarchy. Those who could draw upon their social resources of power to create social change (i.e., individuals with social power, such as the elites), became involved in this eugenic project. Consequently, advocates of the norms, reflected in the criteria of “better babies,” had an ideal image of a baby that they looked upon as a standard and as an ideal. This image of a “better baby” represented a collective representation based on power in action, which was then re-transmitted through collective representations of standards and ideals.

The better baby contests also highlight the plans for sterilization, in order to avert socially unwanted births. This needs to be contrasted with the projects for the

²⁴ Those considered for sterilization in this lobby group were generally those that were poor, immigrants or

reproduction of the fit, i.e., encouraging the reproduction of those that are deemed socially desirable. This is a fundamental distinction in eugenics: there is positive eugenics and negative eugenics. The difference is defined as follows:

“positive eugenics,” which aimed to foster more prolific breeding among the socially meritorious, and “negative eugenics,” which intended to encourage the socially disadvantaged to breed less - or better yet, not at all (Kevles 1985: 85).

This difference between positive and negative eugenics demonstrates two different attitudes toward reproduction.

The two positions claim that positive eugenics encourages certain, higher-classed individuals to reproduce; and conversely, negative eugenics encourages lower-classed or feeble-minded individuals not to have any children. In other words, those who were considered ‘healthy’ represented individuals that were both physically and socially advantaged (i.e., deemed normal or ideal), according to the criteria of social classes developed by middle or higher social status.²⁵ Eugenic emphasis is established in the social realm of collective representations that shape criterion of those who are considered socially advantaged or disadvantaged. It indicates that the socially affluent are those who were encouraged to reproduce, and then by default, those who were socially disadvantaged, like the poor, ‘feeble-minded’, or ill, became likely candidates for negative eugenic strategies.

‘feeble-minded’

²⁵ The characteristics I am speaking of include physical, mental, and social. In addition, it is not solely an attitude based on class, this attitude was further perpetuated and legitimized by various medico-scientific authorities, like doctors.

Eugenics supporters believed that eugenics would be a vehicle in a move toward public and individual health, economic stability (particularly during the times of economic depression in the 1930's) and national pride (Osborn 1940: 294-295). Support for eugenics represented strategies within debates because they conveyed collective moral ideals, couched in scientific discourse that targeted the reproduction of social stratification.

This power relation was transmitted by eugenic discourse and was mapped onto existing social tensions. In addition, eugenic study was based upon many race and class assumptions, but it also created a space for targeting change in sexual and reproductive conduct (Hasian Jr. 1996: 5). Subsequently, this removed reproductive autonomy and re-appropriated reproductive capacities into the hands of the higher-classes through regulation. Consequently, this class-based attitude to controlled reproduction is a symptom of social change.

Eugenics was seriously considered in Canada in 1918, with the creation of the Canadian National Committee on Mental Hygiene (CNCMH), and in 1929 with the establishment of the Royal Commission on Public Welfare (McLaren 1990: 59, 112). Soon after, in 1930, the Eugenics Society of Canada was formed headed by William L. Hutton, a medical doctor from Brantford (McLaren 1990: 107, 113).²⁶ These national

²⁶ Other prominent Canadian eugenicists included Madge Thurlow Macklin, a Mendelian geneticist who focused on the hereditary causes of cancer and worked to improve public health, and Dr. Charles Kirke Clarke, a medical officer from Toronto who stipulated that venereal disease was a factor in high infant mortality and spread by prostitutes (McLaren 1990: 73, 133). Clarke further claimed that venereal disease was considered to be a prostitute disease, and consequently, prostitutes were deemed to transmit disease through their reproductive capacities, and hence, would be likely candidates for sterilization programs.

institutions studied eugenics as a viable option for improving the health (mental, physical and social) of the Canadian population.²⁷ This demonstrates that Canada had institutional mechanisms for defining diseases, and by default, they defined what constituted health. In addition, these national institutions illustrate that there were institutional agents who negotiated constructions of reproductive and genetic health during the proliferation of eugenic ideologies in Canada in the early 20th century. They were engaged in a national campaign that, they argued, would change the social infrastructures through medico-scientific means.²⁸

In other words, eugenics was not exclusively medico-scientific at this time; rather, social and moralized ideals of health were constant concerns for these eugenic-based institutions. The Second World War weakened the Canadian eugenics movement. Since growing international concerns of the extreme Nazi platform in Germany were based on eugenic projects for improving the population, eugenic attempts were associated with the Nazi ideology. In Germany alone, there were “race hygiene” attempts, guided by Nazi politics, to remove any genetic trace of those that were deemed socially undesirable, including Jewish people, Polish people, gypsies and those that identified as homosexuals

²⁷ These institutions were not the only collectives that considered eugenics in Canada. There were provincial agents that did their own studies on how to on the validity and applicability of social life. Much of the eugenic based legislation in Canada was provincially decided. For example, Alberta and British Columbia enacted sexual sterilization acts. (for Alberta's sterilization act, see Appendix 1).

²⁸ The infrastructures I am discussing include social status, 'race' and immigrant concerns, and what was considered to be moral degeneracy (such as prostitution).

(Carlson 2001: xiv).²⁹ The Holocaust, was an extreme form of eugenic rationalities leading to the delegitimization of eugenics.

Overall, nationalized eugenics projects developed strategies for promoting a particular kind of social change. They represented an initial step toward using medico-scientific technologies engaged in biopolitical strategies based upon the manipulation of genetics to improve social, physical and mental health. However, as shown above, this had little to do with 'health' and a lot to do with power and stratification.

Eugenics and 'Life' as a Vatican Object

Eugenic systems of judgment in Canada were pursued, as illustrated by the better baby competitions and nationalized institutional studies. But, there was opposition as well. One dedicated opposing religious collective included some members of the Roman Catholic Church whose interventions were published in the Vatican's catechisms. These positions were applied in Catholic doctrine and ecclesiastical practice. I focus on the Vatican writings because they were the most prolific published opposition to eugenics projects. This does not imply a generalization about the Vatican as a single, isolated, monolithic institute. Rather, the Vatican is an assembly of individuals with diverse opinions, perspectives and interpretations of the meaning of Catholicism.³⁰ One such

²⁹ Race Hygiene is the concept to remove or eliminate races who are considered disadvantaged or undesired.

³⁰ For further examples that demonstrate the diversity of perspectives of Catholicism, modernity and reform of the Church, refer to McBrien (1987, 1973), Hitchcock (1979), Jodock (2000) and Baum (1987).

opposing figure was Pope Pius XI.³¹ Regarding the social context of regulating marriages in order to gain or avert specified characteristics, Pope Pius XI argued as follows:

For there are some who over solicitous for the cause of eugenics, not only give salutary counsel for more certainly procuring the strength and health of the future child - which, indeed, is not contrary to right reason - but put eugenics before aims of a higher order, and by public authority wish to prevent from marrying conjectures of their investigations, would, through hereditary transmission, bring forth defective offspring. And more, they wish to legislate to deprive these of that natural faculty by medical action despite their unwillingness; and this they do not propose as an infliction of grave punishment under the authority of the state for a crime committed, not to prevent future crimes by guilty persons, but against every right and good they wish the civil authority to arrogate to itself a power over a faculty which it never had and can never legitimately possess (Pope Pius XI, 2004: #68).

Thus, although eugenics has beneficent intentions (i.e., it is for the health of the child), Pope Pius XI remained skeptical about eugenicist claims since all people are capable of receiving the sacrament of marriage, and marriage doctrines regulate the classes of individuals who are authorized to form a union. This, according to Pope Pius XI, expressed that eugenic regulations of marriage are attempts to subvert Church authority by recourse to scientific authority, this would imply the denigration of marriage as a sacrament, i.e., a gift of God administered by the Church. This quote demonstrates that eugenics was not exclusively confined to the medico-scientific field. Rather, there were deeply rooted religious concerns that were voiced by members of the Vatican.

³¹ Written in the *Casti Connubii*, Encyclical of Pope Pius XI on Christian Marriage to the Venerable Brethren, Patriarchs, Primate, Archbishops, Bishops, and Other Local Ordinaries Enjoying Peace and Communion with the Apostolic See. (2004)

The legitimacy of selective eugenic power is questioned by the writings of Pope Pius XI, and further conveys that eugenic power has not supposed to be solely in the hands of the government, civil authorities or any human institution in that manner. Papal opposition to eugenics, since questions of legitimate birth are determined by marital doctrines, was thus involved in a struggle against the incursion of medico-scientific criteria of judgment into the terrain of institutions governed by Divine revelation as the basis of religious authority. This indicates that eugenics was problematized in and through a variety of disciplinary institutions and discourses that represent collective subjects, i.e., the Vatican, under Pope Pius XI, that expressed theological opposition to the medico-scientific imperialism of eugenics projects. Moreover, the idea of a higher order exemplifies the transcendental aspect of theological arguments that root themselves in the substantive rationalities of religious institutions and practices.

The Vatican's writings on eugenics, abortion, genetic and reproductive technologies are based on the definition of life found in the Catechism of the Catholic Church. This position on life is aptly articulated in the Catholic Catechism on abortion:

Human life must be respected and protected absolutely from the moment of conception. From the first moment of existence, a human being must be recognized as having the rights of a person - among which is the inviolable right of every innocent being to life (Catechism of the Catholic Church #2270)

This definition of life in the Catechisms holds that life, begins at conception, thus, in the womb. This life is seen as a human being with full rights. In other words, the scientific object of life as constituted through reproductive and genetic technologies do not attribute

life, as understood in the Catholic doctrine, to an unborn child. Rather, they define it as a zygote, fetus, and an embryo, depending on the stage of gestation. These terms denote a specific scientific understanding which does not interpret the unborn as a human person; it is seen as an undeveloped being.³² However, Catholic attitudes toward abortion are heterogeneous,³³

Many Catholics . . . support permissive legislation [on abortion caused by rape, incest, danger to the mother's life, or radical fetal deformation], while remaining firmly opposed to abortion on moral grounds . . . Very, very few Catholic theologians favour abortion-on-demand (McBrien 1987:156).

The fundamental differences in definitions of life found in Catholic doctrine and Canadian legislation pertaining to reproductive and genetic technologies and in neo-natal research, have come to the fore with the introduction of eugenics into medico-scientific discourse and the social encouragement of reproductive and genetic technological research. Public bioethical discourses have reduced the significance of religious perspectives; rather the professionalization of the field of bioethics has replaced the authoritative dialogue in reproductive and genetic research.

Questioning different conceptions of life and criteria for assessing and intervening in human life shows that there are a range of social factors brought to bear on

³² For further reference, the abortion legislation that exists currently in Canada is under the Criminal Code which states that a qualified medical practitioner is permitted to perform an abortion or “miscarriage” if the woman so chooses (Canada Criminal Code #287, Procuring Miscarriage <http://laws.justice.gc.ca/en/c-46/42515.html>). This illustrates the legal definition of a human life that does not identify the unborn to be a child/human until it is completely removed from the birth canal (refer to Section 223. (1) in the Canada Criminal Code for the legal definition for when a child becomes a human being).

³³ A radically different point of view on abortion exists in an organization based in Washington called

reproductive and genetic technological applications. Reproductive and genetic technologies do not exist in isolation: they are complex social things, imbricated in a variety of social apparatuses and networks. As shown above, these included eugenicists, the medico-scientific community, the Vatican, the broader Catholic Church and state apparatuses.

Canadian Participation in Contemporary Public Bioethical Debates

Although eugenics lost its social power as a valid scientific endeavor after WWII, what eugenics in Canada has shown, is that there is an obvious social side to reproductive and genetic strategies. The 'biological,' through public bioethical debates, becomes a social concern when applied to individuals or collectives. Canada's recent involvements in bioethics include the Human Genome Project (HGP) and the Royal Commission on Reproductive and Genetic Technologies.

The Human Genome Project has an international history, in which Canada played a part. The project was initiated in the United States. In 1988, the Office of Technology Assessment (OTA) first proposed the Human Genome project to the United States Congress (Lee 1991: 11). This 15 year pursuit had a 3 billion dollar cost, primarily funded by the U.S. government. It is considered to be the largest project of biological research in history (Heller 1996: 1). Although initiated by the U.S., the HGP soon involved other countries, including Italy, Japan, Canada, the United Kingdom and the

Commonwealth of Independent States (Heller 1996: 21). The overall project was widely recognized as a pivotal moment in reproductive and genetic science.

The Human Genome Project was designed to understand the blueprints of life. Its foremost goal was to combine the series of international projects to interpret the mapping and sequencing of all human chromosomal and mitochondrial DNA, excluding the DNA within gamete (Heller 1996: 21). It focused on three main objectives: first, to examine and understand base pair/nucleotide sequencing that forms the DNA within the 46 human chromosomes; second, to identify the locus of every gene to create a DNA map; and third, to apply the genomic information obtained to the analysis of predisposition to genetic diseases (Peters 1997: 3). These objectives are rooted in assumptions about the genetic causes of disease. The agenda of the HGP also demonstrates that there are assumptions that genetic diseases can be simply read off a genetic map, believed to inscribe the specificity of biological constitution. This resulted in a form of geneticist reductionism that obscured environmental, cultural and political determinants that articulate and constitute human life.

Canadian involvement in the Human Genome Project began at a slow pace. The United States and Italy had initiated national efforts 3 years before Canada (Cook-Deegan 1994: 204). Canada became initially interested in the human genome efforts in 1989, when a committee that included Ford Doolittle, James Friesen, Micheal Smith, and Ronald Worton, submitted a White Paper to the Canadian Parliament (Cook-Deegan

1994:204).³⁴ Canada's Minister of Science and Technology responded positively and began to coordinate state involvement including,

funding from the Ministry of Science. The Medical Research Council (MRC) agreed to champion this alternative, and the NSERC [National Sciences and Engineering Research Council] and the Social Sciences and Humanities Research Council formed an Inter-Council Human Genome Advisory Committee (Cook-Deegan 1994: 204).

This multi-council funding proposal highlights the role of state incentives in Canada for involvement in the international HGP efforts to map and sequence the human genome.

Soon in 1992, the Canadian Genome Analysis and Technology Program (CGAT) and the research committees on the social, legal and ethical implications (MELSI) were formed as a part of the international genome project (Knoppers 1998: ix). The two programs were combined to create the CGAT-MELSI Advisory committee that focused on,

culture and genetics, population screening, genetics and insurance, genetics and comparative international approaches, and finally, on the commercialization of genetics (Knoppers 1998: xi).

Once again, one can note the interdisciplinary constitution of the field of public bioethical debates. The issues highlighted by the CGAT-MELSI committee draw attention to the

³⁴ Incidentally, Worton was a member of the Human Genome Organization (HUGO). This international organization is a collective of scientists, professors and doctors working, "to promote international discussion and collaboration on scientific issues and topics crucial to the progress of the world-wide human genome initiative in order that the analysis of the human genome can be achieved as rapidly and effectively as possible." (Human Genome Organization 2004). Furthermore, HUGO also has a committee specifically devoted to socio-ethical issues in genome research (Stranc and Evans 1998: 97).

main ethical concerns that have been discussed in a number of circumstances concerned with agricultural, human and environmental applications of the genome project. Thus, this demonstrates that the Human Genome Project was also a multi-dimensional program. This produced multi-faceted strategies involving political, economic, social and cultural variables in the decision-making process of pursuing a national genomic project.

The Human Genome Project did not emerge without debate and controversy. The main threads of the debate were based on socio-ethical concerns. Although the Royal Commission of 1993 compiled thorough research and publications that emerged from this commission, the Royal Commission did not have a strong impact on Parliament. There was a public hearing focused on public concerns about reproductive and genetic technologies. One question posed was “How do we define health in our society?” However, this question was framed in terms of what health care procedures should be publicly funded (Baird *et al.* 1991:16).

In June 1996, Bill C-47 was proposed and tabled in Parliament. However, it did not become legislation due to a change in government (Health Canada 1999). Consequently, there was little national attention paid to reproductive and genetic technologies until 1999. At this time, the Minister of Health revisited the issue and it was put on the agenda of the September 1999 Health Minister's Conference (Health Canada 1999). This reinvigoration of reproductive and genetic technological debate put politico-legal questions about reproductive and genetic technologies back on the table in the House of Commons.

In 1995, the Canadian government created the Biologics and Genetic Therapies Directorate (BGTD). This directorate is a governmental organization devoted to regulating the safety and use of various pharmaceutical and biological products including genetic therapeutic products (The Biologics and Genetics Directorate 2004). This agency is a combined effort of four institutions. The institutions at the center of policy and regulatory policies are: the biologics and radiopharmaceuticals evaluation center; the center for biologics research; and the offices of planning and quality management (The Biologics and Genetics Directorate 2004). Moreover, the BGTD is an institution reliant on scientific evidence to ensure safe products for Canadian consumers. The BGTD agenda focuses on the regulation of genetic therapies, and determines which are considered safe (on the basis of scientific criteria). Those decisions then form the basis of legislative recommendations. Thus, the BGTD is a regulatory agency that is directly involved in the formation of regulations pertaining to the use and application of genetic technologies, the dimension of the broader social struggles and contests surrounding biotechnology.

The legislation that was enacted in October 2003 (originally Bill C-13: The Assisted Human Reproduction Act), was a preliminary document concerned with reproductive and genetic technological boundaries, i.e., which actions that use genetic materials are prohibited and controlled. The law includes socio-ethical content drawn from the Royal Commission of Reproductive and Genetic Technologies of 1993. The legislation remains incomplete because of the multiples doors that have been opened by

the Human Genome Project that followed in the field of reproductive and genetic research.

The Canadian politico-legal domain illustrates that socio-ethical concerns emerge from increased knowledge of genetics, reproduction and biotechnologies. Thus, it is necessary to emphasize the point that throughout Canadian biotechnological history, there are different paradigms, perspectives and forms of argumentation in biotechnology surrounding and shaping reproduction and genetics. These diverse perspectives (including the Vatican/religious, legal, social, ethical) are constitutive struggles that produce a culture's understanding of biotechnological applications. Given this circumstance, one must re-evaluate the assumption that biotechnology is exclusively based in medico-scientific endeavours. These debates have a complex social history produced by the constitutive tensions and struggles amongst numerous social, political, legal, ethical, religious and medical apparatuses.

Reproductive and genetic technologies are not recent social facts; rather, the history of eugenics, and past debates in reproductive and genetic technologies continue to inform current public bioethical debates and one must attend to both the continuities and discontinuities surrounding reproductive and genetic technologies and public bioethical debates (cf. Foucault 1991: 70). In other words, discourses are informed by diverse historical factors and hence, discourses do not simply appear from 'nowhere.' There is a relation of interdependence between the order of discourse and the broader socio-historical context in which it appears: each informs and articulates with the other, leading

to change and development. The diverse history of public bioethical debates and what is currently understood about the genome, is another layer superimposed on the knowledges that have been formed over time. There is no linear progression: beneath public bioethical debates lies a heterogeneous history of reproductive and genetic manipulation, imbricated in different spheres of knowledge that leave their impression in vast paradigms of reproductive and genetic technological research.

The social changes that reproductive and genetic technologies have advocated concentrated on the awareness of human abilities to manipulate, alter and change the genetic constitution of, not just one generation, but that of the health of future generations as well. Consequently, the concepts of disease and health are being re-negotiated in light of contemporary developments in genetic knowledge.

With the rise of new genetic knowledge, fundamental assumptions about the body became problematized. Public bioethical debates have challenged philosophical, social, legal and religious perspectives that attempt to fix the boundaries of life, disease and health, in their respective ways. These multiple facets of public bioethical debates have broadened the scope of research and discussion of corporeality, including what is meant by the concepts of life, disease and health. I argue that concepts of disease and health are foundational normative reference points of the public bioethical debates that are attempting to frame and shape reproductive and genetic technologies.

In the next chapter I explore how the shaping, maintaining and aspirations to having healthy individuals and populations have become a political dream shared by medico-scientific, social, ethical experts. Furthermore, the concept of a healthy body is not exclusively an assumption in reproductive and genetic technological debates, but it is also an idealized pursuit within Canadian culture. Consequently, my claim that the notion of a healthy body has become a 'norm' and 'ideal,' illustrates the nodal points in public bioethical debates concerned with reproductive and genetic technological research. This tacit assumption however has not often been acknowledged or analyzed in the field of public bioethical debates.

Chapter Four

HEALTH AND DISEASE:

THE CULTURAL SHAPING OF NORMS AND IDEALS

The main concern in this chapter is with the concepts of health and disease in public bioethical debates. These concepts are generally polarized and divided by a contested theoretical line. Genetic knowledge, thus far, reconstitutes the human body as an object of knowledge, before conception, during gestation, during an individual's lifetime, or afterwards, in order to predict what their corporeal and genetic future entails. That is, the medico-scientific community functions as the authority determining definitions of an individual with regards to their health, and is able to predict certain genetic illnesses before the symptoms are phenotypically expressed. Consequently, health concerns have changed from “what is wrong with me?” to “what will be wrong with me?” This shift in the conception and target of health from the present to the future demonstrates a discontinuity in the problematic of health. A body then, is never considered healthy 'in itself;' rather the body is seen as a host where there is always the potential to contract disease, a likelihood which now can be ascertained before birth, and sometimes before conception. What does this mean for the theoretical line that divides health and disease?

Since the notion of disease is defined by medico-scientific authorities, then by default, the body is considered healthy if there are no abnormalities or identifiable

diseases in the body. Thus, if concepts of disease are applied before conception or birth, then the notion of health becomes an issue of the future, especially in cases of the probability calculations of late-onset diseases. Consequently, disease and health are concepts that are not distinctly separated, nor are they polar opposites. Thus, disease is also a concept at the center of public bioethical debates in reproductive and genetic technologies. Genetic diseases thus become the targets of reproductive and genetic technologies geared toward the removal of genetic abnormalities. When genetic abnormalities are removed, the genetic constitution of the individual becomes part of a standard genetic model believed to generate healthy populations. Thus, the valorization of health, relative to disease becomes legitimized through the dominant medico-scientific discourse, and further, their discursive agents impose authoritative definitions of healthy corporeality on the broader society.

Genetic technologies are attempting to create and maintain healthy individuals and collectives, not to design them in a way that embellishes or enhances the present characteristics.³⁵ However, is using reproductive and genetic technologies to maintain health and remove disease a form of enhancement? Although speculations about creating a super-human (i.e., high IQ, strong, and phenotypically determined), are a common object of critique, it should not be the main concern. The critical anthropologist needs to focus on how disease and health are understood and applied via reproductive and genetic technologies in the medico-scientific field, and how these concepts generate socio-political effects.

Below, I compare and contrast ideas of health and disease cross-culturally in order to distill a common framework surrounding these concepts that indicate a pattern of attaining, maintaining and valorizing health as the predominant goal of medicine and politics. Furthermore, if health is the center of technological attention, then health, as defined within medico-scientific discourse, is what reproductive and genetic technologies are striving toward. What I argue in this chapter is that health is both the standard and ideal motivating and normatively regulating the dominant representation of the body in contemporary society. I further contend that the valorization of health is a crucial focus of criticism in public bioethical debates of reproductive and genetic technologies.

Canguilhemian Reflections: Health, Disease, Idealism and Normalcy in Public Bioethical Debates

What constitutes a healthy body?³⁶ Medico-scientific communities have documented endless diseases in many publications, leading to a particular definition of the concept of diseases. However, if reproductive and genetic technologies claim that they are searching for ways to fight genetic disease, this implies that using these technologies to remove disease, will result in a body considered healthy after the intervention of technological procedures. Now, the main focuses of public bioethical debates are concerns of disease and health. Thus, disease is devalued or unwanted and hence, deemed an undesirable form of life.

³⁵ Legal ramifications do not allow for the creation of designer babies in Canada.

³⁶ Whether this body is social, political, or corporeal.

At the same time, concepts of health and disease are based in cultural understandings of the body, spirit and mind. The cultural definitions of health and disease idealize health in public bioethical debates. However, cross-cultural understandings of health and disease show that health is not only a norm, it is a norm that is physically unattainable, thus, health has transcended the status of being normal and has become an ideal.

Health and disease are assumed to be polarized concepts.³⁷ Biomedical science believes that single gene disorders are localized in the body and can be identified by the use of genetic technologies. These pinpoint a specific gene that has the potential to be altered, and thus fixed, guided by a genetic standard. This idea of fixing genes to bring the body back into a state of normalcy or health demonstrates that there are criteria governing a pursuit of a physical state, which directs medico-scientific principles of treatment. These treatments attempt to bring the diseased body into a state of health or normalcy. Furthermore,

The state of health is a state of unawareness where the subject and his body are one. Conversely, the awareness of the body consists in a feeling of limits, threats, obstacles to health. Taking these formulae in their full sense, they mean that the actual notion of the normal depends on the possibility of violating the norm (Canguilhem 1978: 46).

³⁷ I.e., when an individual is healthy, they are assumed to be absent of disease. In other words, if an individual contracts a disease, they are considered to be no longer healthy. This is a generalized popular belief in Western medicine.

Thus, Canguilhem argues that the concept of being healthy is one that depends on the possibility of becoming sick. In the conventional scientific view, the body is then deemed 'normal' when the body is healthy. When boundaries of health or normality are crossed by the body, the body is deemed to be in a state of disease. For reproductive and genetic technologies, altering or manipulating genes to remove disease is its main objective. However, if the techniques of genomic manipulation become the standardized method for removing disease, then the normal genome, or standard genome becomes the genome that people desire. This is the process through which the standard or normal becomes the ideal. The concept of the normal within medico-scientific discourse implies the following:

Since *norma*, etymologically, means a T-square, normal is that which bends neither to the right nor left, hence that which remains in a happy medium; from which two meanings are derived: (1) normal is that which is such that it ought to be; (2) normal, in the most usual sense of the word, is that which is met with in the majority of cases of a determined kind, or that which constitutes either the average or standard of a measurable characteristic (emphasis in original; Canguilhem 1978: 69).

In other words, 'normal' is simultaneously the qualitative goal (what is, ought to be) and the quantitative standard (i.e., based on the majority of cases).³⁸ This further substantiates Canguilhem's claim that the norm is both the ideal of the future, and the average constitution of the present. Thus, this creates a space in which to redefine the individual being as normal in the sense that it is both healthy in the present and the future.

³⁸ The concepts of qualitative and quantitative characteristics of normality are analyzed in Canguilhem's theory of the normal and pathological. This is further detailed below.

However, the temporal dimension is also connected with a spatial dimension, namely, the environment.

Taken separately, the living being and his environment are not normal: it is their relationship that makes them such . . . A living being is normal in any given environment insofar as it is the morphological and functional solution found by life as a response to the demands of the environment (Canguilhem 1978: 81).

Notions of the normal and the environment are interrelated. Hence, this coupling of the living being and the environment conveys that the sense that what is deemed normal is not, and cannot be a fixed concept: “The normal is not a static or peaceful, but a dynamic and polemical concept” (Canguilhem 1978: 146). Consequently, the standard or normal changes and fluctuates; there is no statically defined normal. The normal is a flexible state determined by qualitative and quantitative factors surrounding the living being which are bound and articulated by environmental constraints and conditions.

The concept of health is tied to the idea of the normal because, in conventional biomedicine, being healthy is what individuals ought to be and is based on biological standards. Being healthy is considered normal – the body is understood as harmonious and balanced according to its state within its environment. To contract a disease indicates abnormalities in the body which need therapeutic rectification.

Canguilhem argues that the line between the normal and pathological is thus unstable and indistinct:

If the normal does not have the rigidity of a fact of collective constraint but rather the flexibility of a norm which is transformed in its relation to individual conditions, it is clear that the boundary between the normal and the pathological becomes imprecise (Canguilhem 1978:105).

The boundaries between the norm and pathological are flexible and dependent on environmental factors. Further, since they are flexible concepts, the definitions of the normal and pathological become increasingly ambiguous. The understanding of the pathological state

does not consist in the absence of every norm. Disease is still a norm of life but it is an inferior norm in the sense that it tolerates no deviation from the conditions in which it is valid, incapable as it is of changing itself into another norm. The sick living being is normalized in well-defined conditions of existence and has lost his normative capacity, the capacity to establish other norms in other conditions (Canguilhem 1978: 106).

In other words, if disease is not a bodily state that deviates from the norm, assuming that health is the norm, then disease is a different type of norm within a different set of conditions. Consequently, Canguilhem argues that there are a variety of norms for evaluating bodily states. The gradations of disease and health are indicative of the different perspectives that classify and identify different norms, and thus, a disease does not necessarily follow the popular assumptions that health and disease are opposite corporeal states. Alternatively, they are considered normal in different contexts and allow for different perceptions of diseases. In addition, disease can be conceptualized in a way that does not mean it is a deviation from a norm; rather disease constitutes a different norm altogether.

Now, the concept of disease can also be considered as a norm understood in quantitative terms. This condition refers to an ontological conception of disease reliant upon a quantitative analysis (Canguilhem 1978: 171). The idea of the norm demonstrates that the norm is not just one defined reality; rather it is simultaneously different bodily states, dependent on environmental conditions, indicating qualitative variation. This qualitative differentiation characterizes the positivist conception of disease (Canguilhem 1978: 171). Both the ontological and positivist conceptions are theories that have similar perceptions of disease and health. They further convey that notions of health and disease are perceived in different ways according to the theoretical lens through which they are viewed. For example, the medico-scientific community perceives illness as a deviation from the standard.

At the same time, individuals in their environment have their own experience of their afflictions. Canguilhem states that:

disease is a positive, innovative experience in the living being and not just a fact of decrease or increase. The content of the pathological state cannot be deduced save for a difference in format, from the content of health; disease is not a variation on the dimension of health; it is a new dimension of life (1978: 108).

Furthermore,

disease is characterized by the fact that it is a reduction in the margin of tolerance for the environment's inconsistencies . . . This reduction consists in being able to live only in another environment and not merely in some parts of the previous one (Canguilhem 1978: 116).

Thus, disease does not simply refer to the degree to which a living being can tolerate different contexts that is able to identify different normative states; it is a different state of life.

Canguilhem's emphasis on adaptation in different environments has a proximity to Darwinist notions of the survival of a species, i.e., individuals that can adapt to a multitude of environments will be the ones who survive and continue to reproduce. The concept of adaptation in Canguilhem's theory of health and disease provides tools for framing the assumptions built into public bioethical debates. Canguilhem's concept of health is based on adaptive capacity. This notion of health has come to inform the idea that health is the ideal and norm in public bioethical debates. Medicine shapes the interpretation of the diseased as abnormal. However, Canguilhem develops a counter-discourse that demonstrates that the diseased state is normal. Thus, his arguments challenge the conventional conceptions of health or norm versus disease. In his own words,

In a sense one could say that continual perfect health is abnormal. But that is because the word 'health' has two meanings. Health, taken absolutely, is a normative concept defining an ideal type of organic structure and behavior; in this sense it is a pleonasm to speak of health because health is organic well-being. Qualified health is a descriptive concept, defining an individual organism's particular disposition and reaction with regard to possible diseases . . . When we say that continually perfect health is abnormal, we are expressing the fact that the experience of the living includes disease. Abnormal means precisely non-existent, inobservable. Hence it is only another way of saying that continual health is a norm and that a norm does not exist. In this misconstrued sense, it is obvious that the pathological is not abnormal (Canguilhem 1978: 77).

Qualitative differences in health are based on the potentiality or susceptibility of disease. Moreover, since there is no person who lives their entire lives without disease, it is strange to say that a person that never contracts a disease is normal. Thus, contrary to the dominant medico-scientific discourse, Canguilhem argues that the pathological is then a norm because it is normal to have a disease. In addition, Canguilhem's conception of abnormal refers to a state that does not exist or is not observable, and thus, cannot be part of the medical discourse.

Medical discourse shapes characterizations of different bodily states and investigates accordingly the existent corporal phenomena that emerge due to different experiences. This results in the absence of abnormal, non-existent phenomena and experiences, in medical discourses because medical inquiry is unaware of phenomena that do not exist and are not observable with contemporary techniques. The problem of the abnormal again involves an attempt to make 'health' an ideal. Thus, those that are continually healthy are considered to be ideal (deemed that which ought to be). Hence, the concepts of health as an ideal and health as a norm are interconnected.

In reproductive and genetic technologies, biological norms are rooted in the concept that the body is a vehicle that distributes and perpetuates genetic information. If there are any mutations or deviations from the standard or normal genome sequence, the genetic examiner has predictive capabilities to postulate about future genetic diseases. Hence, those who are deemed to deviate from the standardized genetic sequences are

considered to be at risk for developing genetic disorders, and thus demonstrate that a genetic norm or standard exists to monitor genetic health.

Canguilhem provides an alternative theory contending that health and disease are socially constituted and established through experience, norms and body/environment balancing. This shows that social factors are inherent in the understanding of health and disease, since the social is part of the environment. Whether a disease or physical affliction is deemed as a norm, it remains dependent on different contexts. There are diseases that are considered social and there are diseases that are established in laboratories. What differentiates the two is how disease is characterized in the body and further explained in the social sphere.

Health and Disease: Culture-Bound Concepts

What constitutes health in a culture? Canguilhem's idea of physical adaptation, which includes the interactions of the body in the environment provides a different conception of norms in medical discourse. However, with Canguilhem, the concepts of health and disease are based in individual experience and environmental adaptation. If generalized concepts of diseases are defined and perpetuated by medico-scientific institutions, then concepts of health would then be defined by these institutions as well. The use of reproductive and genetic technologies directly informs many institutional definitions of genetic health. However, the influence of experience is significant, and thus, concepts of disease and health are culturally-bound by socio-cultural relations and

experience. Here, I discuss the culture-boundedness of disease and health, and further demonstrate that both concepts are culturally relative.

Health has also been centered around the notion of immunity, and tolerance has been centered around the notion of warding off various diseases by living a healthy lifestyle. Martin (1994) argues that in order “to capture the sense in which awareness of and regard for the body's health as defined by the functioning of its immune system have come to be so general in the society that one cannot avoid it, wherever one turns” (184). That is, the idea of health has developed into a concept centered on the concept of the immune system. “Immunity is induced in the body by stimulating antibodies” (Martin 1994: 30). The idea here is that natural bodily defenses increase the body's tolerance to disease.

Militarist analogies (e.g., 'defenses') of corporeality indicate that there is a cultural/ideological base in Martin's idea of health.³⁹ The cultural basis of Martin's analysis of corporeal disease and health reflects her idea that both the body, inside and out, biologically and culturally, is socialized into social discourses that create diverse perceptions of how bodies are self-regulating and institutionally regulated, according to determinants of health (i.e., the relative strength of the immune system). Furthermore, this is perpetuated by diverse political, social and medical agents who claim that living healthy gives a person a well-balanced state that does not tolerate diseases or bodily

³⁹ The analogy of war includes the natural defense mechanisms of the immune system fighting the invasion of disease.

weaknesses. Although, the cultural basis for understanding disease in Western medicine is predominantly understood in biological terms, an interconnection between culture and biology exists:⁴⁰

What has happened is that culture now takes the place once occupied by biology, to lock individuals and groups *a priori* into a genealogy, into a determination that is immutable and intangible in origin . . . In sum, culture can also function like a nature (emphasis in original; Martin 1994: 283).

In other words, culture and biology are influenced by each other, and Martin states that biology and culture are interrelated factors that lock individuals into predetermined places. In effect, culture and biology take individuals and determine their socio-cultural and biological corporeality. This shapes an individuals' worldviews and hence their ways of perceiving and assessing their corporeal states of 'health' or 'disease.'

Other perceptions of health and disease are dependent on institutional definitions established by the dominance of medico-scientific authorities. Medical institutions are in a position of overarching authority to define the criteria for diseases. Since medical practices exist universally in every culture, differences remain in the ways that cultures apply these practices in their society. Medical institutions are themselves culturally located and thus, medical rituals and healing practices are based in cultural beliefs and values. Thus, "Each civilization defines its own diseases . . . Each culture creates its

⁴⁰ By Western medicine, I mean exclusively forms of diseases and treatments that are empirically studied in a laboratory (e.g., Down Syndrome is caused by an extra chromosome in position 21, also known as trisomy 21).

response to disease” (Illich 1995: 118). Although health and disease are different types of norms, one can detect the ripples of the interdisciplinary aspects of public bioethical debates being incorporated in this analysis of disease and health. Disease and health are not just defined by institutions; there are diverse socio-cultural factors that influence the defining of disease.

Foucault analyzes the discursive foundations of the logic of medicine and public health. Socio-cultural aspects are armed with definitions of disease that are deployed in surveillance mechanisms in medical institutions and infrastructures. According to Foucault, “Medicine made its appearance as a clinical science in conditions which define, together with its historical possibility, the domain of its experience and the structure of its rationality” (Foucault 1994: xv). The experience of the individual combined with medical (or formal) rationalities to facilitate the dominance of medical definitions that are widely held and legitimated. Formalized institutional rationalities have created a form of legitimacy that values health over disease, further creating an authoritative apparatus geared toward the maintenance of health as defined by those institutional rationalities.

For Foucault the concept of disease has shifted from being a single observing gaze, to disease as being perceived in two different ways; one way identifies social diseases to be removed through moral regulation; the other wishes to study disease by isolating it, for example, in a laboratory (Foucault 1994: 42-43, 108-109). This leads to the separation of social diseases and the naturalization of diseases. The definitions that emerge from medico-scientific perceptions and formalized rationalities, are rooted in the

observing gaze, and as such, they are culturally bounded because the observing gaze is a form of formal rationality, established in scientific discourse, and its institutional conditions, rooted in cultural assumptions and understandings.

The idea of the gaze is important to understanding how concepts of diseases are constructed in conventional modern medicine. Foucault argues that a perception based on the medical gaze constitutes particular conceptions of disease and the medicalized body (Foucault 1994: 108-109). That is to say that the medical gaze is an expression of institutional dominance and authority. Medical institutions are distinct because they are supposed to explain and create rationales for framing specific bodily experiences, such as disease. But it is bodily experiences and events that allow disease to be sensed by individuals that are then subjected to medico-scientific institutions. These experiences are constructed outside of the clinic and hence emerge in a broader cultural context.

Cultural understandings and beliefs reflect individual and institutional perceptions of bodies and the awareness of them that involve relations between themselves and their environments. As noted above, the conceptual line that separates the concepts of disease and health is not clear. Canguilhem states that health and disease are norms in different conditions, however, this sensibility is absent in medico-scientific discourse.

Multi-Cultural Perspectives on Health and Disease

Differences in cultural perceptions of disease are also indicative of the extent to which the conceptual line that divides the concepts of health and disease is ambiguous.

Different perceptions and experiences of disease demonstrate the various ways in which each perception of disease and health are produced as can be shown by cross-cultural analysis of health and disease. Below I outline perceptions of disease and health in the Ethiopia, Thailand, Serbia, and Ojibwa.

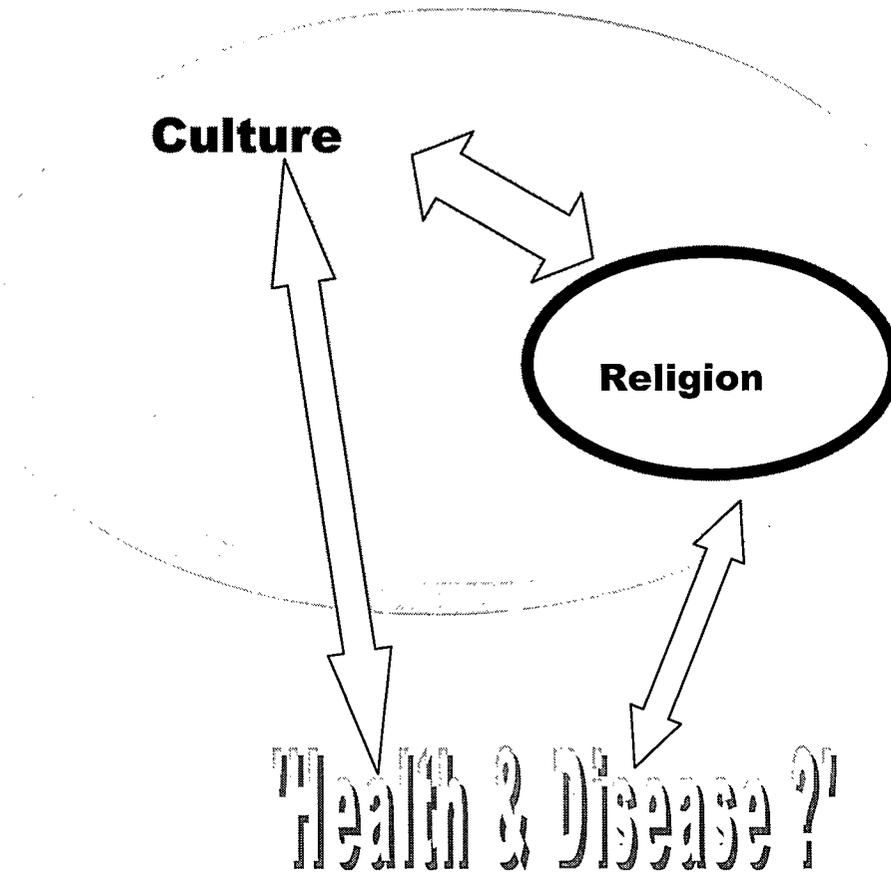


Figure 4.1: Cultural Location of Perceptions of Health

During the 1960s in the Gondar Province in Ethiopia, the Amhara explained physiology by relating disease to the invocation of their God. They also developed their own etiological taxonomy:

Amhara construct disease etiologies by selecting from five categories of information: The pathogenic agent (which may be purposive or non-purposive), the relationship between the pathogenic agent and the victim (which may be adventitious or deliberate), a variety of pathogenic acts, the pathogenic substance (which may be therapeutically homogeneous or heterogeneous), and the morbid physiological processes (which may be known or unknown) (Young 1971: 19).

The Amhara construction of disease was both physiological, and mystical. As Young claims, the disease may be either naturally caused or invoked in the Amhara culture. The ways in which disease and health are constructed by religious system of the Amhara is shaped by their cultural practices and beliefs, which are reflected in their healing rituals. For them, health refers to a state in which the body is in a balanced state of well-being (*tena*) and removed from pain (Young 1971: 4). The Amhara's concepts of disease and health are based in their knowledge of their physiology and their God.⁴¹ This discourse of the body in the Amhara demonstrates the way in which their religion is linked with their medical beliefs.

The role of religion in defining health and disease is not solely an Amhara tradition. Many cultures believe that their God is responsible for making individuals sick. For instance, in Bang Chan, Thailand, the relationship between “good health and

⁴¹ In Amhara physiology the heart is the most important organ that regulates body activity, controls body movement and is the center of intellect (Young 1971: 3).

longevity to proper religious and moral behavior was fundamental” (Hanks 1963: 96). Since there is a hospital system in place in Thailand, if a disease is not cured by traditional means, individuals can opt to get medical care in the city (Hanks 1963: 96). There is a balance between the way disease is treated by both the traditional mechanisms which are based in religious thought and the more recent developments of hospital care.

Another example, is the concept of disease in the Serbian culture of the 1920s and 1930s. Many of their diseases were named after evil spirits and there was a common belief that “many of the spirits are caused by animals, ghost animals or spirits” (Kemp 1935: 28-29). It was believed by the Serbian people during that time that

sickness, however caused, is first and above all a punishment, visited upon an evil-doer or his children. The sins of the parents are mainly responsible for insanity, cretinism, congenital deformities and chronic diseases from childhood . . . Amongst the sins which are considered the most serious are: working on a holiday, neglecting the patron saint or the duties of hospitality and charity to the poor and to the stranger (Kemp 1935: 42-43).

The Serbian way of interpreting disease by recourse to the notion of punishment illustrates the inherent moral terrain in which disease was rationalized. The cultural acceptance that disease was a punishment by a higher power means that there was a belief that mystical forces affect to the bodies of people if they do not discipline their lives according to the moral regulations concerned with averting sickness. Thus, disease and health are not just medico-scientific anomalies or textbook symptoms; rather, the perception of disease is rooted in religious and social traditions.

The idea that society can be regulated by means of averting disease is prevalent in the Ojibwa culture. “Causes of illness are sought by the Ojibwa within their web of interpersonal relationships, both human and cosmic” (Hallowell 1991: 93). Again, the notion of supernatural intervention appears in Ojibwa understandings of the cosmos. Furthermore, the fear of disease, which they believed was a punishment, provoked anxiety for many members and “introduced the psychosomatic factors necessary for the functioning of the major negative sanctions on Ojibwa culture” (Hallowell 1991: 93). Thus, “Their chief means of social control was anxiety about diseases caused by sin.” (Vecsey 1983: 148). Thus, the way sickness and health are defined play a fundamental role in reproducing social order amongst the Ojibwa.

Health and disease have been moralized in many cultures. Legal documents (as discussed earlier) also demonstrate the ways in which the definitions of health and disease can be used as a means of social control. What is interesting here is that there are alternative definitions for health and disease that use transcendental and substantive arguments, rationales and understandings in contrast to the colonization of the problem and concern with health by medico-scientific discourse in contemporary Canadian public bioethical debates. In Western medicine, substantive rationalities, like those found in religion, have been marginalized in favour of formal rationalities. This means that public bioethical debates have been founded on strict definitions of health and disease, and thus, lacks the incorporation of multi-cultural understandings into the fundamental concepts of formalized bioethical discourse.

Public bioethical debates use the concepts of health and disease as points of reference. However, as this chapter argues, there are multiple perceptions of health and disease that challenge the ethnocentrism of public bioethical debates. Cross-cultural analysis presents alternatives to how health and disease can be identified even if used as social mechanisms of control and surveillance.

Chapter Five

THE IDEAL OF HEALTH:

THE CANADIAN CASE AND ITS NORMATIVE CONSEQUENCES

Health and disease are concepts normatively valorized depending on the contexts in which they are constituted. As argued above, the conceptual line that divides health and disease is unstable and culturally variable. Although, there are criteria for defining diseases in Western medicine, the idea and ideal of health draws upon non-scientific representations of well-being and lifestyle balance. Moreover, as institutional definitions of disease and formal rationalities become dominant in popular discourse and public bioethical debates, regulative techniques and forms of discursive shaping continue to multiply. The result of this process is that biomedical concepts of health and disease have become the dominant means used to rationalize and justify projects of social control in the field of public bioethical debates.

The purpose of this chapter is to demonstrate the different ways in which reproductive and genetic technologies have influenced the concepts of health and disease in Canada. Further, the ambiguities surrounding the understanding of health and disease shows that Canadian debates about reproductive and genetic technologies need to more directly attend to questions of culture in order to broaden the understanding of the impact of bioethics and reproductive and genetic technologies of Canadian life.

Reproductive and Genetic Technologies: Bodily Idealism and Normalcy

Reproductive and genetic technologies concretely embody the dominant concepts of health and disease. They are indicative of the objectives of medico-scientific communities. Medico-scientific experts claim that reproductive and genetic technologies exist for the benefit of the health of individuals. However, the ambiguities of the concepts of health and disease remain and obscure what the medico-scientific community, backed by the state, is striving to achieve, i.e., the ideal body, and the standardization of individual bodily states, i.e., the 'normal' body.

Approaches that define the diseased body as opposed to the approaches that define the potential susceptibility of a body to disease involve different normative criteria. Genetic therapy and genetic diagnosis are different medical practices. Gene therapy targets the body that has already contracted a disease, and reproductive and genetic technologies are used in order to treat the disease and attempts to remove it from the body. On the other hand, genetic diagnosis is a method of detection and treatment for individuals who are deemed to be a risk of contracting a genetic disease in the future.

Both genetic diagnosis and therapies are approaches that assume that a healthy body is the objective of the application of technologies. In other words, the practices of reproductive and genetic technologies assume that disease will be removed, and aim for a healthy body, which is desired and expected. Health is further idealized in these

circumstances because the application of reproductive and genetic technologies suggests the cultural aversion (i.e., a negative valorization) to the predisposition to disease. The practices of genetic diagnosis in predicting genetic diseases and the procedures of gene therapy to treat genetic diseases are based in a culture dominated by the ideal of health.

Reproductive, medical and genetic technologies are an increasing field of interest in anthropology, particularly with the public awareness of the Human Genome Project (HGP). The HGP is an international project where scientists are attempting to map and sequence the entire human genome (Judson 1992:63). With this type of knowledge at hand, it is possible to understand which genetic code expresses specific traits in an individual (Cantor 1992:104). HGP opens a different chapter in genetic diagnosis that establishes the idealism of health by removing the potentiality or probability of future diseases.

Reproductive technologies create the possibility of producing an individual who is considered ideal. For example, test-tube baby technologies involve the union of a sperm and an egg through *in vitro* fertilization (Van Dyck 1995:62). In combination with genetic technologies, theoretically, fetuses can be custom-built before conception in the hope of producing an ideal individual. Such techniques inherently involve “speculations about the possibilities of science to remake nature” (Van Dyck 1995:69). Those who are infertile can take advantage of these technologies to reproduce and reflect the belief that they will improve the life of their child through genetic manipulations. The hope that the

child will likely be more accepted (i.e., not stigmatized) in society because they are healthy.

The reproductive technology of amniocentesis is used to detect abnormalities in the genome of fetuses during pre-natal testing (Nelkin 1992:178). This process can identify Down Syndrome, mosaics or alterations on the sex chromosomes (Nelkin 1992:178). It can also find and identify up to 180 different genetic disorders, such as the sickle cell trait (Nelkin 1992:178). If gene therapy does not exist for some of these disorders, the parents have a choice whether to abort the fetus. Furthermore, experts can use the information derived from the human genome project to manipulate the genome of the fetus to remove an unwanted genetic abnormality before birth.

Unlike *in vitro* fertilization, *in vivo* procedure is done inside the body of the woman who wishes to be impregnated. A woman can become artificially inseminated with her partner's sperm or the sperm from a variety of donors (Kaplan and Tong 1996:225). The donor she chooses tend to be ones believed to be closest to her idealized mate with her choice of desired characteristics, in the hope that the child will inherit some of these traits, bringing the genetic line of her offspring closer to her ideal. This donor capability is not only limited to men since women can be donors as well. Thus, a more contemporary phenomenon, that is becoming a large commercial industry, is the availability and selling of women's eggs (Cohen 1999). The procedure by which eggs are removed from a woman is more difficult than procuring sperm from a man. However, this commercialization of reproduction remains in the realm of speculations made by

bioethicists because currently in Canada there are legal ramifications if there is any attempt at selling body parts.⁴²

There is some hesitation about the application of reproductive and genetic biotechnologies. Some of the arguments made concern the commodification of biological material, hence the perception of our bodies is altered: eggs, sperm, wombs and other reproductive material have become saleable items (Martin 1987:145; Hanson 1999:272). Corea (1985:39), suggests that if the extreme were to occur, women will no longer be seen as individuals; rather their purpose would be to sell parts of their bodies, a subject position perilously close to that of prostitutes. For Rogers, this may lead to a future in which,

Women have given birth to their own grandchildren. Dead men have become fathers. At least one black woman has deliberately delivered a white child. Because of laboratory mistakes, several women, both black and white, have delivered children of races different from their own . . . Soon, babies could be conceived from the eggs of aborted fetuses, making them the children of mothers who were never born (Rogers 1997:1158).

There is some credence to Rogers' position because mistakes have occurred due to a confusion of test tubes.⁴³ However, these arguments are based on the notion of 'what if' rather than 'what is'. In other words, basing arguments critical of biotechnology on speculations that reproductive materials will be sold, or that individuals will design

⁴² Assisted Human Reproduction Act (2004), 7(1) states "No person shall purchase, offer to purchase or advertise for the purchase of sperm or ova from a donor or a person acting on behalf of a donor"; 7(2) states, "No person shall (a) purchase, offer to purchase or advertise for the purchase of an *in vitro* embryo; or (b) sell, offer for sale or advertise for sale an *in vitro* embryo."

⁴³ Refer to the Irvine scandal in Rogers (1997).

Einstein babies is somewhat far fetched. What I propose here is that what seems to be common throughout each of these bioethical arguments and criticisms is the persistence of an ideal image of a healthy baby. However, the diagnosis, treatment, removal or aversion of genetic disease is the pervasive cultural basis supporting the claims of medico-scientific genetic technologies.

In Canada, there is a national Healthy Living Strategy which serves as a guide to health. The main goals of the health strategy are “to improve overall health outcomes and to reduce health disparities” (Health Canada 2004a). Another example of this type of governmental discourse has recently proposed the *Health Protection Act* that

replaces the *Food and Drugs Act*, the *Hazardous Products Act*, the *Quarantine Act* and the *Radiation Emitting Devices Act*. Existing laws remaining in force, such as the *Tobacco Act*, would be amended to be compatible with the new legislative framework without changing their substantive provisions . . . The core values that would guide health protection decision making are primacy of health and safety, openness, and accountability (emphasis in original, Health Canada 2004b).

This Health Protection Legislative renewal is a proposed project that would endeavour to regulate how Canadians receive treatment, and how the government will respond to any disease-related emergencies. Further, the main focus of this proposal is to protect the health of the Canadian population, consequently, the goal of this government program is to maintain public and individual health.

There are other institutional mechanisms that monitor the health of the population such as, the Influenza Surveillance, West Nile Virus Surveillance, and the Canadian

Perinatal Surveillance System (Health Canada 2004c). These systems of surveillance are made possible by governmental institutions specifically structured to monitor certain diseases within the population. Their chief goal is the ability to control disease, not the population. However, these Acts and the surveillance techniques deployed demonstrate that disease is considered a national threat and thus, is monitored. Canada's governmental system attempts to prepare itself for any threat by targeting and intervening in individuals or groups so as to produce a state of health through state controlled means.

In public bioethical debates, concepts of health are both the norm and idealized. Health Canada, similarly reflects this valorization of health over disease. The normative judgments placed upon collectives, individuals and representations demonstrate the effective legitimization of formal rationalizations in public bioethical debating lead to the marginalization of others. Canadian government Acts indicate that the medico-scientific notion of health remains the foremost value. And yet, the concept of disease remains the 'other' of health. Moreover, surveillance techniques help moralize social networks geared toward the protection of the health of individuals and populations in a veritable 'war on disease.' Disease depends on a physiological understanding of the body, which in turn, is assessed by medical authorities which may spur governmental or national concern. Disease is seen as a threat to the population and the government, and thus, disease remains unwelcome, thus justifying governmental concern with how diseased individuals are treated and governed in Canada.

The use of state medicine, such as the surveillance policies of Health Canada, has historically been a common way of exercising social control. During the 18th century in France, medical police were created to monitor the health of the population (Foucault 2000: 340). The introduction of a state operated group created to conduct surveillance on the health of the population indicates how social control, based on the conceptions of health and disease, has been applied. It had the unintended consequence of creating a fear of disease in the general population. This fear of disease, that escalated into a mass paranoia in France, was superficially alleviated by a quarantine model that required diseased individuals to remain at home, receive daily inspections, and undergo regular disinfections (Foucault 2000: 145).

This quarantine model was designed to purify the environment from disease and attempted to maintain the health of those that feared becoming ill (Foucault 2000: 146). It was a technique of social control that separated those that were diseased and protected those that were healthy. Today, it is the hospital that physically divides those that have a serious sickness and those that are relatively healthy.

Although the discourse of Health Canada makes no reference to transcendence or substantive arguments in its formal rationalizations, aspects of substantive rationality appear in the ways that health and disease are treated in Canada. An example of this are the governmental programs focused on First Nations and Inuit health.⁴⁴ Because

⁴⁴ As a note, I do not want to generalize about all First Nations and Inuit communities. There are many different communities, with diverse worldviews. Thus, I am using the notion of First Nations and Inuit health in the same manner as Health Canada that is, based on community concerns and environmental

Aboriginal health has been understood by Health Canada to be both institutional and experiential, First Nations and Inuit communities became a specific concern. Furthermore, Canadian policy makers are working with individuals that are from First Nations or Inuit communities to develop health policies and programs designed to improve the health of these communities.

The negotiations that occur in the government that shape health policy are informed by substantive arguments put forth by members of communities and their elders. For example, an elder provided input and gave advice on the *Aboriginal Roundtable on Sexual and Reproductive Health* (Health Canada 1999). The participants of the Roundtable acknowledged that any recommendations will be “within the bounds of Aboriginal traditions and values” (Health Canada 1999). Although their capacity to change regulation is limited, this case indicates that concepts of health and disease can be culturally modified and that the Canadian government, at times, recognizes the complex normative field surrounding questions of health and disease, that requires both substantive and formal rationalizations.⁴⁵

The definitive boundaries of what constitutes disease and health are rooted in culture, society, regulations and religion. “In other words, disease classification is inherently dependent on social as well as biological factors” (Aronowitz 1998: 12).

concerns (Health Canada 2004d).

⁴⁵ The power to change the existing programs by roundtable discussions is limited because they give recommendations to the government. They, themselves do not have authority to change the regulations already put into place. This reminds us of the limitations of power that Royal Commissions undergo. They are a body to recommend, not to change legislation.

Hence, disease and health are not universal constants. They are treated and characterized differently by each culture, and their definitions are not the same throughout.

This raises another issue: if the concept of disease refers to a bodily state that is generally unwanted, this implies that what is sought is the maintenance, preservation and protection of health, no matter how it is defined. Personal perceptions of health as a bodily state that individuals' desire is also connected to the constant fear or suspicion that there remains a chance of contracting a disease in the future. Thus, individuals attempt to maintain health because they do not want to live with the social, physical or spiritual consequences of living as an individual with a disease.

The lives and behaviors of cultural members are examined through a dispersed and expansive medical eye which calls upon them to engage in cautious self-diagnosis. Cancer prevention strategies, for example avoiding exposure to ultra-violet rays, relinquishing the pleasures of tobacco and alcohol, ridding one's diet of processed foods, assume an easy slippage into the realm of disease which may be avoided or delayed through changes in individual behaviors . . . Contemporary notions of cancer prevention are grounded precisely in a valuing of self-inspection, of seeing and declaring the truth about oneself as both defined and eluded by clinical voices, for purposes of combating disease (Spitzack 1992: 56).

Thus, for Spitzack, the ways in which the threat of disease and even self-control and surveillance become factors in social control. Furthermore, it alienates those that have contracted a disease, and further de-values them in society. The body, and concepts of disease and health are in the main defined by medical institutions and call for interventions on the individual if they are experiencing symptoms or diagnosed with an illness. The ideological colouring of medical discursive practices is well indicated in the

colloquial phrase, “combating disease,” it serves as a rationale for precaution and intervention, based on the advice of medical practitioners. Individuals will even change their lifestyle in order to avoid being afflicted. These individuals want to remain healthy, or become healthy. Hence, the threat of disease becomes a justification for war-like strategic intervention and programs of social control. In effect, these are the concrete consequences flowing from the standardization and idealization of a bodily state of health.

In public bioethical debates, social control and surveillance indicate the broader institutionalization of biomedical concepts of health and disease. At the same time, the predominance of formal rationalities informs popular ideas of disease. The proliferation of this discourse, in turn, triggers social fear and paranoia, the attempted alleviation of which functions to further legitimate biomedical and biopolitical interventions.

Health and Disease: The Canadian Context

Health remains the end or objective of reproductive and genetic technologies and public bioethical debates continue to base their arguments on the assumption that healthy individuals and healthy populations are widely understood and accepted as political goals. The assumption that the biomedical notion of health is universally understood and accepted reflects the exclusionary mechanism constitutive of the field of public bioethical debates. Although, some substantive rationalities exist in public bioethical debates, their arguments have been altered to conform to the formal rationality standards. Thus, substantive rationalities have been excluded from the predominantly formalized public

bioethical debates. However, both approaches are in agreement about health as the goal and inherent rationale for discussing reproductive and genetic technologies. What this circumstance obscures is that no single, universally accepted definition of health exists:

The language of science alone is insufficient to describe health: the languages of story, myth and poetry also disclose its truth . . . we cannot understand health by analyzing it (breaking it down) only by building its different facets together. Health is then found to be a greater whole than the simple sum of its parts (Wilson 1975: 60).

Wilson argues that the concept of health is not the sole purview of medicine. But the idea of health is the stuff of interdisciplinary contestation. This provides strong reasons for why the field of public bioethical debates should be restructured. This would facilitate debate about the normative effects of reproductive and genetic technologies. As Wright has argued,

Tribal societies, anthropologists, and even the natural usage in our language seem to imply that health is an inherently moral concern. On the other hand, doctors, philosophers, and scientists all tell us that it is a morally neutral, objective, and scientific concern. The Marxists claim that it is a political concern . . . Advocates of holistic health want it to be a concern of the whole individual but not of social institutions. Finally, bioethicists recognize the moral implications of the term but immediately displace these implications as relevant only to the rarefied and exclusive practice of experts (Wright 1982: 64).

Wright aptly conveys the ambiguity that exists when attempting to define health. Perspectives on health are complex and multiple, and they all contribute to the wider cultural understanding of what constitutes health. He also highlights how professional or expert definitions of health dominate bioethics. In addition, if bioethics basis its notion

of the norm and ideal of health on exclusively expert or professional perspectives, the arguments they make remain constrained and myopic.

The complexity of the public bioethical debate field is evinced by Health Canada's goals for "improving, maintaining and/or enhancing health" (Health Canada 2004a). In this governmental discourse the problem remains that health and disease are split by a blurred line and are contested categories. The way Health Canada defines health is as follows:

Healthy living applies to both the population in general and to individuals. At a population level, healthy living refers to the practices of population and sub-population groups that are consistent with improving, maintaining and/or enhancing health. As it applies to individuals, healthy living is the practice of health enhancing behaviours or living in healthy ways. It implies the physical, mental and spiritual capacity to make healthy choices. Healthy living means making positive choices about personal health practices such as healthy eating, not smoking, building a circle of social contacts, and staying physically active. These choices are strongly influenced by the environments where people live, work, learn and play (Health Canada 2004a).

Health Canada discourse illustrates the different ways in which health effects people's lifestyles and behaviours. However, in Canada's Performance Report of 2003, health is defined as follows:

Health is a state of complete physical, mental and social well-being, and not merely absence of disease. Population health is influenced by various determinants: genetics, social and economic environment, biophysical environment, individual behaviour, as well as the health care system (Government of Canada 2003: 30).

This definition of health has a more holistic understanding of health. Thus, socio-cultural, environmental, economic, psychological and biological factors are seen as elements comprising the overall health of individuals and populations. The indicators for health include life-expectancy, self-rated health status, infant mortality and healthy lifestyles (Treasury Board of Canada Secretariat 2004).⁴⁶

Maintaining good health is the norm and the ideal in each of these situations. As the examples illustrate, being classified as a healthy individual establishes the way in which people are regarded in society. Individuals do not want to be seen or dealt with in a way that, for example, shames them (i.e., disease as a form of divine punishment). Genetic health is another way of determining the soundness of a body and of a future body leading to a particular type of reflexivity in collective and individual subjects. Thus, the concepts of disease and health become not just issues of the present, but concerns for the future.

The Limits of Genetic Health and Genetic Disease Discourse

Thus far, I have argued that disease and health are flip sides of the same coin. In other words, they are both considered bodily norms in different contexts, contingent on the degree of balance obtaining between the body and its environment. The healthy or diseased body then, is embedded in social ideologies, as well as institutional impositions

⁴⁶ This is the way people assess their overall health and convey that information into categories of excellent, very good, fair or poor (Government of Canada 2003: 36) Healthy lifestyles includes body/mass index and physical activity (Treasury Board of Canada Secretariat 2004).

that form part of that environment. This makes possible an interdisciplinary approach to the body. Further, taking into account the multiplicity of perspectives renders a more holistic view of the body, even if each discipline maintains its specified and limited focus. For instance, biology focuses on the materiality of the body, and sociology focuses on the sociality of the body. In reproductive and genetic research, it comes as no surprise that the focus is on the genetic constitution of the body. I claim that genetic health is determined by a genetic standard or norm based on medico-scientific understanding. However, I further contend that this is a vague and potentially dangerous standard that is open to critique.

The category of genetic diseases is governed by conventional scientific notions of the norm, which refer to how bodies which are healthy are considered as normal in their proper contexts. This is because genetic diseases are based on predictive medical techniques, where diseases can be predicted to happen, rather than based upon immediate, actual cases that present without warning. Thus, the state of the body, as a carrier, or as diagnosed with a late-onset genetic disease, determines the state of health or normality of an individual in the future, based on the medico-scientific approach to bodily normalization.

However, since health and disease are both considered norms, then why are genetic diseases considered to be forms that deviate from a norm or standard?⁴⁷ Genetic disease is determined by biological logic or formalized rationalities that are based on the

⁴⁷ In actuality, there is no 'standard' genetic code, this will be outlined in detail further in this section.

probabilistic reasoning in Mendelian genetics (Thagard 1999: 28-30). The simplest genetic diseases to identify are those that inherit a single gene that carries a disease (i.e., Mendelian diseases such as alkaptonuria), and the more complex genetic diseases are those that are multifactorial (e.g., hypertension) that requires both genetic and environmental factors to express the disease (Thagard 1999: 28-30).⁴⁸ Both approaches to genetic diseases remain based in the idea of the genome as the fundamental causal factor determining the health and disease of the body, understood in terms of inheritance. Although the environment is considered a part of maintaining genetic health, the focus is on the genome of the individual. However, the future possibility and fear of disease, needs to be considered when determining the limitations of genetic normality.

The main difference between present health and disease issues and genetic disease concerns, is that the judgment of health is based on future probability, and hence, the disease has not yet occurred in the individual (since all that is known is produced by the pre-diagnosing of the genetic disease; i.e., the identification of a genetic abnormality). The understanding of health and disease thus shifts from the notion based on present or past experiences to *possibilities* of experiences, a discontinuity similar to the one described by Foucault concerning the shift in the medical perception of disease that went from the experience of symptoms to the examination of material resources found in the body, such as organs and bones (Foucault 1994).

⁴⁸ For examples of genetic diseases refer to Appendix 2.

Genetic disease is both material and conditional. However, the causes of genetic diseases are based on an understanding of the genetic health and composition of the parents. Parental genetic constitution then becomes a concern when couples decide that they want to reproduce. The idea of coming from good genes is not just a colloquial expression; rather, it is founded on the patterns of inheritance that may determine an individual's genetic health. Reproductive and genetic technologies have the ability to detect and isolate the genome as a material component of the body that is susceptible to disease. Because of these technologies, the body is now conceptualized as being fragmented.

In Canada, the *Assisted Human Reproduction Act* demonstrates the way in which genetic health is to be maintained for both the parents and for the offspring.

The health and well-being of children born through the application of assisted human reproductive technologies must be given priority . . . the benefits of assisted human reproductive technologies and related research for individuals, for families and for society in general can be most effectively secured by taking appropriate measures for the protection and promotion of human health . . . the health and well-being of women must be protected . . . human individuality and diversity and the integrity of the human genome, must be preserved and protected (*Assisted Human Reproduction Act 2004*).

In other words, the Act conveys the notion that maintaining and protecting the health of everyone involved is the main priority of this legislation. In terms of genetic health, it is the idea of “diversity and integrity” that needs further examination. The application of reproductive and genetic technologies involves the calculation of risk geared toward the removal of the possibility attempts to remove any possibility of contracting a known

disease, or harming the individual in question during a medical procedure. One of the goals of the Human Genome Project is to identify individuals who are predisposed to certain genetic diseases and those who worked on this project are currently attempting to understand how to treat genetic diseases to shape healthy individuals.

Genetic health care is one arena in the Canadian Health Care system in which the concern to preserve the healthy genomes guides genetic research. This is premised on the concept of health as dependent on “human biology, the external environment, lifestyle, and health care organization” (Science Council of Canada 1991: 19). But, by default, to consider any concept of biomedical health implies that the focus is placed on the bodies that are not diseased. The outline for genetic disease articulated in this report by the Science Council of Canada does not offer what health consists of in the body; rather they give a vague description of the factors affecting health, based on the boundaries of disease.

There is a general assumption about standardized genetic health and genetic health is simultaneously the norm and the ideal body in Health Canada discourse. Thus, the concept of having a specific genetic code that determines the health of an individual exists, by assumption or default. In other words, genetic diseases are based on the notion that certain genetic characteristics are abnormal or different from the normal variations that exist in healthy human DNA codes. But, it is an ideal of health or a standard genetic code that is being positively valorized as a human ideal. However, the concept of a standard genetic code is not as specific as one may assume: there is no definitive genetic

code that unifies the conditions for health and disease (Wilson 2002: 27). The variations of individual genomes are infinite and are always changing, and thus, “a normal genome is an impossibility; that would be like saying that there is a normal course of evolution” (Wilson 2002: 28). Furthermore, as concerns the notion of genetic diseases,

In actuality, other factors participate in the formation of proteins, including ribosomes, messenger RNA (mRNA), transfer RNA (tRNA), and amino acids, as well as external factors such as environmental stresses like viruses or toxins. Making the situation even more complicated, some traits are polygenic (that is, they involve multiple genes). Moreover, gene expression is dynamic (meaning that in a matter of minutes genes can be switched on and off) (Wilson 2002: 28-29).

Genetics then cannot be the sole the factor in biological development. Thus, an ecology of living continues to be a strong influence on individual development. Subsequently, this claim re-affirms the need for more serious consideration of the environment. According to this view, disease and health are based on the corporal potentiality to the susceptibility of diseases imbricated in an ecology of living. This leads to the following question: if I were to be a person with a gene that may be turned on or off by the environment, am I a person who is diseased?⁴⁹ Furthermore, the idea that there is a strict genetic code for normality or health is scientifically untenable. No two humans have the same genetic code, and because of this, having a specific code that determines health cannot be used as a basis for universal therapeutic treatment regimes.

⁴⁹ For example, PKU (phenylketonuria) can be regulated with diet restrictions in children. They have to have a low protein, and low phenylalanine diet in order to develop without the symptoms of the genetic disease (University of Washington 2004).

The concepts of health and disease have shifted with the onset of complex and detailed genetic knowledge. The idea that a person is healthy changes when they are faced with the knowledge that they are candidates with high probability of expressing a late-onset genetic disease. Consequently, the concepts of standard and norm have changed with the changing perspectives of the genetic body because those that seem to have a normal body (i.e., appear disease-free), may actually include individuals who understand that they will develop a disease in the future.

The ability to predict disease has grown considerably because of the information developed through understanding the mapping and sequencing of the genome in the Human Genome Project. This results in

people who feel healthy and who as yet suffer no functional impairment will increasingly be labeled as unhealthy or diseased. This occurs even in the absence of genetic markers for disease when people who feel healthy are discovered to have risk factors, such as moderate hypertension, for the future onset of disease. . . . Thus, there will often be significant periods of time in individuals' lives when they will come to think of themselves as unhealthy or diseased though they neither feel sick nor suffer from losses of function. Moreover, in many cases no fully effective therapy will exist for an individual's condition. For many people, this labeling will undermine their sense of themselves as healthy, well-functioning individuals and will have serious adverse effects both on their conceptions of themselves and on the quality of their lives (Brock 1994: 29).

The identity of an individual who has been diagnosed with a future disease then comes to be formed through an interaction between themselves and their environment. This is an ambiguous state to identify with. The knowledge of the future onset of a disease, or an individual with an increased risk of developing a disease, affects the concepts of health

and disease because they become indistinguishable in present experience. An individual then is normal in their conditions of life while carrying the ticking time-clock of disease. However, they are also normal in the sense that they are healthy, within their environment, until the onset of the disease. Thus, the boundaries of genetic disease and genetic health, like those of overall health and disease, become both spatially condensed and temporally displaced.

Genetic health and disease are established on more factors than exclusively the DNA code. There are arguments that claim that genetics produces a reductionist perspective on the body. According to Ruse (1994), genetics,

generally is clearly committed to ontological reductionism. The claim is not that every organism is made up of genes and nothing but genes. We know that is false. Rather, the claim is that the overall physical body – animal, plant, or microorganism – is no more than the parts, of which the genes are a subset. Presumably, as a geneticist one believes that the genes carry the information for producing all of the parts, including themselves . . . The point is that as living organisms we do not have bodily parts and *then* something else (emphasis in original, 37).

Thus, genetic reductionism is a theory that is too simplistic to describe the body with regards to genetics, health and disease: genes are not a simple blueprint determining the complexities and variabilities of life.

The ways that notions of the body, both diseased and healthy, contribute to interdisciplinary perceptions of bodily constitution, shows that these cultural concepts cannot be couched in polarized terms. The concepts of genetic health and disease are

complex, and public bioethical debates remain simplistic so long as this complexity is inadequately considered. Thus, even the biological terms of non-reductionist accounts of the genetic determinants of states of being, put the lie to the myopic biases dominant in contemporary public bioethical debates concerning human reproductive and genetic technologies.

Chapter Six

CONCLUSION: A LIFE OF ONE'S OWN RE-ASSESSING CONCEPTS OF HEALTH AND DISEASE IN PUBLIC BIOETHICAL DEBATES

The central contention of this thesis is that the dominance of medico-scientific discourse in the field of public bioethical debates has constrained normative debate about the meaning and implications of health in Canadian society. This circumstance has been exacerbated by the epistemic shift that occurred in medical practice with the emergence of genetic science that now attempts to target the future, by intervening in the present. Thus, there needs to be a shift in conceptualizing reproductive and genetic technologies in public bioethical debates. Health is the one major goal in the research of reproductive and genetic technologies. This also highlights the circumstance that an idealized image of a future society determined according to genetic criteria of health and normalcy has provided the dominant normative reference point for public bioethical debates concerned with reproductive and genetic technologies.

With the completion of the Human Genome Project, there is hope that some genetic diseases will be located and eliminated. Yet, the normative assumptions of health remain the main driving factor in the attempt to understand the human genome. Health is assumed to be what everyone wants, but cannot fully attain. Canguilhem argues that health is both a standard state of normality and an ideal physical state, which individuals

attempt to achieve. His analysis of health informs the discourses of genetic health. Canguilhem further states that living without disease for a lifetime is an impossibility, thus there is little hope for continual health (as an ideal) for the duration of one's lifetime. In essence, health is an unattainable physiological state that continues to be the predominant motivator in the development and application of reproductive and genetic diseases.

The constrained character of normative debates in the public bioethical debate field has occluded and/or marginalized a wide variety of conceptions of health, disease and their imbrication in more culturally *qua* non-scientific bases for normative judgments. This circumstance has historical roots that can be traced back to the ways in which eugenics projects were proposed, developed and debated from the time of the emergence of genetic science, through to the various eugenicist attempts to transform Canadian society, for instance. This is evinced by the case of Better Baby Contests that occurred in Canada during the 1920s.

As Canguilhem has pointed out, the 'norm,' or 'normal,' as defined within biomedical discourse, still denotes, as it once did long ago, a culturally specific normative standard that is connected to idealized notions of corporeal and social states of being. Contemporary biomedical discourse functions as if this is not the case, as if claims about health are not normative even though, as Canguilhem, Foucault and myself, following in

their footsteps, have argued to the contrary. In chapter four, I have shown how the biomedical concepts of health, disease, the normal and pathological inherently imply a dream of an ideal, healthy, normal, disease-free future society. Thus, it is necessary to attend to and question the tacit political project that exists in biomedical discourse and biomedical practice.

Formal rationalities are the dominant discursive form of normative debates in public bioethics. Substantive rationalities have now adopted a discursive form of formal rationality in order to obtain a hearing in public bioethical debates. Nevertheless, different systems of thought, such as theology, remain to challenge the popular assumptions that have unwittingly accepted the predominant formal rationalities of public bioethical approaches. Thus, I contend that bioethics is not a coherent, monolithic resource for addressing problems in the concepts of health.

In order to appreciate the complexity surrounding the contested meaning of health and its implications for projects engaged in attempts at the transformation of society, it is necessary to consider both the multi-disciplinary influences at work in the field of public bioethical debates and to consider the variety of other cultural understandings of health and their connection with a specific culture's normative ideals. Durkheimian theory shows that there is a disparate nature to the field of normative debates, and hence, heterogeneity is an inherent feature shaping public bioethical debates. I have

demonstrated this through my discussions and analysis of the religious discourses in the Vatican and the various cultures as Amhara, Thai, Serbian and Ojibwa. These cultural examples all feared the contraction of disease due to their belief that disease was a form of punishment from supernatural forces.

Such systems of belief also served to legitimate practices of social control. In this respect, there is some similarity between Canadian culture and these cultures: in each, there is a close connection between beliefs about health, disease and social control. In doing so, I have shown why and how anthropological sensibilities need to be brought to bear on a critical analysis of public bioethical debates concerned with the regulation, application and potential normative implications of human reproductive and genetic technologies. This creates the possibility of a counter-discourse that can intervene in the current field of public bioethical debates and hence, make it more sensitive to the multiple perspectives on health and the contestable nature of the meaning of health, disease, normalcy and well-being.

Is the ideal of health a bad thing? After all who wants to be sick? What this question begs, is exactly the question concerning the criteria we use to determine health and disease. The point of this thesis is to show that the medico-scientific discourses that dominate political, social, and personal perceptions of health and disease obscure the extent to which our experiences of ourselves and the collective representations that we

use to make sense of our states of being (e.g., biomedical discourse) are both culturally contested and culturally variable. We should not be so quick to accept a medico-scientific interpretation of our states of being allowing this to form the sole basis of normative criteria for debating and assessing human reproductive and genetic technologies. Instead, we should reflect on the normative implications of acquiescing to medico-scientific judgments, and the ways in which these are reflected in valorized idealizations of a perfected, disease-free, future society. In other words, being sick just might indicate a way in which we can simply be otherwise.

Appendices

Appendix 1

The Sexual Sterilization Act: Part One

Statute of the Province of Alberta, 1928, chap. 37, as quoted in Blais 1942 (185)

HIS MAJESTY, by and with the advice and consent of the Legislative Assembly of the Province of Alberta, enacts as follows:

1. This act may be cited as “The Sexual Sterilization Act.”
2. In this act, unless the context otherwise requires:
 - (a) “mental hospital” shall mean a hospital within the meaning of *The Mental Diseases Act*;
 - (b) “Minister” shall mean the Minister of Health.
3. (1) For the purpose of this act, a Board is hereby created, which shall consist of the following four persons:
 - Dr. E. Pope, Edmonton;
 - Dr. E. G. Mason, Calgary;
 - Dr. J. M. McEachran, Edmonton;
 - Mrs. Jean H. Field Kinuso.
- (2) The successors of the said members of the Board shall from time to time, be appointed by the Lieutenant Governor in Council, but two of the said board shall be medical practitioners nominated by the Senate of the University of Alberta and the Council of the College of Physicians respectively, and two shall be persons other than medical practitioners, appointed by the Lieutenant Governor in Council.
4. When it is proposed to discharge any inmate of a mental hospital, the Medical Superintendent or other officer in charge thereof may cause such inmate to be examined by or in the presence of the board of examiners.

Appendix 2

Examples of Genetic Diseases

Quoted from Science Council of Canada 1991(18-24)

Single Gene Disorders

Adult Polycystic Kidney Disease (APKD)

One in every 1000 newborns will eventually develop APKD. The early signs of the disease include pain, blood in the urine, frequent kidney infections, and high blood pressure . . . APKD is now a major reason for renal dialysis.

Cystic Fibrosis (CF)

About one in 2000 Caucasian newborns develops CF. Approximately one in 20 Caucasians carries a copy of the gene that causes CF if present in a double dose. CF affects the glands that secrete tears, sweat, saliva, and mucus. Excess production of sticky mucus in the lungs makes breathing difficult and results in progressive lung and heart damage . . . The abnormal mucus level prevents adequate flow of pancreatic enzymes, limiting the effectiveness of the digestive system . . . Canadian geneticists identified the CF gene in 1989. There are a number of different forms of the gene that can result in CF. At present, about 70% of persons carrying a mutant CF gene can be identified.

Duchenne Muscular Dystrophy (DMD)

About one in every 3500 males is born with the gene that causes DMD. The disease is extremely rare in females. The disease is characterized by progressive and eventually fatal muscular weakness and wasting. The symptoms usually begin before the age of five. Death due to respiratory infection or heart failure usually occurs by the third decade of life.

Familial Hypercholesterolaemia (FH)

One in every 500 people in North America has one copy of the gene that causes FH. One in a million newborns has two copies of the gene . . . FH affects cholesterol levels. People with two copies of the gene have extremely high blood cholesterol levels, which usually induce death from coronary heart disease by the age of 30. People with one copy of the FH gene also have abnormally high cholesterol levels. About 50 percent of men with one copy of the gene have symptoms of coronary heart disease by 50 years of age. The corresponding proportion for women is about 33 percent.

Haemochromatosis

About 10 percent of the Canadian population carries one copy of the gene that causes the disease when present in a double dose. Carriers may have some symptoms. Two or three people in every 1000 have haemochromatosis. The gene for

haemochromatosis causes excessive and damaging accumulation of iron in organs such as the liver, heart, and pancreas. Iron accumulation can produce enlargement of the liver, diabetes, and heart disease. If left untreated, haemochromatosis can be fatal.

Haemophilia A and Von Willebrand Disease

Usually only males develop haemophilia A. The disease affects one in every 10 000 newborn males. Von Willebrand disease affects as many as one in 200 people (male and female). Both haemophilia A and Von Willebrand disease result from a deficiency in factor VIII, a substance involved in blood clotting. The basic feature underlying both diseases is the tendency to bleed. The symptoms of the two conditions vary considerably in severity. Mild cases of both diseases involve excessive bleeding only in response to serious trauma such as surgery. In severe cases of haemophilia A, bleeding in the joints without any external cause may start by six months of age. The average life span of someone with haemophilia A is about 40 years.

Huntington Disease

One in every 10 000 Caucasians has Huntington disease. For every person with the disease, there are an average of five to eight relatives at risk. Usually the disease is transmitted to offspring before it is diagnosed in the parent. The disease involves degeneration of a specific region of the brain. This produces symptoms that include movement disorder, intellectual dysfunction, and personality changes. Huntington disease is progressive and eventually fatal, usually 15 to 20 years after onset. In most cases its symptoms begin to appear between 30 and 45 years of age. Persons inheriting the gene from their father tend to experience earlier onset of the disease than those inheriting it from their mother.

Sickle Cell Anaemia

Two copies of the gene result in sickle cell anaemia, which can be fatal. The disease produces an abnormal form of haemoglobin which interferes with blood circulation. Individuals with only one copy of the gene are carriers and may themselves show mild symptoms of the disease. People who have only one copy of the gene are resistant to falciparum malaria infection. This resistance is a “selective advantage” and has favoured maintenance of the sickle cell gene in the population.

Multifactorial Diseases

Alzheimer Disease (AD)

Two to three percent of Canadians over 60 years of age have AD. The proportion increases to about 20 percent in people over 80. The disease progresses from forgetfulness to complete inability to care for oneself. It is estimated that AD contributes the death of at least 10 000 Canadians every year. The proportion of cases of AD with a genetic basis has not been established but estimates range from 10 to 100 percent. In some families the disease is inherited as an autosomal dominant. Genetic markers for familial AD have been identified on chromosome 21 but the gene thought to produce AD has not yet been identified. Other genetic and environmental factors probably modify the

gene's impact, for instance by influencing the age at which symptoms of the disease appear.

Coronary Heart Disease (CHD)

A family history of CHD occurring by 55 years of age is the strongest risk factor for CHD. Several other risk factors with genetic involvement have also been identified, including high cholesterol levels, high blood pressure, and diabetes.

The cholesterol levels of genetically related individuals tend to be more similar than the levels of unrelated individuals sharing the same household. Between 2 percent and 4 percent of the population has a known single-gene disorder (familial hypercholesterolaemia) that leads to CHD. There is also a genetic trait (hyperalphalipoproteinaemia) that appears to protect against CHD.

Blood pressure levels of family members also tend to be more alike than those of genetically unrelated individuals sharing the same household. One-quarter of all people with hypertension (high blood pressure) are under 60 years of age and also have one or more siblings with the same condition. Many from this group also have lipid abnormalities (e.g., abnormal cholesterol levels).

CHD often affects people with diabetes mellitus. There are many different types of diabetes, and there is evidence for genetic involvement in any of them.

There are other genetic conditions that contribute to the overall incidence of CHD. For example, homocystinuria is a relatively uncommon recessively inherited disorder. However, between 0.5 and 1.4 percent of the population carries one copy of the gene that causes the disease when present in a double dose. People with one copy of the gene have a much greater chance than average of early onset of arterial disease.

Lung Cancer

Damage to chromosome 3 has been associated with all the major forms of lung cancer. In some cases this damage may involve an inherited component. Lung cancer is more common in some families than other, even when smoking is taken into account. Smoking is more likely to cause lung cancer when there is a family history of the disease. A genetically influenced biochemical response to cigarette smoke has been identified that is associated with 20 to 40 times the average risk of one type of lung cancer.

Schizophrenia

There are many different types of this disease. Symptoms may include hallucinations, disordered thought, delusions and disorganized behaviour.

The risk of developing schizophrenia varies with the closeness of one's genetic relationship to a person with the disease and the number of affected people in the family. For example, the brother or sister of a schizophrenic has between a 40 percent and 60 percent chance of developing schizophrenia if both parents are also affected. The risk falls to about 15 percent if one parent is affected and to 10 percent if neither parent is affected. If one member of a pair of identical twins is schizophrenic, there is a 55 percent chance the other twin will also develop the disease.

Evidence for genetic involvement in schizophrenia also comes from studies of adopted children. Individuals adopted early in life share genetic characteristics with their

biological parents but share environmental experiences with their adoptive parents. Adoptees are about three times more likely to develop schizophrenia if their biological parents have the disease than if their adoptive parents are affected.

Schizophrenia may in some (but not all) cases be associated with a particular region of chromosome 5. Studies indicate that there may be different genes involved in different families.

Bibliography

- Aronowitz, Robert A.
 1998 *Making Sense of Illness: Science, Society, and Disease*. Cambridge: Cambridge University Press.
- Assisted Human Reproduction Act
 2004 *An Act Respecting Assisted Human Reproduction and Related Research*. Bill C-6, Statutes of Canada, Chapter 2, 3rd Session, 37th Parliament, Assented to March 29, 2004.
- Baird, Patricia *et al.*
 1993 *Proceed With Care: Final Report of the Royal Commission on New Reproductive Technologies*. Ottawa: Minister of Government of Canada.
 1991 *What We Heard: Issues and Questions Raised During the Public Hearings*. September 1991. Ottawa.
- Baum, Gregory
 1987 *Compassion and Solidarity: The Church for Others, CBC Massey Lectures*. Toronto, CBC Enterprises.
- Bijker, Wiebe E. and John Law
 1992 "General Introduction." Pp. 1-14 in Wiebe E. Bijker and John Law (eds.); *Shaping Technology/Building Society: Studies in Sociotechnical Change*. Cambridge, Massachusetts: The MIT Press.
- Blais, Hervé
 1942 *Les Tendances Eugénistes au Canada*. Montréal: L'Institut Familial.
- Brock, Dan W.
 1994 "The Human Genome Project and Human Identity." Pp. 18-33 In Robert F. Weir, Susan C. Lawrence and Evan Fales (eds.); *Genes and Human Self-Knowledge: Historical and Philosophical Reflections on Modern Genetics*. Iowa City: University of Iowa Press.
- Canada Health Act
 2001 *Canada Health Act: Chapter C-6*. Electronic document. <http://www.hc-sc.gc.ca/medicare/Documents/C6.pdf> retrieved November 2, 2004.

- Canguilhem, Georges
1978 *On the Normal and Pathological*. Trans. Carolyn R. Fawcett. Dordrecht, Holland: D. Reidel Publishing Co.
- Cantor, Charles
1992 "The Challenges to Technology and Informatics." Pp. 98-111 In Daniel J. Kevles and Leroy Hood (eds.); *The Code of Codes: Scientific and Social Issues in the Human Genome Project*. Massachusetts: Harvard University Press.
- Carlson, Elof Axel
2001 *The Unfit: History of a Bad Idea*. New York: Cold Spring Harbour Laboratory Press.
- Catechism of the Catholic Church,
#2270 Part Three, Life in Christ; Section Two, The Ten Commandments; Chapter two "You Shall Love Your Neighbor As Yourself"; article 5, The Fifth Commandment
- Clarke, Adele E. and Joan H. Fujimura
1992 "Introduction" Pp. 3-44 in Adele E. Clarke and Joan H. Fujimura (eds.); *The Right Tools for the Job: A Work in Twentieth-Century Life Sciences*. New Jersey: Princeton University Press.
- Cohen, Cynthia B.
1999 "Selling Bits and Pieces of Humans to Make Babies: *The Gift of the*
- Coll, Cynthia Garcia, Elaine L. Bearer and Richard M. Learner
2004 *Nature and Nurture: The Complex Interplay of Genetic and Environmental Influences on Human Behavior and Development*. New Jersey: Lawrence Erlbaum.
- Cook-Deegan, Robert
1994 *The Gene Wars: Science, Politics and the Human Genome*. New York: W.W. Norton and Co.
- Corea, Gena
1985 "The Reproductive Brothel." Pp. In Gena Corea *et al.* (eds.); *Man-Made Women: How New Reproductive Technologies Affect Women*. London: Hutchinson and Co.
- Datta, Ronjon Paul
2003 "Making a Sociological Difference." Comprehensive Examination Paper, Department of Sociology/Anthropology, Ottawa, Ontario.

- Datta, Ronjon Paul and Frank Pearce
2004 "Foucault's Transgressors, Criminals and Aesthetes: From Targets of Domination to Political Imagination." Unpublished manuscript. Kingston, Ontario: Department of Sociology, Queen's University
- Dreyfus, Hubert L. and Paul Rabinow
1983 *Michel Foucault: Beyond Structuralism and Hermeneutics. Second Edition, With and Afterward by and an Interview with Michel Foucault.* Chicago: The University of Chicago Press.
- Durkheim, Emile
1999a "Division of Labour, Crime and Punishment: Reading 3: The Division of Labour in Society." Pp. 33-57 in Kenneth Thompson (ed.); *Readings From Emile Durkheim.* New York: Routledge.
1999b "Suicide: Reading 6: Suicide." Pp. 92-115 in Kenneth Thompson (ed.); *Readings From Emile Durkheim.* New York: Routledge.
- Eliade, Mircea
1959 *The Sacred and The Profane: The Nature of Religion.* Willard R. Trask (trans.). New York: Harcourt, Brace and World Inc.
- Ellis, Havelock
1911 *The Problem with Race-Regeneration.* New York: Moffat.
1939 *My Life.* London: Spearman.
- Evans, John
2002 *Playing God? Human Genetic Engineering and the Rationalization of Public Bioethical Debate.* Chicago: University of Chicago Press.
- Foucault, Michel
2003a "Truth and Power." Pp. 300-318 in Paul Rabinow and Nikolas Rose (eds.); *The Essential Foucault: Selections from The Essential Works of Foucault, 1954-1984.* New York: The New Press.
2003b "The Subject and Power." Pp. 126-144 in Paul Rabinow and Nikolas Rose (eds.); *The Essential Foucault: Selections from The Essential Works of Foucault, 1954-1984.* New York: The New Press.
2003c "The Birth of Biopolitics." Pp. 202-207 in Paul Rabinow and Nikolas Rose (eds.); *The Essential Foucault: Selections from The Essential Works of Foucault, 1954-1984.* New York: The New Press.
2003d "Polemics, Politics, and Problematizations: An Interview with Michel Foucault." Pp. 18-24 in Paul Rabinow and Nikolas Rose (eds.); *The Essential Foucault: Selections from The Essential Works of Foucault, 1954-1984.* New York: The New Press.

- 2000 "The Birth of Social Medicine." Pp. 134-156 In James D. Faubion (ed.); *Power*. New York: The New Press.
- 1994a *The Birth of the Clinic: An Archaeology of Medical Perception*. New York: Vintage Books.
- 1994b *The History of Sexuality: Volume 1*. New York: Vintage Books.
- 1991 "Chapter Two: Politics and the Study of Discourse." Pp. 53-72 in Graham Burchell, Colin Gordon, and Peter Miller (eds.); *The Foucault Effect: Studies in Governmentality: With Two Lectures by and an Interview with Michel Foucault*. Chicago: The University of Chicago Press.
- 1980a "Two Lectures." *Power\Knowledge*. New York: Pantheon Books.
- 1980b "Truth and Power." *Power\Knowledge*. New York: Pantheon Books.
- 1972 *The Archaeology of Knowledge*. New York: Pantheon Books.

Galton, Sir Francis

- 1973 *Inquiries into Human Faculty and Its Development*. New York: AMS Press.

Government of Canada

- 2003 *Canada's Performance Report: Annual Report to Parliament, 2003*. Ottawa: Her Majesty the Queen in Right of Canada.

Hallowell, Alfred Irving

- 1991 *The Ojibwa of Berens River, Manitoba: Ethnography into History*. Fort Worth: Harcourt Brace Jovanovich College Publishers.

Hanks, Jane Richardson

- 1963 *Maternity and its Ritual in Bang Chan*. Ithaca, New York: Cornell University Press.

Hanson, Mark J.

- 1999 "Biotechnology and Commodification Within Health Care". *Journal of Medicine and Philosophy*. 24(3):267-287.

Hasian Jr., Marouf Arif

- 1996 *The Rhetoric of Eugenics in Anglo-American Thought*. Athens, Georgia: The University of Georgia Press.

Health Canada

- 2004a *Healthy Living: Health Canada*. Electronic document. www.hc-sc.gc.ca/english/lifestyles/healthyliving/index.html retrieved September 14, 2004.

- 2004b *Health and Safety First! A Proposal to Renew Federal Health Protection Legislation: The Minister of Health Seeks Your Opinion.* Electronic document.
www2.itssti.hc-sc.gc.ca/HPCB/Policy/LegislativeRenewal.nsf/EnglishAII/ED5B120DED25284B85256D3B006FFD76?OpenDocument&L=E& retrieved September 14, 2004.
- 2004c *Diseases and Conditions.* Electronic Document
www.hcsc.gc.ca/english/diseases/index.html retrieved on September 14, 2004.
- 2004d *Community Programs.* Electronic Document <http://www.hc-sc.gc.ca/fnihb/cp/index.htm> retrieved on November 2, 2004.
- 1999a *Aboriginal Roundtable on Sexual and Reproductive Health.* Electronic Document.
http://www.hcsc.gc.ca/fnihb/sppa/ppp/sexual_reproductive_health.htm#Key%20Issues retrieved on November 2, 2004.
- 1999b *Reproductive and Genetic Technologies Overview Paper.* Electronic document. <http://www.hc-sc.gc.ca/english/rgt/overview.html> retrieved March 19, 2001.
- Heller, J. C.
1996 *Human Genome Research and the Challenge of Contingent Future Persons.* Omaha, Nebraska: Creighton University Press.
- Hindess, Barry
1987 "Rationality and the Characterization of Modern Society." Pp. 137-153 in Scott Lash and Sam Whimster (eds.); *Max Weber, Rationality and Modernity.* London: Allen and Unwin.
- Hitchcock, James
1979 *Catholicism and Modernity: Confrontation or Capitulation?* New York: The Seabury Press.
- Human Genome Organization (HUGO)
2004 *Mission Statement.* Electronic document. <http://www.hugo-international.org/hugo/HUGO-mission-statement.htm> retrieved February 15, 2004.
- Hunt, Alan
1999 *Governing Morals: A Social History of Moral Regulation.* Cambridge: Cambridge University Press.
- Illich, Ivan
1995 *Medical Nemesis: The Expropriation of Health.* London: Marion Boyars Publishers Ltd.

- Jodock, Darrell (ed.)
2000 *Catholicism Contending with Modernity: Roman Catholic Modernism and Anti-Modernism in Historical Context*. Cambridge, U.K.: Cambridge University Press.
- Judson, Horace Freeland
1992 "A History of the Science and Technology Behind Gene Mapping and Sequencing." Pp. 37-80 in Daniel J. Kevles and Leroy Hood (eds.); *The Code of Codes: Scientific and Social Issues in the Human Genome Project*. Massachusetts: Harvard University Press.
- Kaplan, Lawrence J. and Rosemary Tong
1996 *Controlling Our Reproductive Destiny: A Technological and*
- Kass, Leon
2002 *Life, Liberty, and the Defense of Dignity: The Challenge for Bioethics*. San Francisco: Encounter Books.
- Kevles, Daniel J.
1985 *In the Name of Eugenics: Genetics and the Uses of Human Heredity*. Los Angeles: The University of California Press.
- Khanna, Sunil K.
1997 "Traditions and Reproductive Technology in an Urbanizing North Indian Village." *Social Science and Medicine*. 44(2): 171-80.
- Knoppers, Bartha Maria
1998 "Forward: The CGAT-MELSI Program." Pp. ix-xi. In Knoppers, Bartha Maria (ed.) *Socio-Ethical Issues in Human Genetics*. Cowansville, Québec: Les Éditions Yvon Blais Inc.
- Landsman, Gail
2003 "Emplotting Children's Lives: Developmental Delay vs. Disability." *Social Science and Medicine*. 56(9): 1947-1960.
- Lazarus, Ellen S.
1997 "Politicizing Abortion: Personal Morality and Professional Responsibility of Residents Training in the United States." *Social Science and Medicine*. 44(9): 1417-1425.
- Lee, T.F.
1991 *The Human Genome Project: Cracking the Code of Life*. New York: Plenum Publishing Co.

- Lukes, Steven
1973 "Introduction." Pp. 1-36 in Steven Lukes (ed.); *Emile Durkheim: His Life and Work: A Historical and Critical Study*. London: Penguin Books.
- MacKenzie, Donald and Judy Wajcman
1999 "Introductory Essay: The Social Shaping of Technology." Pp. 3-27 in Donald MacKenzie and Judy Wajcman (eds.); *The Social Shaping of Technology, Second Edition*. Buckingham: Open University Press.
- Marshall, Patricia A.
1992 "Anthropology and Bioethics." *Medical Anthropology Quarterly*. 6(1): 49-73.
- Martin, Emily
1994 *Flexible Bodies: Tracking Immunity in American Culture – From the Days of Polio to the Age of AIDS*. Boston: Beacon Press.
1987 *The Woman in the Body: A Cultural Analysis of Reproduction*. Boston: Beacon Press.
- McBrien, Richard P.
1987 *Caesar's Coin: Religion and Politics in America*. New York: MacMillan Publishing Co.
1973 *The Remaking of the Church: An Agenda for Reform*. New York: Harper and Row.
- McLaren, Angus
1990 *Our Own Master Race: Eugenics in Canada 1885-1945*. Don Mills: Oxford University Press.
- Meade, J. E. and A. S. Parkes (eds.)
1965 *Biological Aspects of Social Problems: A Symposium Held by the Eugenics Society in October 1964*. Edinburgh and London: Oliver and Boyd.
- Missa, Jean-Noel
1999 "From State Eugenics to Private Eugenics" *Balliere's Clinical Obstetrics and Gynecology*. 13(4): 533-541.
- Muller, Jessica H.
1994 "Anthropology, Bioethics and Medicine: A Provocative Trilogy." *Medical Anthropology Quarterly*. 8(4): 448-467.

- Nelkin, Dorothy
1992 "The Social Power of Genetic Information." Pp. 177-190 In Daniel J. Kevles and Leroy Hood (eds.); *The Code of Codes: Scientific and Social Issues in the Human Genome Project*. Massachusetts: Harvard University Press.
- Osborn, Frederick
1940 *Preface to Eugenics*. New York: Harper and Brothers.
- Palsson, Gisli and Paul Rabinow
2001 "The Icelandic Genome Debate." *Trends in Biotechnology*. 19(5): 166-171.
- Paul, Diane B.
1995 *Controlling Human Heredity: 1865 to the Present*. New Jersey: Humanities Press
- Paxson, Heather
2003 "With or Against Nature? IVF, Gender and Reproductive Agency in Athens, Greece." *Social Science and Medicine*. 56(9):1853-1866.
- Peters, T.
1997 *Playing God: Genetic Determinism and Human Freedom*. New York: Routledge.
- Pope Pius XI
2004 *Casti Connubii, Encyclical of Pope Pius XI on Christian Marriage to the Venerable Brethren, Patriarchs, Primate, Archbishops, Bishops, and Other Local Ordinaries Enjoying Peace and Communion with the Apostolic See*. Electronic document.
http://www.vatican.va/holy_father/pius_xi/encyclicals/documents/hf_p-xi_enc_31121930_casti-connubii_en.html retrieved on August 15, 2004, originally written on Dec. 31, 1930.
- Potter, Van Rensselaer
1971 *Bioethics: Bridge to the Future*. Englewood Cliffs, New Jersey: Prentice Hall.
- Reid, Roddey and Sharon Traweek
2000 "Introduction: Researching Researchers." Pp. 1-18. In Roddey Reid and Sharon Traweek (eds.) *Doing Science + Culture: How Cultural and Interdisciplinary Studies are Changing the Way We Look at Science and Medicine*. New York: Routledge.

- Rogers, Karen T.
1997 "Embryo Theft: The Misappropriation of Human Eggs at an Irvine Fertility Clinic has Raised a Host of New Legal Concerns for Infertile Couples Using New Reproductive Technologies". *Southwestern University Law Review*. 26(4): 1134.
- Ross, Kelley L.
2003 *Terms used in Mircea Eliade's: The Sacred and the Profane, The Nature of Religion*. Electronic document. <http://www.friesian.com/vocab.htm> retrieved on July 1, 2004.
- Roy, David J., John R. Williams and Bernard M. Dickens
1994 *Bioethics in Canada*. Scarborough, Ontario: Prentice-Hall.
- Ruse, Micheal
1994 "Knowledge in Human Genetics: Some Epistemological Questions." Pp. 34-45 in Robert F. Weir, Susan C. Lawrence and Evan Fales (eds.); *Genes and Human Self-Knowledge: Historical and Philosophical Reflections on Modern Genetics*. Iowa City: University of Iowa Press.
- Sacchini, Dario and Leonardo Antico
2000 "The Professional Autonomy of the Medical Doctor in Italy." *Theoretical Medicine*. 21(5): 441-456.
- Science Council of Canada
1991 *Genetics in Canadian Health Care*. Ottawa: The Publications Office of the Science Council of Canada.
- Shore, Cris
1992 "Virgin Births and Sterile Debates." *Current Anthropology*. 33(3): 295-314.
- Spitzack, Carole
1992 "Foucault's Political Body in Medical Praxis." Pp. 51-68 in Drew Leder (ed.); *The Body in Medical Thought and Practice*. Dordrecht, The Netherlands: Kluwer Academic Publishers.
- Stranc, Leonie and Jane Evans
1998 "Issues Relating to the Implementation of Genetic Screening Programs." Pp. 43-107. In Knoppers, Bartha Maria (ed.) *Socio-Ethical Issues in Human Genetics*. Cowansville, Québec: Les Éditions Yvon Blais Inc.
- Strathern, Marilyn
1995 "Future Kinship and the Study of Culture." *Futures*. 27(4): 423-435.

- Thagard, Paul
1999 *How Scientists Explain Disease*. New Jersey: Princeton University Press.
- The Biologics and Genetics Directorate
2004 *Welcome to the Biologics and Genetics Directorate*. Electronic Document.http://www.hc-sc.gc.ca/hpfb-dgpsa/bgtd-dpbtg/aboutus_e.html retrieved on February 15, 2004.
- Thomson, Gerald E.
2001 “A Baby Show Means Work in the Hardest Sense’: The Better baby Contests of the Vancouver and New Westminster Local Councils of Women, 1923-1929.” *BC Studies*. Winter 2000/2001(128): 5-36.
- Treasury Board of Canada Secretariat
2004 *Canada’s Performance Report 2003*. Electronic document. http://www.tbs-sct.gc.ca/report/govrev/03/cp-rc1_e.asp retrieved on November 12, 2004.
- Turner, Leigh
2003 “Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings.” *Health Care Analysis*. 11(2): 99-117.
- University of Washington
2004 *What is the diet for PKU?* Electronic document. <http://depts.washington.edu/pku/diet.html> retrieved on November 12, 2004.
- Van Balen, F. and A. Ph. Visser
1997 “Perspectives of Reproductive Health.” *Patient Education and Counseling*. 31(1): 1-5.
- Van Dyck, Jose
1995 *Manufacturing Babies and Public Consent: Debating the New Reproductive Technologies*. New York: New York University Press.
- Vecsey, Christopher
1983 *Traditional Ojibwa Religion and Its Historical Changes*. Philadelphia: American Philosophical Society.
- Watson, James D. and Francis H. C. Crick
1953a “Genetical Implications of the Structure of Deoxyribonucleic Acid.” *Nature*. May 30, 1953. 171(4361): 964-967.
1953b “Molecular Structure of Nucleic Acids: A Structure for Deoxyribose Nucleic Acid.” *Nature*. April 25, 1953. 171(4356): 737-738.

- Wilson, James C.
2002 “(Re)writing the Genetic Body-Text: Disability, Textuality, and the Human Genome Project.” *Cultural Critique*. (50): 23-29.
- Wilson, Michael
1975 *Health is for People*. London: Darton, Longman and Todd Ltd.
- Wright, Will
1982 *The Social Logic of Health*. New Jersey: Rutgers University Press.
- Young, Allan Louis
1971 *Medical Beliefs and Practices of Begemder Amhara*. Ann Arbor: Michigan University Microfilms.