

**Privacy Across Cultures:
Indigenous Self-Determination and the Politics of Information**

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Abstract

The surveillance of Indigenous Peoples by the Canadian state constitutes a threat to Indigenous self-determination. State discourses concerning Indigenous Peoples are oriented away from self-determination and fail to question practices, like surveillance, that fall outside of their limited purview. This thesis undertakes a critical case study of *The First Nations and Inuit Health Information System*, highlighting problems in the state's surveillance of Indigenous health information. The case study is approached through a discourse analysis of law and public policy, and through a review of privacy and surveillance literature. The central conclusion of this work is that state discourses of Aboriginal rights and self-government must be reoriented towards self-determination. Simultaneously, state discourses of privacy protection, discourses that resist surveillance, must accommodate Indigenous groups by moving towards a collective conceptualization of privacy. So long as Indigenous (informational) self-determination is excluded from state discourse Canada will continue to act as a colonizing state.

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Introduction

What you are about to read is a critical exploration of state discourses. My intention, first and foremost, is to broaden the conditions of possibility, within these discourses, for Indigenous self-determination. The Canadian state, by and large, works to foster the conditions of self-determination for its citizens. However, my research has indicated that, where Indigenous Peoples are concerned, far from fostering the conditions of self-determination, the Canadian state actually frequently inhibits them.

To demonstrate the subtle way state activities collude to undermine Indigenous self-determination, this thesis considers the state's application of the concept of privacy across cultures. It observes a divestiture of Indigenous self-determination from state discourses and suggests that such divestiture ought to be viewed in broad terms, in how it might relate to an assemblage of seemingly disconnected practices that together perpetuate colonial behaviour. Consideration of the privacy of Indigenous Peoples, as a legal and policy issue, provides a noteworthy example of the way Indigenous interests are marginalized by systemic processes. These interests simply do not appear on the radar screen of policy and law makers working in the fields of privacy and surveillance. Neither do Indigenous privacy interests appear on the radar screen of policy and law makers working in the field of Aboriginal rights and self-government. By drawing these disparate fields together for interrogation under the rubric of Indigenous self-determination this thesis catches elements of colonial behaviour that have been buried between discursive fields. It highlights these elements with the purpose of rehabilitating institutions of the Canadian state from their colonial history.

In this regard and in spite of the critical picture I am about to construct, I wish to emphasize my cautious optimism for the future of the Canadian state. I believe that it can be a more inclusive, accommodating, and radically pluralistic state. I see, in Canada, a state that is situated to advance the cause of self-determination not through the authoritarian imposition of it, which is the height of hypocrisy, but through the relinquishment of political space to a multiplicity of self-determining voices. Such

relinquishment would involve the acceptance of *individual and collective* self-determination as a pre-condition to the creation of policy and law. This dual action -- the relinquishment of space and the acceptance of self-determination -- would propel policy and law makers towards a critical consideration of the ways their policies and laws might be implicated in the perpetuation of social stratification. In the case of policy and law concerning Indigenous Peoples, the dual action of relinquishment and acceptance would engage law and policy makers dialogically with multiple articulations of self-determination across multiple issues.

Presently, the failure of state institutions to accept Indigenous self-determination as a pre-condition of policy and law may be correlated with the deployment of a range of state practices that are harmful to Indigenous Peoples. To demonstrate this point, I focus on the practice of surveillance. I argue that the state's surveillance of Indigenous groups replicates and reinforces a paternalistic mentality within state institutions towards Indigenous Peoples. This is the same paternalistic mentality that sought to justify racist, assimilationist policies such as those that resulted in residential schooling; it is a mentality characteristic of colonialism. This mentality is both enabled *by* and reinforced *with* state surveillance practices, which challenge in significant yet relatively unquestioned ways, the right of Indigenous Peoples to be self-determining.

Before I begin in earnest, however, I would like to take a moment to clarify a few concepts that I will use throughout the course of the thesis. I have already used the term *discourse* quite a bit, and indeed, methodologically, this thesis is primarily a discourse analysis. When I use this term, I am drawing heavily from the works of Michel Foucault, who tried "to define how, to what extent, at what level discourses... can be objects of political practice..."¹ According to Alan Hunt and Gary Wickham, Foucault's notion of discourse captures the fact that

people live and experience within discourse in the sense that discourses impose frameworks which structure what can be experienced or the meaning that experience can encompass, and thereby influence what can be said, thought and done. Each discourse allows certain things to be said, thought and done and

¹ Michel Foucault, "Politics and the Study of Discourse," The Foucault Effect: Studies in Governmentality With Two Lectures by and an Interview with Michel Foucault, Graham Burchell, Colin Gordon, and Peter Miller (eds), (Chicago, 1991), p. 69.

impedes or prevents other things from being said, thought and done.²

For Foucault, discourse is more than words spoken or text written. It has real world effects and shapes what gets talked and thought about.³ Hence, I loosely use the term *discourse*, in this fashion, to evoke the socio-political context in which the documents under scrutiny were produced.

I also rely heavily, in *my discourse*, on the concept of the *state*. This concept, in many ways the foundational concept of *the science of politics*, is traditionally constructed as a sovereign body that controls bounded territory, backed by a monopoly of violence if necessary. Generally, the state is viewed as inhering in, but lying behind, the “institutions of organized and formal political authority...”⁴ While I could carry on with a treatise about the analytical promises and pitfalls of this concept, and indeed numerous treatises have been written, I would like instead to offer a simple and specific definition of the way the term *state* is used in this thesis. The following field of study is trained upon texts produced by and for institutions, such as the Government of Canada, The Supreme Court of Canada, and Health Canada. I conceptualize these bodies together as *institutions of the state*. I examine text produced by and for these bodies, which I refer to as *state discourses*.

My consideration of state discourses draws upon different literatures that can rightly be conceived of as *academic discourses*. As discourses, these academic texts may themselves be questioned with many of the same techniques that are used to question state discourses. I have therefore tried to be implicitly conscious, in my use of these texts, of “the way in which they interlock or exclude one another, the transformations that they undergo, and the play of their location, arrangement, and replacement.”⁵

Finally, and most importantly, all of the concepts I have just mentioned reflect back upon the central goal of this thesis: the creation of space within state discourses for

² Alan Hunt and Gary Wickham, Foucault and the Law: Towards a Sociology of Law as Governance, (London, 1994), p. 8.

³ *Ibid.*, pp. 8-9.

⁴ Mitchell Dean, Governmentality: Power and Rule in Modern Society, (London, 1999), p. 8.

⁵ Michel Foucault, The Archaeology of Knowledge and The Discourse on Language, (New York, 1972), p. 34.

Indigenous self-determination. This might easily have been a thesis concerned with Aboriginal self-determination. Indeed, the terms *Indigenous* and *Aboriginal* are often used interchangeably. Each term is used, in the contemporary Canadian lexicon, to denote the diverse group of peoples who have descended from the original inhabitants of the area now known as Canada. As I use them in this thesis, however, they have subtly different meanings from one another.

Both terms are problematic insofar as they group together very different peoples under the same moniker – they tend to mediate and universalize identities. However, these terms, prone as they are to co-optation and *conservative (re)absorption*⁶ into structures of domination, signify a platform of unified resistance. This thesis uses the term *Aboriginal* to connote a concept that is in the process of being co-opted. In other words, the way the term *Aboriginal* has been deployed in state discourses almost makes it more useful to the state than to Peoples who would self-identify as Aboriginal. Conversely, this thesis uses the term *Indigenous* to connote a concept that is still vested with a modicum of meaning not absorbed by the conservative establishment, not transformed by state discourses. The term *Indigenous* has not yet been used in a comprehensive way by the Canadian legal system or by Canadian policy makers.⁷

This thesis asks the Canadian legal and policy systems to make space, in their discourses, for Indigenous self-determination. It might be observed here, that in asking

⁶ Geoffrey Kay, *Development and Underdevelopment: A Marxist Analysis*, (London, 1975), p. 103, cited in: Colin Leys, *The Rise and Fall of Development Theory*, (Oxford, 1996), p. 54.

I have borrowed the concept of conservative reabsorption from Marxist development theory. The term was first used by Geoffrey Kay to describe the assimilation of radical language by the conservative establishment. Kay was concerned that the terminology he and other development theorists used was being subverted to maintain the status quo. In this paper, conservative (re)absorption denotes the processes whereby nodes of resistance are transformed into buttresses of the hegemonic order. For instance, the conservative (re)absorption of Aboriginal rights happens when the Canadian Court specifically interprets an Aboriginal right, such as self-government, in relation to Federal understandings and norms of governance.

⁷ A caveat is in order here. I do not intend to suggest that, as the term *Aboriginal* has been absorbed by state discourses it has changed the identities of those Peoples who self-identify as *Aboriginal*. That would be tantamount to suggesting that peoples are determined by discourse. Rather, I mean that as state discourse has transformed the phrase *Aboriginal rights* (for example) to the purposes of its institutions, it has constructed a vision of Indigenous Peoples. This vision is generally an instrumental one, one that allows the state to reconcile Indigeneity (which at times questions the state's very legitimacy) within the state's sovereign framework. Indigenous Peoples are not determined by this vision. They must, however, frequently contend with it.

for the creation of space in state discourses for Indigenous self-determination, I am asking for the absorption and transformation of the term *Indigenous* in the same fashion that the term *Aboriginal* has been absorbed and transformed. Indeed, this is a risk. However, I am not willing to advocate the decoupling, in state discourses, of the term *Indigenous* from the term *space*. By using the concept of *Indigenous space* I am suggesting a concept that cannot be absorbed. In essence, the transformation of *Indigenous* by state discourses would negate *Indigenous space*. By definition, the concept, as I am using it, cannot suffer conservative (re)absorption.

As I envision it, *Indigenous space* in state discourses is a consequence of both the unique history and the distinctive socio-economic circumstances of Indigenous Peoples. This is a sovereign space into which Indigenous Peoples can step with their unique discourses. This is a space that asks state law and policy makers to shed their ethnocentric, preconceived notions about what is good for Indigenous Peoples prior to their admittance. This is a space in which dialog occurs on equal footing and in which parties share mutual respect. Though Canadian law and policy makers may enter this space, it remains immutably Indigenous: it is given shape and scope according to whichever self-determining Indigenous person or group chooses to enter it. Ultimately, *Indigenous space* is a place, or more precisely a multiplicity of places, within state discourses for Indigenous voices.

I have strategically chosen to understand Indigenous space in negative, yet essential terms because I perceive a substantial power imbalance in the dialogic space that currently exists for Indigenous-state interaction. The multiplicity of spaces I am talking about, were they a reality, would push Canada towards pluralism. In this incarnation, Indigenous space would be difficult to justifiably limit. It would resist current practices whereby institutions of the state identify a conceptual space, such as Aboriginal rights, or Aboriginal self-government, or Aboriginal title, and then proceed to outline the limitations that surround and compress that space. The emphasis given over to the limitations of Indigenous space by institutions of the state, in state discourses, tends to undermine any progressive statements they might make concerning the obligations they owe to Indigenous Peoples.

A brief example will illustrate what I am talking about. When the Supreme Court of Canada considered Aboriginal title in its 1997 *Delgamuukw* ruling, a decision that will be considered in some detail in chapter one, it found that “lands held pursuant to aboriginal title have an inescapable economic component.”⁸ This statement seems to open the door to significant economic leverage for Indigenous groups choosing to assert their Aboriginal title. However, this progressive pronouncement was simultaneously undercut by the Court’s articulation of an inherent limit on Aboriginal title.⁹ In this decision, the Court unilaterally posited the scope of *the limitations* of Aboriginal title instead of simply discussing the scope of Aboriginal title. This maneuver would seem to channel Indigenous voices in the negotiation over Aboriginal title into a space where limitations, rather than possibilities, are the basis of discussion.

There are stark consequences for *Indigenous self-determination*, a concept that will be discussed in greater detail in the first chapter, of the state’s focus on limitations. On the surface it may seem reasonable for the court to discuss the limitations of Aboriginal title the way it did. After all, a political world without limits is practically inconceivable. Still, a subtle hypocrisy, a double-standard that affirms the self-determining capacity of the Canadian state while denying that same capacity to Indigenous groups, is embedded in the Court’s justification of the inherent limit on Aboriginal title. As Patricia Monture-Angus observes, the Court

...provided two examples of the scope and need for this limitation: if land is used as a hunting ground it cannot be strip mined; or if the land has ceremonial or cultural significance it cannot be paved as a parking lot. Not only are these two examples extreme, they are not realistic. The simple fact is that threats to Aboriginal lands have not historically been internal but rather external (from commercial interests such as mining and lumber companies or hydroelectric development, or from governments). It was not Haudenosaunee people at Oka who attempted to build nine more holes of a golf course over a burial ground.¹⁰

Given that threats to Indigenous lands have historically come from external sources, sources sanctioned by the state, how does the Court justify its right to frame the dialogue

⁸ *Delgamuukw v. British Columbia*, [1997] 3 S.C. R. 1010, at para. 166, online at: http://www.lexum.umontreal.ca/csc-scc/en/pub/1997/vol3/html/1997scr3_1010.html.

⁹ *Ibid.*, at para. 166.

¹⁰ Patricia A. Monture-Angus, *Journeying Forward: Dreaming First Nations Independence*, (Halifax, 2002), p. 127.

concerning the limitations of Aboriginal title? Should not Indigenous groups now, at this point in the history of dialogic interaction, have the space to posit limitations of their own? Such limitations would of course be subject to negotiation - the point is, however, that negotiation would begin from an Indigenous articulation of limitations instead of a state articulation of limitations.

To achieve, in state discourse, a theoretical starting point more favorable to Indigenous Peoples I strategically define Indigenous space and Indigenous self-determination in essential terms, thus establishing a rhetorical position that matches the state's rhetorical understanding of its own space and self-determination. My deployment of essentialism proceeds from the assumption that the state presently dominates dialogue with Indigenous Peoples by holding its sovereign, self-determining capacity as a nation-state to be indivisible and unquestionable. At bottom, the state essentializes Canadian self-determination such that it excludes the self-determination of Indigenous Peoples. To counter this essentialism, I draw from Gayatri Spivak's articulation of *strategic essentialism*, and posit an Indigenous space for self-determination within state discourse that is equally unquestionable.¹¹ From Spivak and her commentators we have learnt that "[e]ssentialism is bad, not in its essence -- which would be a tautology -- but only in its application."¹² The state's essentialism is poorly applied because it excludes the possibility of *non-Canadian* forms of self-determination, including Indigenous self-

¹¹ Gayatri Chakravorty Spivak and Elisabeth Grosz, "Criticism, Feminism, and the Institution," *Interviews, Strategies and Dialogues: Gayatri Chakravorty Spivak*, (New York, 1990), pp. 11-12.

Spivak has suggested that, while she is fundamentally concerned with heterogeneity, she has chosen, from time to time, to adopt a universal discourse "because universalisation, finalisation, is an irreducible moment in any discourse." Spivak argues that marginalized groups might generate power by seeing "what in the universalizing discourse could be useful and then [going] on to see where that discourse meets its limits and it's challenge within that field." In this sense, she notes that "[y]ou pick up the universal that will give you the power to fight against the other side, and what you are throwing away by doing that is your theoretical purity. Whereas the great custodians of the anti-universal are obliged therefore simply to act in the interest of a great narrative, the narrative of exploitation, while they keep themselves clean by not committing themselves to anything. In fact they are actually run by a great narrative even as they are busy protecting their theoretical purity by repudiating essentialism."

¹² Michael Kilburn, 'Glossary of Key Terms in the Work of Gayatri Chakravorty Spivak', *Postcolonial Studies at Emory Web Site*, (Druid Hills, 1996), on-line at: <http://www.emory.edu/ENGLISH/Bahri/Glossary.html>, last updated 23/11/01, viewed 11/29/02.

determination. To counter the state's essentialism, to level the playing field, I advocate essential definitions of Indigenous space and of Indigenous self-determination.

It is not enough, however, to counter the state's essentialism through a simple act of reversal. Such reversal would be tantamount to a legitimization of the state's approach to dialogue. Merely claiming a counter-essentialism would widen the gulf between institutions of the state and Indigenous Peoples and effectively stifle dialogue. To be strategic about engaging with the state's essentialism I propose definitions of Indigenous space and Indigenous self-determination that are essential only insofar as they essentialize multiplicity. In other words, where the state essentializes its space to the exclusion of Indigenous self-determination, Indigenous space only excludes exclusive essentializations. Indigenous self-determination and Indigenous space are open to Canadian self-determination and Canadian space so long as these concepts are themselves open to other articulations of self-determination.

Unfortunately, the state has **unnecessarily** closed the space it accords Indigenous Peoples in its discourses in such a way that Indigenous self-determination is excluded. When it is articulated at a collective level, the state understands self-determination as a threat to its institutionalized existence. Thus posed, self-determination seems, to the state, too risky to even contemplate. The state therefore blocks Indigenous self-determination from its field of vision, metaphorically blinding itself to spaces that are deeply imprinted by the blunt touch of its instruments. This blindness to certain discursive spaces combines with the uncritical deployment of certain other practices and results in a perpetuation of colonial behaviour towards Indigenous Peoples. One of these practices, surveillance, receives scant attention in state discourses and yet significantly undermines the capacity of Indigenous Peoples to be self-determining. Over the course of four chapters, this thesis demonstrates the problematic way that surveillance practices have accompanied the divestiture of Indigenous self-determination from state discourses.

The first chapter argues that the Canadian state, through juridical and policy narratives, has systematically moved the Aboriginal rights and Aboriginal self-government discourses away from a discussion of self-determination. Indeed, this chapter contends that the concepts of self-government and Aboriginal rights have suffered such (re)absorption in state discourses that they are now of limited utility for

Indigenous Peoples. The conscripted status of these concepts is evidenced by the state's push to hold them up as resolutions to pressing social problems while simultaneously constructing them in ways that do not challenge the status quo. In this context, the discourses surrounding Aboriginal self-government and Aboriginal rights have had difficulty moving beyond the pragmatic matters of policy implementation and rights adjudication. Consequently, the state has not facilitated Indigenous self-determination through the mechanisms of Aboriginal rights or self-government.

The second chapter builds on this observation by arguing that the discourses of Aboriginal rights and self-government, because they have not been oriented towards self-determination, do not contemplate practices that are harmful to Indigenous Peoples: for instance, surveillance. The chapter begins by arguing that surveillance practices are instrumental in processes of social ordering and reinforce status-quo arrangements. Using the concept of informational self-determination, which is not contemplated by discourses of Aboriginal rights or self-government because these discourses exclude Indigenous self-determination more generally, this chapter notes that a person's social position is shaped by the information *out there* about them. Inability to determine or control the destiny or circulation of this information undermines a person's capacity to be self-determining. Recognition of the threat posed by surveillance to informational self-determination has resulted in the development of the concept of *information privacy*. The chapter concludes, however, with the observation that neither the academic literature on surveillance nor the academic literature on information privacy have discussed the surveillance and privacy issues of Indigenous Peoples.

The third chapter considers how the concept of information privacy is given effect in Canadian law and policy. It furthermore notes that Indigenous groups, and indeed groups in general, have been excluded from the Canadian information privacy regime. Building on comparative analysis of privacy protection regimes, I suggest that such exclusion has occurred because the Canadian regime is dominated by a liberal and individualistic conceptualization of privacy. Its statutory mechanisms are not, therefore, suited to protecting the privacy of groups and exclude a collective conceptualization of privacy. In contrast to this individualistic conceptualization, I highlight two Indigenous articulations of privacy. These articulations give effect to a collective conceptualization

of privacy that, by virtue of their collectiveness, are excluded from state law and policy concerning privacy protection.

Together, these three chapters show that state surveillance of Indigenous Peoples is **not** contemplated in state discourses on Aboriginal rights and self-government; **neither** is it contemplated in state discourses concerning information privacy protection; **neither** has it been contemplated in academic discourses concerning privacy and surveillance. The almost complete neglect of the surveillance of Indigenous Peoples by all of these discourses has, therefore, led to unquestioned practices that challenge the right of Indigenous self-determination.

The fourth chapter begins the process of questioning these unquestioned practices by exploring the state's surveillance of Indigenous Peoples' health information. It critically examines The *First Nations and Inuit Health Information System* (hereafter FNIHIS), a database management system designed by the state to house and manipulate Indigenous Peoples' personal health information. There is currently under way a transition process that will transfer control of this system from Health Canada to the Assembly of First Nations. As the fate of the system is now in flux, my analysis of it in this chapter is periodized, and pertains only to the system as it was designed by Health Canada. The analysis is, nevertheless, noteworthy because it points to un-scrutinized practices that potentially undermine Indigenous projects of self-determination.

The main reason for focusing on the FNIHIS during this period, as it was designed by Health Canada, is to emphasize and critique the data structure initially sanctioned by the state. I am not so much interested, in this thesis, with how various communities have deployed the FNIHIS. Indeed, this would be an interesting empirically driven research project - however, going down such a path would take me beyond the scope of this inquiry. My central concern with this case study is to explore potential problems that could grow out of state surveillance of Indigenous health information. As the FNIHIS has the functional capacity to conduct detailed health surveillance, and as it was, during my period of analysis, controlled by Health Canada, it should have raised the privacy concerns of academics and policy/law makers working in the fields of privacy and surveillance and in the fields of Aboriginal rights and self-government. It failed to

raise the relevant questions in these fields and is consequently deserving of critical inquiry.

Thus, the thesis begins on the broad conceptual foundation of self-determination. Self-determination, as I have outlined it above and as I will define it in the first chapter, is the umbrella under which I gather together discourses from different tables. I use this concept to interrogate state discourses on Aboriginal rights and Aboriginal self-government, and state discourses on surveillance and privacy, and arrive, in the end, at an exploratory discussion of the health surveillance of Indigenous Peoples. If readers consider this structure throughout the course of the argument, they will note that *my discourse* performs the same narrowing action that it observes in the discourses on Aboriginal rights and Aboriginal self-government and in the discourses on surveillance and privacy. Each of these discourses begins from broad precepts and narrows down to specific issues and problems at the expense of considering other issues and problems. Every discourse selects that which is important and, as a result of this selection process, excludes from its boundaries factors that merit consideration.

My thesis consciously mimics (or I might even say necessarily mimics) the reductive processes of the discourses I examine. It therefore buttresses two implicit claims that I am making concerning the nature of discourse: namely, that a discourse, owing to the necessity of focus, cannot be all encompassing; and, that when some discourses become dominant, eclipsing others, they delimit the field of vision, blinding thought and action to worlds of possibility.

Hence, I argue that as discourses become dominant they must be countered by articulations of circumstances that lie outside of their purview. Such articulations are meant to unsettle the certainty and stability of reason upon which discourses claim their dominance. These articulations occur in response to the marginalization of important issues by dominant points of view within discursive fields. Dominant discourses, therefore, demand contestation on multiple fronts, in multiple ways, and through multiple voices. This thesis is one act of contestation.

The Conservative (Re)Absorption of Aboriginal Rights and Self-Government

Law is frequently deployed as a just mechanism for the resolution of conflict. Truly, Canadian law has become one of the dominant discourses in which disputes between Indigenous Peoples and the state are waged. Unfortunately, this legal discourse, frequently framed in terms of Aboriginal rights, seems predisposed to generating outcomes that favour state interests over Indigenous interests. Although the constitutionalization of Aboriginal rights created a measure of space for Indigenous interests within the Canadian constitutional fold, this space has become increasingly narrow. As will be made evident, successive rulings by the Supreme Court of Canada have had the effect of making Aboriginal rights less a tool of Indigenous Peoples and more a tool of the state.

Aboriginal rights are not the only concept to have suffered a modicum of conservative (re)absorption. The concept of Aboriginal self-government has been similarly realigned through the state policy narratives. Together with the narrative of law, state policy narratives have functioned to dissociate Aboriginal rights and Aboriginal self-government from broader projects of Indigenous self-determination. These movements have the effect of putting fundamental yet racist assumptions beyond the realm of question. They facilitate the reformulation of paternalistic attitudes in language and through practices that have not yet been subject to criticism.

This chapter first seeks to demonstrate, by looking at legal and then policy narratives, that the state discourses, voiced through judicial and legislative institutions, have been oriented away from discourses of Indigenous self-determination. Where these discourses diverge from the principle of self-determination they fail to adequately cope with state attempts, whether intentional or not, to (re)construct an oppressive relationship. The chapter concludes by focusing on an integral element of self-determination, informational self-determination, and by arguing that this element of the overall project

of Indigenous self-determination is threatened by state surveillance practices. Whether intentional or not, these practices potentially undermine processes of decolonization.

This chapter is divided into three sections. The first section will be devoted to a consideration of the principle of self-determination. In the second section, a reading of three Supreme Court cases illustrates the movement of the Aboriginal rights discourse, as it has been defined by the judiciary, away from the principle of self-determination. In the third section a reading of three federal policy statements illustrates the orientation of the self-government discourse, as it has been defined in the policy arena, away from the principle of self-determination. Consideration will be given, by way of conclusion, to the possible consequences of these discursive formulations for Indigenous informational self-determination.

Different Worlds

It does not take long to recognize that the contemporary meaning of Indigenous self-determination is a world apart from the contemporary meaning of Aboriginal rights and Aboriginal self-government. The concept of self-determination may be defined, if only in abstract terms, as the right and ability to choose one's destiny without external compulsion.¹³ The idea of self-determination comes from an affirmation of "the human drive to translate aspiration into reality"¹⁴ and, although self-determination inheres in the self, it is difficult to conceive of outside of a collective existence.¹⁵ Individual and collective self-determination are thus inextricably intertwined. "Collective self-

¹³ Frank Cassidy, "Introduction: Self-determination, Sovereignty, and Self-government," in Aboriginal Self-Determination: Proceedings of a Conference held September 30 – October 3, 1990, Frank Cassidy (ed), (Lantzville, 1991), p. 1.

I wish to acknowledge an intellectual debt to Frank Cassidy who, over the course of several lectures and discussions, developed, articulated, and supported useful distinctions between self-determination, self-government, and Aboriginal rights.

¹⁴ S. James Anaya, Indigenous Peoples in International Law, (New York, 1996), p. 75.

¹⁵ Monture-Angus, Journeying Forward, p. 8.

determination,” therefore, “depends on the conscious coordination of individual powers of self-determination.”¹⁶

Interstitially situated between individual and collective will, the term has found its most frequent expression in the state-centric discourse of international law. S. James Anaya notes that the term *self-determination* first gained prominence in the modern era in the political discourse around the First World War. During this period, the principle of self-determination was linked to western liberal democratic ideals. In this context the term became associated with the rights and duties of independent sovereign states. However, as international law became more concerned with upholding universal rights inherent in humans, rather than in states, the idea of self-determination took on new *individualist* meanings.¹⁷ Self-determination also remains closely linked to philosophically universal principles. The roots of the concept can be traced to ancient Greek, Roman, Asian, and African philosophy.¹⁸

In international law, the principal inflection accorded to the meaning of Indigenous self-determination is drawn from the 1994 *UN Draft Declaration of The Rights of Indigenous Peoples*. The *Draft Declaration* was produced through a process that sought to balance the aspirations of Indigenous Peoples with the state’s concerns.¹⁹ This process had the effect of decoupling the right of self-determination from the right of secession.²⁰ Broad ranging in scope and articulated at the level of international

¹⁶ Taiaiake Alfred, *Peace, Power, Righteousness: An Indigenous Manifesto*, (Toronto, 1999), p. 26.

¹⁷ Anaya, *Indigenous Peoples in International Law*, pp. 76-77.

Anaya observes: “Self-determination is not separate from other human rights and norms; rather, self-determination is a configurative principle or framework complimented by the more specific human rights norms that in their totality enjoin the governing institutional order.”

¹⁸ *Ibid.*, p. 76.

¹⁹ Karen Knop, *Diversity and Self-Determination in International Law*, (Cambridge, 2002), p. 255.

²⁰ *Ibid.*, pp. 256-257.

This conceptual decoupling was reflected in the position that the Canadian state adopted towards the *Draft Declaration*. Throughout negotiations, the Canadian government sought to produce a new concept of self-determination that would be severed from the concept of self-determination already articulated in international law. The Canadian government hoped that this new concept would be sufficiently distant from existing concept’s association to secessionist rights.

abstraction the *Draft Declaration* cannot be specific in its consideration of the concept of self-determination. Nevertheless, it would be worthwhile to consider certain points of the *Draft Declaration* as a starting point for thinking through the basic components of Indigenous self-determination.

The *Draft Declaration* explicitly contemplates Indigenous self-determination in article 3: “Indigenous peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.”²¹ This definition draws attention to the political, economic, social and cultural spheres of self-determination. Mathew Coon-Come, Chief of the Assembly of First Nations, has developed this definition a little further:

As Peoples, we have the fundamental human right of self-determination. This means, as stated in the International Bill of Rights, that we have the right to determine our own political future. It means we have the right to freely dispose of our natural wealth and resources. It means we have the right to never be deprived of our means of subsistence. In short, it means that indigenous peoples, like all peoples, have the right not to be subjected to colonization and dispossession.²²

Coon-Come’s articulation of self-determination emphasizes the concept’s substantive elements and its importance to the process of de-colonization.

The 1996 report of the Royal Commission on Aboriginal Peoples (hereafter RCAP) gives further emphasis to the connection between de-colonization and self-determination. For instance, RCAP began its discussion on governance with the philosophical assumption that humans possess an “inherent freedom to discover who and what they are.”²³ In this context, RCAP linked the Aboriginal right of self-government

²¹ United Nations, Sub-Commission on the Prevention of Discrimination and Protection of Minorities, UN Working Group on Indigenous Populations, UN Draft Declaration of The Rights of Indigenous Peoples, (Geneva, 1994), on-line at: [http://www.unhchr.ch/huridocda/huridoca.nsf/\(Symbol\)/E.CN.4.SUB.2.RES.1994.45.En?OpenDocument](http://www.unhchr.ch/huridocda/huridoca.nsf/(Symbol)/E.CN.4.SUB.2.RES.1994.45.En?OpenDocument). Viewed on: 18/01/03. The document can also be found at the University of Saskatchewan Native Law Centre web-site. See: <http://www.usask.ca/nativelaw/ddir.html>. This web-site also contains a comprehensive bibliography relating to the *Draft Declaration*: http://www.usask.ca/nativelaw/ddir_biblio.html.

²² Assembly of First Nations (Mathew Coon-Come), “National Chief Matthew Coon Come Remarks On Behalf Of Indigenous Peoples ‘Contribution Of Civil Society’ Summit Of The Americas Québec,” (Quebec, 2001), on-line at: <http://www.afn.ca/press%20releases%20%26%20speeches/april%5F20.htm>. Viewed on: 18/01/03.

²³ Canada, The Royal Commission on Aboriginal Peoples, “Chapter 3 – Governance: Aboriginal Perspectives,” Restructuring the Relationship - Final Report (Volume 2), (Ottawa, 1996), p. 1.

directly to the principle of self-determination. *Government*, the signifier of a western concept, with its common English connotations, is, however, only one means of exercising the right of self-determination.²⁴

There might be some conceptual confusion at this point of confluence between rights, self-government, and self-determination. The rights discourse is the discursive field upon which the discourses of self-government and self-determination usually unfold. Aboriginal rights are a sub-division of the rights discourse and extend to the activity of self-government and other activities, such as fishing, forestry, mining, and activities yet to be decided. Self-determination, however, is not easily confined to the discursive field of rights. It can mean much more than self-government, and much more than the ability to pursue ancestral cultural practices. As Frank Cassidy has observed, a group of people can exercise self-government and can make significant choices concerning their political, cultural, economic, and social affairs without experiencing self-determination. This might occur because self-government is practiced in circumstances that are ultimately defined and limited by external forces.”²⁵

Permit me to spend some time juxtaposing the concept of Aboriginal rights with the concept of self-determination so that I can highlight the distinction I am making between the two. In liberal political theory, Aboriginal rights have classically been described as an example of minority rights. Will Kymlicka, for instance, has argued that Indigenous Peoples are a subset of a larger category of national minorities or stateless nations.²⁶ This categorization scheme begins with an attempt to identify Indigenous Peoples. In this scheme, Aboriginal rights, which are a subset of minority rights, correspond to a particular group. The important question in this equation is what criteria a person must possess to claim an Aboriginal identity and its corresponding rights.²⁷

²⁴ *Ibid.*, p. 1.

²⁵ Cassidy, “Introduction: Self-determination, Sovereignty, and Self-government,” p. 1.

²⁶ Will Kymlicka, “Theorizing Indigenous Rights,” Politics in the Vernacular: Nationalism, Multiculturalism, and Citizenship, (Toronto, 2001), p. 120. See also: Will Kymlicka, Finding Our Way: Rethinking Ethnocultural Relations in Canada, (Toronto, 1998), p. 6. Alan Cairns also begins from a position similar to Kymlicka’s. See: Alan C. Cairns, Citizens Plus: Aboriginal Peoples and the Canadian State, (Toronto, 2000).

²⁷ Kymlicka, “Theorizing Indigenous Rights,” p. 122.

There is one fundamental problem with this theoretical equation. It demands that Indigenous Peoples conform to Aboriginal rights rather than tailoring Aboriginal rights to fit Indigenous Peoples.

This *Aboriginal rights as minority rights model* assumes that Aboriginal rights, and indeed all rights, flow from the state (that is, the modern Westphalian state). This assumption fails to emphasize one basic element of the right to Indigenous self-determination – its existence prior to the modern state. In other words, Indigenous self-determination causes the existence of Aboriginal rights and not vice versa. In this sense, the classic liberal model confuses the rights associated with Indigenous self-determination with rights created *by* the state for citizens *of* the state. It assumes that Indigenous self-determination, because it has sometimes been articulated in the language of rights following the normalization of the Westphalian state, must have been created by the Westphalian state.

From this confusion flows a further conflation. As philosopher Vine Deloria Jr., has quipped, “when one asks a liberal about minority groups, he unconsciously seems to categorize them all together for the purposes of problem solving.”²⁸ The Indigenous right of self-determination flows from pre-Westphalian societies. The more general concept of minority rights holds that they flow from the Westphalian state’s need to diffuse ethnocultural conflict.²⁹ Conflating the two diminishes a particular and powerful aspect of Indigenous self-determination. In basic terms, this conflation makes Aboriginal rights a tool of the state rather than a tool of Indigenous Peoples.

Hence, it would be misdirected to dwell in the debates that surround minority rights. While they form, in a sense, the backdrop for a broad theoretical discussion about the utility of rights in the modern era, minority rights debates do not adequately consider the particularity of the Indigenous right of self-determination. Conceptually, minority rights tend to be ahistorical mechanisms. They are not capable of tapping into the specific histories of Indigenous Peoples. For these reasons, this thesis does not engage

²⁸ Vine Deloria Jr., Custer Died for Your Sins: An Indian Manifesto, (New York, 1969), p. 171.

²⁹ Will Kymlicka and Ian Shapiro, “Introduction,” Ethnicity and Group Rights, Will Kymlicka and Ian Shapiro (eds), (New York, 1997), p. 4

the growing literature surrounding minority rights. Rather, this thesis argues that the rights of Indigenous Peoples are prior to and therefore outside of the Westphalian state. They ought to stand in opposition to the acts of appropriation that compromised the territorial base of Indigenous societies.

Were they more fully cognizant of this history and directed towards self-determination, Aboriginal rights would be used by those who possess them, as tools in law that protect their interests. But this definition is an oversimplification. Those who possess the rights cannot be described uniformly. It would be worthwhile to note, at this point, that the Indigenous right of self-determination is articulated through an assemblage of languages and “composed of complex sites of interaction and struggle.”³⁰ James Tully has made the important observation that, while this assemblage of languages creates a measure of systemic flexibility, the common concepts of the discourse place limitations on forms of expression.³¹ Aboriginal rights, when they are expressed in a contemporary setting, such as a Court of law, are always performing an automatic act of translation.³² It is important to recognize, therefore, that Aboriginal rights distort the assertions that Indigenous Peoples would make in their own language.³³ It is likely that these rights are incapable of wholly expressing Indigenous interests.

The words *Indigenous* and *Aboriginal* are English words. They were originally created to recognize a specific form of difference and to overcome certain forms of discrimination.³⁴ In actuality, they correspond to groups of vast diversity. Hence, where Aboriginal rights are asserted in a concrete context, they assume a particular form and content specific to the person or persons’ interests they are deployed to protect. It is safe to assume that the interests that these rights were designed to protect are often different

³⁰ James Tully, Strange Multiplicity: Constitutionalism in an Age of Diversity, (Cambridge, 1995), pp. 37-38.

³¹ *Ibid.*, p. 38.

³² Jeremy Webber, “Beyond Regret: Mabo’s Implications For Australian Constitutionalism,” Political Theory and the Rights of Indigenous Peoples, Duncan Ivison, Paul Patton, and Will Sanders (eds), (Cambridge, 2000), p. 66.

³³ Tully, Strange Multiplicity: Constitutionalism in an Age of Diversity, p. 39.

³⁴ Manuhua Barcham, “(De)Constructing the Politics of Indigeneity,” Political Theory and the Rights of Indigenous Peoples, Duncan Ivison, Paul Patton, and Will Sanders (eds), (Cambridge, 2000), p. 150.

from place to place and from time to time. Consequently, if Aboriginal rights are to be vehicles of self-determination, they must be capable of assuming protean form and content from place to place and from time to time.

Due both to the diversity of Indigenous Peoples and to the linguistic limitations of the concept, any precise definition of Indigenous self-determination is impossible where it does not correspond to a specific person and interest. In other words, it is futile to attempt to discuss the actualization of the right of Indigenous self-determination until the moment it is exercised by an Indigenous person or group. Aboriginal rights, as they are entrenched in the Canadian Constitution, are ascribed no specific meaning. Section 35(1) of *The Constitution Act, 1982* recognizes and affirms “existing aboriginal and treaty rights” (See Appendix 1).³⁵ Section 35 does not attempt a definition of Aboriginal rights. It was only constitutionally possible to recognize and affirm their existence.

Given that a specific definition of Aboriginal rights is beyond the competency of the Canadian constitution, it might help to regard these rights simply as space. Section 35 has been described as a space around which the Canadian constitutional road has been paved.³⁶ The Indigenous right of self-determination pre-dated any assertion of Canadian sovereignty. Its existence, prior to the Canadian legislative order, creates considerable doubt over the Canadian state’s ability to define the shape and form of Aboriginal rights.³⁷ Consequently, these rights demarcate a space on the jurisdictional map for

³⁵ Canada, Department of Justice, “Section 35(1),” *The Constitution Act, 1982*, (Ottawa, 1982), on-line at: http://www.solon.org/Constitutions/Canada/English/ca_1982.html. Viewed on: 28/04/01.

³⁶ Patricia A. Monture-Angus, “The Familiar Face of Colonial Oppression: An Examination of Canadian Law and Judicial Decision Making,” *Royal Commission on Aboriginal Peoples Research Report* (CD-ROM), (Ottawa, 1997), p. 7.

³⁷ John Borrows, “Wampum at Niagara: The Royal Proclamation, Canadian Legal History, and Self-Government,” *Aboriginal and Treaty Rights in Canada: Essays on Law, Equality, and Respect for Difference*, Michael Asch (ed), (Vancouver, 1997), p. 169.

Borrows makes two significant points in this article. First, treaties signed between Indigenous Peoples and the Canadian state cannot be interpreted according to the written words alone. Second, when treaties are interpreted with the intent of understanding all parties, they appear as partnerships rather than as unilateral declarations. Taken together, these two points suggest that the articulation of Aboriginal rights in Canadian law can only ever be a recognition of existing power. To presume to have granted the power that Aboriginal rights signify is to misunderstand the historical and contemporary power that Indigenous Peoples have exercised and continue to exercise.

Indigenous Peoples. They must remain broadly defined. At bottom, Aboriginal rights ought to be nothing more than a space which Indigenous Peoples may fill as they require in their interactions with the Canadian state.

More precisely, Aboriginal rights ought to represent space insofar as they constitute a sphere in which Indigenous Peoples exercise self-determination. At present, state discourses do not constitute a space that facilitates the exercise of self-determination. In state discourses this space is beleaguered by a notion that the Canadian Crown holds absolute, indivisible sovereignty over all territory within Canadian borders. This articulation of sovereign self-determination is posited as justification for infringing on Indigenous political space. In effect, this notion of sovereignty subordinates Indigenous space to Canadian space. Consequently, in interactions with the Canadian state, Indigenous Peoples often find the political space for their self-determination to be very permeable.

(Re)absorption in Law

The claim that state discourses do not facilitate Indigenous self-determination is definitively illustrated by a thumbnail sketch of three landmark Supreme Court of Canada cases: *R. v. Sparrow*, *R. v. Van der Peet*, and *Delgamuukw v. British Columbia*. As will become clear through a reading of these three cases, successive rulings by the Supreme Court of Canada have had the effect of making Aboriginal rights less a tool of Indigenous Peoples and more a tool of the state.

It will be argued that, when Aboriginal rights are not directed towards self-determination, they serve an assimilative function rather than a protective function. Each of the three cases discussed in this section represents an attempt by the state to reconcile competing visions. This drive towards reconciliation can best be understood in light of the historical relationship between Canadian Courts and Indigenous Peoples.

The past 30 years have seen Canadian Courts take a more active role than ever in defining the relationship between Indigenous Peoples and the state. Prior to this period, most Indigenous Peoples did not view the Courts as a vehicle of change. RCAP highlights a number of reasons for the small role the Courts assumed in the Aboriginal

rights discourse during this period. Chief of these reasons was that many Indigenous Peoples did not view non-Indigenous Courts as having any jurisdiction over them. During this period, the doctrines of parliamentary supremacy and crown sovereignty were accepted by judges and legislators without question.³⁸ Under these conditions, it is likely that Indigenous Peoples viewed their chances in Court with skepticism.

Where Indigenous People did attempt to bring matters to Canadian Court, the state made this process very difficult. For instance, it wasn't until 1951 that the prohibition on retaining counsel or raising money for litigating was removed from the Indian Act.³⁹ Notwithstanding these obstructions, Indigenous Peoples did manage to use the Courts to some advantage. As recognition of the rights of Indigenous Peoples grew in international law, Canadian Courts slowly began to recognize wider conceptualizations of Aboriginal rights. The origins of the modern legal framework for Aboriginal rights are to be found in the 1965 ruling, *R. v. White*, in which the Supreme Court of Canada began to shift away from the logic that Aboriginal rights were *created* by the crown and *granted* to Indigenous Peoples. Unlike earlier rulings, this decision recognized that the *1763 Royal Proclamation* merely confirmed the existence of long standing Indigenous rights; it did not create them.⁴⁰

The 1973 decision in *Calder v. A.G.B.C.* built substantially on the foundation laid down in cases like *R v. White*. Michael Asch has described this decision as a “singular moment in Canadian history” for confirming the existence of Aboriginal title.⁴¹ Although *Calder* lost the trial, the six judges who wrote substantive decisions agreed that Aboriginal rights derived from the fact of Indigenous occupation of their traditional territories before contact.⁴² This recognition signified the Court's rejection of the *terra*

³⁸ Canada, The Royal Commission on Aboriginal Peoples, “Chapter 7 – Stage Four: Negotiation and Renewal,” Looking Forward, Looking Back – Final Report (Volume 1), (Ottawa, 1996), p. 15.

³⁹ Monture-Angus, “The Familiar Face of Colonial Oppression,” p. 17.

⁴⁰ Canada, The Royal Commission on Aboriginal Peoples, “Chapter 7 – Stage Four: Negotiation and Renewal,” p. 19

⁴¹ Michael Asch, “From *Calder* to *Van der Peet*: Aboriginal Rights and Canadian Law, 1973-96,” Indigenous Peoples' Rights in Australia, Canada, and New Zealand, Paul Havemann (ed), (Auckland, 1999), p. 428.

⁴² *Ibid.*, p. 431.

nullius thesis.⁴³ This admission, by Canada's highest Court, directly contradicts British and later Canadian claims to a legitimate assertion of sovereign power. Tracing Canadian sovereignty to its historical root does not yield any justification for Crown control over all territory in Canada. Given that the claim to sovereignty is used as the basis and ultimate justification for legislating peoples on the territory claimed by the Canadian state, Indigenous and non-Indigenous alike, and given that the state perceives Indigenous self-determination as a threat to its sovereign order, there has plainly been a move to separate self-determination from Aboriginal rights.

As Asch suggests, since the Calder decision, two different conceptions of Aboriginal rights have been on the agenda. The first conception poses Aboriginal rights as cultural or economic rights. The second conception poses Aboriginal rights as political rights or rights to authority and self-determination.⁴⁴ At the same time that these conceptions were advanced, judicial consideration of Aboriginal rights remained beholden to ethnocentric assumptions.⁴⁵

Consequently, with each incremental widening of Aboriginal rights, legal analysis was, and is, always still constrained by its roots in historical precedent. As Patricia Monture-Angus has convincingly argued, the use of Canadian legal precedent tends to skew the judiciary's interpretation of Aboriginal rights in favour of Crown interests. For instance, the restriction from obtaining legal counsel, when in place, precluded any form of comprehensive claim. Hence, precedent prior to 1951 is limited to claims made on an individual basis about certain individual rights to hunt and fish. The collective nature of

⁴³ Brian Slattery, "Aboriginal Sovereignty and Imperial Claims," *Osgoode Hall Law Journal*, 29(4), 1991, p. 682.

The doctrine of *terra nullis*, which literally means 'vacant lands', was used by colonial powers to justify their claims to the 'discovery' of North America. Brian Slattery has elucidated the colonial mentality beneath *terra nullis*. He states: "Indigenous peoples, it is thought, lacked sovereign status in law and so had no international title to the territories they occupied. On this view, the lands of North America were legally equivalent to vacant territories which could be appropriated by the first European state to discover or occupy them."

⁴⁴ Asch, "From Calder to Van der Peet: Aboriginal Rights and Canadian Law, p. 432.

⁴⁵ Catherine Bell and Michael Asch, "Challenging Assumptions: The Impact of Precedent in Aboriginal Rights Litigation," *Aboriginal and Treaty Rights In Canada*, Michael Asch (ed), (Vancouver, 1997), p. 38.

the Indigenous right to self-determination is almost completely excluded from the Aboriginal rights discourse.⁴⁶

Hence, when the judiciary does not find precedent of such claims in Canadian legal history, it has been prone to assume that such claims did not exist. In *not* focusing on what has *not* been said, the judiciary necessarily scrutinizes an incomplete picture.⁴⁷ Such a starting point is problematic because, where the balancing of interests is grounded on historical information, as it often is in state-Indigenous litigation, the Canadian perspective is privileged, pre-disposing the judiciary to render decisions in favour of the Crown.⁴⁸ Accordingly, the degree to which Indigenous Peoples can use the judicial system as an agent of change is questionable. Bearing these historical roots in mind, it will now be argued that Aboriginal rights as they are defined in Canadian law, actually reinforce certain kinds of domination.

From the legal perspective then, Aboriginal rights have come to be associated with a very selective and limited lexicon. This is not to say that Aboriginal rights are completely defined in law. Rather, it is to note that, at least from the perspective of the state, Aboriginal rights seem to have been packed into a very controlled space. The present legal interpretation begins from a critical appraisal of the Crown's assertion of sovereignty.⁴⁹ The invalidation of the *terra nullius* thesis is accompanied by a significant challenge to the legitimacy of the Crown's claims to be sovereign. Moreover, as RCAP suggests, early colonizers did not demonstrate sovereign power over Indigenous Peoples. Rather, a situation of rough equality characterized the initial post-contact era.⁵⁰

Recognition of this initial situation of rough equality calls into further question the foundational assumptions that underpin Canadian sovereignty. Brian Slattery, who

⁴⁶ Monture-Angus, "The Familiar Face of Colonial Oppression," pp. 17-20.

⁴⁷ Tully, Strange Multiplicity: Constitutionalism in an Age of Diversity, p. 51.

⁴⁸ *Ibid.*, pp. 17-20.

⁴⁹ It would be incorrect to speak of legal interpretation in the singular. There are a tremendous number of different legal interpretations and opinions that comprise the legal discourse on Aboriginal rights. This paper risks oversimplification so that some dominant characteristics of this discourse can be highlighted.

⁵⁰ Canada, The Royal Commission on Aboriginal Peoples, "Chapter 5 – Stage Two: Contact and Cooperation," Looking Forward, Looking Back – Final Report (Volume 1), (CD-ROM), (Ottawa, 1996).

has had a strong influence on the judiciary's articulation of Aboriginal rights through the 1990s, begins from this critique of Canadian sovereignty. He has argued that the doctrine of Aboriginal rights defines the constitutional link between the Crown and Aboriginal Peoples.⁵¹ Through Aboriginal rights, the Crown is able to reconcile its current claims to sovereignty with the fact that its original claim to sovereignty was illegitimate. Slattery situates the origin of Aboriginal rights in the principles of colonial law that outlined the relationship between the British Crown and Aboriginal Peoples.⁵²

Slattery's conceptual framework for Aboriginal rights appears explicitly in the 1990 *Sparrow* ruling. The Court uses this framework to hash out the meaning of Aboriginal rights as they are defined in section 35. It focuses specifically on the terminology of section 35(1). Here, the Court set about defining the terms *existing* and *recognized and affirmed*. Analytically, the ruling passes through two movements.

First, the Court held that the term *existing* pertained to rights that were in existence when the 1982 Constitution Act came into effect. By this rationale, extinguished rights were not revived by the enactment of section 35(1).⁵³ In other words, *existing* rights were those rights that had not been quashed by the Crown. The constitutionalization of those rights meant that the Crown could no longer extinguish Aboriginal rights on a whim. Having defined *existing* in terms of *extinguishment*, the Court was then compelled to elaborate the meaning of extinguishment. It created a test that would aid the judiciary in determining when Aboriginal rights had, in fact, been legitimately extinguished.

The extinguishment test created in *Sparrow* has had a twofold effect. The first effect was to strengthen the position of Aboriginal rights in the Canadian constitutional order. Where the Crown had not made "clear and plain" its intention to extinguish Aboriginal rights, which was arguably everywhere no treaties existed to this effect, Aboriginal rights persisted.⁵⁴ In essence, the extinguishment test imposed strict

⁵¹ Brian Slattery, "Understanding Aboriginal Rights," *The Canadian Bar Review*, vol. 64, 1987, p. 733.

⁵² *Ibid.*, p. 782.

⁵³ *R. v. Sparrow* [1990] 1 S.C. R. 1075, p. 1091, on-line at: http://www.lexum.umontreal.ca/csc-scc/en/pub/1990/vol1/html/1990scr1_1075.html. Viewed on: 28/04/03.

⁵⁴ *Ibid.*, p. 1099.

limitations on the Crown's power over Aboriginal rights. The powerful point of this first effect was underscored by the Court's acknowledgment that past government regulation of Aboriginal practices did not amount to extinguishment of Aboriginal rights.⁵⁵ This line of reasoning reaffirmed the Court's position in *White and Calder*: Aboriginal rights amount to a recognition of an already existing Indigenous space by Canadian law. After the patriation process, this space was constitutionally enshrined. And, as noted earlier, the negative definition given Aboriginal rights in section 35(1) of the constitution does not preclude recognition of the existence of an Indigenous right of self-determination. Unfortunately, as the court began to elaborate the meaning of the word *existing* in relation to extinguishment, the possibility that Indigenous self-determination could be read into section 35(1) began to decrease.

The Court's discussion of the extinguishment test gave the impression that the crown possessed the innate ability to both regulate and extinguish Aboriginal rights. This was the second effect of the Court's extinguishment test and the foundation on which later compressions of Indigenous space are built. It is true that extinguishment became more difficult to secure after the constitutionalization of Aboriginal rights.⁵⁶ However, the Court unquestioningly accepted the premise that the Crown had only to 'justify' its actions where it infringed upon or extinguished Aboriginal rights.

According to the *Sparrow* decision, the test for determining and addressing a violation of Aboriginal rights is as follows. If an individual or group believes that there has been an infringement on an existing Aboriginal right, they must ask the following questions: is the limitation unreasonable; does it impose undue hardship; and does it obstruct the preferred means of exercising the right? If, after asking these questions, it can be proven that an infringement has occurred, the Crown must then attempt to demonstrate that its interference is justified. To determine justification the Crown must answer the following questions: is the legislative objective valid; has the Crown maintained its fiduciary role; has there been as little infringement as possible; has compensation been made available; and has the individual or group in question been

⁵⁵ *Ibid.*, p. 1097.

⁵⁶ *Ibid.*, p. 1098.

consulted? This list is not exhaustive. In constructing this justificatory standard the Court believed that it was placing a heavy burden on the Crown.⁵⁷

However, the fact that the Crown is left the room to justify to its Court - hardly a neutral arbiter - its infringement of Aboriginal rights remains questionable. Depending on the political circumstances in which an Indigenous person or group has to prove that an infringement took place, the demonstration of justification may be all too easy. In this way, the Court structured the meaning of the word *existing*, in Section 35(1), in a manner that would accommodate the prior existence of Aboriginal societies within a framework of the present existence of Crown sovereignty.

The second analytical movement made by the Court was to structure the meaning of the phrase *recognize and affirm*. On this account, the Court set out clear guidelines on the place and significance of Section 35(1) within the context of Canadian law. In a positioning statement the Court held that it must clearly adhere to two principles established by precedent: first, it must liberally interpret Section 35 in favour of Indigenous Peoples;⁵⁸ second, it must not view Aboriginal rights “in a vacuum” (that is, it must contextualize them historically).⁵⁹ Again, these two principles promised significant space within section 35 rights for the concept of self-determination.

Yet, like the Court’s structuring of the term *existing*, the terms *recognize and affirm* were defined in relation to Canadian political space rather than Indigenous political space. Therefore, the Court’s second analytical movement, like the first, emphasized the conditions under which Aboriginal rights could be legitimately regulated. This emphasis again had a twofold effect. While the principles of interpretation set out in the second section of the ruling seem to be a recognition of a constitutional space for Indigenous self-determination, they are undermined by an ultimate emphasis of the Crown’s power to regulate and extinguish Aboriginal rights.

⁵⁷ *Ibid.*, p. 1113-1119.

⁵⁸ See *Nowegijick v. The Queen* [1983] 1 S.C.R. 29, p. 36, cited in: *R. v. Sparrow* [1990] 1 S.C. R. 1075, at p. 1107.

⁵⁹ See *R. v. Taylor and Williams* [1981] 34 O.R. (2d) 360, cited in: *R. v. Sparrow* [1990] 1 S.C. R. 1075, at p. 1107.

Hence, the *Sparrow* decision, while progressive on some fronts, also defined the logic under which Aboriginal rights would be narrowed. The Court noted:

It is worth recalling that while British policy towards the native population was based on respect for their right to occupy their traditional lands, a proposition to which the Royal Proclamation of 1763 bears witness, there was from the outset never any doubt that sovereignty and legislative power, and indeed the underlying title, to such lands vested in the Crown.⁶⁰

This normative assertion by the Court was the basis on which it ruled that section 35(1) did not “provide immunity from government legislation.”⁶¹ Rather, section 35(1) mitigated the state’s assertion of sovereignty by reconciling sovereign power with sovereign obligation. The rationale laid down in 1990 in the *Sparrow* decision has permeated each subsequent ruling on the scope and content of Aboriginal rights.

By 1996, the Court had proceeded from considering the place of section 35 within Canadian law to attempting to outline a framework for determining the specific content of Aboriginal rights. For the first time, the Court attempted to define the unique character of Aboriginal rights and the means by which they would be recognized under section 35.⁶² The *Van der Peet* ruling articulated a framework that linked the content of section 35 rights to the “practices, traditions and customs central to the aboriginal societies that existed in North America prior to contact with the Europeans.”⁶³ This connection to the past thus mediated the specific content of Aboriginal rights.

Chief Justice Lamer, writing for the majority, employed purposive reasoning to get at the meaning of Section 35(1).⁶⁴ Lamer argued that the purpose underlying 35(1)

⁶⁰ *R v. Sparrow*, at p. 1103.

⁶¹ *Ibid.*, at p. 1110.

⁶² Michael Murphy, “Culture and the Courts: A New Direction in Canadian Jurisprudence on Aboriginal Rights?” *Canadian Journal of Political Science*, vol. 34(1), 2001, p. 121.

In 1996 the Court read 3 important and related decisions: *Van der Peet*, *Gladstone*, and *N.T.C. Smokehouse Ltd.* *Van der Peet* was the most articulate of these decisions and was the ruling from which *Gladstone* and *N.T.C. Smokehouse Ltd.* drew their analyses.

⁶³ *R. v. Van der Peet*, [1996] 2 S.C.R. 507, at para. 44, online at: http://www.lexum.umontreal.ca/csc-scc/en/pub/1996/vol2/html/1996scr2_0507.html. Viewed on: 5/11/01.

⁶⁴ Joel Bakan, *Just Words: Constitutional Rights and Social Wrongs*, (Toronto, 1997), pp. 15-21.

was the protection and reconciliation of interests which arise from the fact that Aboriginal Peoples lived in North America in distinct societies before the arrival of Europeans.⁶⁵ Hence, he continued, the test for identifying Aboriginal rights must isolate “the crucial elements of those pre-existing distinctive societies.”⁶⁶ This test is problematic for a number of reasons, not the least of which is that Indigenous Peoples are asked to enumerate and validate their specific cultural practices to an alien institution.

Essentially, the *Van der Peet* decision defines away the contradiction between recognizing Aboriginal rights and *reconciling* (or in more stark terms, *assimilating*) Indigenous Peoples within the broader context of Canadian society.⁶⁷ Note an important shift that took place between the 1990 *Sparrow* ruling and the 1996 *Van der Peet* ruling: section 35(1) was no longer about the *recognition and affirmation* of Aboriginal rights; rather its meaning was transformed to connote the *protection* of Aboriginal interests, and the *reconciliation* of those interests with Canadian interests.⁶⁸ The infringement test developed in *Sparrow* was designed to recognize section 35 rights by reconciling government power with government obligation.⁶⁹ Government could regulate Aboriginal rights but had to give them special consideration.

Bakan has described the development of the purposive reasoning paradigm in judicial decision making. This paradigm developed in the wake of the failure of fundamental meaning paradigm. The fundamental meaning paradigm held that constitutions would compel judges to legally correct answers to constitutional questions. Conversely, the purposive reasoning paradigm postulates that, while constitutional provisions provide some structure to the adjudicative process, they do not determine uncontroversial solutions to disputes. Consequently, judges, like other policy makers, must engage in the balancing of interests. According to the interpretative framework minted under the purposive reasoning paradigm, such balancing was best achieved through an engagement with the purposes and principles underlying the constitution. For Chief Justice Lamer’s argument in favour of using *purposive reasoning* to unmask the meaning of Aboriginal rights, see: *R. v. Van der Peet* at para. 21.

⁶⁵ *R. v. Van der Peet*, at para. 31.

⁶⁶ *Ibid.*, at para. 44.

⁶⁷ Asch, “From Calder to Van der Peet: Aboriginal Rights and Canadian Law, 1973-96,” p. 439.

⁶⁸ *R. v. Van der Peet*, at paras. 44-47.

⁶⁹ This obligation is known in law as a fiduciary obligation. The fiduciary obligation first appeared in Canadian law in 1984 in *Guerin v. The Queen* [1984] 2 S.C.R. 335. As Patrick Macklem has observed, fiduciary obligations are obligations created and enforced by the judiciary. These obligations are placed, by the judiciary, on persons who are empowered, in fact or in law, to “act in relation to a particular matter in the interests of another person” (note omitted – See: Patrick Macklem, *Indigenous Difference and the Constitution of Canada*, (Toronto, 2001), pp. 252-253). Kent McNeil has noted, however, that the *Guerin*

What the *Van der Peet* ruling makes clear is that Section 35(1) rights are meant to function as a bridge between Indigenous society and Canadian society. Their purpose is no longer to *recognize and affirm* (the actual wording of section 35), but to *protect and reconcile*. The language of ‘protect and reconcile’ borders on the paternalism that has been such an unfortunately dominant aspect of the relationship between the Crown and Indigenous Peoples. As Michael Asch has argued, while Indigenous Peoples may have rights to self-determination, these rights are excluded from the legal definition of Aboriginal rights. Moreover, while Aboriginal rights are recognized by the constitution, *Van der Peet* indicates that Courts will not recognize a right to self-determination where such recognition challenges the sovereignty of the crown.⁷⁰

A year later, in 1997, when the Court ruled in *Delgamuukw v. British Columbia*, the focus on *reconciliation* as a point of capture continued to feature prominently. There, the Court reaffirmed its earlier assertion that Aboriginal rights were “aimed at the reconciliation of the prior occupation of North America by distinctive Aboriginal societies with the assertion of the Crown sovereignty.”⁷¹ Within this framework, the Court set out to judge the content of Aboriginal rights according to its assessment of ‘aboriginality.’

Aboriginal title was a concept that could have re-created a source of space for self-determination. However, the concept is discussed in a proprietary way and thus, when read in conjunction with the reconciliatory function of Aboriginal rights, it gets limited almost entirely to administrative governance. Aboriginal title, according to the Court, is in many ways tantamount to other proprietary rights and, consequently, enjoys the same protection under common law. More than this though, Aboriginal title enjoys

decision only discussed the notion of a fiduciary relationship where Indigenous lands had been surrendered to the crown. The Court’s emphasis on this aspect of the fiduciary relationship was therefore merely highlighted to soften its assertion of state sovereignty. Hence, the notion of the fiduciary obligation remains problematic insofar as it attempts to reinforce state assertions concerning the legitimacy of its sovereignty (See: Kent McNeil, “Envisaging Constitutional Space for Aboriginal Governments,” *Queens Law Journal*, vol. 19(1), 1993, p. 109).

⁷⁰ Asch, “From Calder to Van der Peet: Aboriginal Rights and Canadian Law, 1973-96,” p. 440.

⁷¹ *Delgamuukw v. British Columbia*, at para. 81.

Aboriginal persons; it is a collective right to land held by all members of an Aboriginal nation. Decisions with respect to that land are also made by that community.”⁷⁷

Nevertheless, where the Court’s recognition of Aboriginal prior occupation and communal possession constituted a step forward for Aboriginal rights in *R v. White*, in *Delgamuukw*, it was the ground on which the Court articulated the idea of an inherent limit on the use of land. The Court stated:

The content of Aboriginal title contains an inherent limit that lands held pursuant to title cannot be used in a manner that is irreconcilable with the nature of the claimants’ attachment to those lands.⁷⁸

The definition of title seemed, insofar as it possessed a material component, a promising shift from the cultural restrictions placed on Aboriginal rights in the 1996 rulings. Nevertheless, the Court continued to demand, following *Van der Peet*, that the exercise of Aboriginal title be reconciled with Crown Sovereignty.⁷⁹

As surely as litigation made gains for the cause of Indigenous self-determination, each of the three above decisions (re)inscribed an underlying assertion of Crown sovereignty. The underlying affirmation of state sovereignty, an affirmation made prior to any affirmation of Aboriginal rights, considerably narrowed, if not extinguished all together, the space for self-determination within section 35(1). The risk of pushing an agenda in Court rests on the serendipity of the judiciary’s purposive interpretation of the case at hand. The framework for enumerating rights in *Van der Peet* offers to accommodate certain specific Indigenous interests while co-opting the potential for a broader dialogue into one of rights.

This section has argued that Aboriginal rights, as they are defined in Canadian Law, have been conceptually separated from the idea of rights as a space of self-determination. There have been moments where the Court seemed to imply that

⁷⁷ *Ibid.*, paras. 114-115.

Kent McNeil’s paper, The Post-Delgamuukw Nature and Content of Aboriginal Title, highlights this passage of the *Delgamuukw* ruling as an illustration of the Court’s acknowledgment of Aboriginal Peoples’ inherent right to self-government (see: p. 32).

⁷⁸ *Ibid.*, para. 125.

⁷⁹ James Tully, “The Struggles of Indigenous Peoples *For* and *Of* Freedom,” Political Theory and the Rights of Indigenous Peoples, D. Ivison, P. Patton, and W. Sanders (eds), (Cambridge, 2000), p. 48

Aboriginal rights could create a space of self-determination within the Canadian constitutional framework. However, these moments have been repeatedly undercut by the Court's ultimate affirmation of Crown sovereignty. Nowhere is this dual stance more pointed than in the 1990 *Sparrow* decision.

Within the confines of the interpretive framework laid out in *Sparrow*, the *Van der Peet* decision effectively re-directed the meaning of section 35. There, rights were transformed from what could have been a space of self-determination to what became a mechanism for reconciliation. In the 1997 *Delgamuukw* decision, the reconciliation mechanism continued to channel debate away from the space that Aboriginal title created for self-determination and towards the restrictive/regulatory power that the notion of title gave to the state.

This chapter thus far has made three points. First, Aboriginal rights ought not be discussed simply as minority rights. Second, Aboriginal rights ought to remain undefined until they are defined by Indigenous Peoples. Third and flowing from this second point, Aboriginal rights ought to represent Indigenous (rather than Canadian) political space. Where they do not represent Indigenous space, first and foremost, they may not facilitate Indigenous self-determination. Where the space of Aboriginal rights is structured by the state, their capacity to facilitate Indigenous self-determination is diminished. A key implication of this orientation away from Indigenous self-determination has been a lack of attention, in the Aboriginal rights discourse, to informational self-determination.

Essentially, what is being emphasized here is that there are two competing visions about the rights of Indigenous peoples. The first vision is expressed conceptually as an Indigenous right of self-determination, which, outside of particular contexts, can only be expressed as space. The second vision, expressed conceptually as Aboriginal rights, began from the same premise as the right of self-determination: space. However, as has been demonstrated, the state has succeeded in structuring Aboriginal rights, narrowing them by giving them specific form and content where they demand the opposite.

(Re)absorption in Policy

Canada supports the principle of self-determination for indigenous people, within the framework of existing states, where there is an inter-relationship

between indigenous and non-indigenous jurisdictions that gives indigenous people greater levels of autonomy over their own affairs but that also recognizes the jurisdiction of the state. Canada's understanding of self-determination is that it would be exercised in a manner which recognizes the inter-relationship between the jurisdiction of the existing state and that of the indigenous community, and where the parameters of jurisdiction are mutually agreed upon.⁸⁰

This section of the chapter will discuss the ways that government policy has perpetuated the narrowing of the space of self-government. It will be argued that this narrowing, this focus on implementation and definition, precludes from the debate a discussion of certain forms of state domination. In other words, the emphasis on the pragmatic implementation of self-government and the focus on settling once and for all Canada's 'Aboriginal problem' have bred a mentality of limited application.

In the legal realm, the emphasis on creating frameworks of interpretation has functionally structured the space of section 35(1). In other words, the mentality that Aboriginal rights need to be defined, and defined in terms of a reconciliatory function, has structured the space within section 35(1) in a way that facilitates its regulation by the state. The more the Courts structure the space of Aboriginal rights, the less Aboriginal rights can be associated with Indigenous interests. The more specifically the Courts define Aboriginal rights, the more surely Aboriginal rights become a tool of the state rather than a tool of Indigenous Peoples.

As it dominates in the legal realm, so too does the structured space mentality dominate in the realm of public policy. The Government has begrudgingly followed much of what the Courts have told them.⁸¹ In this respect, there has been a gradually increasing recognition of the concept of self-government reflected in public policy. Yet, at each junction of recognition, there has been a corresponding assertion of refusal:

⁸⁰ United Nations, "Report on the Working Group on Indigenous Populations on its Eleventh Session. Addendum. Comments by the Government of Canada, UN Doc. E/CN.4/Sub.2/1993/29/Add.1 (1993). Cited in: Knop, *Diversity and Self-Determination in International Law*, p. 257.

⁸¹ It would be worth restating that, had the Court not recognized Aboriginal title in 1973, it is unlikely that the government would have moved so far from its overtly assimilationist 1969 White Paper. The White Paper, part of Trudeau's *Just Society* campaign, proposed the elimination of protection for reserve lands, the end of legal status for Aboriginal peoples and the devolution of obligation from the federal government to provincial governments. For a discussion of the effect of the White Paper and similar policies, see: Canada, The Royal Commission on Aboriginal Peoples, "Chapter 7 – Stage Four: Negotiation and Renewal," p. 2.

refusal to negotiate certain issues; refusal to accept the futility of implementing final solutions; and refusal to adequately fund the claims of Indigenous Peoples.

In 1996, the main conclusion of RCAP was that the policy direction, pursued for more than 150 years, first by colonial, and then by Canadian governments, had been wrong. Successive governments have tried, sometimes wittingly, sometimes unwittingly, to absorb Indigenous Peoples into Canadian society. This policy direction has been, more or less, consistently assimilationist. It has failed on two levels: it has not integrated Indigenous Peoples into Canadian society; it has not promoted the principles of peace, harmony and justice.⁸² The federal government responded to the Royal Commission in 1997. It barely engaged with the Report. Like much of its previous policy, the Government's response was focused on highlighting its success in policy innovation, while making little in the way of substantive commitments to deeper principles of self-determination.⁸³

To a large degree, Canadian governments believe they are making benevolent concessions by even agreeing to deal with Indigenous claims. This belief stems from conceptualizations about the historical relationship between the Crown and Aboriginal Peoples. Based on these conceptualizations, the Canadian system has created a representation of Indigenous Peoples that it can comfortably reconcile within its dominant cultural framework. Simply put, Canadian governments have created the average aboriginal; an image of the rights and obligations Indigenous Peoples should have as Canadian citizens; an image informed by the textual history of the state.

This vision, or representation, conflicts with the vision that many Indigenous People have of their history. Arguably, Aboriginal rights discourse has become the hegemonic discourse within state parameters. This chapter has argued that Aboriginal rights have come to be directed, by state discourse, towards reconciliation. This trend

⁸² Canada, The Royal Commission on Aboriginal Peoples, People to People, Nation to Nation: Highlights from the Report of the Royal Commission on Aboriginal Peoples, (Ottawa, 1996), p. 4.

⁸³ Canada, Department of Indian Affairs and Northern Development, Gathering Strength – Canada's Aboriginal Action Plan, (Ottawa, 1997), p. 13.

Witness also the range of self-congratulatory policy statements in response to RCAP on-line at: http://www.ainc-inac.gc.ca/gs/index_e.html.

towards reconciliation, at the expense of self-determination, seems to be repeated over and over again in recent policy statements. It has not appeared more starkly than in the 1995 policy statement dealing with the inherent right to self-government.

In 1995 the Ministry of Indian Affairs and Northern Development claimed, in a statement on self-government, that recognition of an “Inherent Right to Self-Government under section 35 of the Canadian Constitution [had] been the cornerstone” of the Government’s policy since its election in 1993.⁸⁴ The same statement argued for the necessity of implementing “practical and workable agreements on how self-government [could] be exercised.”⁸⁵ Indeed, this concern for practicality was prevalent in the 1993 comprehensive claims policy where the Government advocated the exchange of undefined Aboriginal rights for clearly defined treaty rights.⁸⁶

Both the 1993 and 1995 policy statements indicate the Federal Government’s desire to acknowledge its constitutional obligation while maintaining ultimate control over all territory within Canadian boundaries. The Government’s inherent right policy reflects the fact that the Government is caught in a conceptual quagmire: the comprehensive claims policy was designed to resolve debates and legal ambiguities associated with Aboriginal rights and title while making no “attempt to define what rights [Indigenous Peoples] may have had in the past;”⁸⁷ the inherent right policy was designed to make “self-government a reality within Canada”⁸⁸ while side-stepping debate over the meaning of self-government. This maneuver reflects the government’s desire to achieve some final solution to the ‘Aboriginal problem’. In the search for finality, the more important discourse around the conditions for self-determination has been eclipsed.

⁸⁴ Canada, Department of Indian Affairs and Northern Development, Aboriginal Self-Government: The Government of Canada’s Approach to Implementation of the Inherent Right and the Negotiation of Aboriginal Self-Government, (Ottawa, 1995), p. i.

⁸⁵ *Ibid.*, p. 1.

⁸⁶ Canada, Department of Indian Affairs and Northern Development, Federal Policy for the Settlement of Native Claims, (Ottawa, 1993), p. 5.

⁸⁷ *Ibid.*, p. 5.

⁸⁸ Canada, Department of Indian Affairs and Northern Development, “Aboriginal Self-Government,” p. 1.

Federal policy has attempted to come up with a system that would allow Indigenous Peoples to become self-reliant.⁸⁹ While attempting to create structures within which Indigenous Peoples could achieve self-reliance, the Government proceeded directly to working out the details of program and services transfer agreements. However, in failing to recognize the larger foundational point of self-government, federal policy has restricted the area of discourse solely to the management of those programs and services being transferred.

By refusing to recognize that self-government encompasses a larger meaning, the policy denied Indigenous Peoples the very source of authority on which actual self-reliance must be founded. By limiting the scope of self-government to matters that are internal to Aboriginal communities, the 1995 Inherent Right policy effectively divorces self-government from self-determination.⁹⁰ This form of limited self-government, government in a rigidly institutional sense, is clearly an inadequate stand-alone method of fostering Indigenous self-determination. Self-determining communities express themselves in both matters internal *and external*. In this form, self-government must be seen as merely one tool with which Indigenous Peoples can build an autonomous sphere for themselves within Canada.⁹¹

This policy approach has been harshly criticized by Taiaiake Alfred. He argues that the discourse over self-government has been largely co-opted. In his forceful words:

Symbols are crucially important, but they must not be confused with substance: when terminology, costume, and protocol are all that change, while unjust power relationships and colonized attitudes remain untouched, such 'reform' becomes nothing more than a politically correct smokescreen

⁸⁹ *Ibid.*, pp. 2, 4.

Note that the inherent right policy advocates Aboriginal self-reliance but not autonomy: "The inherent right of self-government does not include a right of sovereignty in the international law sense, and will not result in sovereign independent Aboriginal nation states." Recognition of the inherent right may have been a cornerstone of the government's Aboriginal policy since 1993, but this recognition has also always been tempered by the understanding that the state will retain ultimate control. Hence, the dominant cornerstone of Aboriginal policy has not been the *recognition* of inherent rights but rather the *regulation* of inherent rights.

⁹⁰ *Ibid.*, p. 3.

⁹¹ This assumes that autonomy is what is desired. However, if complete autonomy from the Canadian state is not desirable (if, for example, autonomy seems to threaten rather than enable the preservation of one's way of life), self-governance should give Indigenous Peoples control over their level of association.

obscuring the fact that no real progress is being made...⁹²

By allowing indigenous peoples a small measure of self-administration, and by forgoing a small portion of the money derived from the exploitation of indigenous nations' lands, the state has created incentives for integration into its own sovereignty framework. Those communities that cooperate are the beneficiaries of a patronizing false altruism that sees indigenous peoples as the anachronistic remnants of nations, the descendants of once independent peoples who by a combination of tenacity and luck have managed to survive and must now be protected as minorities. By agreeing to live as artifacts, such co-opted communities guarantee themselves a role in the state mythology through which they hope to secure a limited but perpetual set of rights...⁹³

Indeed, this focus on self-administration seems to have created incentives to a subtler form of assimilation. Alfred argues that the majority of public policy aimed at Indigenous Peoples is really a mechanism through which the state secures Indigenous consent for the regulation of Indigenous self-determination.⁹⁴

As evidence that the subtle, assimilative mentality, of which Alfred writes, continues to permeate federal government policy, we need look no further than the forthcoming *First Nations Governance Act*. In 2001, in response to the 1999 *Corbiere* decision,⁹⁵ the Government of Canada began to develop legislation that would "modernize the governance components of the Indian Act."⁹⁶ The proposed *First Nations Governance Act*, while progressive on some fronts, continues to perpetuate many of the same structuring movements made in previous policy that have the effect of limiting governance to administration. This act is intended to function in the interim,

⁹² Taiaiake Alfred, *Peace, Power, Righteousness: An Indigenous Manifesto*, (Toronto, 1999), p. 27.

⁹³ *Ibid.*, p. 60.

⁹⁴ *Ibid.*, pp. 59-60.

⁹⁵ See: *Corbiere v. Canada (Minister of Indian and Northern Affairs)*, [1999] 2 S.C.R. 203, on-line at: http://www.lexum.umontreal.ca/csc-scc/en/pub/1999/vol2/html/1999scr2_0203.html. This Supreme Court decision held that section 77(1) of the *Indian Act* conflicted with section 15 of the *Canadian Charter of Rights and Freedoms*. Section 77(1) had restricted the right to vote in band council elections to on-reserve members. The Supreme Court ruled that bands could not deny off-reserve members the right to participate in decisions that affected their interests.

⁹⁶ Canada, Department of Indian and Northern Affairs, *Background: First Nations Governance Act*, on-line at: http://www.fng-gpn.gc.ca/fnga_bkgrd_e.asp. Viewed on: 13/03/03.

“pending the negotiation and implementation of the inherent right of self-government.”⁹⁷ Given the lack of progress in many treaty negotiations across the board, the legislation is therefore poised as a default policy regulating self-government. Although it claims that groups will be enabled to design and implement their own government regimes, it continues to stipulate frameworks in which such regimes will be implemented. Bands may, with regard to leadership, for instance, develop their own set of rules for selection. However, this set of rules *must include*, among others, the stipulation that the term of office for elected members of the council may not exceed 5 years.⁹⁸

From the perspective of Canadian political culture, this may seem like a reasonable demand. It is designed to defend the democratic electorate against despotic leadership in the long term. After all, who would want to have to endure 10 years of one person’s rule! Still, with this stipulation is thrust on Indigenous government a system of electoral politics that has significant shortcomings. It has been widely acknowledged in classical political analysis of the Canadian electoral system that the 5 year electoral cycle makes long term political projects extremely difficult to carry through to fruition. In the current context, it appears that the project of Indigenous self-determination in many communities, with the radical social change it requires, is truly a long-term project. Examples such as this demonstrate the wide gulf that government policy has created between the concept of Aboriginal self-government and Indigenous self-determination.

Conclusion

This chapter has focused on the conservative (re)absorption of the concepts of Aboriginal rights and Aboriginal self-government. In each case, it has demonstrated that institutions of the state, whether in the judicial or legislative sphere, have oriented discourse away from the concept of self-determination. The orientation away from self-determination has therefore eschewed wider, more difficult political problems of social justice in favour of pragmatic politics. This movement has not been without utility.

⁹⁷ Canada, Department of Indian and Northern Affairs, First Nations Governance Act, section 3(a), on-line at: http://www.fng-gpn.gc.ca/FNGA_act_e.asp. Viewed on: 13/03/03.

⁹⁸ *Ibid.*, section 5(1)(c).

Small gains are here and there accomplished. However, the confinement of state discourses to Aboriginal rights and self-government, as they have been defined by institutions of the state, sets limitations on what is talked about. Following Foucault, we may observe that the discourses of Aboriginal rights and self-government are “limited practical domains which have their boundaries, their rules of formation, [and] their conditions of existence.”⁹⁹

Though they may occasionally overlap the discourse of self-determination, the discourses of Aboriginal rights and self-government fail to adequately address many of the issues within the practical domain of self-determination. They do not consider state practices that undermine Indigenous Peoples’ ability to govern themselves where these practices do not have a direct relation to the *science of government*. The harmful nature of such unquestioned activity only becomes apparent when it is interrogated with the concept of self-determination. Let me return to this concept to close out the chapter. At the outset, self-determination was abstractly defined as *the right and ability to choose one’s destiny without external compulsion*. In the contemporary world, the project of self-determination has grown acutely complex.

According to theories of modernity, the advent of new information technologies, and the accompanying revolution in modes of communication, has had the seeming effect of blurring the boundaries that traditionally constituted the self.¹⁰⁰ From these theoretical perspectives, we may begin the process of analytically thinking through aspects of self-determination that are not facilitated by the pragmatic activity of institutional administration. One aspect of self-determination that state discourses on Aboriginal rights and self-government have failed to contemplate is the right and ability to choose the destiny or circulation of one’s personal information without external compulsion.

⁹⁹ Michel Foucault, “Politics and the Study of Discourse,” p. 61.

¹⁰⁰ See, for instance: Anthony Giddens, *Modernity and Self-Identity*, (Stanford, 1991), p. 2, 7.

Giddens argues that: “modern social life is characterised by profound processes of the reorganisation of time and space, coupled to the expansion of disembedding mechanisms – mechanisms which prise social relations free from the hold of specific locales...” This condition confuses traditional notions of the self. Giddens continues: “The reflexivity of the self, in conjunction with the influence of abstract systems, pervasively affects the body as well as psychic processes. The body is less and less an extrinsic ‘given’...” It functions “outside the internally referential systems of modernity...”

This aspect of self-determination, which we may call informational self-determination, involves control over the “collection, storage, and disclosure of personal information (by government, financial institutions, medical organizations, educational establishments, and others).”¹⁰¹ It is towards this aspect of self-determination that the focus of analysis will now turn.

Discussion of the governance of Indigenous information in the discourses of Aboriginal rights and Aboriginal self-government has been curiously absent. The absence of such discussion is curious because control, or lack thereof, over one’s personal information directly affects a person’s ability to be self-governing. Where a group does not control its personal information, that information may be used in ways that undermine the life chances of individuals who belong to that group. Personal health information could be used, for instance, not only to determine the level of health funding received by communities, but also to direct how that funding is spent. The lack of consideration given over to issues such as this one in state discourses has arguably occurred as a result of the state’s orientation of these concepts away from the larger project of self-determination. As a consequence, these discourses simply fail to address practices, such as surveillance, that disrespect Indigenous Peoples and undermine their efforts to break cycles of colonialism.

The failure of these discourses to substantively address the state sanctioned surveillance of Indigenous peoples raises the question of whether such surveillance is intended to aid in the perpetuation of an unbalanced power dynamic. In the next chapter of this thesis, the analysis moves from the broad project of Indigenous self-determination to consider a particular aspect of the project: informational self-determination. Informational self-determination is not a separate entity from self-determination. If one does not have informational self-determination, one cannot claim to have self-determination. Similarly, if one cannot claim self-determination, then one cannot claim to have informational self-determination.

I am choosing to focus on informational self-determination so that I can more easily describe the subtle, new, and growing trend of informational surveillance, or

¹⁰¹ Colin J. Bennett, Regulating Privacy: Data Protection and Public Policy in Europe and the United States, (Ithaca, 1992), p. 13.

dataveillance, and its potential implications for Indigenous groups. What will become plain over the course of the next two chapters is the way seemingly mundane state practices impinge on Indigenous People's projects of self-determination. Worse than this, however, is the fact that these practices are generally unquestioned because they lie beyond the purview of the Aboriginal rights and self-government discourses.

Surveillance -- The State's Subtle Attempt to Limit Indigenous Self-Determination

In the previous chapter I argued that the concepts of Aboriginal rights and self-government, as they have been structured by the state, do not facilitate Indigenous self-determination. Instead of being directed towards self-determination, Aboriginal rights have come to be directed towards the reconciliation of Indigenous cultures with the dominant Canadian culture. Instead of being directed towards self-determination, self-government has come to be directed towards the transfer of Canadian administrative forms to Indigenous societies. By orienting the discourses of Aboriginal rights and self-government away from self-determination, the Canadian state seems to have constructed a fairly restrictive framework for Indigenous interests within Canadian society. Furthermore, and as a result of this orientation away from self-determination, the Aboriginal rights and self-government discourses do not contemplate the potentially harmful practices of the state that fall outside of their narrow parameters. By predisposing the discourses of Aboriginal rights and self-government to issues of reconciliation and administration, several issues important to self-determination have been marginalized. One of these issues concerns the state's surveillance of Indigenous Peoples.

When state surveillance practices are conceived in instrumental terms, in how they relate to the state's attempt to divest jurisprudence and public policy from the concept of Indigenous self-determination, they call for critical scrutiny. Such critical scrutiny begins with the observation that an extraordinary level of interaction exists between Indigenous Peoples and the state. This interaction produces a large amount of data that state institutions monitor, manipulate, and draw upon in their policy formation and judicial and administrative decision making. As will be discussed, surveillance practices, such as these, are neither neutral nor objective. Insofar as these practices reinforce the divestiture of Indigenous self-determination from state discourses of Aboriginal rights and self-government, they merit a hard look.

This chapter poses surveillance as a potential threat to projects of Indigenous self-determination. It begins with a review of sociological literature concerning surveillance, focusing particularly on literature that addresses the surveillance of personal data. Following this review, attention is turned to the subtle character of data surveillance and the way it mutes, through technological mediation, processes of social ordering and discrimination. The chapter then returns to the concept of informational self-determination and to the subject of its protection by information privacy regimes.

Following these sections, I would like to conclude the chapter with three central points. First, state surveillance of Indigenous Peoples threatens to reinforce their marginalized status even as it promises better life-chances. Second, although state surveillance threatens Indigenous informational self-determination, the effects of surveillance on Indigenous interests have not yet been researched. Third, the absence of Indigenous Peoples from surveillance literature and the absence of surveillance considerations from state discourses of Aboriginal rights and self-government have heretofore excluded this important social ordering practice from scrutiny.

The Surveillance Threat

The state's traditional monopoly over the means of violence is supplemented by new means of gathering and analyzing information that may even make the former obsolete. Control is better symbolized by manipulation than coercion, by computer chips than by prison bars...

The new surveillance is justified by positive social goals – the need to combat crime and terrorism, to protect health, or to improve productivity. Extensions occur gradually; it is easy to miss the magnitude of the change and broader issues it raises.¹⁰²

I have chosen to highlight, with this quotation, a particular aspect of surveillance. Although, as will become clear in the ensuing discussion, surveillance is a very nuanced feature of modern society, this quotation directs readers to consider the teleology of surveillance practices. Surveillance practices sometimes serve a malevolent control function. They are conduits through which power relations are mediated. They may be broadly characterized as “focused attention to personal life details with a view to

¹⁰² Gary T. Marx, *Undercover: Police Surveillance in America*, (Berkeley, 1988), p. 220.

managing or influencing those whose lives are monitored.” As David Lyon has poignantly observed, surveillance practices are “the power of classification, of social sorting. ...of social orchestration.”¹⁰³ It is this fact above all, that surveillance may be used as a mechanism for ordering society, that makes surveillance a threat to Indigenous self-determination.

For analytical purposes, we may distinguish between traditional surveillance, the physical observation of one person by another, and data surveillance.¹⁰⁴ This thesis is primarily concerned with data surveillance, or as Roger Clarke calls it -- *dataveillance* -- which is a derivative of both personal and mass surveillance. Dataveillance employs the assemblage of technologically driven information systems to generate information about individuals or groups. In this sense, it cannot be said that dataveillance is inherently good or bad. The information generated by processes of dataveillance can be put towards different ends. Before discussing the various implications of dataveillance in further detail it will be useful to first consider some theoretical insights regarding the nature and purpose of surveillance in general.

Anthony Giddens has argued that surveillance is one of the defining features of modern society.¹⁰⁵ Indeed, it would be difficult to dispute the fact that surveillance practices have paced the development of the modern state. Without these practices, few routine features of modern life would be possible. Surveillance is necessary to the collection of taxes, the provision of social welfare services, the operation of credit, the

¹⁰³ David Lyon, Surveillance Society: Monitoring Everyday Life, (Buckingham, 2001), p.152.

¹⁰⁴ Roger Clarke, “Introduction to Dataveillance and Information Privacy, and Definitions of Terms,” Roger Clarke's Dataveillance and Information Privacy Pages, (Canberra, 1999), on-line at: <http://www.anu.edu.au/people/Roger.Clarke/DV/Intro.html#DV>. Viewed on: 18/01/03. Last Updated: 16/09/99.

Within each kind of surveillance, Clarke has made a further distinction between personal surveillance and mass surveillance. Personal surveillance can be defined as “the surveillance of an identified person. In general, a specific reason exists for the investigation or monitoring. It may also, however, be applied as a means of deterrence against particular actions by the person, or repression of the person's behaviour.” This can be contrasted with mass surveillance, which Clarke defines as “the surveillance of groups of people, usually large groups. In general, the reason for investigation or monitoring is to identify individuals who belong to some particular class of interest to the surveillance organization. It may also, however, be used for its deterrent effects.”

¹⁰⁵ Anthony Giddens, The Nation State and Violence, (Los Angeles, 1981).

conduct of statistical research, and so on.¹⁰⁶ Although theories of surveillance are relatively new, surveillance having been its own focal point only in the last 10 years or so, surveillance activities and themes have been explored by 19th century sociologists onwards.¹⁰⁷ Two seminal figures to have explored these activities and themes have been Karl Marx and Max Weber. Marx and Weber each considered the activity of watching over people to be intimately connected with economic and bureaucratic systems respectively.¹⁰⁸

Most discussions of modern surveillance practices, however, begin from the work of Michel Foucault. Foucault reworked Bentham's notion of the Panopticon to create a new model for social analysis. He argued that the major effect of surveillance in the panoptic society was the creation of a state of consciousness in the monitored subjects, that assured the automatic functioning of power.¹⁰⁹ Hence, panoptic surveillance was a mechanism for automating and disindividualizing power.¹¹⁰ The panoptic mechanism, Foucault suggested, made the exercise of disciplinary power "lighter, more rapid, more effective, a design of subtle coercion for a society to come."¹¹¹ Arguably, modern societies have, through surveillance practices, developed rational means of ordering communities that effectively dispensed with traditional methods of public punishment.¹¹²

¹⁰⁶ Christopher Dandeker, Surveillance, Power and Modernity: Bureaucracy and Discipline From 1700 to The Present Day, (Cambridge, 1990), p. 2.

¹⁰⁷ David Lyon, The Electronic Eye: The Rise of Surveillance Society, (Minneapolis, 1994), p. 24.

¹⁰⁸ *Ibid.*, p. 25.

¹⁰⁹ Michel Foucault, Discipline and Punish: The Birth of the Prison, Alan Sheridan (trans), (New York, 1977), p. 201.

It is worth noting here that George Orwell's book, 1984, has also had a profound effect on the way modern surveillance practices tend to be viewed. His discussion of the *Big Brother* society, in which total surveillance fostered the growth of a totalitarian world, is still evoked today in criticism of the state-directed, centralized collection of personal information. Although the *Big Brother* concept has considerable rhetorical purchase, we may omit it here because Foucault's theoretical narrative encompasses and even goes beyond the problems highlighted by Orwell's assessment.

¹¹⁰ *Ibid.*, p. 202

¹¹¹ *Ibid.*, p. 209.

¹¹² Lyon, The Electronic Eye, p. 7.

Consequently, surveillance theories influenced by the Foucauldian School of analysis highlight the masking, decentralization, and dissemination of disciplinary power accompanying the seemingly mundane practice of monitoring people's day-to-day existence.

From this perspective, David Lyon has taken up the project of thinking through questions of justice and fairness where "people's everyday activities are monitored and their habits, commitments and preferences classified by the would be omniscient organization." "Such classification," he argues, "often serves to reinforce inequalities of life chances."¹¹³ Building on Foucault's analysis, Lyon suggests that external controls have been replaced by disciplinary practices that ensure life continues in a regularized way. While there have been surveillance practices so long as there have been societies, surveillance in the modern era has become more intense.¹¹⁴ This intensity is focused by the fact that the surveillance systems of modern society rely on and reproduce classifications of normal behaviour. Such classifications result in the production of superficial, but very real, distinctions between what is and is not acceptable.¹¹⁵

With the analytical lens of justice so positioned, we may examine the problematic way that surveillance practices produce and reinforce social norms by scrutinizing the classification processes that have been built into dataveillance systems. Dataveillance is the most important kind of surveillance to consider when thinking about informational self-determination. By Clarke's definition, we may understand dataveillance to mean automated monitoring through computer readable data, rather than through physical observation.¹¹⁶ This kind of surveillance is unique because it "involves the surveillance of populations in general, and of targeted individuals in particular, through observation of

¹¹³ *Ibid.*, p. 19.

¹¹⁴ *Ibid.*, p. 22.

¹¹⁵ *Ibid.*, p. 7.

¹¹⁶ Roger Clarke, "Dataveillance: Delivering '1984'", *Framing Technology: Society, Choice and Change*, L. Green and R. Guinery (eds), (Sydney, 1994), on-line at: <http://www.anu.edu.au/people/Roger.Clarke/DV/PaperPopular.html>. Viewed on: 18/01/03. Last updated: 09/01/93.

Clarke makes a distinction between individual dataveillance and mass dataveillance. This is merely an analytical distinction.

the copious and increasing data trails generated by their activities.”¹¹⁷ Dataveillance has been made possible by developments in information technology and has only become prominent in the last three decades. One of the principal technological applications beneath dataveillance is the database management system (hereafter DBMS). Today, DBMSs are computer software applications that allow the selective retrieval of information from an aggregate of data -- in other words, a database.¹¹⁸ Electronic DBMSs have all but eclipsed traditional, paper-filled databanks.

The enabling technology behind DBMSs began to emerge in industrialized states during the late 1960s. This technology was aimed at solving some specific problems associated with traditional, paper-file based databanks. The main problem was that traditional databanks did not allow organizations a *big-picture* view. That is, the traditional databanks were fragmented such that it was, in many instances, impossible for an organization to see various relationships between its data sets. Computerized technology promised to address this problem because it could highlight different relationships in the total universe of an organization’s data. By amalgamating an organization’s information into a single database and creating a DBMS to manipulate that database, computer technology offered organizations a more flexible system of data management.¹¹⁹ This approach to managing data attempts to “treat the organisation’s data, i.e., its database, as a resource which is shared by all relevant application programs.”¹²⁰

In order to facilitate such interoperability, the usual organizational structure of a DBMS is such that one *fact* is entered into one field and similar *facts* are coded similarly. This structure allows organizations to discern patterns of their choosing through comparing, or matching, one list against another.¹²¹ There are generally three interrelated

¹¹⁷ Roger Clarke, “Technologies of Mass Observation,” Roger Clarke's Dataveillance and Information Privacy Pages, (Canberra, 2000), on-line at: <http://www.anu.edu.au/people/Roger.Clarke/DV/MassObsT.html>. Last updated: 27/10/00. Viewed on: 18/10/03.

¹¹⁸ Lyon, The Electronic Eye, p. 46.

¹¹⁹ Elisabeth Oxborrow, Databases and Database Systems: Concepts and Issues, (Bromley, 1986), pp. 3-6.

¹²⁰ Barry Eaglestone and Mick Ridley, Object Databases: An Introduction, (London, 1998), p. 10.

¹²¹ Lyon, The Electronic Eye, p. 46.

goals that motivate this method of discerning patterns: the generation of statistical information; the allocation of administrative resources; and, the direction of investigative activity. It is noteworthy that these are goals set by and used for organizations. Any benefit these goals promise to the individuals whose information is manipulated by DBMS technology comes only, if ever, by way of trickle down effect. In other words, the better services promised by organizations using peoples' personal information are tied to the condition that such use of information betters the organization. Hence, the representations achieved by DBMS technology tend to reflect the specific needs of whichever organization is using the technology.¹²²

Let us pause for a moment to explore, by way of simple analogy, how organizations can use the selective function of DBMS technology as a tool for sorting and discrimination. Imagine you are searching for a book in your local library. Odds are that, instead of finding your title in a card catalogue, you will be using an electronic DBMS to perform your search. You use the library DBMS to navigate the large aggregate of books. You might run the following keyword search string: '*human rights AND individual NOT collective*'. These parameters allow you to sort out all the books on collective human rights from the aggregate list of books on human rights. You are left with a list of books on individual human rights to scrutinize. Imagine this process, but with people, and you begin to get a sense of the political power that DBMS technology can facilitate.

The dataveillance that is enabled by DBMS technology has been characterized as "the reduction of complexity through the elimination of unnecessary or irrelevant information."¹²³ The usual goal of such a reduction in complexity is the production of information/knowledge that can be used to make informed choices. As a mode of information/knowledge production, dataveillance is often promoted because it promises efficiency at a fraction of the cost of information/knowledge production generated

¹²²Philip E. Agre, "Beyond the Mirror World: Privacy and the Representational Practices of Computing," *Technology and Privacy: The New Landscape*, Philip E. Agre and Marc Rotenberg (eds), (Cambridge, MA, 2001), p. 39

¹²³ Oscar H. Gandy, "Coming to Terms with the Panoptic Sort," *Computers, Surveillance, and Privacy*, David Lyon and Elia Zureik (eds), (Minneapolis, 1996), p. 136.

through traditional surveillance methods. Consider the example of health surveillance. Prior to the epoch of the computerized database, it may have been next to impossible to discern disease patterns in large amounts of population data. Patterns that *were* discovered cost a giant expenditure of human resources. The electronic surveillance of health information, especially in the context of a fiscal health care crisis, promises to be a cost-saving mechanism by cutting down on the human resources required for surveilling disease (a practice known in the biomedical discourse as epidemiology). On top of this cost-saving feature, the dataveillance of health information promises the procurement of *better* information. *Better* information leads to better predictions. This streamlining allows preventative measures to be taken thereby decreasing costs over the long run.¹²⁴

Hence, dataveillance is appealing to those who would deploy it because it produces the promise of *better* information/knowledge. Building on an argument articulated by Shoshana Zuboff, David Lyon contends that a greater “reliance upon the ‘facts’ produced by the computer systems generates new management styles... performance appears as ‘objective’ data.”¹²⁵ This is an important point: the confidence generated by dataveillance engenders a different style of governance than would be possible in the absence of dataveillance. Decision-making proceeds with certainty, in a more or less zero-sum fashion, on the assumption that data are accurate. However, Clarke has noted several risks that attend this mode of information/knowledge production. Some of the most striking of these are the creation of a climate of suspicion, the erosion of self-reliance and self-determination, decision-making on the basis of acontextual data, an inversion of the onus of proof, and the facilitation of repressive governance.¹²⁶

¹²⁴ William Staples, *The Culture of Surveillance: Discipline and Social Control in the United States*, (New York, 1997), pp. 105-107.

¹²⁵ Lyon draws this argument out of Shoshana Zuboff's *In the Age of the Smart Machine*, (New York, 1988), pp. 315-317. See: Lyon, *The Electronic Eye*, pp. 69-70.

¹²⁶ Clarke, “Dataveillance: Delivering ‘1984’.”

Dataveillance -- The Janus Face

We must be cautious, however, not to dismiss surveillance outright as a social evil. It bears remembering that surveillance is widely practiced in the modern era. Most people tend to view surveillance as the relatively minor price for the benefits, information, and knowledge that it produces. From this perspective, proponents of surveillance criticize sociological surveillance theory for over-emphasizing the negative aspects of surveillance. This critique would hold that surveillance practices have little or no tangible negative effect on society at large. Simply watching people in no way interrupts the goings on of their every day lives. This argument goes further to suggest that the only people who would mind surveillance are the people who have something to hide. *Good citizens* should have nothing to hide – if surveillance contributes to a safer world, so much the better.

Yet, as one commentator has argued, it is worth asking whether there is a direct correlation between surveillance practices and the goals that are used to justify them. Simson Garfinkel has suggested that there are deep problems with “a society that views law-abiding citizens as potential terrorists, yet does little to effectively protect its citizens from real threats to their safety.”¹²⁷ If surveillance is not directly linked to the creation of a more stable society, what function does it serve? These questions push critical inquiry to go beyond the immediate cause-effect arguments offered by proponents of surveillance practices. By moving beyond the cause-effect arguments critical investigation comes to question the relationship between categorical suspicion and the generic conceptualization of *the good citizen* in the former argument.

The critical tradition of western political theory has done much to unsettle notions of the inherent *good* and the inherent *bad*. The categories of *good* and *bad* are, this tradition argues, more creatures of socially constructed norms than anything else. Hence, if we accept the premise that the categories of *good* and *bad* have something to do with the social production of normative guidelines, we can begin to understand that the *ideal* of the *ideal citizen* is subject to prevailing political climates.

¹²⁷ Simson Garfinkel, *Database Nation: The Death of Privacy in the 21st Century*, (Sebastopol, 2000), p. 4.

Mark Poster highlights this socially constructed character of the *ideal citizen* in his reading of Foucault's panopticon. The panoptic mechanism operates through the production of norms to divide the population into *good* and *bad*. The goal of the panopticon is to rehabilitate *the bad*, transforming them into *the good*. This process requires a criterion that enables the recognition of *the good*, *the bad*, and the developmental stages in between.¹²⁸ Those who participate in the criterion's creation have a decided advantage within the subsequent panoptic system over those who are excluded from participation. Poster gives a lucid rendition of the way that dataveillance necessarily misconceives of the data-subject. A few passages are worth quoting at length:

The electronic information gathering that constitutes databases, for all its speed, accuracy and computational power, incurs a tremendous *loss* of data, or better, imposes a strong reading on it. Contemporary surveillance in databases relies on digital as opposed to analog encoding of information. Digital encoding imposes a binary reduction of information. It is a language of zeros and ones combined into great complexities but still deriving from that simple grid.

...A database might consist of the following fields: an individual's first and last name, social security number, street address, city, state, zip code, phone number, age, sex, race, unpaid parking violations, x-rated video cassettes rented, subscriptions to communist periodicals. The agency that collects information in this database constitutes individuals according to these parameters.

...[DBMS technology enables] a multiplication of the individual, the constitution of an additional self, one that may be acted upon to the detriment of the "real" self without that "real" self ever being aware of what is happening.¹²⁹

These passages emphasize the crucial importance of being able to determine what personal information one allows to be collected. They implicate the DBMS as a mediator of processes that superimpose a dominant reality over other, subordinate realities. At bottom, they depict a mode of ordering information such that it is easily manipulated and compared against normative criterion. Where one has not participated in the creation of

¹²⁸ Mark Poster, *The Mode of Information: Poststructuralism and Social Context*, (Chicago, 1990), p. 90.

¹²⁹ *Ibid.*, pp. 94-98.

the criterion that will be used to interpret and adjudicate the information derived from dataveillance, one risks being harmed by the system's misconception of the *self*.

Haggerty and Ericson push Poster's analysis to a nuanced consideration of the relationship between surveillance and the maintenance of status quo roles. Drawing from the work of Gilles Deleuze and Felix Gutarri, they describe a surveillant assemblage, consisting of a multiplicity of surveillance practices that work together to uncover heretofore opaque flows of information.¹³⁰ The surveillant assemblage abstracts human bodies from their territorial settings and separates them into discrete flows. These flows can then be assembled into *data doubles* that can be targeted for intervention.¹³¹ They argue that the surveillant assemblage produces *data doubles* that are pragmatic markers for access to resources, services, and power.¹³² Often, the manipulation of the *data double* has a real world effect on the *double's* real world referent.

We may, for a moment, oversimplify the situation to make the point that DBMSs enable different kinds of dataveillance for different people. These different kinds of dataveillance depend on the kind of representation these different people had in the process that created the dataveillance criterion. Such representation in turn is dependent on the protean and contingent social universe in which norms are created. While we may have difficulty dissecting and precisely analyzing the changing conditions of the social universe, we can be assured of one fact. Almost inevitably, some will be silenced and excluded from the negotiations that manufacture norms. Why, then, are surveillance practices not resisted on principle alone?

Indeed, surveillance theory that draws from Foucault's panopticon does not address the empirical fact that subjects of dataveillance do not generally tend to regard themselves as being under surveillance. David Lyon argues that the panoptic model focuses too much on power and misses the subtler aspects of surveillance. Lyon tries to

¹³⁰ Kevin D. Haggerty and Richard V. Ericson, "The Surveillant Assemblage," *The British Journal of Sociology*, vol. 51(4), 2000, p. 611.

¹³¹ *Ibid.*, p. 606.

¹³² *Ibid.*, p. 613.

go beyond the panoptic model of analysis while retaining the insight derived from Foucault's approach.¹³³

Lyon argues that surveillance always has two faces; it both enables and constrains.¹³⁴ Surveillance practices, such as epidemiology, offer rich benefits insofar as they promise to isolate the causes of disease. However, as noted earlier, these practices also have deep surveillance dimensions associated with them.¹³⁵ Surveillance is often wielded in ways that disadvantage some groups rather than others, even where this power is a side-effect of policies meant to achieve other goals. Still, the biggest obstacle to fostering resistance to surveillance tends to be that most people willingly consent to their surveillance because of the benefits it promises. People tend to chalk surveillance up to the price one pays for the speed and security offered by the other face.¹³⁶ Lyon argues that these promises must be scrutinized. His work addresses people's consent to surveillance by critiquing the promised benefits in light of the social costs.

Lyon is concerned to engage in transformative scholarship. He mounts a convincing argument. Institutions manipulate the information derived through dataveillance to inform the decisions they make and to justify the policies they pursue. As the above arguments demonstrate, the collection, manipulation, and use of personal information by organizations abstracts and thereby misconceives the data-subject. While this process can, sometimes, generate information that is used to the benefit of the data-subject, there is an equal chance that the information generated will be deployed to the detriment of the data-subject. Theorists of surveillance practices are correct to question claims that surveillance is: 1) a necessary component of modern life; and, 2) working for the greater good.

However, while surveillance theory has demonstrated that it is a necessary analytical tool in any consideration of informational self-determination, it cannot claim to be a sufficient one. There remain significant shortcomings with the application of

¹³³ Lyon, The Electronic Eye, p. 72.

¹³⁴ Lyon, Surveillance Society, p. 3.

¹³⁵ *Ibid.*, p. 138

¹³⁶ *Ibid.*, p. 136.

surveillance theory to the surveillance practices that impinge upon Indigenous informational self-determination. This shortcoming is due largely to the fact that surveillance theorists have given little consideration to the differential way that state surveillance affects Indigenous Peoples. There have, however, been two important surveillance studies, which will be discussed in more detail in subsequent chapters, that have application to the state's surveillance of Indigenous Peoples in Canada.

Oscar Gandy's The Panoptic Sort, which will be discussed in the next chapter, explores the way that surveillance practices in the United States inform and are informed by racially constructed social divisions. He links the social classifications used by market-driven dataveillance processes to the historically determined exercise of economic and political power. These classification practices, he argues, maintain a connection to historical processes of racial discrimination that marginalize African-Americans.¹³⁷ This work is important to our discussion because it highlights the way dataveillance further marginalizes already marginalized groups. However, owing to its focus on market-driven dataveillance in the United States, it does not bear directly on our consideration of the Canadian state's dataveillance of Indigenous Peoples.¹³⁸

Jennifer Poudrier's insightful essay, "'Racial' Categories and Health Risks: Epidemiological Surveillance Among Canadian First Nations," interrogates the epidemiological surveillance of diabetes among Indigenous populations. This essay will be instrumental to the case study undertaken in the final chapter of this thesis. It

¹³⁷ Oscar H. Gandy, The Panoptic Sort: A Political Economy of Personal Information, (Boulder, 1993), pp. 82-83.

¹³⁸ Non-state surveillance of Indigenous information remains qualitatively different (though no less troubling) from state surveillance of Indigenous information. As an indication that non-state surveillance of Indigenous Peoples is troubling, consider a recent story posted on the Canadian Broadcasting Corporation Website which noted that some insurance companies in Quebec have ceased to cover people living on a native reserve "because the risk is too high." Worse than this, one Mohawk man noted that "non-native people that reside within the boundaries of the reserve of Kanasetake can get insurance," whereas he could not. See: CBC News Online Staff, "Insurance Co's Refuse to Cover Native Communities," on-line at: http://www.cbc.ca/stories/2003/02/18/Consumers/native_030218. Last Updated: 18/02/03. Viewed on: 15/04/03.

These discriminatory practices in the private sector are enabled by dataveillance and merit critical interrogation. Such interrogation is, however, beyond the scope of this thesis. Here, I have chosen to focus on state dataveillance of Indigenous Peoples because the state, to my mind, represents the most immediate threat to Indigenous self-determination.

critically approaches the health surveillance that is justified by (and justifies) the biomedical health discourse.¹³⁹ However, while this work is important, it proceeds from a broad, sociological perspective. Consequently, only minimal analysis is given over to the state's negotiation of its power, through particular health policies, or to Indigenous practices of self-determination that resist the state in this context. All in all, not much scholarship has been given over to assessing the problem of the surveillance of Indigenous Peoples. Neither has much scholarship been given over to ways Indigenous Peoples might address state surveillance.

I would now like to turn to a key basis of resistance and conceptual response to the surveillance problematic: informational self-determination. The concept of informational self-determination offers a way of approaching dataveillance practices with a recognition that, though they often need to be resisted, they are unlikely to disappear. Before turning to informational self-determination, however, I want to briefly reiterate the following two assertions. First, we must not conceive of dataveillance as a wholly negative phenomenon. It is a necessary aspect of modern life. At the same time, we must not permit the necessity of dataveillance to place its practice beyond question. Although dataveillance practices, in their complex multiplicity, are difficult to separate and scrutinize, we must continually be aware of the politics that underpin them. Dataveillance is founded upon a system of identification, classification, and assessment,¹⁴⁰ and it is this system that must remain open and under constant interrogation.

Second, the system that underpins dataveillance is deeply connected to the system of norms that structure society. Owing to this deep connection, we may expect that those marginalized in society will be the ones further marginalized by dataveillance practices. Of the social groups (which are themselves socially constructed) that populate the area now known as Canada, no group, perhaps save prisoners, has historically received more state surveillance than Indigenous Peoples. The Department of Indian and Northern

¹³⁹ Jennifer Poudrier, "'Racial' Categories and Health Risks: Epidemiological Surveillance Among Canadian First Nations," *Surveillance as Social Sorting: Privacy, Risk and Digital Discrimination*, David Lyon (ed), (London, 2003), pp. 111-134.

¹⁴⁰ Gandy, *The Panoptic Sort: A Political Economy of Personal Information*, pp.15-18.

Affairs, in its various historical incarnations, is the oldest governmental organization in Canada. Its records on Indigenous Peoples date from the beginning of the eighteenth century. The department continues to see itself as the principal chronicler of all aspects of Indigenous life.¹⁴¹ Changing modes of surveillance seem to have further facilitated rather than diminished these practices, spreading them beyond the Department of Indian and Northern Affairs. In this regard, state surveillance of Indigenous Peoples threatens to reinforce their marginalized status even as it promises better life-chances. The final section of this chapter discusses the concepts of informational self-determination and information privacy, arguing that they are useful tools for the interrogation and resistance of harmful surveillance practices.

Informational Self-Determination and Information Privacy

As the concept of self-determination enabled, in the last chapter, a critique of state discourses of Aboriginal rights and Aboriginal self-government, so too does the concept of informational self-determination enable an interrogation of state surveillance practices and a critique of the state's information privacy discourse. Using the concept of informational self-determination, we may ask whether state surveillance practices do not subtly recast the state's paternalist attitude towards Indigenous Peoples. The concept of informational self-determination demands that the state's treatment of Indigenous Peoples' information be brought under scrutiny. The next chapter will scrutinize the state's information privacy discourse in some detail. Now, however, I would like to discuss, at a conceptual level, informational self-determination and its corollary, information privacy.

This thesis has already noted that Indigenous self-determination has a multiplicity of meanings. Likewise, outside of a particular context, informational self-determination can only be defined in abstract terms. At the close of the last chapter, the abstract definition given informational self-determination was the right and ability to choose the

¹⁴¹ Kevin D. Smith, "Surveillance, Measurement, Judgment, and Reform: Indian Reserves in the British Columbia Interior and the Panoptic Mechanism," Unpublished Master's Thesis, Department of History, University of Victoria, 1996, pp. 27-28.

destiny or circulation of one's personal information without external compulsion. This definition was then refined by noting that informational self-determination involves control over the collection, storage, and disclosure of one's personal information.¹⁴² The right of informational self-determination is important for social, political, economic, and cultural reasons. One commentator has situated informational self-determination at the very basis of human choice and decision making. "Individuals who exercise self-determination," writes Paul Schwartz, "should be defined as people who, as part authors of their lives, substantially shape their existence through the choices they make."¹⁴³ Schwartz goes on to argue that the collection, storage, and disclosure of personal information compels or coerces decision making "when it undermines an individual's ability to make choices about participation in social and political life."¹⁴⁴ At bottom, the right to informational self-determination is intended to protect against the loss of human dignity, autonomy, and respect that could stem from a loss of control over one's personal information.¹⁴⁵

As was noted at the end of the first chapter, the maintenance of control over one's personal information has become an acute problem in the modern era. The widespread use of information technology, such as the DBMSs used by institutions of the state to manage and manipulate people's data, has multiplied the places and points of access to one's personal information. As the *self* has been increasingly inserted into matrices of information technology, *data doubles* have proliferated and traditional boundaries have been eroded. This increasing erosion of embodiment means that the focal point of institutionalized decision-making is shifting beyond the immediate space of the corporeal.¹⁴⁶ Consequently, the technological transformations that are today multiplying the self are making informational self-determination more complex. At bottom, the

¹⁴² Bennett, *Regulating Privacy*, p. 13.

¹⁴³ Paul M. Schwartz, "Privacy and Democracy in Cyberspace," *Vanderbilt Law Review*, vol. 52(6), p. 1655.

¹⁴⁴ *Ibid.*, p. 1658.

¹⁴⁵ Bennett, *Regulating Privacy*, p. 26.

¹⁴⁶ David Lyon, *Surveillance Society*, p. 15.

erosion of an easily identifiable *self* has made the destiny of one's information difficult to calculate, let alone control.

As much as technological transformation has made possible our society of knowledge and convenience, these same transformations are facilitating unprecedented levels of surveillance. Recognition of such surveillance and its adverse effects has given rise to personal information protection, or data protection regimes in most developed countries. The concept of data protection is derived from the German, *Datenschutz*, and was coined to refer to the rights that citizens have to control their personal information. According to Viktor Mayer-Schönberger, the concept of *Datenschutz* was supported by the German Constitutional Court's 1983 ruling in which the German state census was deemed unconstitutional.¹⁴⁷ The German Court articulated *Datenschutz* in response to changing modes of data collection. In its decision, the German Court held that existing legislation placed too heavy an emphasis on the protection of data and not enough emphasis on the protection of people. Accordingly, it looked to the principle of informational self-determination to compel data processing organizations to bring the data subject back into the loop.¹⁴⁸

In North America, informational self-determination is often subsumed under the rather nebulous concept of information privacy. Like other terminology used in this thesis, the word *privacy* has no singular meaning. While the meaning of privacy changes over time and space, there is general agreement that the condition of privacy is something that every human needs on some level. A substantial amount of social, psychological, and anthropological research supports this point.¹⁴⁹ The most frequently cited early-modern definition of privacy comes from the American Judge Louis Brandeis who, in 1890, asserted that privacy was an individual's "right to be let alone."¹⁵⁰ More

¹⁴⁷ Viktor Mayer-Schönberger, "Generational Development of Data Protection in Europe" *Technology and Privacy: The New Landscape*, Philip Agre and Marc Rotenberg (eds), (Cambridge, 1997), p. 229.

¹⁴⁸ *Ibid.*, p. 230.

¹⁴⁹ Alan F. Westin, *Privacy and Freedom*, (New York, 1967), pp. 32-39.

¹⁵⁰ Samuel Warren and Louis Brandeis (1890), "The Right to Privacy," *Harvard law Review*, vol. 4, pp. 193-220. Cited in: David Baniser, Sarah Andrews, *et al.* *Privacy and Human Rights 2002: An International Survey of Privacy Laws and Developments*, (Washington, 2002), p. 2, on-line at: <http://www.privacy.org/pi/survey/phr2002>. Viewed on: 18/01/03.

contemporarily, Roger Clarke has suggested that privacy is “the interest that individuals have in sustaining a ‘personal space’, free from interference by other people and organizations.”¹⁵¹ Canada’s current Privacy Commissioner has frequently defined privacy as “the right to control access to one’s person and to information about oneself.”¹⁵² The Privacy Commissioner’s statement reflects the fact that the concept of privacy is often fused with the concept of data protection. This particular combination of concepts tends to frame the privacy discourse in terms of the management of personal information.¹⁵³

These and other definitions of privacy tend to be grounded on contestable assumptions about individualism and about the divide, or lack thereof, between civil society and the state. Few definitions adequately consider essential cultural, class-related, or gender differences.¹⁵⁴ Moreover, as Bennett and Raab argue, individualist definitions of privacy generally conceive of society in atomistic terms.¹⁵⁵ From this point of view:

The modern claim to privacy ... is based on a notion of a boundary between the individual and other individuals, and between the individual and the state. It rests on notions of a distinction between the public and the private. It rests on the pervasive assumption of a civil society comprised of relatively autonomous individuals who need a modicum of privacy in order to be able to fulfil the various roles of the citizen in a liberal democratic state.

Whether justified in philosophical, political or utilitarian terms, privacy is almost always seen as a claim or right of individuals that is threatened by a set of social and technological forces.¹⁵⁶

¹⁵¹ Clarke, Introduction to Dataveillance and Information Privacy, and Definitions of Terms.

¹⁵² See, for instance: Canada, Office of the Privacy Commissioner, (George Radwanski), “The Privacy Challenge - Connecting Citizens with all Levels of Government,” presented at the 2002 eGovernment Conference, Ottawa, May 9, 2002, on-line at: http://www.privcom.gc.ca/speech/02_05_a_020509_e.asp. Last updated: 20/01/03. Viewed on: 20/01/03.

¹⁵³ Baniser, Andrews, *et al.*, Privacy and Human Rights 2002, p. 1,

¹⁵⁴ Colin J. Bennett and Rebecca Grant, “Introduction,” Visions of Privacy: Policy Choices for the Digital Age, (Toronto, 1999), p. 5.

¹⁵⁵ Colin J. Bennett and Charles D. Raab, The Governance of Privacy: Policy Instruments in Global Perspective, (Aldershot, 2003), p. 14.

¹⁵⁶ *Ibid.*, pp. 14-16.

Together, these assumptions constitute what Bennett and Raab have called *the privacy paradigm*. The privacy protection that has grown out of this dominant paradigm tends to be based on four key assumptions which Bennett and Raab concisely explain.

First, it has been assumed that privacy protection must be procedural and cannot be substantive. This assumption notes that privacy can be a highly subjective value and it is therefore impossible to designate this or that kind of personal information as inviolable. Second, rights to informational self-determination ought not be regarded as a property rights. This assumption stemmed from the perceived difficulty of assigning a financial value to seemingly intangible information.¹⁵⁷ Consequently, privacy protection functioned at arms length from the often economic forces motivating organizations to carry out dataveillance.

A third erroneous assumption is that privacy protection is achieved if the security of personal information can be guaranteed. This assumption stems from a confusion between privacy and security. Therefore, privacy protection focused on the data rather than the individual as the object of protection.¹⁵⁸ Fourth and finally, since privacy rights are in the province of the individual, groups and organizations have generally been precluded from claiming the right to privacy.¹⁵⁹ This assumption is tied to the liberal conceptualization of privacy.

¹⁵⁷ *Ibid.*, p. 6.

Bennett and Raab observe: “Consumers may have some bargaining power with a direct marketing firm that wants to trade lists of named individuals; citizens, however, have no bargaining power when faced with a warrant or any other potentially privacy-invasive technique backed up by the sanctions of the state. Let us recall that, at the outset of the privacy debate, it was the power of government agencies that were considered to pose the most significant challenges.”

¹⁵⁸ *Ibid.*, p. 6

We must here draw a distinction between information privacy and information security. It is true that security mechanisms, such as encryption, can protect x from y and y from x. However, neither x nor y may be safe from z who has legitimate access to the system in which the personal information of x and y is housed. As Bennett and Raab note, information security is a necessary but not sufficient condition to ensure information privacy.

¹⁵⁹ *Ibid.*, p. 7.

This fourth assumption is not limited to policy or legal outputs. Indeed, it seems to monopolize public imagination. As David Phillips and Michael Curry have argued, popular discourses of privacy in North America have, over the last thirty years, reflected this paradigmatic, individualist conceptualization of privacy. Since the 1970's, popular media have linked computerized data management techniques with privacy concerns. However, rather than focusing on bureaucratic social management, privacy, and discrimination, the media discourse has employed "regressive privacy frames."¹⁶⁰ In essence, the media discourse has focused on personal affronts associated with data collection, such as identity theft and telemarketing. It has simultaneously ignored such structural effects as increased inequity and the creation of a society fractured into exclusive and precise segments.¹⁶¹

This fourth assumption of the privacy paradigm has the greatest bearing on our discussion here. It is firmly ensconced in the social imaginary, and therefore, very difficult to overcome. The ramifications, however, for limiting privacy rights to individuals are substantial for Indigenous groups wishing to exercise these rights in the Canadian state. As will be argued in the next chapter, the dominant privacy paradigm precludes Indigenous groups from using statutory information privacy protection mechanisms.

Conclusion

As the Canadian state has entered the discursive space of Aboriginal rights and Aboriginal self-government, its discourses on these matters have been oriented away from the concept of self-determination. Indeed, these discourses rarely move beyond the pragmatic realm of self-administration. This orientation away from self-determination has also been a *de facto* orientation away from informational self-determination. As

¹⁶⁰ Phillips, David J. and Curry, Michael R., "Privacy and the Phrenetic Urge: Geodemographics and the Changing Spatiality of Local Practice," Surveillance as Social Sorting: Privacy, Risk, and Automated Discrimination, David Lyon (ed), (New York, 2003) p. 147.

¹⁶¹ *Ibid.*, p. 15.

such, state discourses fail to contemplate a range of practices that impinge upon Indigenous interests through dataveillance.

With the goal of highlighting the silence in this discursive domain, this chapter opened by posing state surveillance as a threat to projects of Indigenous self-determination. It argued that a particular kind of surveillance, the surveillance of personal information -- or dataveillance -- infringes upon peoples' abilities to be self-determining. The first section of this chapter argued that dataveillance functions as a mechanism through which power relations are mediated. This mechanism serves to sort society into a segmented population. As it sorts the population, it simultaneously reinforces the identities it ascribes to people. The dataveillance mechanism is thus a self-perpetuating system of discrimination.

The second section of this chapter suggested that the dataveillance mechanism is a subtle one. The argument built on an observation of the first section, that discrimination is embedded in the technological structure of DBMSs, to suggest that most people are relatively accepting of their dataveillance. The subtle character of dataveillance, in conjunction with the benefits it promises, makes it difficult to see dataveillance practices as discriminatory. However, by examining the normative decisions that underpin the categories used by DBMS technology, we may undertake a critical interrogation of dataveillance practices. Finding links between these categories and prevailing social stratification cues us to the specific dataveillance practices that reinforce such stratification. For Indigenous Peoples, where state dataveillance practices are linked to a paternalistic mentality, these practices should be opened to scrutiny.

The third section of this chapter suggested that the best way to determine whether dataveillance practices reinforce unbalanced power relations is to interrogate them with the concept of informational self-determination. If dataveillance practices diminish a person's capacity for informational self-determination, then they threaten a power disequilibrium between the data-controller and the data-subject. That dataveillance practices have, in the modern era, come to pose such a threat is reflected in the fact that most industrialized states have developed information privacy regimes. This chapter concluded with a discussion of the dominant privacy paradigm that directs privacy protection regimes. In the next chapter, I will examine the way this paradigm has

manifested itself in Canadian legal and policy discourses. These privacy protection mechanisms will be discussed in terms of their applicability as tools for building Indigenous informational self-determination.

Information Privacy - Policy and Legal Spaces for Informational Self-Determination

Thus far we have noted that informational self-determination is an integral part of the larger project of self-determination. It has been widely recognized in most industrialized countries that, if one does not determine the destiny or circulation of one's information, free from external compulsion, that information may be used to undermine one's life chances. There are enough historical examples of the totalitarian character of dossier societies. Stalin's Russia and Hitler's Germany recall great abuses of state driven surveillance practices.

We have also noted that the recognition of the importance of informational self-determination has been heightened with the advent of database management systems (hereafter DBMS) technologies that facilitate the collection, storage, and manipulation of people's personal information. These technologies have mediated new forms of information/knowledge production about individuals and groups and have given rise to a concern that this knowledge will be misused. This concern, in turn, has resulted in the creation of numerous information privacy, or data protection regimes, in most western, industrialized nation-states. These regimes originated in Western Europe and North America in the 1970s and 1980s.¹⁶² In Canada, and in an increasing number of countries globally, data protection regimes are overseen by independent oversight agencies.¹⁶³

The first section of this chapter picks up from the conceptual discussion of last chapter by moving to consider the Canadian state's policy and legal responses to the surveillance problematic. It observes that the Canadian response to dataveillance has largely been framed in terms of the dominant privacy paradigm. This paradigm has shaped public policy and law such that they work almost exclusively for individuals. This paradigmatic, liberal, individualistic focus on privacy protection by policy and law

¹⁶² Colin J. Bennett, "What Government Should Know About Privacy: A Foundation Paper," presented at the Information Technology Executive Leadership Council's Privacy Conference, June 19, 2001, on-line at: <http://www.gov.on.ca/MBS/english/fip/pub/wgskap.html>. Viewed on: 18/01/03. Last Updated: 31/02/03.

¹⁶³ *Ibid.*

is not positioned to see larger threats to collective informational self-determination. Canadian privacy protection law and policy are, therefore, incapable of adequately protecting Indigenous Peoples' *sui generis* privacy interests.¹⁶⁴

In considering these state discourses of privacy protection I would like to make the following key assertion: the privacy paradigm's emphasis on individual informational self-determination so dominates the Canadian information privacy regime that the concept of group informational self-determination is virtually excluded. We may, therefore, deduce that this emphasis on individual informational self-determination tends to exclude Indigenous groups from making use of privacy protection mechanisms. Indeed, evidence seems to suggest that Indigenous groups have not used privacy protection mechanisms at a provincial level. Such exclusion thereby exacerbates state surveillance practices by leaving Indigenous groups no special mechanism to resist the extraordinary dataveillance they receive. The second section of this chapter, therefore, discusses the protection of the privacy of Indigenous groups with respect to the Canadian regulatory regime.

The last chapter concluded with the observation that state surveillance of Indigenous groups is conducted on a scale unprecedented in non-Indigenous experience. Given such intensive and extensive surveillance, it would seem logical that Indigenous groups would have space in Canadian privacy protection law and policy to articulate mechanisms that would safeguard their informational self-determination. Yet, the informational self-determination of Indigenous groups is contemplated neither in state discourses of Aboriginal rights and self-government, nor in state discourses of privacy law and policy. The third section of this chapter explores the beginnings of a discourse

¹⁶⁴ For an enlightening discussion of the notion of *sui generis* in the Canadian Aboriginal Rights discourse, see: John Borrows and Leonard I. Rotman, "The *Sui Generis* Nature of Aboriginal Rights: Does it Make a Difference?" *Alberta Law Review*, vol. 36(1), 1997, pp. 10-11, 36, 38.

Borrows and Rotman note that, in the 1984 *Guerin* decision, the Supreme Court of Canada described Aboriginal rights as *sui generis*. This characterization roughly translates to mean *unique*, and suggests that Aboriginal rights do not take their meaning from the philosophies that underlie the western canon of law. As Borrows and Rotman have argued, Aboriginal rights are *sui generis* because they flow from separate systems of Indigenous law, custom, practice, and tradition, which have grown and developed and changed as Indigenous Peoples have interacted with settler culture in North America. The *sui generis* doctrine, therefore, entails the need to make space in Canadian law for Indigenous conceptions.

on privacy as a group right and as a social value. It considers the prospects of this discourse, and poses it as an answer to the state's dataveillance of Indigenous Peoples. This discourse, which we may call the collective privacy discourse, may be useful to Indigenous groups in resisting state surveillance. I introduce it here, prior to the next and final chapter of this thesis, so that readers may consider its utility in relation to a specific dataveillance practice: health dataveillance in Indigenous communities.

Canadian Policy and Legal Responses to Dataveillance

In Canada, as in most industrialized countries, the information privacy regime has worked, more or less, towards the implementation of the *fair information principles*. These principles, which have evolved over time and which vary from place to place in their exact wording, appear in the data protection legislation of numerous states, in corporate and sectoral codes of conduct, and in international data protection agreements. Bennett and Grant have distilled their main features into the following 10 points:

Organizations that collect and use peoples' personal information...

- 1) must be *accountable* for all the personal information in their possession
- 2) should *identify the purposes* for which the information is processed *at or before* the time of collection
- 3) should only collect personal information with the *knowledge and consent* of the individual (except under specified circumstances)
- 4) should *limit the collection* of personal information to that which is necessary for pursuing the identified purposes
- 5) should not use or disclose personal information for purposes other than those identified, except with the consent of the individual (the *finality* principle)
- 6) should *retain* information only as long as necessary
- 7) should ensure that personal information is kept *accurate, complete and up-to-date*
- 8) should protect personal information with appropriate *security safeguards*
- 9) should be *open* about its policies and practices and maintain no secret information system, and

- 10) should allow data subjects *access* to their personal information, with an ability to amend it if it is inaccurate, incomplete or obsolete.¹⁶⁵

These principles embody a common understanding of how organizations ought to handle personal information. They serve as guidelines as to how an institution might “mediate its relations with the individuals with whom it comes into contact...”¹⁶⁶ It would be worth noting, here, that while these principles are definitely oriented towards the individual, they do not explicitly preclude group considerations.

As these principles have come to be articulated in Canadian law and policy though, they have primarily been formed within a liberal, individualist conceptualization of information privacy. This paradigmatic conceptualization of information privacy is a fairly limited framework in which to posit informational self-determination. More specifically, this framework is limited on two levels. First, the liberal characterization of information privacy tends to assume both a uniformity amongst data-subjects and an equal level of surveillance for all. In other words, this conceptualization of information privacy does not imagine that some people may receive more or different dataveillance than others. It does not, therefore, put forth statutory mechanisms that are capable of treating data subjects in differential terms. In short, this paradigmatic, liberal conceptualization does not facilitate the creation of different levels of information privacy for different people based on the more or less dataveillance they receive.¹⁶⁷

Second, this conceptualization predisposes a framing of privacy in an individual and atomistic sense. It tends to evacuate social components from the concept of privacy in addition to making any group conceptualization of privacy difficult. Thus framed, such a conceptualization of information privacy may actually facilitate rather than hinder surveillance practices. In essence, this conceptualization of information privacy applies to individuated *selves*, abstracted from the context of their social relations; this is congruent with the way that dataveillance mechanisms abstract the individual from

¹⁶⁵ Colin J. Bennett and Rebecca Grant, “Introduction,” Visions of Privacy: Policy Choices for the Digital Age, Colin J. Bennett and Rebecca Grant (eds), (Toronto, 1999), p. 6.

¹⁶⁶ *Ibid.*, p. 6.

¹⁶⁷ Colin J. Bennett and Charles D. Raab, The Governance of Privacy: Policy Instruments in Global Perspective, (Aldershot, 2003), p. 34

society for the purposes of sorting, classifying, and assessing.¹⁶⁸ When monitored data-subjects are systematically differentiated into groups during the course of dataveillance, these differentiations are not determined by data-subjects themselves, but by the organizations that scrutinize data-subjects. People might be identified, for instance, in terms of the number of times they have been to the hospital, in terms of the amount of money they have spent on alcohol, or even in terms of their alleged genetic predispositions. These modes of identification can eclipse the way data-subjects would identify themselves. Hence, the paradigmatic, liberal conceptualization of information privacy breeds a peculiar paradox that is best interrogated with the concept of informational self-determination.

When we think about privacy through the concept of informational self-determination, we begin with the question of who determines what information is private. In simple terms, if it is not the individual or group that determines the destiny or circulation of their information, if the individual or group is unable to determine what information remains private and what information gets disclosed, then informational self-determination does not exist. Accordingly, we may ask whether and to what degree the liberal information privacy regime engenders the capacity of the individual or group to make such decisions concerning the disclosure of their personal information. If data subjects are conceived of, by information privacy regimes, in atomistic terms, the entire social context in which their privacy interests are articulated is erased. Arguably, information privacy regimes that fail to contemplate the social component of personal information conceive of informational self-determination in a vacuum. Arguably, the erasure of this context actually facilitates, rather than obstructs, surveillance. Such a focus on the individual misses less explicit, systematically driven surveillance practices that hone in on particular, marginalized groups of society.

Moreover, where data subjects are continuously contrasted and differentiated by dataveillance practices, the liberal condition of equal privacy is more of an ideal than a reality. When statutory mechanisms reflect this liberal ideal, they cannot offer each person an equal amount of privacy protection. Hence, where information privacy is

¹⁶⁸ Lyon, *Surveillance Society*, p. 150.

conceived of in liberal, individualistic terms, the privacy of marginalized groups is undermined by the surveillance interests of the dominant group. This paradigmatic conceptualization of information privacy therefore only facilitates informational self-determination in a limited sense: if you are not marginalized to begin with, these laws will work for you; otherwise, too bad.

In the realm of public policy, when information privacy is conceived of in liberal and individualistic terms, it tends to assume a rather homogenous meaning. Thus framed, information privacy carries the same meaning from one setting to another, blurring the distinction between whatever different kinds of privacy people might experience.¹⁶⁹ For policy makers, however, the utility of such a conceptualization is that it is easily situated in a framework with other, competing concepts, such as crime prevention, state security, and epidemic control. Within such a framework, privacy interests can be weighed off against these other interests so that policy makers can strike an appropriate balance. However, as Charles Raab has argued, although it may be possible to balance privacy against other interests in a theoretical sense, achieving such a balance in actuality is likely impossible. Indeed, there are so many variables and interrelations that cannot be conceived within such a theoretical *balancing framework* that it is generally fallacious to speak of striking a balance.¹⁷⁰

For instance, in a recent piece of public policy dealing with securing the consent of Indigenous Peoples for the collection, use, and disclosure of their personal medical information in the Non-Insured Health Benefits Program, Health Canada takes the following stance. Under the bold title, “You Can Expect Your Privacy To Be Protected,” is written the following assurance:

Health Canada recognizes its responsibility to protect your personal information. When a request for benefits is received, Health Canada will collect, use and disclose your personal information according to applicable laws. This

¹⁶⁹ James Rule *et. al.*, The Politics of Privacy: Planning for Personal Data Systems as Powerful Technologies, (Westport, CT, 1980), p. 21.

¹⁷⁰ Charles D. Raab, “From Balancing to Steering: New Directions for Data Protection,” Visions of Privacy: Policy Choices for the Digital Age, Colin J. Bennett and Rebecca Grant (eds), (Toronto, 1999), pp. 76-77.

allows the NIHB Program to confirm the need for benefits and to pay for the benefits which you receive.¹⁷¹

This policy statement makes it plainly evident that Health Canada intends to collect, use, and disclose the personal medical information of Indigenous Peoples using the Non-Insured Health Benefits Program. Thankfully, Indigenous Peoples can withdraw their consent and “have the [wonderful!] option of paying for eligible non-insured health benefits.”¹⁷²

Clearly, the meaning of privacy in this policy statement is commodified such that it may be traded for health benefits. It is true that Health Canada promises to treat the personal information of Indigenous Peoples according to applicable laws. Still, the policy states that the government will collect peoples’ names, addresses, identification numbers, names of children, past and current treatment, information concerning peoples’ medical and dental conditions, and laboratory results among other things. This information may be shared with the contractor administering the claims process, health practitioners and their professional licensing bodies, and medical insurance plans among other organizations.¹⁷³ The kind of privacy protection Health Canada has in mind here is beyond me. At any rate, the drafters of this policy probably felt that they were offering something of equal value to merit such privacy intrusions. Privacy, statically defined as such, is balanced against health benefits. However, this particular calculus fails to account for the larger social effects of such a trade-off. Here, bureaucratic dataveillance enhances the potential for repressive control. These modes of dataveillance “heighten the concrete and potential influence of centralized powers, both by what they accomplish and

¹⁷¹ I am indebted to Taiaiake Alfred for directing me towards this policy. See: Canada, Health Canada, First Nations and Inuit Health Branch, Non-Insured Health Benefits: Consent Overview, on-line at: <http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/nihb/consent/pamphlet.htm>. Viewed on: 18/04/03. Last Updated: 12/09/02.

¹⁷² *Ibid.*

However, people withdrawing their consent still “need to complete a NIHB Client Reimbursement Request Form **and submit all receipts and any required documents to Health Canada** or to a First Nations or Inuit organization who is providing non-insured health benefits.” (emphasis mine)

¹⁷³ *Ibid.*

by what people fear they may accomplish.”¹⁷⁴ In this case, consent to dataveillance is encouraged by the threat of making health benefits more difficult to obtain. Hence, the government attempts to naturalize the process whereby Indigenous Peoples report their health status to the state.

In law, as in policy, information privacy has been conceived of in similar liberal, individualistic, and static terms. The *privacy issue* first appeared on the legal agenda in Canada, as in other places, in response to three important developments: the computerization of personal information systems in the public sector; use by the state of the Social Insurance Number as a general identification number; and an increasing sense of alienation from government agencies. These developments prompted the creation of the Office of the Privacy Commissioner in 1977, as part of the broader Canadian Human Rights Act. The privacy sections of this Act were not retired until 1982 when Canada passed a stand alone *Privacy Act*.¹⁷⁵ The *Privacy Act* makes the Privacy Commissioner an independent officer of Parliament. Under this act the Commissioner has a mandate to

investigate complaints and conduct audits under two federal laws; publish information about personal information-handling practices in the public and private sector; conduct research into privacy issues; and promote awareness and understanding of privacy issues by the Canadian public.¹⁷⁶

Consequently, the Commissioner may subpoena witnesses, compel testimony, enter premises in order to obtain documents and conduct interviews, and conduct audits of federal institutions, recommending changes where necessary.¹⁷⁷

The federal *Privacy Act*, then, regulates the collection, use, and disclosure of personal information held by federal public agencies. This public sector legislation was subsequently augmented by legislation meant to regulate the flow of personal information in the private sector. The *Protection of Personal Information and Electronic Documents*

¹⁷⁴ Rule *et. al.*, *The Politics of Privacy*, p. 79.

¹⁷⁵ Bennett, “What Government Should Know About Privacy: A Foundation Paper.”

¹⁷⁶ Canada, Office of the Privacy Commissioner (George Radwanski), “About Us,” Office of the Privacy Commissioner, (Ottawa, 2002), on-line at: http://www.privcom.gc.ca/au_e.asp. Viewed on: 20/01/03. Last Updated: 20/01/03.

¹⁷⁷ David Baniser, Sarah Andrews, *et al.* *Privacy and Human Rights 2002: An International Survey of Privacy Laws and Developments*, (Washington, 2002), p. 135, on-line at: <http://www.privacy.org/pi/survey/phr2002>. Viewed on: 18/01/03.

Act (hereafter PIPEDA), which began to take effect in some jurisdictions and sectors in 2001, covers private sector organizations that process personal information during commercial activity.¹⁷⁸ The Privacy Commissioner has similar investigative powers under PIPEDA as under the *Privacy Act* and is additionally empowered to conduct research into privacy issues and promote privacy among Canadians.¹⁷⁹

Provincially, there are three categories of privacy regulation: public sector law; private sector law; and, sector specific law. Where there is no provincial oversight authority, federal information privacy laws are paramount. Many provinces have also moved to initiate sector specific laws in the areas of consumer credit reporting, credit unions, private investigators and other professionals, and, particular to our interests here, health information. Alberta, Manitoba and Saskatchewan have all moved to enact health privacy legislation (Ontario too is moving in this direction). These laws will then apply to personal health information held by hospitals, government ministries, regulated health care professionals, and other health care facilities.¹⁸⁰ In each of these provinces, statutory mechanisms frame health information privacy in individual terms.¹⁸¹

In Canadian legal and policy discourses concerning information privacy, the dominant mode of thought is situated squarely within the liberal individualist paradigm. These mechanisms are therefore geared towards fostering the conditions for individual informational self-determination. They do not facilitate the conceptualization of information privacy in collective terms and therefore do not adequately contemplate

¹⁷⁸ Bennett, "What Government Should Know About Privacy: A Foundation Paper."

PIPEDA's application was sequentially broadened from banks, telecommunications companies, broadcasting companies, and airline and other transportation companies, to include all commercial activities in the private sector.

¹⁷⁹ Baniser, Andrews, *et. al.*, Privacy and Human Rights 2002, p. 136.

¹⁸⁰ *Ibid.*, p. 144.

¹⁸¹ See: the Alberta Health Information Act (2001), on-line at: <http://www.qp.gov.ab.ca/documents/acts/H05.cfm>, viewed, 18/04/03; the Saskatchewan Health Information Protection Act, on-line at: <http://www.qp.gov.sk.ca/documents/english/firstread/1999/bill-29.pdf>, viewed, 12/04/03; the Manitoba Personal Health Information Act (1997), on-line at: <http://web2.gov.mb.ca/laws/statutes/ccsm/p033-5e.php>, viewed, 18/04/03, last updated, 10/04/03; and, the proposed Ontario Personal Health Information Privacy Act 2000, on-line at: http://www.health.gov.on.ca/english/public/pub/ministry_reports/phipa/bill_159.pdf, viewed, 18/04/03.

collective informational self-determination. By marginalizing the possibility of the formulation of collective informational self-determination, the Canadian legal and policy discourses concerning information privacy exclude group claimants who would articulate their *sui generis* interest in privacy based on their Indigenous identity. The next section of this chapter considers the privacy interests of Indigenous Peoples through the concept of collective informational self-determination.

Privacy and Indigenous Groups

It would be worth noting, at this point, that Indigenous Groups in Canada seem to have made little use of statutory privacy protection mechanisms. While there is no publicly available information on the usage of privacy protection mechanisms by Indigenous Peoples at the federal level, we may observe that, at the provincial level, the majority of the grievances filed by Indigenous groups seem to be over access to information rather than privacy.¹⁸²

There could be any number of reasons why Indigenous groups have not made use of statutory privacy protection mechanisms. On pure speculation, these reasons may include: a general cynicism about the efficacy of Canadian legal tools, a rejection of the notion of information privacy as it has been dominantly articulated (a point I will now explore), or, even the fact that no privacy transgressions have occurred. I do not suspect that this third possibility, that no privacy transgressions have occurred, is likely to be the case. Indeed, as our earlier discussion of the state's consent policy for Non-Insured Health Benefits suggests, and as our next chapter concerning the state's surveillance of Indigenous Peoples' health information will argue, the privacy of Indigenous Peoples has been constructed in a liberal, individualist, and static way by the state. This

¹⁸² I am grateful to John Borrows for initially making this observation in a conversation we had on October 15, 2002. Professor Borrows' observation was substantiated by a survey of four provincial Information and Privacy Commissioner web-sites. In Ontario, British Columbia, Quebec and Alberta, actions taken by Indigenous groups relate primarily to gaining access to information. I was only able to locate one instance of an Indigenous group using a statutory privacy protection mechanism (See: Office of the Information and Privacy Commissioner of Alberta, "Report on the Investigation into a Complaint about a Breach of Privacy, contrary to Part 2 of the *Freedom of Information and Protection of Privacy Act*," July 22, 2002, Investigation Report F2002-IR-004, on-line at: <http://www.oipc.ab.ca/ims/client/upload/2002-IR-004&chronology.pdf>. Viewed on: 18/01/03).

conceptualization fails to adequately address the state's surveillance of Indigenous groups. Such extraordinary surveillance, in turn, increases the likelihood that privacy transgressions do and will occur.

Arguably, Indigenous groups have not made use of statutory mechanisms in Canada owing to some combination of cynicism about the efficacy of these mechanisms and a rejection of the way these mechanisms conceptualize privacy. Given the history of the state's treatment of Indigenous Peoples in legal and policy arenas, it is easy to see why Indigenous groups would be cynical about using state mechanisms for their privacy protection. A less certain claim concerns the ways Indigenous Peoples might conceptualize privacy. The vast diversity of Peoples that are called *Indigenous* makes the project of identifying *Indigenous Privacy per se* an impossible one. If we hold the concept of informational self-determination to be the paramount principle governing any definition of information privacy, we see that such *privacy* can only be positively articulated by the person or group choosing to invoke it.

It is still useful, however, to survey the public record for evidence where Indigenous Peoples have articulated the concept of privacy. By surveying the public record for Indigenous articulations of the concept of privacy, we may begin to get a sense of whether or to what degree such articulations are incongruent with the paradigmatic liberal individualist articulation of privacy. I must qualify again, however, that I do not intend here to suggest that the articulations surveyed are representative of all conceptualizations of Indigenous privacy. Rather, my intention is to critically interrogate the paradigmatic conceptualization of privacy by holding up alternative constructions.

There is anecdotal evidence to suggest that privacy, conceived of in broad, abstract, and cross-cultural terms, is an integral value within many, if not all, Indigenous Cultures. It finds explicit expression, for instance, in Article 13 of the UN Draft Declaration on the Rights of Indigenous Peoples:

Indigenous peoples have the right to manifest, practice, develop and teach their spiritual and religious traditions, customs and ceremonies; the right to maintain, protect, and have access **in privacy to their religious and cultural sites**; the right to the use and control of ceremonial objects; and the right to the repatriation of human remains.

States shall take effective measures, in conjunction with the indigenous peoples concerned, to ensure that indigenous sacred places, including burial sites, be preserved, respected and protected. (emphasis mine)¹⁸³

In this statement, privacy assumes a specific meaning in relation to the protection of cultural heritage. It is a response to the involuntary displays of Indigenous communities and cultural heritage as tourist attractions and historical sites. These displays recall the Eurocentric expositions of a century ago.¹⁸⁴ In response to such colonial behaviour, privacy here takes on connotations of a group ‘right to be let alone.’

Privacy has also found explicit expression in a recent Assembly of First Nations declaration concerning Health Canada’s Non-Insured Health Benefits Consent Process:

...the First Nation’s Chiefs in Assembly demand that Health Canada actively respect the autonomy of the First Nations’ governments across Canada to research, conduct internal consultations and **find its own solutions to the issues of Privacy**, Prescription drug abuse and Provider abuse (emphasis mine).¹⁸⁵

Here privacy is identified as a discourse over which the state seeks to dominate. It is recognized as a policy area over which Indigenous governments need autonomous

¹⁸³ United Nations, Sub-Commission on the Prevention of Discrimination and Protection of Minorities, UN Working Group on Indigenous Populations, UN Draft Declaration of The Rights of Indigenous Peoples.

Similarly, Article 31, while it does not explicitly mention privacy, emphasizes the importance of Indigenous control over Indigenous information. This article states: “Indigenous peoples are entitled to the recognition of the full ownership, control and protection of their cultural and intellectual property. They have the right to special measures to control, develop and protect their sciences, technologies and cultural manifestations, including human and other genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs and visual and performing arts.”

¹⁸⁴ Marie Battiste and James (Sa’ke’j) Youngblood Henderson, Protecting Indigenous Knowledge and Heritage: A Global Challenge, (Saskatoon, 2000), pp. 109-110.

In one case in the United States, for instance, *Fools Crow v. Gullet* (1982) 541 F. Supp. 785 (D.S.D. U.S.A), the authors note that Lakota elders contested the development of their most sacred mountain, Bear Butte in South Dakota because they feared the desecration and exploitation of their religious practices. At the time of the case, tourists “had already begun to interrupt some ceremonies and to disturb the privacy of individual Lakota who were seeking visions in remote parts of the mountain. A federal court rejected these claims, stating that interference from tourists would not be an insurmountable obstacle to the continued ceremonial use of Bear Butte.” This case clearly demonstrates a lack of cultural sensitivity on the part of the American Court. Privacy was held up as a shield against this insensitivity.

¹⁸⁵ Assembly of First Nations, “Resolution no. 15/2002 – RE: Non-Insured Health Benefits Consent Process,” Assembly of First Nations Annual General Assembly, July 16, 17, 18, 2002, on-line at: <http://www.afn.ca/resolutions/2002/aga%202002/res15.htm>. Viewed on: 19/01/03.

control. In this instance, the term *privacy* comes close to connoting information privacy. It rejects, however, the policy approach, discussed in the previous section of this chapter, of trading privacy for health benefits. In place, it suggests a local, community response to privacy.

It is noteworthy that neither of these statements is framed in individualist terms. Each statement emphasizes the collective element of privacy. In this context, I would like to return, for a moment, to the concept of self-determination. As Patricia Monture-Angus has stated, self-determination is “about our relationships. ...It is difficult for individuals to be self-determining until they are living as part of their community.”¹⁸⁶ Recalling our discussion of self-determination in the first chapter of this thesis, we may observe that it is founded upon individual freedom from within free communities. It is difficult to imagine individual self-determination without collective self-determination. Similarly, it is difficult to think about individual informational self-determination removed from context. Informational self-determination too has collective aspects. The paradigmatic, liberal, individualist information privacy discourse, however, excludes this collective aspect and we must ask whether Indigenous groups too are excluded.

I have already suggested that, where Indigenous groups are excluded from using the protection mechanisms of the information privacy regime, they are susceptible to dataveillance practices that would threaten their capacity to be self-determining. Let us draw from Oscar Gandy’s observations an understanding of the way marginalized groups are further marginalized by dataveillance practices. Though these observations concern market-place surveillance, they plainly describe the way these practices flow from and reinforce status quo population segmentation. They point to the need for an accommodation of collective information privacy in the Canadian privacy protection regime.

The focus of Gandy’s work is largely upon the private sector’s use of dataveillance to sort the American population. His book emphasizes the way that the discriminatory function of dataveillance both enforces and is reinforced by social segmentation. Citing a study of the limited success of African-Americans and other

¹⁸⁶ Monture-Angus, *Journeying Forward*, p. 8.

minorities to obtain home mortgages, Gandy observes that race was consistently being used to shut out all but exceptional applicants. Minorities were denied mortgages two and three times more often than whites. The assumption that these differences could be explained by income did not hold up to scrutiny. In fact, when income was held constant, discrimination actually increased.¹⁸⁷ The racial profiling, which dataveillance enabled, functioned, in this instance, to sort out individuals on the basis of their association with groups. Once sorted into a group, the boundaries of confinement became difficult to overcome. In this case, the inability of members of a group to secure credit, and thus leverage themselves into a wealthier segment of the population, was perpetuated by virtue of their having been associated with a less wealthy, racially determined segment.

In Gandy's study, peoples' personal financial behaviour was scrutinized against an index of attributes designed to predict the likelihood that a person would repay a loan. Here, dataveillance involved three integrated processes. The first process was one of identification. This identification was of a minimal kind and focused only on attributes that had administrative relevance. It was a practice of identifying people with histories, records, and signatures.¹⁸⁸ The second process, classification, involved the assignment of the identified individual to certain conceptual groups. This process facilitated "inferences about deep structure from surface appearance."¹⁸⁹ Gandy observed that, through this process of classification, dataveillance institutionalized biases because of a tendency to fill in blind spots with familiar or expected outcomes. The third process, assessment, was a form of comparative classification. By comparing groups against each other, this process established norms. It de-contextualized individuals from their particular circumstances.¹⁹⁰

The previous chapter demonstrated how dataveillance practices enable social sorting. Gandy's work is useful to our consideration of the effects of dataveillance on Indigenous Peoples because it links these discrete acts of social sorting to the

¹⁸⁷ Gandy, *The Panoptic Sort*, p. 201.

¹⁸⁸ *Ibid.*, p. 15.

¹⁸⁹ *Ibid.*, p. 16.

¹⁹⁰ *Ibid.*, p. 18.

perpetuation of social inequality. His discussion of the processes of identification, classification, and assessment that underpin dataveillance demonstrate the way dataveillance practices reify racially determined social groupings. On the basis of his analysis, we can understand the need for the Canadian privacy protection regime to make space for a collective conceptualization of information privacy. For those who are marginalized in society, the paradigmatic liberal regime is not sufficient. It does not account for the systematic discrimination they receive prior to, and then because of, their historically determined marginalized status.

Towards a Collective Privacy Discourse

The concept of *collective privacy* attempts to break with the paradigmatic formulation of information privacy. This concept, perhaps best articulated by Priscilla Regan, chooses to focus on the social dimensions of privacy. As such it may constitute a point of departure for Indigenous conceptualizations of privacy, should Indigenous groups choose to resist their dataveillance using privacy protection mechanisms. Regan argues that using the individual as a basis for privacy protection is a conceptually weak foundation. Dataveillance is not a technique that individuals use in relation to other individuals. Rather, it is used by organizations and affects all individuals' relationship to these organizations.¹⁹¹ Flowing from this observation, Regan explores a conceptualization of privacy that emphasizes its collective value.¹⁹²

To begin with, Regan argues that every person has a common interest in privacy. This interest is common in the same way that every person has a common interest in freedom of conscience. Widespread acceptance of privacy in some form or another suggests that a "prior commitment is made to an overarching concept of privacy from which we derive the meaning of privacy in particular circumstances."¹⁹³ This formulation is reminiscent of the way that self-determination was formulated earlier in

¹⁹¹ Priscilla M. Regan. Legislating Privacy: Technology, Social Values, and Public Policy, (Chapel Hill, 1995), p. 213.

¹⁹² *Ibid.*, p. 221.

¹⁹³ *Ibid.*, p. 224-225.

this thesis. In its connection between the universal and the particular, this abstract, overarching concept of privacy can thus be established as a collective good.

Drawing from economic theories of groups, Regan argues that no one member of society can enjoy the benefit of collective privacy without others also benefiting. Collective goods cannot be divided. Neither can they be exclusionary.¹⁹⁴ Situated in late-modernity, people seem to have less and less control over their *data doubles*. Under these conditions, collective information privacy can be conceived of as a common value when it is articulated as a social claim rather than as an individual claim. To quote Regan:

Instead of defining privacy as the right of the individual to control information about and access to himself or herself, privacy would be defined as the right of a society to require institutions using personal information to do so in a manner that respects the shared interests in that information.¹⁹⁵

If they were formulated in this way, privacy protection instruments could represent the best way to shield Indigenous information from state misuse.

Such a conceptualization of information privacy would accommodate collective interests in informational self-determination. It would entail mechanisms that would be used by groups to resist state surveillance. As we shall see in the next chapter, these mechanisms might conceptualize a community's data in a proprietary way. Information generated from this data would be subject to the community's *Ownership, Control, Access, and Possession*. Creating space for an approach such as this would be one way to transform state discourses on information privacy, Aboriginal rights, and self-government, so they would be able to contemplate Indigenous informational self-determination. This approach would acknowledge and address the state's differential application of dataveillance practices. More importantly, however, the institutionalization of a collective conceptualization of privacy would signify to law and policy makers the need to interrogate their dataveillance practices, in particular relation to

¹⁹⁴ *Ibid.*, pp. 227-228.

¹⁹⁵ *Ibid.*, p. 232.

Indigenous Peoples, to see where they might impinge upon Indigenous self-determination.

Conclusion

This chapter charted the discursive space of the Canadian legal and policy responses to surveillance. It observed that this space is dominated by the paradigmatic, liberal, individualist conceptualization of information privacy. Examination of the state's recent policy concerning the Non-Insured Health Benefits Program, as well as consideration of the way health information is defined in federal and provincial law, demonstrated the dominance of the privacy paradigm. I argued that this formulation in law and policy precludes groups from articulating their privacy rights. Such exclusion is highly problematic because some groups receive more surveillance than others. Groups that are marginalized, like Indigenous groups, ought to have access to space in the Canadian legal and policy privacy discourses to articulate mechanisms that will resist the extraordinary surveillance they receive.

A survey of the public record highlighted two examples of *privacy* as it had been articulated by Indigenous groups. These articulations diverged from the paradigmatic conceptualization reflected in state legal and policy discourses. Each of these examples connoted a collective conceptualization of privacy. While this survey can, by no means, claim to be representative of *Indigenous Privacy per se*, it is indicative of the existence of alternative ways of conceptualizing privacy. These ways, readers will note, are excluded from state discourses.

In the next chapter I consider the ramifications of the exclusion of Indigenous Peoples from state privacy discourses and the exclusion of privacy from state discourses of Aboriginal rights and self-government. I examine a specific instance of the state's dataveillance of Indigenous information. I use the *First Nations and Inuit Health Information System*, a comprehensive health database, as a case study to explore some effects of dataveillance on Indigenous informational self-determination. I also consider the way in which a more collective conceptualization of privacy might help to further projects of Indigenous self-determination.

**Unhealthy Until Proven Healthy –
The Positively Negative Consequences of the State’s Dataveillance of
Indigenous Health Information**

I would like to take you back in time....What happened in the 1800s and early 1900s, I am told by the elders, is that certain diseases swept across our lands and the lands of the Big Trout Lake people. Smallpox, chicken pox, tuberculosis, mumps, measles. Diseases that [our healers] didn’t know how to heal or how to counter with their herbal medicines. [These diseases] totally decimated our villages. [They] totally decimated the clan structure that we knew, the clan system that governed our lives...

My grandfather, who was a headman in Bearskin Lake at that time, heard about the treaties that had happened in Northern Manitoba in the Island Lake area. Through the missionaries or the Hudson Bay managers that were already in the area, he wrote a letter to the Queen, requesting that they be allowed to sign treaty with the Queen of England or the King of England. It was only because of these illnesses that plagued our people, and because the conservation officers were really hard on our people and confiscated their livelihood, that...my grandfather was, in a way, forced to request for the treaty to be signed in Big Trout Lake.¹⁹⁶

Chief Frank Beardy
Muskrat Dam First Nation community
Big Trout Lake, Ontario, 3 December 1992

This quotation speaks of the devastation wrought on healthy societies by epidemics that crossed the Atlantic with European colonists. According to the Royal Commission on Aboriginal Peoples (hereafter RCAP), considerable historical and paleo-

¹⁹⁶ Frank Beardy, cited in: The Royal Commission on Aboriginal Peoples. “Chapter 3 – Health and Healing,” Gathering Strength - Final Report (Volume 3), (Ottawa, 1996), pp. 137-38.

The treaty Beardy is referring to in this quotation is Treaty 9. Treaty 9 is one of the eleven numbered treaties negotiated between the Government of Canada and Indigenous Peoples between 1871 and 1921. The Treaty covers land in northern Ontario and was signed in 1905 and 1906 by government representatives and numerous leaders of the Cree and Ojibwa Peoples who lived in the area. The written text of the treaty contains a series of promises made by the Government in return for the apparent agreement of Indigenous Peoples to surrender rights, initially, to 130 000 square miles of ancestral land. The written text also suggests that the Indigenous Peoples agreed to move to reserves totaling only 524 square miles. For an in-depth analysis of this treaty and the conflict of interpretation between written and oral understandings, see: Patrick Macklem, “The Impact of Treaty 9 on Natural Resource Development in Northern Ontario,” in Michael Asch (ed) Aboriginal and Treaty Rights in Canada: Essays on Law, Equality, and Respect for Difference, (Vancouver, 1997), pp. 97-134.

biological evidence exists to demonstrate that, prior to contact with Europeans, Indigenous Peoples in the area now commonly known as Canada enjoyed good health. This evidence further suggests that many of the illnesses common today were once rare. RCAP observed that Indigenous Peoples were well aware of the connection between contact with newcomers and the spread of epidemic. In expectation of fair compensation, many nations agreed to relocate in areas distant from colonial settlements.¹⁹⁷ Clearly, the connection between the health of Indigenous Peoples and the current geo-political make-up of the area now known as Canada is a strong one.

In Frank Beardy's testimony to RCAP, ill health is linked directly to the political degradation of the Muskrat Dam Nation. Beardy's statement highlights the complicity of the newcomers in creating the unfavourable health situation that they later capitalized upon. It was ill health that pushed the Muskrat Dam Nation into an unfavourable treaty. Ill health, and the perception of ill health, played a definitive role in this instance of drawing Indigenous Peoples into a relationship with the state. From the subordinated position of *ill*, the Indigenous place in this relationship assumed characteristics of dependency.

While Indigenous Peoples today do not have to contend with smallpox, research seems to indicate that ill health afflicts Indigenous Peoples more than non-Indigenous Peoples. A recent survey of five chronic conditions' indices (diabetes, cancer, heart disease, hypertension and arthritis / rheumatism) stated that "the prevalence of all five conditions among First Nations exceeds that of all Canadians in all major age-sex groups."¹⁹⁸ Indeed, in 1996, RCAP noted that Indigenous Peoples endured ill health "at levels usually associated with impoverished developing countries." The Commission rightly proclaimed that the "persistence of such social conditions in this country – which is judged by many to be the best place in the world to live – constitutes an embarrassment to Canadians..."¹⁹⁹ These health indicators need to be viewed from two points.

¹⁹⁷ *Ibid.*, pp. 111-113.

¹⁹⁸ T. Kue Young *et. al.*, First Nations and Inuit Regional Health Survey, (Ottawa, 1997), on-line at: <http://www.afn.ca/Programs/Health%20Secretariat/PDF's/f.pdf>. Viewed on: 13/03/03.

¹⁹⁹ The Royal Commission on Aboriginal Peoples. "Chapter 3 – Health and Healing," p. 1.

At one level, the state of Indigenous Peoples' health is directly connected to their ability to carry out projects of self-determination. As the quotation that opened this chapter suggests, ill health was in many cases directly linked to the displacement of Indigenous Peoples from ancestral lands to tiny reserves. Clearly, the decimation of Indigenous communities by epidemics made resistance to settler encroachment difficult. In the absence of physical well-being, paths to self-determination seemed difficult, if not impossible, to build. In RCAP's words, the "relationship between self-determination and health is a circle... thus, only when whole health is achieved will successful and mature self-determination be possible."²⁰⁰

At another level, perceptions of health need to be viewed in the larger socio-economic circumstances from which they are derived. If we politicize the term *health*, if we frame *health* as a discourse, we open it up to scrutiny on a normative basis. In this sense, "health is never simply a neutral, biological category." Instead, "all definitions of health... are laden with ideological nuances and can never be separated from cultural norms and values."²⁰¹ Literature on the sociology of health has done a good job of questioning the normative processes involved in the social construction of illness and well-being. By examining health as a discourse, by linking social organization to medical practice, this literature argues that the relationship between disease and social structures is often a reciprocal one. Focusing on the connection between the health discourse and social structures, social constructivist analyses observe that "social relations contribute to the creation of diseases, and the language of disease, which is presumed to be 'natural', serves to conceal the nature of social relations."²⁰² The consequences for diagnoses, if we accept that health and social relations are intertwined, are that illness and well-being can never be assessed in neutral or natural ways.

Unfortunately, health is still generally conceptualized as a natural and neutral category against which it is possible to determine degrees of non-health. In this

²⁰⁰ *Ibid.*, p. 109

²⁰¹ Naomi Adelson, *Being Alive Well': Health and the Politics of Cree Well-Being*, (Toronto, 2000), p. 3.

²⁰² Sarah Nettleton, *The Sociology of Health and Illness*, (Cambridge, 1995), p. 26,

formulation, health is determined in terms of the relative absence of disease.²⁰³ Focusing on the social constructivist elements of health, anthropologist Naomi Adelson has observed that a

biomedical concept of health permeates and is literally embodied in what people define as their own sense of well-being, so that values such as self-discipline, self-denial, control and will power are woven through – and impossible to disentangle from – interpretations of health.²⁰⁴

The social consequences of a discourse dominated by this conceptualization of health run deep. As Adelson argues, being healthy thus tends to restrict people to certain proscribed biological and social moralities. Those who do not conform to this naturalized concept of health are in jeopardy of being corrected.²⁰⁵

Adelson does note that this theorization of the health discourse risks being somewhat heavy handed. It leaves little room for individual agency or for forms of resistance that are rooted in self-discipline, self-denial, control, and will power. Still, this theorization is useful here, as we make a link back to surveillance literature, in our consideration of the effect that dataveillance can have on informational self-determination. When we theorize the health discourse as a normative one, we can begin to look for interests that motivate its promotion. Furthermore, from this normative point, we may begin to scrutinize the mechanisms through which the health discourse is promoted, mediated, and facilitated.

Building on the claim made in the previous two chapters, this chapter works through the theoretical problems that dataveillance poses to Indigenous self-determination by grounding analysis in an exploratory example of health surveillance. It opens with a brief discussion of health information and its particular sensitivity to dataveillance. It then considers the way the state has bought into the promise of health dataveillance by rationalizing privacy trade-offs. This discussion is then followed by a descriptive analysis of the *First Nations and Inuit Health Information System* (hereafter FNIHIS), a database management system (hereafter DBMS) designed by Health Canada

²⁰³ Adelson, 'Being Alive Well', pp. 4-5.

²⁰⁴ *Ibid.*, p. 7.

²⁰⁵ *Ibid.*, pp. 7-8.

to manage the health information of Indigenous Peoples. The chapter suggests that the FNIHIS, insofar as it replicates and deploys state dataveillance practices, may engender conditions under which liberal, individualistic normative assumptions about health are internalized by Indigenous Peoples. If it is the case that this technological apparatus encourages Indigenous Peoples to buy into particular beliefs about health and lifestyle, then serious questions must be raised concerning the state's deployment of this apparatus.

These questions, raised in the context of Indigenous self-determination, must address dataveillance practices as part of larger processes of governance. Asked in conjunction with questions asked concerning state discourses of Aboriginal rights and self-government, these questions critically interrogate processes that (re)affirm a *paternalist* dynamic in the Indigenous-State relationship. In searching state dataveillance practices for the existence of such a dynamic, this chapter will consider the link between the categories used by the FNIHIS and prevailing social stratifications. It will be argued that the categories used by the FNIHIS risk recasting the Indigenous-state relationship in colonial, paternalist terms.

The Dataveillance of Health Information

Information processing plays a significant role in the provision, regulation, and financing of medical services by government.²⁰⁶ According to Alan Westin, people's medical information is used by organizations in three areas. First, it is used to direct patient care by doctors, nurses, community health representatives, clinics, and nursing homes. Second, it is used in supporting and administrative activities by service payers, administrators, and quality care reviewers. The state, for instance, uses health information to determine how much it will spend on health care. Third, it is used in broader applications, often termed secondary uses, for credential and evaluation decisions, public health reporting, academic research, and marketing.²⁰⁷ These three

²⁰⁶ Paul M. Schwartz, "The Protection of Privacy in Health Care Reform," *Vanderbilt Law Review*, vol. 48(2), p. 300, 1995.

²⁰⁷ Alan F. Westin, "Interpretive Essay," Health Information Privacy Study 2 – Health Information Privacy Survey, Harris-Equifax, (Atlanta, 1993), pp. 7-8.

areas of use result in a large number of people accessing health information. As David Flaherty has noted, sometimes as many as 75-100 people end up seeing a person's medical records.²⁰⁸

If health information is widely sought after, it is also, generally speaking highly sensitive.²⁰⁹ Most people recognize that their personal medical history, in the wrong hands, could adversely affect their lives. Ann Cavoukian and Don Tapscott highlight the following example to illustrate the sensitivity of health information:

[American Congresswoman Nydia Velázquez gave the following testimony before a Senate Judiciary in 1994]: During my campaign for Congress, I realized that no one is immune from privacy violations. I had my private, personal medical records leaked to the newspapers in New York City....Just imagine what I felt like, three weeks after I won this victory in the primary, when I woke up one morning with a phone call from my friend Peter Hamill, a reporter at the *New York Post*. He told me that the night before, the *Post* had received an anonymous fax of my records from St. Claire Hospital. The records

²⁰⁸ David Flaherty, Privacy and Data Protection in Health and Medical Information – Notes for a Presentation to the 8th World Congress on Medical Information, (Vancouver, 1995), p. 2

In the case of an audit conducted to prevent fraud or fiscal abuse, for instance, the Ministry responsible for financing health care can request photocopies of individual's medical records. These records may then be distributed to various committees during the course of the audit. In Ontario, a physician who is being audited is given a list of up to 200 patients, whose records he or she must make available to the auditor. The inspector photocopies these records and includes them in the report that is sent to the Medical Review Committee of the College of Physicians and Surgeons. See: Ann Cavoukian and Don Tapscott, Who Knows: Safeguarding Your Privacy in a Networked World, (Toronto, 1997), p. 118.

²⁰⁹ Westin, Health Information Privacy Study 2, p. 10.

While this data is now somewhat dated, it is still worthwhile to note that, at the time this survey was conducted, 85% of people polled believed that protecting the confidentiality of medical records was "absolutely essential" or "very important" in health care reform. Additionally, 64% did not want medical researchers to use their records for studies, even if the individual was never identified personally, unless researchers first got the individual's consent. More recent public opinion data from Canada suggested that 74% of people "believe that the information they provide their physicians is kept confidential." Additionally, 11% of people "indicated they had on at least one occasion held back information from a health provider because they were concerned about who it would be shared with or for what purposes it would be used." Finally, 72% of people "believe any government legislation designed to protect privacy and confidentiality of health information should focus on the private and public sectors equally." These statistics were compiled for the Canadian Medical Association by Angus Reid (now Ipsos Reid) and were released on the 29th of November, 1999. Cited in: Canadian Medical Association, "Canadians Highly Value the Privacy and Confidentiality of their Health Information," on-line at: <http://www.cma.ca/cma/common/displayPage.do?pageId=/staticContent/HTML/N0/12/advocacy/ws/1999/11-29.htm>. Viewed on: 21/04/03. See also: Alberta Medical Association, "Health Reform in Alberta: Issues for Discussion," on-line at: http://www.albertadoctors.org/advocacy/sustainability/Privacy_and_security_Jan%20_11_02.pdf. Viewed on: 18/04/03.

showed that I had been admitted to the hospital a year ago, seeking medical assistance for a suicide attempt. He told me that other newspapers across the city had received the same information and the *New York Post* was going to run a front-page story the next day...When I found out this information was being published in the newspaper and that I had no power to stop it, I felt violated. I trusted the system, and it failed me.²¹⁰

There are countless similar but less high-profile examples of how people's medical information has been used in ways that restrict their life-chances. The testimony of Congresswoman Velázquez demonstrates the fallout that can occur when a person's medical information is mishandled.

When a person is associated with a social group that faces systemic discrimination, his or her medical information is doubly sensitive. As is the case for Indigenous Peoples, for instance, the sheer amount of information generated through interactions with the state proportionately increases the probability that their information will be mishandled over probabilities faced by non-Indigenous groups. One source carefully outlines the danger that Indigenous Peoples could face if their medical information is misused by the state. The Indigenous Peoples Council on Biocolonialism notes that advances in DBMS technology have facilitated the collection and logging of DNA samples that can be used to search for molecular clues to hereditary diseases. The Human Genome Project, for instance, has made use of "rapid technological advances" to work towards the identification of the nearly 30 000 genes that make up Human DNA.²¹¹

While this kind of research promises great leaps in medical knowledge there is a tendency to under-theorize other, less benevolent uses of the information/knowledge that is produced. The Council states:

...the Human Genome Diversity Project (HGDP) proposes to collect the DNA samples of indigenous peoples and store the collections in gene banks... Referring to indigenous populations as "isolates of historic interest (IHI's)" the HGDP plans to immortalize the DNA of disappearing populations for future study. The initial conceptualization of the HGDP has been widely criticized for its consideration of indigenous peoples as mere research subjects, with little

²¹⁰ Nydia Velazquez, "Testimony before the Senate Judiciary Committee, 1994," cited in: Ann Cavoukian and Don Tapscott, *Who Knows: Safeguarding Your Privacy in a Networked World*, (Toronto, 1997), p. 116.

²¹¹ United States, Department of Energy and National Institutes of Health, "About the Human Genome Project," *Human Genome Project Information*, (Washington, 2003), on-line at: <http://www.ornl.gov/hgmis/project/about.html>. Viewed on: 18/01/03. Last Updated: 18/02/03.

regard for the continued livelihood of the targeted populations.

...[Additionally] Scientists expect to reconstruct the history of the world's populations by studying genetic variation to determine patterns of human migration. In North America, this research is focused on validation of the Bering Strait theory. It is possible these new "scientific findings" concerning our origins can be used to challenge aboriginal rights to territory, resources, and self-determination. Indeed, many governments have sanctioned the use of genomic archetypes to help resolve land conflicts and ancestral ownership claims among Tibetans and Chinese, Azeris and Armenians, and Serbs and Croats, as well as those in Poland, Russia, and the Ukraine who claim German citizenship on the grounds that they are ethnic Germans. The secular law in many nations including the United States has long recognized genetic archetypal matching as a legitimate technique for establishing individual identity.²¹²

These developments clearly indicate that the collection, storage, and manipulation of the personal medical information of Indigenous Peoples by states and other organizations could lead to actions that adversely affect Indigenous Peoples.

To understand how these effects might play out in a Canadian context, we may draw upon the insights of Jennifer Poudrier's thoughtful article, entitled "'Racial' Categories and Health Risks." Here, Poudrier offers a critique of the epidemiological surveillance of Indigenous Peoples. To begin with, she asserts that the biomedical discourse, in which epidemiological surveillance is rooted, tends to rationalize and reduce the human body and illness to a physiological, biological and cellular level. This is the level at which identification occurs. Where the biomedical discourse emerges in the context of power relations, it forms, regulates, and relies upon definitions of *sickness* and *health* that are inscribed on individual and social bodies.²¹³ This is the level at which classification occurs. In Canada, the relatively unquestioned power of the biomedical discourse has had a direct connection to the advancement of colonial policies, which have been justified on assessments informed by identification and classification practices.

Poudrier draws on the historical work of Mary-ellen Kelm to illustrate the role of the biomedical discourse in perpetuating colonialism. Kelm, who focused on the

²¹² IPCB, "Indigenous Peoples, Genes and Genetics: What Indigenous Peoples Should Know About Biocolonialism – A Primer and Resource Guide," (Wadsworth, 2000), on-line at: <http://www.ipcb.org/publications/primers/htmls/ipgg.html>. Viewed on: 18/01/03.

²¹³ Poudrier, "'Racial' Categories and Health Risks: Epidemiological Surveillance Among Canadian First Nations," p. 114.

emergence of a tuberculosis epidemic among Indigenous populations between 1900 and 1950, observed that Indigenous bodies were characterized as racially susceptible to disease. Colonial medicine, through the work of field matrons, missionaries, and doctors, served to pathologize the Indigenous body. This pathologization failed to take account of the correlation between the spread of tuberculosis and increased contact between Indigenous groups and European settlers. It therefore falsely constructed the Indigenous body as *diseased* and *dangerous*. This formation, regulation, and definition of Indigenous Peoples' health ended up shaping a range of racist policy directed at the Indigenous population.²¹⁴

Poudrier wonders if, in the modern context, similar discursive formations are at work. To address her concerns, she examines the discourse of epidemiology. This discourse has become the science of general population health and is based on information derived from statistical and mathematical calculations, risk ratios, and control group analysis. Determinants of disease are uncovered by comparing sub-groups within the population against other groups. Following this methodology, epidemiological dataveillance has produced information about healthy sexual behaviour, about the relationship between health and physical activity, about how long it is safe to stay in the sun, and about how much fresh produce to consume each day.²¹⁵

Presented with a list of healthy and unhealthy behaviours, individuals are likely to self-regulate with the purpose of ensuring that they are living a healthy lifestyle. When behaviours are presented in these binary terms, there is a significant disincentive to engage in any kind of activity associated with being unhealthy. As Robert Crawford eloquently states:

No longer living 'toward death' but in flight from it, the healthy self mobilizes all available resources to fend-off the threat of dissolution. The unhealthy then come to represent the inevitability we would deny. They disturb the dream of technology and its promise of health delivery. In the unhealthy... the scientific

²¹⁴ Mary-Ellen Kelm, Colonizing Bodies: Aboriginal Health and Healing in British Columbia, 1900-50, (Vancouver, 1998), cited in: Poudrier, "'Racial' Categories and Health Risks: Epidemiological Surveillance Among Canadian First Nations," p. 116.

²¹⁵ Poudrier, "'Racial' Categories and Health Risks: Epidemiological Surveillance Among Canadian First Nations," p. 117.

world view confronts the reality of failed systems of management and control. As the ritual of rational control moves ‘upstream’ toward prevention... the unhealthy, labeled as complicitous in their fate, and said to compromise the physical and economic well-being of all, are further stigmatized as obstacles to the achievement of health.²¹⁶

Framed in these terms, epidemiological dataveillance, and its consequent discourse, assumes the characteristics of a tool of disciplinary power over problematic populations and dangerous lifestyles. As Poudrier notes, many Indigenous communities today are portrayed as poverty and disease-ridden places – the image of *unhealth*. These portrayals are used to legitimize the paternalistic management of Indigenous health by the state. Such management marginalizes larger projects of self-determination.²¹⁷

Public Policy -- Buying into the Promise of Health Dataveillance

Epidemiological surveillance and health management is today made possible by information technologies, such as the DBMS. According to the Advisory Committee on Health Infostructure, health surveillance requires a “clinical data repository” to “track emerging diseases and threats to health (e.g. contaminated food, bio-terrorism).”²¹⁸ The Advisory Council on Health Infostructure has recognized the dataveillance implications of the collection, storage, and use of health information. It has deployed the paradigmatic information privacy discourse in response to these implications. The Council has defined information privacy as “the right of individuals to determine when, how, and to what extent they share information about themselves.”²¹⁹ This definition clearly embodies the

²¹⁶ Robert Crawford, “The Boundaries of the Self and the Unhealthy Other: Reflections on Health, Culture, and AIDS,” *Social Science and Medicine*, vol. 38(10), 1994, p. 1357.

²¹⁷ Poudrier, “‘Racial’ Categories and Health Risks: Epidemiological Surveillance Among Canadian First Nations,” p. 120.

²¹⁸ Canada, Health Canada, Office of Health and the Information Highway, Advisory Committee on Health Infostructure, F/P/T Advisory Committee on Health Infostructure Tactical Plan for a pan-Canadian Health Infostructure 2001 Update, on-line at: http://www.hc-sc.gc.ca/ohih-bis/pubs/2001_plan/plan_e.html. Viewed on: 09/03/02. Last Updated 12/20/01.

²¹⁹ Canada, Health Canada, Office of Health and the Information Highway, Advisory Council on Health Infostructure, “Privacy Concepts,” Canada Health Infoway: Paths to Better Health – Final Report of the Advisory Council on Health Infostructure, on-line at: http://www.hc-sc.gc.ca/ohih-bis/pubs/1999_pathsvoies/info_e.html#exec. Viewed on: 15/03/03. Last Updated: 28/03/01.

liberal, individualist conceptualization, discussed in the previous chapter, that currently dominates the privacy protection discourse. Thus situated within this paradigm, the council was able to argue that:

privacy, although a fundamental value and right, is not an absolute right in law and in Canadian society... in matters affecting public health, there are justifiable circumstances in which privacy must be weighed against the public good. Such balancing should never involve considering the sacrifice of personal privacy on a broad scale, even to achieve some overwhelming public benefit. Rather, the consideration might relate to a case-by-case review to assess whether a presumed public benefit is of sufficient value to warrant – in that case and for that purpose – a limited intrusion of privacy with specific restrictions and safeguards.²²⁰

In the main, this statement sounds reasonable. Privacy, in general, will not be derogated. It will only be intruded upon where such intrusion is of sufficient public benefit to be warranted, and, under these circumstances, the decision to intrude will only be made on a case-by-case basis.

Still, where the health information of those who face systemic discrimination is concerned, who decides whether or not the presumed public benefit is of sufficient value to warrant an intrusion? Presumably, if the data subject decides, then no intrusion of privacy occurs. If the data subject is exercising informational self-determination, s/he is, in terms of the privacy discourse, determining *de facto* what is private and what is not. However, from the use of the term *intrusion* in the above quotation, we may deduce that the state, and not the data subject, decides when intrusions of privacy within the health infoway are warranted. If the state decides when intrusions of privacy are warranted, then there is significant reason to be concerned that the capacity for informational self-determination of peoples who face systemic discrimination will be diminished.

If readers will recall, for a moment, our discussion in chapter one of the 1990 Supreme Court of Canada decision in *R v. Sparrow*, we may highlight some worrying commonalities. In each case, we may note that the right in question is situated by the state in a relationship of conflict with the *greater good*. In this relationship, a characteristic formulation of the liberal rights paradigm, the power of the right is undermined because it is framed in terms of minority versus majority interests. Minority interests can never be absolute in relation to the universe of majority interests. The

²²⁰ *Ibid.*

universe of majority interests is mathematically rigorous – interests that contradict *them* are rendered calculable and subtracted by the state. So, for instance, in the interpretive framework created by the *Sparrow* decision, the state had space to justify to *its* court - hardly a neutral arbiter - that an infringement of Aboriginal rights was necessary.²²¹ Similarly, Health Infoway policy suggests that the state may intrude into a person's private medical affairs where such intrusion is of a presumed public benefit.²²² Thus, the protection these rights provide is always subject to the political context in which they are articulated. For marginalized groups that operate, for the most part, in adverse political contexts, the protection these rights promise is lacking.

In each case, rights, because they are conceived of as flowing from state prerogative, are subject to state interference. Hence, the power that these rights generate is made paradoxical because it reinforces the presence of an endangering, superior power. Thus formulated, these rights “codify even as they may slightly mitigate certain modalities of subordination or exclusion.”²²³ When this paradox is considered in conjunction with the individualist way health information is defined in Canadian statutes, such as PIPEDA and similar provincial legislation discussed in the previous chapter, it demands scrutiny. Not only does the state reify its presence through this process; it actually also confines resistance to health surveillance to a platform of the individual. Given our discussion in the second and third chapters, concerning different levels of

²²¹ *R v. Sparrow*, pp. 1113-1119.

It is true that this justification must meet stringent standards, or at least stringent by today's *common sense* understanding of the word. Nevertheless, all of these standards are open to the Court's interpretation.

²²² Canada, Health Canada, Office of Health and the Information Highway, Advisory Council on Health Infostructure, “Privacy Concepts.”

²²³ Wendy Brown, *States of Injury: Power and Freedom in Late Modernity*, (Princeton, 1995), p. 12.

Brown ultimately postulates that the political force of rights lies in their creation of ideal, universal representations that contradict substantive social inequalities. Consequently, she suggests that rights which affirm difference may actually undermine the emancipatory power of rights *per se*. I would not go this far. Rights are always context-dependent. It would seem that, historically, there have been many instances where rights that recognize difference have been the right amount of *emancipatory*. Still, it bears keeping this critique in mind when attempting to judge longer term implications of asserting difference-based rights within a system that presumes the power to define the scope of those rights.

surveillance received by marginalized social groups, by Indigenous groups, this confinement is troubling. It creates concern over the nature of the state's claims to act as benevolent protectors of people's information.

This concern motivates the investigation that will be carried out in the remainder of the chapter. We turn now to an examination of the FNIHIS. This examination will begin with a description of the FNIHIS. It will then raise some key questions about the impact of the FNIHIS on projects of Indigenous self-determination. It must be noted at the outset that the following analysis is periodized. As this thesis is being written, the FNIHIS is slated to undergo radical transformation. There is currently underway a transition process that will transfer overall control of the FNIHIS from Health Canada to the Assembly of First Nations.²²⁴ As a consequence of this transition and the concomitant transformation of the FNIHIS, it has been necessary to delimit analysis to the period beginning February 16, 1999 and ending early 2002.

This period begins with the reading of the 1999 federal budget and ends just prior to the initiation of the transfer of the FNIHIS from Health Canada to the AFN in the early months of 2002. By delimiting my analysis of the FNIHIS in this way, my intention is to maintain a focus on state policy. This focus retains its relevance to the current incarnation of the FNIHIS insofar as the surveillance capacity of the system, as it was designed by state institutions, remain unchanged. The important thrust of this analysis, however, is in its identification of practices that may undermine projects of Indigenous self-determination. These practices occur in a seemingly apolitical space and therefore require politicization.

²²⁴ Jane Gray, "First Nation and Inuit Health Information System" *First Nations Health Bulletin – Fall/Winter 2001-2002*, (Ottawa, 2002), pp. 9-10, on-line at: <http://www.afn.ca/programs/health%20secretariat/pdf%27s/hb02.pdf>.

The First Nations and Inuit Health Information System

In its 1999 federal budget, the Government of Canada committed 190 million dollars to the improvement of the health of First Nations and Inuit Peoples.²²⁵ Part of this commitment was designated towards “[h]arnessing the power of information technology.”²²⁶ To this end, the Government followed the recommendations of the Advisory Council on Health Infostructure and began to invest in the development of a comprehensive Aboriginal Health Infostructure, connected to the Canada Health Infoway.²²⁷ It bears mentioning at this point, that the Canada Health Infoway, part of the pan-Canadian information highway, is meant to improve the “quality, accessibility, portability and efficiency of health services across the entire spectrum of care.”²²⁸ The Health Infoway is premised on the belief that “there is a shortage of hard, empirical information on health effects” and that “the means of gathering information to evaluate the health and cost implications of decisions already made simply do not exist.”²²⁹

To overcome this perceived shortage, the government sought to invest in such initiatives as the National Health Surveillance Network.²³⁰ It was careful to argue, however, that the Aboriginal Health Infostructure would be an autonomous initiative, separate from the National Health Surveillance Network and therefore consistent with Indigenous interests. The FNIHIS, designed by and for Indigenous Peoples, it stated, would be a key element of this Aboriginal Health Infostructure. In an expanded FNIHIS,

²²⁵ Canada, Department of Finance, “Budget Speech, 1999 – Strengthening Health Care for Canadians, (Paul Martin),” Budget 1999, (Ottawa, 1999), on-line at: <http://www.fin.gc.ca/budget99/speech/speech2e.html#Health>. Viewed on: 16/03/03. Last Updated: 06/03/02.

²²⁶ Canada, Department of Finance, “Budget 1999 – Key First Nations and Inuit Health Initiatives,” Budget 1999, (Ottawa, 1999), on-line at: <http://www.hc-sc.gc.ca/english/budget/1999/factsht6.htm>. Viewed on: 15/03/03.

²²⁷ *Ibid.*

²²⁸ Canada, Health Canada, Office of Health and the Information Highway, Advisory Council on Health Infostructure, “Executive Summary,” Canada Health Infoway: Paths to Better Health – Final Report of the Advisory Council on Health Infostructure, on-line at: http://www.hc-sc.gc.ca/ohih-bsi/pubs/1999_paths/voies/info_e.html#exec. Viewed on: 15/03/03. Last Updated: 28/03/01.

²²⁹ *Ibid.*

²³⁰ Canada, Department of Finance, “Budget 1999 – Key First Nations and Inuit Health Initiatives.”

the government saw “the deployment and maintenance of a community-based health information system to all First Nation communities.”²³¹ The original version of the FNIHIS had been established in communities in Ontario in 1988. It was a DBMS intended to give health care providers more precise information about the community and its health care needs. It contained information on status and non-status residents who used community health services. It was also intended to reduce the amount of paperwork required of health care providers by storing health information in one easy-to-access place.²³²

As the system was developed between 1988 and 1999, planners pursued ten major objectives:

- 1) The elimination of duplication and a reduction in the number of forms
- 2) The standardization of reporting
- 3) The reduction of manual tasks of recording and extracting information
- 4) The standardization of health information collection and recording practices
- 5) An increase in the reliability of health information
- 6) An improvement in the flexibility and storage of health information
- 7) A reduction in the amount of time required to complete reports
- 8) An improvement in program planning and evaluation capabilities at the community, zone and regional levels
- 9) The facilitation of a *proactive* rather than *reactive* approach to community health management
- 10) The empowerment of Indigenous communities to establish program priorities – an empowerment of particular relevance to the transfer of health services to Indigenous control²³³

²³¹ *Ibid.*

²³² Jay Lambert and The First Nations Chiefs’ Health Committee, “First Nations Health Information System,” *First Nations Chiefs’ Health Committee*, (Vancouver, 2002), on-line at: <http://www.fnchc.ca/HIS.html>. Viewed on: 24/09/02.

²³³ Adapted from: Roger Johnson (Health Canada), “The Development of a Comprehensive Health Information System for the First Nations Communities of Ontario Region, Medical Services Branch,”

It is noteworthy that the majority of these goals have to do with streamlining the reporting of health care to the state, rather than directly with the delivery of health care to patients.

By May of 2000, various of these objectives had been reached in several communities. At this point, the FNIHIS was available in 271 health facilities and was serving over 330 Indigenous communities.²³⁴ During the period with which we are concerned, the FNIHIS had within it a number of sub-systems. These sub-systems could accommodate the collection of the following core client health information: patient name; address and phone number; gender; place of birth; and, place of residency. They could also have included, depending on the particular record: band registration numbers; provincial health card numbers; immunization history; reportable diseases; chronic diseases; mortality; abuse profile; medication; medication allergy and adverse reaction; health tests and examinations; maternal health; and, psychosocial (mental and emotional) health.²³⁵ The sub-systems within the FNIHIS were capable of generating sets of health facts that could help to develop ways to improve health care in Indigenous Communities.²³⁶ In its entirety, the FNIHIS could be described, during this period, as a

...health information system that standardizes data collection practices in First Nations Communities. It is designed to be an easy-to-learn computer program to assist health care professionals with a coordinated approach for caring for clients. It also has the ability for health surveillance practices (tracking trends of illness/disease such as diabetes) by producing reports on

conference paper delivered at: *Changing Opportunities: A Conference Addressing Information Technology Issues in Community Health*, Information Technology in Community Health (ITCH), (Victoria, 1994), on-line at: <http://hinf.uvic.ca/ITCH/itch94/papers/johnson.htm>. Viewed on: 16/03/03. See also: Heidi J. Kuran, "Understanding Community Needs – FNIHIS Focus Groups," *In Touch Magazines*, vol. 19, (summer 2001), on-line at: http://www.niichro.com/techno/tech_2.html. Viewed on: 18/09/02.

²³⁴ Kuran (2001), "Understanding Community Needs – FNIHIS Focus Groups."

²³⁵ This comprehensive list was compiled from three sources. See: Heidi J. Kuran, "First Nations & Inuit Health Information System: Are We Ready for Technology?" *In Touch Magazines*, vol. 19, (summer 2001), on-line at: http://www.niichro.com/techno/tech_5.html. Viewed on: September 18, 2002. See also: Lambert *et. al.*, "First Nations Health Information System," *First Nations Chiefs' Health Committee*, (Vancouver, 2002). See also: Gray, "First Nation and Inuit Health Information System".

²³⁶ Kuran (2001), "First Nations & Inuit Health Information System: Are We Ready for Technology?"

data at the community, zone/tribal council, regional and national levels.²³⁷

The database system at this time was capable of producing 200 kinds of health data reports.²³⁸ For the sake of simplicity, we may conceive of this health data as being generally put to two different uses. On the one hand, it is intended to be used for *micro* purposes, such as to assist care givers in the treatment of their particular patients. On the other hand, it is intended to be used for *macro* purposes, such as to fiscally streamline the medical system and regulate the spread of disease.

Health data are intended, at the *micro* level, to facilitate the job of the primary care giver. In the case of the FNIHIS, this data was meant to give trusted people, like doctors, nurses and community health representatives, easier access to information. Today, with greater frequency than ever, individualized health information is transmitted between health care providers. Roberto Rodrigues and his colleagues observe that:

While formerly most information was collected in personal conversations between direct healthcare professionals and the patient, today medical practice and decision making is a spatially distributed process, involving numerous professionals and specialists. Many of these actors never meet face-to-face to discuss a case but each adds his or her own report, which is read, interpreted, and integrated by the primary practitioner responsible for the care event.²³⁹

Thus, DBMS technology would seem to coincide well with new trends in the provision of medical care at the *micro* level.

At the *macro* level, health data are meant to assess the aggregate health of a given population according to analyses of the population's data doubles. Based on these assessments, preventative measures can be taken, resources can be reallocated, efficiency can be maximized and so on. Whereas *micro* level uses of data pertain directly to the *care events* of specific patients, *macro* level uses benefit health care institutions. For instance, data would be used at the *macro* level for what Westin described as administrative activities, public health reporting, academic research, marketing, and so

²³⁷ Jane Gray, "Health Canada to Transfer Control of the First Nations Health Information System," *First Nations Messenger*, vol. 2(6), Oct/Nov 2000, p. 12, on-line at: http://www.afn.ca/The%20Messenger/FN%20Messenger/first_nations_messenger.htm.

²³⁸ Gray, "First Nation and Inuit Health Information System".

²³⁹ Roberto J. Rodrigues *et. al.*, The Regulation of Privacy and Data Protection in the Use of Electronic Health Information: An International Perspective and Reference Source on Regulatory and Legal Issues Related to Person-Identifiable Health Databases, (Washington, D.C., 2001), p. 3.

on. It is often generally assumed that *macro* and *micro* uses of data both benefit patients. This assumption needs to be questioned. Indeed, from some perspectives, the connection between that which benefits the patient and that which benefits the institution is far from clear. In the case of the FNIHIS, there seems to have been somewhat of a disconnect between what was good for government and what was good for promoting community health.

At the time government was investing in the FNIHIS there were a number of concerns about its use in communities. For instance, Heidi Kuran identified the following five areas of concern: poor communications infrastructure; language issues; dislike of technology among frontline health care workers; ownership and privacy of data; and, mistrust of government agencies that can misuse health data.²⁴⁰ Of these concerns, privacy was key. Its consideration caused the following questions to be raised:

- What information should be included in the FNIHIS
- Who should have access to data in the FNIHIS
- Which information should be shared with other health care providers and under what circumstances should it be shared
- How do patients access their own information
- In what way can the information in the FNIHIS be used for secondary purposes
- When is consent required for these secondary uses²⁴¹

Linked to this concern over privacy, Kuran observed that there was “a strong sense that health-related decisions affecting Aboriginal Canadians are not influenced by Aboriginal people. Politicians often make health decisions... Sometimes, Aboriginal people are given health programs that are not appropriate to their needs.”²⁴² Those who doubted the

²⁴⁰ Kuran (2001), “First Nations & Inuit Health Information System: Are We Ready for Technology?”

²⁴¹ *Ibid.*

²⁴² *Ibid.*

utility of the FNIHIS were mostly concerned with ownership and privacy of health data and the degree to which Health Canada would be involved in operating the system.²⁴³

It is little wonder that privacy was such a concern given the comprehensive amount and sensitive kind of information contained in the FNIHIS. It would be worthwhile to turn our attention, for the moment, to a brief examination of the structure of the information contained in the FNIHIS. Let me begin with the observation that there seems to be, in the FNIHIS design, a sub-system concerning a person's *abuse profile* and a separate sub-system concerning a person's *psychosocial* (mental and emotional) *health*. Why have these categories been created as separate entities? According to a study commissioned by RCAP,

The fragmentation of mental health programs into substance abuse, violence, psychiatric disorders and suicide prevention... does not reflect the reality of great overlap among the affected individuals, the professional expertise needed... and the appropriate interventions. In many cases, it is not helpful to single out a specific problem... because focusing attention exclusively on the problem without attending to its larger social context can do more harm than good.²⁴⁴

Indeed, substance abuse and psychosocial health are interconnected issues. According to RCAP, categorizations such as these are not reflective of many Indigenous realities. Let me ask the question again – why are these categories separate?

I am aware that, in some circumstances for instance, having access to a patient's *abuse profile* would be helpful to health care providers. Nevertheless, I want to approach this mode of categorization from a critical perspective to try to understand the ways it might be problematic. We may note that the issue of substance abuse is certainly a sensitive one. Indigenous Peoples have long been painted with the stereotypical brush of alcoholism, for example.²⁴⁵ This stereotype has been greatly exaggerated and is at times completely groundless. According to RCAP, although the Canadian Centre on Substance Abuse reported that alcohol psychosis occurs among Indigenous Peoples at four times the

²⁴³ *Ibid.*

²⁴⁴ Laurence J. Kirmayer *et. al.*, "Suicide in Canadian Aboriginal Populations: Emerging Trends in Research and Intervention," (Ottawa, 1994), cited in: The Royal Commission on Aboriginal Peoples, "Chapter 3 – Health and Healing," pp. 163-164.

²⁴⁵ The Royal Commission on Aboriginal Peoples, "Chapter 3 – Health and Healing," p. 157.

national average rate, other survey sources indicated that alcohol consumption rates among Indigenous Peoples are lower in some measurement categories than among non-Indigenous Peoples.²⁴⁶ Regardless of whether the statistics indicate more or less instances of substance abuse among the Indigenous population, the very existence of an *abuse profile* suggests, in a sense, that Indigenous Peoples continue to live with this stigma.

The *psychosocial health* file also merits critical attention. I do not know how comprehensive these files are. However, I assume that they do not contain detailed information on the history of the Canadian state's neglect of Indigenous Peoples, on the state's dispossession of Indigenous Peoples from their lands or on the state's consistent attempt to systematically dismantle Indigenous culture. Instead, the data in this system seems likely to be structured in such a way that it enumerates particularly diagnosed problems that correspond to a specific framework: the biomedical paradigm. Problems diagnosed according to this paradigm are attributed to specific causes and are accordingly treated with specific measures.

However, we must remember that the biomedical paradigm is not *the* way of knowing health; rather, it is one way among many. The kind of information contained in the FNIHIS seems to correspond specifically to the information needs of diagnoses that come out of the biomedical paradigm. There seems to be no space in the FNIHIS for community or environmental health indices. Arguably, the absence of these indices may skew health assessments based on the data contained in the FNIHIS. If assessments are skewed towards an affirmation of the diagnostic tools of the biomedical model, and if the bio-medical model does not adequately accommodate Indigenous understandings of health, then incomplete diagnoses of health problems are inevitable.

I am not arguing here, that a diagnosis conducted on the basis of the information in the FNIHIS would be wrong from all points. Instead, I am suggesting that health problems could be incompletely diagnosed because a management information system like the FNIHIS channels analyses through its categories of observation. An incomplete diagnosis of this kind cuts two ways. In the first instance, it obfuscates the direction that

²⁴⁶ *Ibid.*, p. 159.

treatment ought to take. The biomedical paradigm, which has dominated formal medical care in Canada, is often characterized as a mechanical approach to medicine. It has historically used a mechanical metaphor to understand the human body (singular). Thus, critics have argued that the biomedical paradigm:

...is reductionist in form, seeking explanation of dysfunction in invariant biological structures and processes; it privileges such explanations at the expense of social, cultural, and biographical explanations. In its clinical mode, this dominant model of medical reasoning implies: that diseases exist as distinct entities; that those entities are revealed through the inspection of 'signs' and 'symptoms'; that the individual patient is a more or less passive site of disease manifestation; that diseases are to be understood as categorical departures or deviations from 'normality.'

...It is not necessarily taught in terms of an explicit paradigm, however, but is implicit in the taken-for-granted occupational culture [of health care providers]. Medical students encounter it through exemplars and assimilate it through the accumulation of firsthand 'experience'. It is thus incorporated into the 'practical reasoning' of the novice and rapidly becomes part of his or her stock of knowledge and assumptions.²⁴⁷

The modes of diagnosis and treatment privileged by the biomedical model therefore, rely on compartmentalized analysis of data, of the kind that DBMS technology, such as the FNIHIS, facilitates.

In the second instance, and perhaps more troubling than the first, biomedical diagnosis tends to place the problem *of* health, and the responsibility *for* health, in large part, on the individual. The atomization of the body proceeds apace with the atomization of society. I would like to pause for a moment to politicize this point: if responsibility for well-being rests with the individual, then responsibility for ill health also rests with the individual. Let me be very clear about what I am suggesting here. If the FNIHIS, through its dataveillance of health information, encourages people to identify with its categorical definitions of health and health problems, then it endorses the validity of the biomedical model as an explanatory framework for illness. If the biomedical framework assesses Indigenous health on an individual basis, to the exclusion of a broader socio-historical perspective, then it misses important determinants of health, such as economic prosperity and environmental conditions. If these important determinants of health are

²⁴⁷ Paul Atkinson, "Discourse, Descriptions and Diagnoses: Reproducing Normal Medicine," *Biomedicine Examined*, M. Lock and D. R. Gordon (eds), (London, 1988), p. 180.

marginalized, if the focal point of diagnoses does not move beyond the individual, then the state discretely absents itself from responsibility for ill health.

Some may object to the picture I have just depicted, arguing that I am overlooking those voices within the biomedical discourse that do attempt a holistic approach to health. Indeed, I am somewhat overstating my case here. I do not want my argument to be obscured by equivocation. The effects of approaching health biomedically are often underemphasized, particularly in terms of how they relate to the underlying social structure. When the biomedical discourse, as it informs state dataveillance of Indigenous People's health information, is viewed uncritically, it risks undermining Indigenous self-determination. The risk in this state driven dataveillance practice is that it will engender and reinforce an internalization of the dominant biomedical health discourse. Such internalization would be further problematic because the state has a virtual monopoly over the information/knowledge production that occurs within this discourse.²⁴⁸

There are a couple of negative side effects that attend the (re)affirmation of the bio-medical discourse through state dataveillance practices. First, because the state maintains a monopoly over knowledge production in this discourse, Indigenous Peoples assume a dependant role within its bounds. This relationship recalls the *paternalistic* dynamic that has been characteristic of the colonial mentality. Second, as these dataveillance practices become normalized, they risk engendering conditions under which illness, rather than health, becomes the central metric of well-being. Recalling the survey of surveillance literature in the second chapter, we may note that a fundamental, negative social affect is commonly associated with dataveillance practices: they tend to encourage categorical suspicion. When surveillance tools are used in crime prevention, they scrutinize everyone in an effort to catch the criminal. Everyone is *guilty until proven innocent*. What affect does categorical suspicion have on health perceptions within the

²⁴⁸ Jennifer Espey, OCAP & Stewardship: A Discussion Paper for the First Nations Statistical Institute, (Ottawa, 2002), p. 13, on-line at: <http://www.firststats.ca/OCAP.pdf>. Viewed on: 18/04/03.

Espey makes a direct connection between knowledge production and governance: "Government of Canada institutions such as Statistics Canada, Health Canada and DIAND [Department of Indian Affairs and Northern Development], have had a virtual monopoly on producing knowledge about, but not of, First Nation peoples for governance purposes. This research has assumed the governance goals of the Government of Canada and then situated First Nation peoples within it. The production of knowledge has assumed, but not explicitly recognized, a colonization model."

biomedical discourse? Arguably, it may foster the sentiment that dataveillance subjects are *ill until proven healthy*.

I observed in the third chapter that, in Canada, dataveillance practices may be resisted by individual citizens using the statutory protection mechanisms of the information privacy regime. This regime, however, marginalizes groups and thus offers Indigenous groups little space to articulate their information privacy rights. In the final section of this chapter, I would like to discuss one model of Indigenous health information privacy that is capable of responding, at a collective level, to the surveillance threat posed by the FNIHIS.

OCAP: A Collective Approach to Information Privacy

The privacy concerns created by the prominent role of the Canadian state in the creation and administration of the FNIHIS have been a driving force behind the current transition process from Health Canada to the AFN. Similar privacy concerns have also generated the beginnings of an Indigenous approach to information privacy that is more amenable to the articulation of group projects of informational self-determination. This approach is governed by four central tenets: *Ownership, Control, Access, and Possession* (hereafter OCAP).²⁴⁹ OCAP has recently emerged as a rallying point as Indigenous Peoples have begun to question who “has the ‘right’ to produce knowledge about whom and for what ends?”²⁵⁰ As Jennifer Espey has argued, OCAP describes the relationship of a community to its information. By definition, the dominant culture has the resources, institutional base and power to have OCAP over its information. For marginalized populations, however, OCAP is a critical issue for self-determination.²⁵¹

OCAP, therefore, emerged out of a social context in which Indigenous Peoples were being systematically excluded from processes of knowledge production. As

²⁴⁹ Assembly of First Nations, “First Nations and Inuit Health Information System, on-line at: <http://www.afn.ca/Programs/Health%20Secretariat/health.htm>. Viewed on: 16/03/03.

²⁵⁰ Brian Schnarch, “OCAP: Self-Determination Applied to Aboriginal Research,” paper presented at the Aboriginal Health Information Symposium, 2002. Cited in: Espey, *OCAP & Stewardship*, p. 15.

²⁵¹ Espey, *OCAP & Stewardship*, p. 31.

Namaste Marsden has observed, for instance, in the area of health research, some Indigenous communities faced systematic barriers to building research models suited specifically to their communities. While the Canadian government had given a mandate to the Aboriginal Health Institute to fund research in Indigenous communities, some community researchers were excluded from applying for these funds because applicants were required to have the minimum qualification of a PhD.²⁵² Barriers of this kind formed the social context in which OCAP was articulated. These processes of exclusion are not dissimilar from systematic indifference to the real, lived experience of Indigenous Peoples evident in state discourses on information privacy.

To understand OCAP principles in action, we may turn to Jennifer Espey's discussion of them as they inform the National Aboriginal Health Organization's (hereafter NAHO) stewardship of Indigenous health information. She contrasts NAHO's stewardship of information with Statistics Canada's stewardship. To begin with, she observes that Statistics Canada's stewardship model focuses on the individual's information privacy rather than the collectivity's. "The only instance," she states, "in which we would think the collective also doesn't need this protection is if we are part of the dominant group."²⁵³ Data possessed by Statistics Canada may therefore be understood as being owned by all Canadians. No ownership distinction is made, regardless of whether data came from an aggregate provincial data set or a single street. By contrast, the NAHO model treats an individual's information as a part of the entire set of information from the community to which the individual belongs. Communities that participate in research, therefore, *Own* the data.²⁵⁴

Other distinctions between the information stewardship models of Statistics Canada and NAHO may also be comprehended in terms of the recognition (or lack thereof) they accord the community. For instance, though Statistics Canada has explicit research protocols, there is not much emphasis on maximizing community control of

²⁵² Namaste Marsden, *An Overview of Models for Community Based Aboriginal HIV/AIDS Research*, (Vancouver, 2002), p. 5, on-line at: <http://www.healingourspirit.org/pdfs/research/cbroverview2002.pdf>. Viewed on: 27/04/03.

²⁵³ Espey, *OCAP & Stewardship*, p. 29.

²⁵⁴ *Ibid.*, pp. 28-29.

research processes. NAHO, on the other hand, focuses on engaging the community throughout the research process. Communities *Control*, for example, the research design process. In the NAHO model, decisions about who has *Access* to the information/knowledge produced from community data are made jointly by NAHO and the community. Statistics Canada, however, is required to publish *all* research results.²⁵⁵ Finally, whereas all data collected by Statistics Canada remain with Statistics Canada, data collected by NAHO “must be returned as grouped results to each community (from whence it came).”²⁵⁶

Conclusion

Humans animate and are in turn animated by technology. This two-way relationship is of paramount importance in our consideration of the FNIHIS. As Langdon Winner has observed, we must not view technology simply as an innocuous *thing* that is employed to facilitate lifestyle. Rather, we must try to think through the society-technology relationship in dialectical terms.²⁵⁷ Focusing on this relationship, I have suggested in this chapter, that state driven dataveillance of Indigenous health information subtly diminishes the capacity of Indigenous Peoples to be self-determining. By considering the example of the FNIHIS, I observed that discrete links exist between the conceptual categories it uses to represent health information, and the biomedical discourse. The biomedical discourse, in turn, has been historically implicated in the marginalization of Indigenous Peoples and must, therefore, be scrutinized for its role in governance.

With the purpose of carrying out such critical scrutiny, the first section of this chapter discussed micro and macro uses of health information. On a micro level, personal health information is used by care givers to direct the aid they give to specific patients. On a macro level, this same information is used for administrative and epidemiological reasons, and a host of other secondary uses. Importantly though, the

²⁵⁵ *Ibid.*, pp. 36-37.

²⁵⁶ *Ibid.*, p. 32.

²⁵⁷ Langdon Winner, *The Whale and the Reactor: A Search for Limits in an Age of High Technology*, (Chicago, 1986), pp. 21-23.

data doubles created by the purposive shaping of health information towards these macro uses, risk eclipsing their real world referents in the discursive domain of biomedicine.

The second section of this chapter considered specific state policy as a prelude to an examination of the FNIHIS. It highlighted the state's heavy investment into DBMS technology and health dataveillance. These investments were made with the intention of improving health care, and, while *privacy* was a consideration, its formulation echoed policy surveyed in the previous chapter in the sense that it was an individual interest to be balanced against broader public health interests. It was furthermore clear, in considering this policy, that the state would be the body in charge of balancing privacy interests off against public health interests. This role is likely to be troubling for Indigenous groups, especially considering the way the state has played a similar role in relation to balancing Aboriginal rights and self-government off against the so called *greater good*.

The third section of this chapter turned to an exploratory examination of the FNIHIS. It was noted that the data structure deployed by the FNIHIS conformed to the biomedical model of diagnosis. The FNIHIS was, in the hands of the state, problematic for two reasons. First, it asked Indigenous Peoples to assess their health using a model in which information/knowledge production is virtually monopolized by the state. Second, as its categories focused on *health problems*, it had the effect of shifting the metric of well-being from *health* to *illness*. To be in the FNIHIS, therefore, was to be conceived of as *ill until proven healthy*.

The final section of this chapter concluded with a discussion of a possible approach to collective information privacy. OCAP, as the basis for collective information privacy, could be a powerful tool with which to resist state dataveillance practices. As the central tenet of OCAP is community control over information, it is a stewardship model that can accommodate collective informational self-determination. This thesis will now conclude with the argument that state discourses need to make space for OCAP type models of information stewardship.

Indigenous Self-Determination and the Politics of Information

I have attempted to bring together disparate literatures in this thesis and, in the process, have covered a substantial amount of ground. My intention in this work was to argue that the state's surveillance of Indigenous Peoples challenges, in significant ways, their right to self-determination. Furthermore, this surveillance is not perceived by the state as harmful. State discourses on Aboriginal rights and self-government, because they are not oriented towards self-determination, do not contemplate practices like surveillance. These discourses focus on procedural and administrative issues and, though the rights they speak of are often held out by the state as mechanisms that will bring justice to the Canadian polity and freedom to Indigenous Peoples, these rights are undermined by acts of colonialism that occur just beyond their discursive scope. To demonstrate this point, my thesis explored several discursive fields and culminated in an exploratory case study that showed how the perpetuation of an unbalanced power dynamic might be negotiated through health surveillance practices.

More specifically, I argued that state discourses of Aboriginal rights and self-government are not oriented towards self-determination. They therefore do not contemplate informational self-determination. The informational self-determination of Indigenous groups, which is an integral part of the wider project of self-determination, is undermined by state surveillance practices. Although state surveillance practices may be resisted in Canada using statutory information privacy mechanisms, these mechanisms, because they are paradigmatically individualistic, seem to exclude Indigenous groups from using them. Hence, because information privacy is not contemplated in state discourses of Aboriginal rights or self-government, and because little space exists for Indigenous informational self-determination in state discourses of information privacy, state surveillance of Indigenous Peoples proceeds relatively unchecked. One example of unchecked surveillance is the *First Nations and Inuit Health Information System*, a mechanism designed, in part, to monitor Indigenous Peoples' personal health

information. Such surveillance subtly challenges Indigenous projects of self-determination by reaffirming the state's central position in the biomedical discourse and by excluding other, non-biomedical approaches to well-being.

I began with the assertion that self-determination is a desirable goal for all peoples. The first chapter argued that, though the concepts of Aboriginal rights and Aboriginal self-government may have, at one time, been vehicles for self-determination, they are no longer today. Each concept has suffered from a conservative (re)absorption, in state discourses, that has oriented it away from Indigenous self-determination. Aboriginal rights have come to be directed towards reconciling Indigenous culture with the dominant culture. Aboriginal self-government has come to be directed towards the pragmatics of administration. In each case, the orientation away from self-determination has resulted in a narrowing of discursive space, such that state movements to (re)construct an oppressive relationship, whether intentional or not, are overlooked.

That such threats are overlooked is evident in the state's lack of respect for Indigenous informational self-determination. Informational self-determination is an integral part of the wider concept of self-determination. It means being able to control the destiny, or circulation, of one's personal information. The second chapter began by noting that the surveillance of personal information, also known as dataveillance, has become increasingly intensive and extensive over the last 50 years. Advances in information technology have resulted in increased flows of personal information, and increased ways of sifting through and manipulating these flows. Surveillance theorists have conceptualized these flows of information as being constituted of additional *selves*, or *data doubles*. This conceptualization allows us to see that the manipulation of one's data double can affect one's real life-chances.

Data doubles are generally constituted according to the needs of the organizations they serve, rather than according to the wishes of the people from which they come. This fact makes informational self-determination difficult. When we politicize the manipulation of data doubles by institutions, we come to understand that such manipulation is informed by, and informs, social stratification. Consequently, the role that surveillance practices play in perpetuating status quo social organization is the basis of their threat to Indigenous self-determination. Unfortunately, this role is rarely

questioned. Most people accept surveillance as a necessary condition of modern living. It is important, therefore, to understand that surveillance is not likely to go away. The most beneficial way to approach surveillance practices is to proceed from this recognition and work, not towards eradicating surveillance, but towards limiting its application by giving people tools to resist it when they deem such resistance necessary. These tools flow from the concept of informational self-determination and are manifest in various forms of information privacy protection laws and policy. While much has been written about the problems of surveillance for informational self-determination and the conceptual response to surveillance in information privacy, scant attention has been paid to the surveillance or privacy of Indigenous Peoples.

Just as academic discourses on surveillance and privacy have neglected Indigenous Peoples, so too has state law and policy concerning privacy protection overlooked Indigenous interests. In Canada, the information privacy regime, while advanced on many fronts, does not conceive of *privacy* in collective terms or as a social value. Instead, because the regime's conceptualization of *privacy* is rooted within a liberal, individualistic paradigm, the concept of collective informational self-determination is almost completely excluded from the regime's discursive field. This means that every one is allotted the same *privacy power*, whether or not they receive more or less surveillance. The third chapter analyzed Canadian legal and policy privacy discourses, which clearly demonstrate this point. As evidence that Indigenous conceptualizations of privacy are excluded, I considered two Indigenous articulations of *privacy* that were examples of a collective conceptualization. Though these examples can hardly be said to be representative of *Indigenous privacy per se*, they are two prominent articulations that, owing to their collective nature, are excluded by the Canadian regime. The third chapter therefore concluded by arguing for the need to create space in Canadian information privacy discourses for collective conceptualizations of *privacy*.

The case study of the *First Nations and Inuit Health Information System* (hereafter FNIHIS), which was the subject of the fourth chapter, was a stark demonstration of the way state surveillance can be harmful to Indigenous Peoples. It linked the state's surveillance practices to the biomedical discourse, which in turn, was

linked to the prevailing social structure where Indigenous Peoples are marginalized. As it was originally built by the state, the structure of the data managed by the FNIHIS seems to correspond more to the institutional needs of Health Canada than to particular community health care needs. In its incarnation during my period of analysis, the FNIHIS engendered two conditions that undermined projects of Indigenous informational self-determination. First, because its structure was so heavily influenced by the biomedical discourse, it excluded other ways of approaching well-being. While legitimizing the biomedical discourse, a discourse in which institutions of the state have a virtual monopoly over information/knowledge production, the FNIHIS marginalized other modes of information/knowledge production. It therefore engendered conditions in which Indigenous Peoples would be dependent on the state for assessments of their well-being.

Second, the FNIHIS, because it was limited to biomedical assessments of health, allowed only for a focus on health problems. It did not accommodate a holistic representation of well-being. Arguably, this focus on health problems fostered a shift in the metric of well-being from health to illness. It engendered conditions under which peoples, by virtue of their inclusion in the FNIHIS, were constructed as ill rather than as healthy. Thus depicted, peoples within the FNIHIS are portrayed as being in need of health. At the same time, the state portrays Indigenous Peoples in this way, it subtly positions itself, by way of the biomedical discourse, as the munificent provider and guarantor of health. This chapter concluded that, because of these effects, the state's surveillance of Indigenous health information needed to be interrogated through the concept of collective informational self-determination. It needed to be resisted through the articulation of a collective mode of information privacy.

One way to think about a collective conceptualization of information privacy is through the principles of *Ownership, Control, Access, and Possession* (hereafter OCAP). These principles offer a mode of information stewardship that regulates the collection, storage, and manipulation of data according to the wishes of both the individuals and the community from which it came. By moving to considerations beyond those of the individual, the principles of OCAP suggest a level of information privacy that is capable of resisting the extraordinary state surveillance received by Indigenous Peoples.

Two main implications flow from the argument I have just made. In the first instance, state discourses of Aboriginal rights and self-government have to move back towards the concept of self-determination. Only by moving back towards this concept can these discourses re-legitimize themselves for Indigenous Peoples. The institutions of the Canadian state have tread too far into the political space of Indigenous Peoples. These institutions have committed themselves to Aboriginal rights and Aboriginal self-government while simultaneously transforming these concepts to their purposes. By orienting the discourses of Aboriginal rights and self-government away from self-determination, the state fails to adequately critique its practices and policies. Though it claims to have shed its behaviour from the epoch of colonial domination, it will continue to carry out paternalistic practices so long as it fails to recognize the spirit of self-determination.

In the second instance, state discourses of information privacy need to create space for collective conceptualizations of privacy. By creating this space, these discourses will acknowledge the differential kind of surveillance received by Indigenous Peoples. Arguably, such space would better accommodate the privacy interests of Indigenous groups. The lack of attention towards Indigenous privacy interests in state law and policy is mirrored by a lack of attention in academic discourses concerning surveillance and privacy. Hence, these discourses too need to create space for Indigenous interests. Further academic research ought to work towards understanding the specific ways that surveillance affects Indigenous Peoples. It ought to acknowledge the specific socio-historical contexts of various Indigenous groups prior to attempting to understand the way that surveillance plays upon individuals.

Were Indigenous self-determination the focal point of these various state discourses that purport to serve Indigenous Peoples, it is unlikely that the FNIHIS would have been structured as it was. This is not to say that the health surveillance of Indigenous Peoples would have been unlikely. Rather, it is to suggest that the state would have approached such surveillance from a less paternalistic perspective. Only by relinquishing this paternalistic mentality, by relinquishing political space to Indigenous Peoples, will institutions of the Canadian state begin to truly break away from colonialism.

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Appendix 1

The Constitution Act, 1982 (Part II)

RIGHTS OF THE ABORIGINAL PEOPLES OF CANADA

SECTION:

- 35 (1) The existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby recognized and affirmed
- (2) In this Act, “aboriginal peoples of Canada” includes the Indian, Inuit, and Métis peoples of Canada
- (3) For greater certainty, in subsection (1) “treaty rights” includes rights that now exist by way of land claims agreements or may be so acquired.
- (4) Notwithstanding any other provision of this Act, the aboriginal and treaty rights referred to in subsection (1) are guaranteed equally to male and female persons.

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Non-Refereed Publications:

Bennett, Colin J. and French, Martin (2003), "The State of Privacy in the Canadian State: Fallout from 9-11", *Journal of Contingencies and Crisis Management*.

French, Martin (2002), "BC's Referendum – Benevolent or Malevolent?" *The Martlet*, vol. 54(28), p. 9.

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