

Autonomy, Equality, and Respect for Difference:

Investigating Principle-Based Approaches to Technologically Mediated Reproductive Contexts

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#### Abstract

The objective of this project will be to explore how the principles of autonomy, equality, and respect for difference are formulated and applied when disability diagnostic technologies affect women's reproductive decision-making. The author will use feminist disability theory and will engage legal research methodology in order to interpret and challenge those three principles as they are presented in both bioethics and jurisprudence. Specifically, the following questions will be explored:

- Does reproductive autonomy lead to undue maternal responsibilities, especially in instances when disabilities can be or have been diagnosed?
- Are there tensions between reproductive autonomy and reproductive equality, specifically between reproductive autonomy on the one hand, and disability equality on the other?
- Does the (either implicit or explicit) assumption in bioethics and law that reproductive technologies be used for the purpose of disability de-selection reflect tensions between reproductive autonomy and equality on the one hand, and the principle of respect for difference on the other?

This research will identify the principles at the heart of discourses and disagreements on reproductive decision-making in an effort to clarify how these principles are being conceptualized, to evaluate whether there is still use for a principle-based approach, and to consider what their best instantiations would look like.

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Contexts

Chapter 1: Introduction

1.1. Introduction

The objective of this project will be to explore how the principles of autonomy, equality, and respect for difference are formulated and applied when disability diagnostic technologies affect women's<sup>1</sup> reproductive decision-making. These principles are conceived both morally in bioethics, and legally in jurisprudence. My project will use feminist disability theory to interpret and challenge those three principles as they are presented in both fields. Specifically, I will explore the following questions:

- Does reproductive autonomy lead to undue maternal responsibilities, especially in instances when disabilities can be or have been diagnosed?
- Are there tensions between reproductive autonomy and reproductive equality, specifically between reproductive autonomy on the one hand, and disability equality on the other?
- Does the (either implicit or explicit) assumption in bioethics and law that reproductive technologies be used for the purpose of disability de-selection reflect tensions between reproductive autonomy and equality on the one hand, and the principle of respect for difference on the other?

These three principles are often invoked in discussions pertaining to reproductive decision-making in general and decision-making that incorporates reproductive technologies in particular, although those making the invocations may have different—

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<sup>1</sup> While this study will focus on women, I acknowledge that gender is largely a social construction and that it is possible for someone to be pregnant and not identify as a woman.

even contradictory—interpretations of the principles in question. Because formulations of autonomy, equality, and respect for difference can be disparate and even in conflict, those engaging in discourses on reproductive decision-making may be disconnected or miscommunicating despite the vocabulary they share in common. This research will identify the principles at the heart of discourses and disagreements on reproductive decision-making in an effort to clarify how these principles are being conceptualized, to evaluate whether there is still use for a principle-based approach, and to consider what their best instantiations would look like.

### *1.1.1. Chapter Outline*

In the following sections of this introductory chapter, the methodologies for this project—specifically feminist disability methodology and legal research methodology—will be explained. This chapter also considers the nature of principle-based approaches, and whether such approaches can be experientially grounded. In a presentation of the fields of analysis, I will consider how bioethics is grounded, and how Canadian constitutional law is interpreted. Finally, I will explain the reproductive context in Canada, including abortion services and their barriers, as well as reproductive technologies.

The chapter following will pertain to the principle of autonomy: moral autonomy of Kantian philosophy, personal autonomy in liberal theories, and relational autonomy in feminist theories. I will explore bioethical concepts of consent and decisional capacity, and will locate autonomy in section 7 of the *Canadian Charter of Rights and Freedoms*

(1982): the rights to life, liberty, and security of the person. This project will go on to characterize reproductive autonomy, legally established in *R. v. Morgentaler* (1988). Finally, I will discuss reproductive autonomy in relation to disability. Reproductive technologies arguably enable autonomous decision-making by making more choices available and by informing decisions. Notwithstanding, the routinization of these technologies may be transforming reproductive choices into obligations. Pregnant women are rendered responsible, that is, are saddled with pregnancy-related responsibilities insofar as they are considered separate entities from the fetuses they are carrying. The conceptual separation of woman and fetus via ultrasound technology allows for the pitting of the interests of women against those of the fetus. This separation may be compatible with a notion of personal autonomy, but may contradict the concept of relational autonomy.

In the third chapter, I will chart the historical development of equality theory, including Aristotelian formal equality, liberal equality of opportunity, and feminist substantive equality. I will account for how each of these theories is made manifest in bioethics, and I will evaluate the medicalization of pregnancy and disability under distributive health models. I will go on to consider the development of substantive equality—found under s. 15 of the *Charter*—in Canadian case law. When discussing reproductive equality (a concept not often invoked in Canadian law, a notable exception being *Doe et al. v. The Government of Manitoba*, 2004), I will note that the concept may redress current barriers to reproductive services, but not as long as it is weighed down with the rhetoric of liberal theory. In reference to disability, one might argue that making

genetic technologies available is a matter of equal opportunity and resource distribution. I will determine whether arguments about access to pregnancy-related resources apply to reproductive technologies. In contrast, the availability and normalization of technologies may have created a need for their use. According to disability critiques, the promotion of reproductive technologies hinges on a discriminatory attitude against disability. I will investigate whether disability critiques generate a tension between disability equality and women's reproductive rights.

For the subsequent chapter, I will discuss the principle of respect for difference, which entails accepting and understanding identity features as instances of human diversity. I will use the concept, as well as its roots in postmodern theory, to further deconstruct autonomy and equality, and to contextualize and embody reproductive decision-making. Although it is not often invoked in bioethics literature, I will consider how a politics of difference transforms the application of autonomy and equality to bioethics issues of consenting subjects and functional health, especially in relation to disabled and other marginalized persons<sup>2</sup>. I will go on to evaluate whether the promotion of reproductive technologies for the purpose of disability avoidance reflects a tension with the principle of respect for difference. For example, pre-implantation genetic

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<sup>2</sup> The term "disabled people" is deliberately employed, and will be used throughout this project. Although people-first language—"persons with disabilities"—is more common in recent disability theory and advocacy, Titchkosky (2001, 2007) argues that people-first language is used to stress personhood and to separate out disability from personhood: "people-first language codes may reconfirm the notion that there are some people in this world whose humanness is debate-able" (2007, p. 196). This study will explore what it means to understand humanity as diverse. I will also problematize notions of personhood that have excluded disabled people and thus legitimized their oppression. It therefore seems fitting to use the term "disabled people," rather than to become entangled in the implications of people-first language.

diagnosis is sometimes used for the purpose of producing disability. Any resistance to this practice may reveal societal discrimination against disability.

Finally, I will close this work by drawing together and analyzing the implications to my discussions of the principles in previous chapters. I will consider how bioethical and legal issues regarding reproductive decision-making with respect to disability ought to be approached. I will further lay out my recommendations for future research and application.

### *1.1.2. Contributions*

This project will seek to disentangle concepts that have long histories and complicated formulations, as well as profound implications for how reproductive decisions are made and honoured, and how bodies are treated. These issues have been explored by critical theorists interested in feminism and disability studies, yet not enough work has been done to connect this critical theory with medical and legal praxis. As a contribution to my field, I will attempt to determine how the connections might be better forged, that is, how critical interpretations of autonomy, equality, and respect for difference apply to bioethical and legal protections of reproductive decisions and regulation of reproductive technologies.

Further, Canadian law has arguably not developed in a rigorous or systematic way regarding reproductive decision-making as it relates to reproductive technologies. Few cases deal with issues around the promotion of fetal health (*Dobson (Litigation Guardian of) v. Dobson*, 1999; *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)*,

1997). The Society of Obstetricians and Gynaecologists of Canada (SOGC) recently developed guidelines for various reproductive technologies, such as prenatal screening (2007a, 2007b), ultrasound technology (2007a), and pre-implantation genetic diagnosis (2009). Assumptions regarding disability de-selection can be found in these guidelines<sup>3</sup>, although actual policy advocating disability de-selection has not developed in Canada. The void may be intentional, or perhaps law and policy have not yet caught up to technological advancements. In either case, there is value to drawing academic and political attention to the topic if only to begin the conversation, and to ensure the terms used in such a conversation are clearly defined.

This project is also meant to include a prescriptive component. My intention is not only to evaluate the formulations of the three principles found at the core of arguments about reproductive decision-making, but also to put forward a theoretical framework that may have the best implications for both women and disabled people. I will do so by employing a conceptual lens that draws from bioethical theory tempered by or grounded in feminism and disability studies. This lens is principle-based, or at least makes use of principles, but also values experience and identity politics. Incorporating experience and identity into rights discourse may be a way of resolving abstract problems in which rights outrank or conflict with one another.

As an example, Sherwin (1998) notes that the apparent dichotomy between the principles of autonomy and equality crops up in legal and medical contexts: “autonomy

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<sup>3</sup> For instance, as discussed later in this study, the SOGC defines prenatal screening in 2007(a) guidelines: “screening is the process of surveying a population, using a specific marker or markers and defined screening cut-off levels, to identify the individuals in the population at higher risk for a particular disorder” (p. 147).

provisions are sometimes interpreted as functioning independently of and outweighing all other moral values. More specifically, autonomy is often understood to exist in conflict with the demands of justice” (p. 25). Rather than dwell on how these principles may be in conflict, Rodgers (2006b) focuses instead on how they are related in the context of women’s reproductive capacities: “reproductive autonomy is key to women’s equality and essential to women’s full and constitutionally protected membership in the Canadian state” (p. 1).

I will consult theoretical literature in an effort to determine what the principles found in bioethical and legal decisions may be missing, and how these principles could—perhaps should—be re-conceptualized. This project will contribute to discourses on reproductive issues and technologies a defence of women’s reproductive rights: a defence which can account for recent advances in modern technology, namely the technologies that have drastically changed reproductive decision-making; and that can also ground reproductive rights in carefully articulated principles of autonomy, equality, and respect for difference, without losing clarity or creating conflict.

## 1.2. Methodology

This project involves both philosophy and law, and so it will employ two methodologies. In the following sections, I will explain critical theory as a general lens of analysis, for critical theory will equip me with the tools needed for identifying and critiquing social realities. Legal research entails mining legal cases for philosophical arguments to understand and deconstruct, and so this research can also be subjected to

critical theoretical analysis. The field of jurisprudence additionally requires a methodological approach especially tailored to suit it, designed for lawyers and paralegals who must also engage in legal research. For this reason, I will employ legal research methodology, which is compatible with critical theory to the extent that both may be used to flag and chart the development of concepts, and both may be used for transformative purposes. In the sections that follow, I will defend the particular conceptual model employed in this project, as well as the selection of autonomy, equality, and respect for difference above other moral and legal principles.

### *1.2.1. Overview of Research: Feminist Methodology*

I will employ critical theory, an umbrella term for a range of philosophies entailing critiques of society and proposals for making society just. The field includes the German idealism of the Frankfurt School and the analytical traditions of the Vienna Circle, as well as Heideggerian phenomenology and Rawlsian social justice theory. When theories moved away from abstract Kant-inspired philosophy, they came to grapple more readily with injustice and oppression (Rush, 2004). Horkheimer (1982) of the Frankfurt School describes critical theory as a transformative project: “[critical theory is meant] to liberate human beings from the circumstances that enslave them” (p. 244). Rush (2004) elaborates: “critical theory is not merely descriptive, [but is instead] a way to investigate social change by providing knowledge of the forces of social inequality that can, in turn, inform political action aimed at emancipation (or at least diminishing domination and inequality)” (p. 9).

Thus, work in this area entails both descriptive and prescriptive components. Alvesson and Skolberg (2009) explain: “critical theory is characterized by an interpretive approach combined with a pronounced interest in critically disrupting social realities. ...Its guiding principle is an emancipatory interest in knowledge” (p. 144). Social conditions and realities are explained, inadequacies and injustices are identified, and recommendations for transformation are offered. The seeds for transformation are contained within social realities. Exceptions and contradictions may challenge the standard and open this standard up to change. For critical theorists of the Frankfurt school, democracy is the vehicle for social change, that is, for the emancipation of those who experience oppression within their social context (Horkheimer, 1982).

I will focus on a specific strand of critical theory—feminisms—according to which minority groups are the vehicle for social transformation and emancipation. Feminist research methodology became a focus for second wave feminisms of the 1980s (Harding, 1987; Reinharz, Bombyk, & Wright, 1983). Across disciplines, proponents of feminist theories were considering alternative approaches to research. For DeVault, “feminists seek a methodology that will support research of value to women, leading to social change or action beneficial to women” (1996, p. 34). Research of this nature is thus meant to specifically target oppressive social organization; it is meant to identify problems and pursue social change relevant to women (racialized women, impoverished<sup>4</sup>

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<sup>4</sup> Much like “disabled person,” the terms “racialized” and “impoverished” are used to highlight that there is a social component and power dynamic entangled in these minority identity markers.

women, queer women, disabled women, and so forth would be recognized later in feminism's history).

For Harding (1987), epistemology (how we come to know reality) and methodology (theory on how to practice research) are separate but related. Landman (2006) notes that feminist methodology engages, even seeks to reinvent, knowledge productive processes:

Feminist methodology is specifically concerned with how, or whether, knowledge produced about social life can be connected with the social realities of women in the context of any methodology that is dominated by men and that neglects consideration of the gendered nature of social life (p. 430).

Feminisms employ a social epistemology according to which gender and other identity categories are understood to play a significant role in knowledge production: “[feminist epistemology] investigates the influence of socially constructed conceptions and norms of gender and gender-specific interests and experiences on the production of knowledge” (Anderson, 1995, p. 54). Our realities are therefore built based on social and political influences. They are pluralistic, and even competing. Longino (2002), a philosopher of science and feminist epistemologist, developed a theory of contextual empiricism, according to which the standard of objectivity is grounded in discourse. That is, knowledge claims are tested through the critical scrutiny of communities. The more diverse and inclusive the community, the more rigorously knowledge claims can be pursued and tested: “a diversity of perspectives is necessary for vigorous and epistemically effective critical discourse” (p. 131).

We therefore see a contextualizing of objectivity in feminist methodology and a favouring of subjectivity. DeVault (1996) explains: “feminist methodologists...seek methods that can incorporate, or at least do not deny, subjectivity. Thus, for those working on feminist methodologies, theorizing links between experience and knowledge has been a central concern” (p. 41). Some proponents of feminisms have embraced standpoint theory, according to which knowledge production is a matter of perspective (Anderson, 1995; Haraway, 1988). Smith (1990) advocates taking one’s embodiment and experience as a starting point for inquiry. Knowledge production processes have been known to hinge on the power and privilege invested in particular vantage points (Harding, 1987). The experiences of women have long been ignored, while “men’s standpoint is represented as universal and neutral” (Morris, 1992, p. 263).

I will ground the principles relevant to this study experientially by identifying the experiences and embodiments of women, but not just women. Advocates of third wave feminisms opened up feminisms to intersections with other socially marginalized identity characteristics (Crenshaw, 1991, 1998; Walker, 1995). Crenshaw (1998) defines intersectionality as overlapping membership to other social categories that are subject to discrimination. She argues that women’s experiences of disadvantage are vastly different depending on other identity characteristics: “any analysis that does not take intersectionality into account cannot sufficiently address the particular manner in which Black women are subordinated” (p. 315). I will therefore also note other identity characteristics that intersect with gender and that as such have been acknowledged in feminist discourses, including the following: race (Fuss, 1989; Walker, 1992, 1995), class

(Fraser, 1989), and—especially for the purpose of this study—disability (Garland-Thomson, 1997a, 1997b; Pothier & Devlin (Eds.), 2006; Sampson, 2006; Wendell, 1997). Garland-Thomson (1997b), for example, proposes developing feminist disability discourse in response to feminisms she would regard as ableist: “the identity category of disability can pressure feminist theory to acknowledge bodily particularity and history” (p. 284).

Disability theory might be a useful method of analysis to the extent that it pertains to a social category that challenges traditional notions of embodiment and personhood. Disability disrupts and deconstructs rigid, exclusionary moral systems and legal and political standards, for it presents the exception to all the rules, an exception that demands accommodation and reconfiguration. Titchkosky (2007) suggests that disability should not be appended to the list of intersections feminists consider, especially since disability has long been ignored in feminisms. She argues instead that disability has the power to radically transform political and intellectual discourses:

Since disability has typically been left out of the politics and theorizing of gender, race, and class, it can serve as a prime discursive field where the meaning of alterity under contemporary conditions can be considered. Disability is not merely the Other to normalcy, but is rather an irreducible productive identity and difference. From here identity politics might move on to address the powerfully political process of recognizing how identities have and have not been recognized, formed, and narrated by everyday life (p. 7).

With this in mind, I will employ a feminism that takes disability as the standard lens of analysis. I am interested in how disability as alterity confronts medical and legal discourses on reproduction, and so I will explore how pregnant bodies function within these discourses as though they are disabled. The comparison is imperfect, for women

and disabled people have different kinds of experiences of embodiment and oppression. When Garland-Thomson (1997b) imagines feminist disability theory, she considers how female and disabled bodies are treated differently: “feminization prompts the gaze, while disability prompts the stare. Feminization alterations increase a woman’s cultural capital, while disabilities reduce it” (p. 287). In both cases, while these two types of embodiments are treated differently, they are both subjected to the same standard for managing and producing embodiment. In the case of women, pregnant bodies are especially medically managed, in ways that I intend to demonstrate are comparable to the ways in which disabled bodies are medically managed. This project will therefore not only analyze how disability is framed through the application of reproductive technologies, and will note that some pregnant bodies are also disabled bodies, but will also treat pregnant bodies as comparable to disabled bodies, at least insofar as the analogy is useful to this study, given that in reproductive contexts women share in common very similar experiences of oppression.

I intend to contextualize the principles that are used (or can be used) in bioethical and legal discourses to protect women from being controlled and oppressed in reproductive spaces. These principles as they are currently being characterized may not be doing the work needed to safeguard reproductive decision-making, and so a contextualization will ensure they are informed by the experiences and embodiments of women, of those who have stakes in this issue. It may be possible to achieve social transformation through an application of these principles so re-conceived.

### *1.2.2. Overview of Research: Legal Research Methodology*

Additionally, the proposed research will use established legal research methodology, a process Myron Jacobstein and Mersky (2002) define in the following way: “the process of identifying and retrieving information necessary to support legal decision-making [which] begins with an analysis of the facts of a problem and concludes with the application and communication of the results of the investigation” (p. 1). That is, established legal research involves charting and evaluating the development of concepts or positions throughout the history of relevant case law. I will embark on an analysis of the theoretical and legal development of principles that have been used or perhaps should be used to ground reproductive rights and to regulate reproductive technologies. I will consider how these principles have applied to reproductive decision-making and what might happen should they be applied.

Legal research methodology involves, firstly, primary research: namely, case law and policy in a specific jurisdiction, in this case Canada. Further, I have investigated legislation and regulations, as well as legal and policy debates on reproductive processes. Much of the primary research can be found in cases from the provincial courts of justice and the Supreme Court of Canada. Courts are responsible for articulating and developing principles like autonomy, equality, and respect for difference, and for building protections based on these principles. In order to enrich my analysis of these three concepts in relation to reproductive decision-making, I will discuss how they differ from the concepts developed in case law outside Canada, for example privacy-based arguments in the American cases *Roe v. Wade* (1973), and the equality-based argument guaranteeing

reproductive rights in Colombia (Ordolis, 2008). I will account for international legislation on reproductive technologies—New Zealand, for example (NECAHR, 2005)—as regulation of these technologies is a relatively new global practice, and I will consider whether Canadian positions on disability compare to New Zealand's, which might help indicate whether Canada's policy gap is meant to reflect a position on disability, or whether Canada has merely not kept pace with technology.

In order to determine how the principles of autonomy, equality, and respect for difference have been formulated and whether these formulations are adequate, I will look outside law, to interpretations of law and critical theory. Secondary legal authorities have been consulted, such as law reviews and legal journals. I will draw from feminist legal theory and disability studies scholarship in order to critique legal articulations of the principles in question. As Boyd and Sheehy (1989) demonstrate when charting the history of Canadian feminist scholarship, this history has developed alongside Canadian jurisprudence; for instance, feminist formulations of equality changed in reaction and relation to Canadian legal applications of equality rights. Critical theories which focus on oppression, as feminisms and disability studies do, are not only informed by jurisprudence, but can also identify what jurisprudence is missing. They are thus of vital importance to include in a critical evaluation of legal principles.

Lastly, I have consulted non-legal sources, such as bioethical evaluations of, and feminist and disability studies critiques on, reproductive technologies. They can predominantly be found in bioethics, feminisms, and disability studies. I will investigate what these sources contribute to discussions about reproductive decision-making. There

are non-legal experts on reproduction insofar as the topic is not simply a legal issue but is also an ethical issue. These experts will be used for the purpose of assessing the reproductive contexts that law is designed to regulate, and will interweave bioethics with law to paint a more comprehensive picture of how reproductive activities are approached. Moreover, the recent trend toward using and promoting reproductive technologies has not been comprehensively regulated within the Canadian legal context, although there are Canadian policies (SOGC, 2007b) and international conventions (CBD, 1992; DHGHR, 1997) that address questions about the technologies. Theoretical analyses of and responses to reproductive technologies will be crucial when this project determines how principles might practically apply to reproductive contexts.

### *1.2.3. Conceptual Framework*

This project will explore principle-based approaches. That is, it will consider approaches taking for granted that the application of principles is an effective way of framing reproductive decision-making and the use of reproductive technologies. Principles are values that inform legal decisions and social norms; rights are entitlements and protections that are based on principles. Principles and rights are invoked in bioethics and law to protect women's decision-making powers in reproductive contexts. There are different ways of conceptualizing or formulating principles, and the differences affect how they frame reproductive decision-making.

Principle-based bioethics, where many of the arguments on reproductive matters can be found, has been supported by Engelhardt (1986), Macklin (1987), and Veatch

(1981, 1997), as well as early religious contributors (McCormick, 1981; Ramsey, 1970). Beauchamp and Childress, responsible for the influential work *Principles on Biomedical Ethics* (2009), set out to defend four clusters of moral principles, including two principles I aim to assess: “respect for autonomy (a norm of avoiding the causation of harm)...[and] justice (a group of norms for distributing benefits, risks, and costs fairly)” (p. 12).

Framing moral and legal issues with principles and rights is not without criticism. Principles may be too abstract, functioning in such a way that they erect barriers which distance rights-bearers from one another (Dillon, 1992; Harvey, 1999). Davis (2006) criticizes human rights, specifically in the context of disability, claiming that inherent in the concept of human rights is “the idea of the complete, independent subject, endowed with rights (which are in actuality conferred by privilege)” (p. 241). Strictly principle-based paradigms have been cast aside by some in favour of a more experiential approach (Gilligan, 1982; Toulmin, 1981).

Reich (1996) notes, however, that this new approach “that takes moral experience more seriously [has not] replaced the previously dominant, principle-based paradigm [because] most properly, bioethics involves both approaches” (p. 103). Harvey (1999), too, believes it is possible to use principles as long as they are construed in such a way that accounts for the relationships that are at the core of human experience. An analysis of principles does not have to discount the acknowledgement that reproductive decision-making must also be contextualized. Indeed, feminists have sought to conceptualize autonomy as relational—a conceptualization which is predicated on a relational self constituted by interpersonal and political connections (Colker, 1992; Nedelsky, 1989,

1993; Sherwin, 1998). In the case of equality, the ideal formulation of the principle might not emanate from a distributive justice model according to which justice is determined by how equitably goods (including rights) are parcelled out (Dworkin, 1981; Rawls, 1999), for such a model has been criticized for being disempowering (Harvey, 1999; Malhotra, 2006).

Autonomy and equality are well established principles with conceptual developments that can each be traced through Canadian case law. They are also two of the four key principles used in bioethics (Beauchamp & Childress, 2009). As such, they are appealed to by bioethicists who have analyzed reproductive decision-making, including and especially decision-making that involves diagnoses of fetal impairments (Buchanan et al., 2000; Callahan, 1970; Purdy, 1996). There has been substantial work done in feminism to critique both autonomy (Glendon, 2003, 2006; Nedelsky, 1989, 1993; Sherwin, 1998) and equality (Colker, 1992; Rodgers, 2006a, 2006b), as well as to consider which formulations of these principles best apply to reproductive decision-making. Autonomy (Ho, 2008; Jackson, 2001; Sherwin, 1998) and equality (Minow, 1991; Rioux & Valentine, 2006; Silvers, 1994, 1998a) have also been examined from a disability studies perspective, both in general and in relation to reproduction. It is thus of crucial importance that this project focuses on these two principles, as opposed to lesser known legal principles that pertain to reproduction (such as privacy, and freedom of conscience) or bioethical principles (such as the principle of beneficence). As this project seeks to provide conceptual clarity for an old and complex legal and philosophical

problem, it ought to focus on the two concepts that have been widely invoked in legal and non-legal discourse alike on the subject of reproductive rights.

In contrast, the principle of respect for difference is not often identified in arguments pertaining to reproductive rights, certainly not to the extent that autonomy and equality are. Respect for difference is, however, relevant to disability rights and as such is found in the UN *Convention on the Rights of Persons with Disabilities* (CRPD, 2006). Other principles in the *Convention* include accessibility and non-discrimination, although more so than these other principles, respect for difference might elucidate how disability-relevant concerns factor into the theoretical grounding of reproductive decision-making.

#### *1.2.4. Time and Setting Selection*

Bioethics, which will both be evaluated as a field that pertains to reproductive decision-making and incorporated into the conceptual model for this project, has existed for thirty years (Viafora, 1996), although moral applied philosophy certainly predates the field of study. Further, I will focus on Canadian case law from approximately the last forty years. It is difficult to settle on a specific cut-off date for this project given that the conceptual development of the principles in question have long histories, but work that is particularly relevant to reproductive rights today is clustered around the women's and disability rights movements of the 1960s and 70s, the establishment of the *Canadian Charter of Rights and Freedoms* in 1982, and the *R. v. Morgentaler* decision in 1988. Feminist and disability-related critiques of reproduction and reproductive technologies constitute a relatively recent body of literature, for disabled people and allies have only

within the last few decades found their voices in academia and public policy, beginning with political movements and the rise of feminism. Canadian law and theory shifted with the establishment of the *Charter*, so much so that the cases before and after the *Charter* came into effect have very different outcomes; *Bliss v. Canada (Attorney General)* (1979), for example, was criticized for its reliance on the concept of equality of sameness (Boyd & Sheehy, 1989; Porter, 2006; Young, 2006). I am also covering a time period when abortion legislation shifted dramatically in Western history, roughly corresponding to when the *Morgentaler* case was decided in Canada. Glendon notes in her comparative study of abortion legislation (including Canada), which was published in 1987:

The first striking finding of a comparative survey of abortion regulation is that fundamental change has occurred in this area all over the Western world in a relatively short period of time. Within less than two decades all but three of these twenty nations abandoned strict abortion laws—introduced for the most part in the nineteenth century—in favour of a more permissive stance (p. 10).

Even as she wrote this passage, Canada's current position on abortion had not taken form in *Morgentaler* (1988). I will focus on jurisprudence and policy that has developed since the shift made in *Morgentaler* because it is at around this point in Canadian history that we see principles like autonomy protecting women in reproductive contexts—the central focus of this work.

The few policies and cases meant to regulate reproductive technologies are recent because the technologies themselves have only recently been developed, and so policy and law have only recently begun the work of catching up to technological advancements. In addition, wrongful birth suits have aided in the framing of reproductive decision-making in relation to developing reproductive technologies, but

have only in recent decades more specifically pertained to technologies and instances when women gave birth to disabled infants (*Arndt v. Smith*, 1997; *Krangle v. Brisco*, 2002).

This study will focus on Canada; it will incorporate foreign policy and law by means of comparison, and will engage international policy and law to the extent that it applies to Canada. Granted, important discourses on bioethics and critical theory exist outside the country and will be used. Just as is the case with time, conceptual developments have a tendency to transcend national borders. When discussing reproductive contexts, however, there is value to limiting the scope of this project given that reproductive contexts vary drastically from one country to the next (Henshaw, 2008). Moreover, legal principles found and developed in Canadian contexts differ in contrast with other contexts, which Chief Justice Dickson of the Supreme Court of Canada pointed out in *Morgentaler*: “we would, in my view, do our own Constitution a disservice to simply allow the American debate to define us, all the while ignoring the truly fundamental structural differences between the two constitutions” (1988, p. 53).

### 1.3. Fields of Research

The three principles evaluated in this project may be conceived medically and legally. As such, they are found in both bioethics (a field of applied ethics related to medical matters) and law. Throughout this project, I will highlight the points of overlap for the two fields, those instances when jurisprudence has been applied to medical—especially reproductive—issues, and medical discourses have informed legal decisions.

The following sections explore how bioethics is currently grounded and how Canadian constitutional law is interpreted.

### *1.3.1. Bioethics*

This project will explore the tenets and possible limitations of bioethics, a thirty-year-old field of study which developed in reaction to medical abuses that took place, most notably, during World War II and throughout the Tuskegee Syphilis Study (Teays & Purdy, 2001). Says Viafora: “stimulated by perplexities and hopes, fuelled by the extraordinary biomedical progress, bioethics was initially conceived as a reflection on the conditions for dealing responsibly with the power of modern medicine” (1996, p. 7).

Bioethics involves the formulation of ethical guidelines for understanding and regulating health-related matters. The movement advocates practical, applied ethics, representing a departure from “high ethics”—ethical theories which are not meant for any particular context.

Engelhardt (1986) questions whether it is possible to establish an objective foundation for ethical canon. If one were to appeal to either intuitions or consequences, the problem of ranking and comparing competing intuitions or outcomes would require theoretical foundations, and “the possibility of establishing such a theory is exactly what is at issue” (p. 34). One might also posit the possibility of a hypothetical observer, a rational agent who would make choices from behind a veil of ignorance (Rawls, 1999). Engelhardt rejects this possible grounding of bioethics as well, arguing that the disinterested party can only judge concrete health-related dilemmas by weighing benefits

and harms, and can only do so by referencing one of many competing hierarchies of benefits and harms.

Engelhardt concludes by further rejecting the use of natural law to ground bioethics. Natural law is typically predicated on a higher power creating an essential set of laws that human law is meant to emulate. There are influential Christian bioethicists who find natural law to be an acceptable way of grounding the field (Lebacqz, 1986; McCormick, 1981); Ramsey (1970) mounts a critique of in vitro fertilization with a theology-based natural law approach, for instance. As noted in Callahan (1990) and Viafora (1996), however, bioethics has become more secularized, such that current bioethicists tend not to rely on natural law or a deity to serve as a basis for moral rules and reasoning.

Beauchamp and Childress (2009) propose instead that ethics is grounded in the consensus of communities: “morality refers to norms about right and wrong human conduct that are so widely shared that they form a stable (although usually incomplete) social consensus” (pp. 2-3). Such an ethics may be provisional, hinging on the composition of the community holding consensus. It may also be in danger of silencing voices in the minority; consensus as General Will—reminiscent of Rousseau—seems impossible in pluralities, and a moral consensus via a majority rules standard requires that people in the minority are outvoted. However, in the absence of a sound explanation for how one might ground ethics in a transcendent, abstract foundation, our best recourse may be to rely on people in contexts to deliberate and decide—as well as to test and revise—ethical codes by consensus.

A principle-based paradigm has dominated the history of bioethics (Engelhardt, 1986; Macklin, 1987; Veatch, 1981, 1997). Such a paradigm relies on principles to ground ethical codes and conduct. According to Reich, “a principal shortcoming of the principle-based approach is that, by emphasizing the abstract features of a universal ethic (such as universal rights, equal dignity, etc.) it has excluded much of the particular moral experience of the moral agents involved” (1996, p. 102). An experiential-based paradigm has emerged in bioethical literature, but it means to incorporate experience into analysis of bioethical principles rather than do away completely with principles (Gilligan, 1982; Reich, 1996; Toulmin, 1981).

There is value to a more experiential paradigm as long as the experiences accounted for include those experiences of marginalized peoples. Originally developed in order to represent the interests of marginalized groups, bioethics has been criticized for taking a different direction since its professionalization (Holmes, 1999; Purdy, 2001). Feminist bioethics has emerged in an effort to prioritize the vantage points of those who lack privilege but have a stake in health matters. This brand of bioethics is experientially grounded because abstractions tend to gloss over already marginalized perspectives (Holmes & Purdy, 1992). The experience that grounds feminist bioethics can be found in relational interactive frameworks as well as personal embodiment, especially given that women have experienced inequality as a result of the medical treatment of their bodies (Bordo, 1993; Mahowald, 1993). Feminist bioethicist Wendell (1996) introduced to bioethics the intersection of gender and disability, proposing that both female and disabled bodies are subject to prejudice in the medical field.

Given that bioethical issues often intersect with disability, it is especially valuable to account for disabled people's perspectives when considering how to proceed with bioethical discourse (Grosz, 1994; Shakespeare, 2006; Wendell, 1996). Scully (2008) argues for the inclusion of the voices of disabled people in the shaping of bioethics: "to address the gaps in our understanding bioethics needs more than just empirical data. The subjective experience of disabled people is a necessary part of grasping what it is like to live within an impaired embodiment" (p. 154). Shildrick (1997) cautions against the historical study of ethics that "has produced numerous more or less monolithic systems of explanation" (p. 1). She advocates a feminist postmodern bioethics that destabilizes paternalistic epistemologies, and that is rooted in embodiments:

The postmodern perspective...seems to undermine not only the hitherto entrenched givens of a male en-gendered epistemology, but also the very ground on which women might seek to position their own project. In so far as the deconstruction of boundaries and the recognition of radical differences is at the heart of postmodernist feminist enterprise, the very category of 'women' becomes difficult to appeal to in any unambiguous way. Where signification is acknowledged as slippery and treacherous, the issue becomes not the creation of new normative standards, but a persistent endeavour to forefront the instability and provisionality of the concepts with which one is dealing (p. 2).

Keeping in mind the disagreements in bioethical discourse, I put forward that this project will engage bioethics as both a field worthy of evaluation and an evaluative tool. I intend to present and assess the field of bioethics and its contributions to the theoretical development of principles that have been applied to reproductive contexts and technologies. The conceptual model that will serve as a lens for my assessment will draw from bioethics, specifically strands of bioethics which have been or can be grounded in

critical feminism and disability theory, both of which hold experience and embodiment to be important starting points for theory.

### *1.3.2. Law*

When investigating the legal field, this project will focus predominantly on cases involving constitutional law—namely, the *Canadian Charter of Rights and Freedoms*. Established in 1982, the *Charter* came into effect in 1985 and replaced the *Canadian Bill of Rights* (1960). Whereas the *Bill* was a federal statute and as such was both limited in scope and too easy for Parliament to amend, the *Charter* as part of the Canadian Constitution did not share these shortcomings. The establishment of the *Charter* enhanced “the role of the judiciary in the governance of Canada” (Sharpe, 2000, p. 191) as the body responsible for upholding and enacting the protections found in the document. The statute consists of rights and freedoms that are held to be essential in a “free and democratic society” (s. 1). These rights and freedoms are the benchmarks that judicial courts use in order to determine whether laws, institutions, and practices are just.

The Supreme Court of Canada developed a purposive approach to interpreting and applying the *Charter* and other statutes. According to the purposive approach—“the cornerstone of *Charter* interpretation” (Sharpe, 2000, p. 208)—courts are not to enact the letter of the law, that is, are not to take the wording in statutes literally. Instead, they are to enact the spirit of the law—the original intention that legislators had when drafting the statute, or the rationale behind the statute.

The purposive approach is characterized in *Hunter v. Southam Inc.* (1984), the first time the courts considered the *Charter's* s. 8 right to privacy. The provincial government of Alberta had ordered a search of Southam Newspaper before the enactment of the *Charter*, though the search took place after. It was determined that the *Combines Investigation Act*, under which the search was ordered, was inconsistent with the *Charter* and thus no longer had effect. In this case, C.J. Dickson characterized the purpose of a constitutional document. For him, a constitutional document must have room for development over time and with changes in context, “to meet new social, political, and historical realities often unimagined by its framers” (supra note 69). He went on: “the *Canadian Charter of Rights and Freedoms* is a purposive document. Its purpose is to guarantee and to protect, within the limits of reason, the enjoyment of the rights and freedoms it enshrines” (p. 156). Chief Justice Dickson reiterated the meaning of the purposive approach elsewhere:

In my view, this analysis is to be undertaken, and the purpose of the right or freedom in question is to be sought by reference to the character and the larger objects of the *Charter* itself, to the language chosen to articulate the specific right or freedom, to the historical origins of the concepts enshrined, and where applicable, to the meaning and purpose of the other specific rights and freedoms with which it is associated within the text of the *Charter*. The interpretation should be...a generous rather than a legalistic one, aimed at fulfilling the purpose of the guarantee and securing for individuals the full benefit of the *Charter's* protection. At the same time it is important not to overshoot the actual purpose of the right or freedom in question, but to recall that the *Charter* was not enacted in a vacuum, and must therefore...be placed in its proper linguistic, philosophic and historical contexts (*R. v. Big M Drug Mart Ltd.*, 1985, supra note 55<sup>5</sup>).

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<sup>5</sup> *R. v. Big M Drug Mart Ltd.* (1985) was the first case to consider the *Charter's* s. 2, freedom of conscience and religion. In this case, the store Big M Drug Mart was charged with selling goods on a Sunday contrary to the *Lord's Day Act*. The Supreme Court of Canada found that the *Act* did indeed violate s. 2.

In this seminal passage, C.J. Dickson advocated interpreting *Charter* rights and freedoms generously, and applying the original intention behind the wording. In this way, the constitutional document continues to be relevant and may yet change in light of the contexts to which it is applied.

As an example, a later legal case reinforcing the purposive approach to statutory interpretation is *Rizzo & Rizzo Ltd. (Re)* (1998), in which a bankrupted company claimed that they owed employees neither termination nor severance pay under the *Employment Standards Act*. According to the *Act*, termination and severance pay were owed only when the employer was responsible for terminating employment, but bankruptcy was not included in the “termination by an employer” language. The Supreme Court of Canada decided that the purpose of both the *Employment Standards Act* and the provisions for termination and severance pay is to protect employees. It would therefore be inconsistent with the spirit of the *Act* and these provisions to rule that bankruptcy does not qualify as an instance when the employer is responsible for termination.

Rather than focus on the wording in the *Employment Standards Act*, the Court considered the intention behind it:

Statutory interpretation cannot be founded on the wording of the legislation alone. The words of an Act are to be read in their entire context and in their grammatical and ordinary sense harmoniously with the scheme of the Act, the object of the Act, and the intention of Parliament (pp. 2-3).

This statement, reiterated by Justice Iacobucci, drew from Driedger (1983), a Canadian legal scholar and leading expert on the purposive approach to statutory interpretation.

For Driedger, the letter of the law, the explicit wording in a document, is not as important

as its purpose, and the intention of the legislators. Justice Iacobucci also noted in his ruling that according to Ontario's *Interpretation Act* (1990), every Act "shall be deemed to be remedial" and shall "receive such fair, large and liberal construction and interpretation as will best ensure the attainment of the object of the Act according to its true intent, meaning and spirit" (as cited in *Rizzo*, 1998, p. 3).

According to Sharpe:

The most difficult issue in the interpretation of *Charter* rights is reconciling the rights of the individual with the competing rights of others and with the interests of the community at large. The problem is especially acute when rights are broadly defined, as they were likely to be following the purposive approach (2000, p. 208).

In light of this potential challenge, the *Charter* imposes a limit to constitutional protections, built into its first section. When applying the *Charter* in legal cases, the Court undergoes a two-step process. It must determine firstly whether a right has been violated, and secondly whether the violation can be saved under the statute's s. 1: "the *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society". The burden of proving the violation rests with the claimant in the first step; it then shifts to the defendant in the second step, to prove the violation is justifiable in this one case in order to uphold freedom and democracy. Section 1 therefore involves reconciling competing collective (the free and democratic society) and individual interests (the *Charter* violation) (Sharpe, 2000).

The test for determining whether a violation can be saved under s. 1 was developed in the case of *R. v. Oakes* (1986). Charged with possession of narcotics that

were allegedly medicinal, David Edwin Oakes challenged the *Narcotic Control Act* on the grounds of s. 11(d)'s presumption of innocence guarantee. Section 8 of the *Act* involves an onus on the accused to prove lack of possession for the purpose of trafficking. This onus contradicts the guarantee that the accused is presumed innocent. The Court ruled that the shift of onus violated s. 11(d) of the *Act* and s. 7 of the *Charter*, and could not be saved under s. 1.

In this case, the Court developed the Oakes Test; under this Test they identified the exceptional criteria according to which rights can be justifiably limited under s. 1. The two functions of s. 1 were identified: "first, it guarantees the rights and freedoms set out in the provisions which follow it; and second, it states explicitly the exclusive justificatory criteria...against which limitations on those rights and freedoms may be measured" (p. 4). That is, *Charter* rights are to be upheld, albeit limited by specific conditions that are justifiable in a free and democratic society. Such a society serves as the standard for limiting *Charter* rights under s. 1 because the purpose of the *Charter* is to guarantee that society be free and democratic. The standard was defined in *Oakes* as follows:

The Court must be guided by the values and principles essential to a free and democratic society which I believe embody, to name but a few, respect for the inherent dignity of the human person, commitment to social justice and equality, accommodation of a wide variety of beliefs, respect for cultural and group identity, and faith in social and political institutions which enhance the participation of individuals and groups in society (p. 40).

The first of two justificatory criteria is as follows: "first, the objective to be served by the measures limiting a *Charter* right must be sufficiently important to warrant

overriding a constitutionally protected right or freedom” (p. 5). That is, the overarching collective interest in saving the infringement to a constitutional right must far outweigh the individual interest in not having one’s right infringed. For the second criterion, “the party invoking s. 1 must show the means to be reasonable and demonstrably justified” (p. 5). The limit must be reasonable and justifiable, as determined by a proportionality test.

This test consists of three components:

To begin, the measures must be fair and not arbitrary, carefully designed to achieve the objective in question and rationally connected to that objective. In addition, the means should impair the right in question as little as possible. Lastly, there must be a proportionality between the effects of the limiting measure and the objective—the more severe the deleterious effects of a measure, the more important the objective must be (p. 5).

For the first component of the proportionality test, the law which would violate a constitutional right must be rationally connected to achieving a certain aim. In so doing, should the law lead to an infringement, this infringement must be minimal, that is, must only infringe upon a right to the most necessary extent. Lastly, the Court must weigh the objective or the aim of the law—an objective which has been rationally connected with the legislation being tested—against the extent to which there are effects to limiting *Charter* rights. A *Charter* limit must be in proportion to a pressing objective.

#### 1.4. Reproductive Context

In what follows, I review Canadian policy on reproduction and the delivery services available. The dearth in abortion regulation has resulted in vastly different services across provinces and territories, and the barriers that have sprung up will be of

interest as this study develops. Further, I will consider the disability diagnostic technologies made available to pregnant women or women seeking to become pregnant. These technologies, I will go on to argue, reshape our legal and moral discourses on reproductive decision-making, and call for a re-framing of the rights applied.

#### *1.4.1. Abortion Services in Canada*

Abortion for health-related reasons was decriminalized in 1969 when the Trudeau administration amended s. 251(4) (later found under s. 287) in the *Criminal Code*: abortion was only possible if “the continuation of the pregnancy of such female person would or would be likely to endanger her life or health”, as determined by an abortion committee comprised of medical professionals. According to abortion advocate Saporta (2009), abortions at the time had to be approved by the Therapeutic Abortion Committees established in hospitals, and cases were only approved if the pregnancy endangered life or health:

In order to obtain a legal abortion, women were forced to face an intimidating process of going before a hospital committee to petition for care. This policy established unequal access to abortion throughout the provinces and territories, and made it particularly difficult for women outside major urban centres to obtain abortion care. It is estimated during this time that 35,000 to 120,000 illegal abortions took place each year (p. 3).

In *R. v. Morgentaler* (1988), Dr. Henry Morgentaler (along with two other physicians) was charged with illegally inducing miscarriages in his clinic in Toronto. The Supreme Court of Canada ruled five to two that s. 251 violated s. 7 of the *Charter* (1982) in such a way that was not in accord with the principles of fundamental justice,

and could not be saved by s. 1. Morgentaler went on to advocate for the expansion of reproductive rights in more legal cases (*R. v. Morgentaler*, 1993; *Morgentaler v. New Brunswick*, 1994; *Morgentaler v. Prince Edward Island*, 1995, *Morgentaler v. New Brunswick*, 2008), and the decision made in *Morgentaler* (1988) was reinforced in subsequent cases (*Borowski v. Canada*, 1989; *Tremblay v. Daigle*, 1989; *R. v. Sullivan*, 1991; *Dobson (Litigation Guardian of) v. Dobson*, 1999).

The *Morgentaler* decision did encounter resistance. The Progressive Conservative federal government at the time introduced Bill 43, which would have re-criminalized abortion, although the Bill was defeated by Senate in 1991 (Richer, 2008). In 1989, Nova Scotia intended to prohibit abortions outside hospitals and deny abortion funding, in an effort to prevent a two-tiered health system and to ensure high quality care; the Supreme Court of Canada struck down this policy in 1993 (Erdman, 2008). New Brunswick also attempted to enact law to prohibit abortion clinics, and this policy too was struck down by the Supreme Court (Erdman, 2008). In 2008, four private members' bills pertaining to abortion were introduced, and Bill C-484—according to which harming or causing the death of an unborn child while committing an offence against the mother would constitute a crime—passed second reading but was ultimately defeated (Richer, 2008).

Abortion is considered a medically necessary procedure by all provincial and territorial colleges of physicians and surgeons in Canada. Inasmuch as abortion is a medically necessary procedure, provinces and territories are bound by the *Canada Health Act* to provide free access to the service in order to qualify for their full federal funding

for healthcare; however, federal governments have not taken many measures to ensure that provinces and territories comply (Richer, 2008). The Liberal *Independent Health Facilities Act* (IHFA, 1990), originally introduced in order to enable governments to regulate and facilitate the delivery of health services, once gave preference to funding non-profit, Canadian-owned providers such as abortion clinics; but with the Conservative Bill 26, this preference in the IHFA was removed, leading to a redefining of medically necessary services and extra billing for those no longer deemed medically necessary (Gilmour, 2002). Says Gilmour:

The IHFA might have provided a framework for increased availability of and choice in abortion services. Owing to political pressures, fears of harassment and violence, limited resources and personnel, and disapproval or indifference, abortions are not available at many hospitals. Often a free-standing clinic is women's only option. While the statute could have been employed to facilitate the establishment of independent health facilities performing the procedure, it was not (p. 286).

Abortion access varies according to the province or territory. Prince Edward Island lacks in-province abortion services, although women in the province can access funding for out-of-province services as long as they obtain a referral from their physician. New Brunswick only offers abortions in hospital settings, and requires that abortions are performed by gynaecologists in the first trimester of pregnancy, only after two physicians have deemed the procedure medically necessary. Prairie provinces typically offer services near the southern US/Canada border, requiring that some women travel vast distances. Only British Columbia, Quebec, and Ontario provide abortions past twenty weeks of pregnancy; in these provinces, waiting lists vary, and are especially long for women in rural areas (Dunn, 2008).

#### *1.4.2. Reproductive Technologies*

The SOGC (2007a) defines prenatal screening in the following way: “screening is the process of surveying a population, using a specific marker or markers and defined screening cut-off levels, to identify the individuals in the population at higher risk for a particular disorder” (p. 147). The SOGC goes on to discuss the purpose of prenatal screening—screening for chromosomal anomalies: “in Canada, the option of invasive testing has been recommended when a woman’s risk of having a pregnancy with a chromosome anomaly was higher than the risks associated with the common invasive procedure (amniocentesis or chorionic villus sampling)” (p. 148). Both of the listed invasive procedures are considered prenatal genetic tests: DNA is extracted from fetal cell sampling and is tested for chromosomal anomalies (MacKay & Fraser, 1993; SOGC, 2009). Amniocentesis may be used to detect abnormal levels of alpha-fetoprotein, which are associated with congenital impairments (MacKay & Fraser, 1993).

Prenatal screening, specifically amniocentesis, was introduced to Canada in the late 1960s, and medical genetic centres using amniocentesis were established in major cities by 1971. By this time Dr. Malcolm Brown was federally appointed to investigate the health risks associated with amniocentesis, which had by then become a matter of public concern. The report he and his team released in 1977 found that the risks were negligible and that the procedure along with genetic counselling were effective in the detection of genetic impairments (MacKay & Fraser, 1993).

Less invasive and far more pervasive, ultrasound technology can now also be used to identify some chromosomal anomalies, such as Down Syndrome (Trisomy 21).

Ultrasounds produce images of what is interior to the body through the use of sound waves (SOGC, 2008). A reason for submitting to an ultrasound when pregnant include, among other reasons, “to check for signs of a possible genetic problem” (SOGC, 2008, p. 2). First used to identify anencephaly, or the absence of a skull and upper brain, ultrasounds have been employed frequently “to detect increasingly subtle structural and functional abnormalities such as gastrointestinal tract anomalies, urinary tract anomalies, congenital heart defects and skeletal dysplasia” (MacKay & Fraser, 1993, p. 15). The SOGC (2005) makes the following recommendation regarding ultrasounds:

The screening ultrasound at 16 to 20 weeks should evaluate 8 markers, 5 of which...are associated with an increased risk of fetal aneuploidy, and in some cases with nonchromosomal problems, while 3...are only associated with an increased risk of nonchromosomal abnormalities when seen in isolation (p. 592).

An alternative to testing in utero, pre-implantation genetic diagnosis “involves the diagnosis of a genetic disease before a pregnancy has been established” (SOGC, 2009, p. 762), such as instances of in vitro fertilization when embryos can be tested before implanted in the uterus. The SOGC recommends pre-implantation genetic diagnosis for carriers of single gene disorders<sup>6</sup> and chromosomal anomalies (or aneuploidies<sup>7</sup>), women who repeatedly failed either to conceive via in vitro fertilization or to carry to term, and older women trying to bear children (SOGC, 2009).

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<sup>6</sup> The most common single gene disorders detected by pre-implantation genetic diagnosis are identified by the SOGC as follows: cystic fibrosis, beta-thalassemia, spinal muscular atrophy, sickle-cell anaemia, Huntington disease, myotonic dystrophy type 1, muscular dystrophy, haemophilia, and fragile-x syndrome.

<sup>7</sup> Aneuploidy refers to an atypical amount of chromosomes, leading to genetic impairments. For example, Trisomy (three copies of a chromosome when chromosomes otherwise tend to come in pairs) produces Down Syndrome (Trisomy 21), Edwards Syndrome (Trisomy 18), and Patau Syndrome (Trisomy 13).

The SOGC (2007a) recommends the following in their recent clinical practice guidelines for prenatal screening of fetal aneuploidies: “all pregnant women in Canada, regardless of age, should be offered, through an informed consent process, a prenatal screening test for the most common clinically significant fetal aneuploidies in addition to a second trimester ultrasound for dating, growth, and anomalies” (p. 149). The SOGC (2007b) provided the logic motivating this shift away from the previous practice of only recommending screening to women over thirty-five or at medical risk: “it is our belief that to deny women access to any information about the health or development of their child, when this information is readily available, is wrong and a disservice to Canadian women and their families” (unpaginated). The technology has thus come to be considered an aid in reproductive decision-making, a way of enabling women to make more informed reproductive choices.

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## Chapter 2: Autonomy

In this chapter, I will examine how autonomy frames reproductive decision-making in the context of disability diagnosis. To begin, I will explore autonomy theories, and will determine how feminist disability discourse confronts these theories. I will then consider bioethics, where the canonical principle of autonomy is made manifest in informed consent and decisional capacity; and law, where autonomy is protected by the *Charter's* s. 7 rights to life, liberty, and security of the person. These themes will be tied together in reference to reproductive autonomy, especially in reproductive contexts that involve reproductive technologies. In these contexts, autonomy language tends to frame the matter in terms of maternal responsibility. I will consider how the burden of responsibility to promote fetal health, even to avoid fetal impairments, is predicated on a specific, and problematic, definition of autonomy.

### 2.1. Theories of Autonomy

This chapter will chart the conceptual development of autonomy, beginning with the moral autonomy of Kantian moral philosophy. I will next characterize personal autonomy, the cornerstone of liberalism. Finally, I will introduce relational autonomy, found in feminisms and disability theories. In every section, I will mount a critique grounded in feminist disability theory. Disabled bodies and pregnant bodies, because they represent leaky, uncomfortable alterity, disrupt autonomy theories—especially those theories that radically isolate individuals and are predicated on abstract notions of

personhood. Given the rich history of the philosophies, this section may require broad brush strokes. I will focus on watershed moments in the conceptual development of the principle, specifically the ones which will best apply to later arguments in this project.

### *2.1.1. Moral Autonomy*

#### Overview of Kantian Theory

The concept of autonomy has been foundational to moral and political philosophies since the rise of Enlightenment humanism of the 1700s, a time which ushered in new scientific, philosophical, and political advances that would define modern Western thought (Lukes, 1973). In his account of the history of modern moral philosophy, Schneewind (1998) credits Enlightenment intellectual Kant with inventing a concept of morality that equates with autonomy. Moral autonomy of the Kantian tradition refers to a person's capacity to self-impose universal moral law, that is, to make choices in accordance with one's moral obligations: "the will of every rational being [is] a will that legislates universal law" (Kant, 1993, 2.431). Kantian moral philosophy represents a departure from (or at least a drastic refashioning of) natural law theories predating the Enlightenment, according to which morality was grounded in God (Crowe, 1977; Haakonssen, 1996). Although God still has a place in Kantian theory, the philosopher argues that autonomy consists in self-governance rather than obedience to a deity. He laments: "we still have a long way to go before men as a whole can be in a position...of using their own understanding confidently and well in [political and religious] matters, without outside guidance" (Kant, 2002, p. 3).

For Kant (1999), morality entails acting in accordance with universal law, the source of which must derive solely from form rather than content. That is, universal law is discernible only via reason, and cannot be empirically grounded. This is because empirically grounded moral systems—those based on subjective interests and motivations—cannot provide a standard by which we might act morally or judge human actions as moral. Any action motivated by an interest in happiness or one's own welfare, for instance, would not be considered a moral action, for it would be driven by the personal rather than the universal, or by a standard which may not be shared by other moral beings (O'Neill, 2002).

Kant (1999) argues that there is only one universal law, that is, one law with content that consists in its form: the categorical imperative. According to a formulation of the categorical imperative, one must “act only according to that maxim whereby you can at the same time will that it should become a universal law without contradiction” (1993, 2.421). A maxim is a subjective principle for action or a practical rule. For a maxim to be moral, it must theoretically hold as a universal law without admitting of any logical contradictions. In one of Kant's examples (1993), a man who is hard-pressed for money considers whether he could universalize the maxim that someone in financial need may borrow money on the false promise that he can repay the loan. This maxim is impossible to universalize because if everybody lied in order to receive loans, that would lead to a lack of trust on the part of those giving money, and as a result the practice of pay lending would collapse. The logical contradiction inherent in a hypothesized, universalized practice of lying indicates that the maxim is immoral.

Kantian moral theory is predicated on the human will, by which one chooses actions. The philosopher interprets pure practical reason (a combination of objective and subjective reasoning) as will. The actions that the will is capable of choosing may be subjective maxims “when the condition is regarded by the subject as valid only for his own will”, and objective laws “when the condition is recognized as objective, that is, valid for the will of every rational being” (1999, p. 14). Arriving at the categorical imperative requires that the agent can choose his<sup>8</sup> own actions independent of external, heteronomous factors (*hetero* meaning different or other, and *nomos* meaning law or governance). It is not enough to say that a moral being obeys moral law; rather, a moral being wilfully chooses actions in accordance with moral law, which can be discerned through rational thought. The will as a condition for morality entails independent reflection, choice, and action.

### Kant on Autonomy

Moral autonomy thus plays a central role in the exercise of the will (Kant, 1993, 1999; Korsgaard, 1996). In Kant’s (1993) own words:

Autonomy of the will is the property that the will has of being a law to itself. ...That the above principle of autonomy [the categorical imperative] is the sole principle of morals can quite well be shown by mere analysis of

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<sup>8</sup> I employ male pronouns only when dealing with authors who did the same. The use of male pronouns to indicate neutrality is a common literary device with built-in sexist assumptions about what has historically been considered neutral, legitimate, and authoritative. Many early modern Western philosophies were arguably not meant to account for women, and this is a significant point to note and to preserve given that it is my intention to mount a feminist critique of these philosophies. That is, it is my intention to point to who is missing in these theories, and why their absence renders these theories problematic.

the concepts of morality; for thereby the principle of morals is found to be necessarily a categorical imperative, which commands nothing more nor less than this very autonomy (2.440).

For this philosopher, a moral being may be motivated to act by his own desires and emotions (in which case he has a heteronomous will and spurious moral principles); or, when acting autonomously, he may be motivated by his rational faculties, which like the rational faculties of all other moral beings, can arrive at the same categorical imperative. Moral autonomy thus provides a basis for moral obligation, for we can only take responsibility for our actions if we have the power to choose them. Morality is rational, and as such rational beings are capable of recognizing it; those with heteronomous wills, wills driven to act by myriad influences external to it, may choose a different course of action, but all those capable of recognizing morality are responsible for enacting it.

As the unit of value in Kant's moral philosophy, autonomy is the justification for both judging and respecting other moral beings. For, moral autonomy is central to personhood, which is the condition for moral consideration. Given that all moral beings are responsible for legislating moral law, it would be immoral not to respect the autonomy of other beings like oneself, those other legislators of moral law. Hence the second formulation of the categorical imperative, called the Autonomy Formula: "act in such a way that you treat humanity, whether in your own person or in the person of any other, always at the same time as an end and never merely as a means to an end" (1993, 2.429). A moral being may be treated as an end in himself when he is recognized as autonomous, as capable of also enacting moral law, and unobstructed from doing so.

Honouring autonomy is therefore a condition for good state governance: “freedom (independence from being constrained by another’s choice) insofar as it can coexist with the freedom of every other in accordance with a universal law, is the only original right belonging to every man by virtue of his humanity” (1996, 6.237). A moral society consists in honouring the autonomy of its members, rather than imposing any particular notion of happiness or welfare on its members. Such a society is characterized as a hypothetical kingdom of ends in the third formulation of the categorical imperative: “every rational being must so act as if he were through his maxim always a legislating member in the universal kingdom of ends” (1993, 2.438). The kingdom of ends is Kant’s utopia—what the ideal contract would look like between other moral beings. Maxims that are moral would harmonize with the kingdom of ends insofar as they would not lead to the compromising of the autonomy of another person, or the treatment of another person as a means rather than as an end in himself.

That which does not qualify as a person is motivated by “alien causes” (1993, 3.446), causes external to it, rather than by will power. The Kantian definition of personhood as the condition for moral value includes autonomy, and his conceptualization of autonomy is predicated on rationality, that which enables one to identify universal law. While persons must be honoured according to the categorical imperative, those things which do not qualify for moral consideration are valuable only instrumentally, as a means for moral beings to achieve their own purposes. This is because things are not rational, cannot will themselves to act, and as such are not autonomous. That which is not autonomous needs not be treated as an end in itself:

Beings whose existence depends not on our will but on nature have, nevertheless, if they are not rational beings, only a relative value as means and are therefore called things. On the other hand, rational beings are called persons inasmuch as their nature already marks them out as ends in themselves (1993, 2.428).

### Critique of Moral Autonomy

The universal character of morality is suspicious, especially given that according to Kant universal law is only identifiable to those deemed worth moral consideration, those members of an exclusionary category. Exclusionary moral systems tend to privilege particular perspectives and misrepresent those perspectives as neutral and authoritative (Harding, 1995; Longino, 2002; Shildrick, 1997). Those legislators of moral law determine who qualifies as a person and how those relegated to the fringes of personhood are treated. Positing the universality of law thus has the effect of legitimizing oppressive practices and silencing those who have been discredited as nonpersons. A definition of personhood that hinges on one's rational faculties and discounts subjectivity has historically excluded disabled people and women, among others (Bartky, 1990; Koch, 2001; Lloyd, 1984; Sherwin, 1998). According to Kittay: "personhood in the past has...been used...to exclude specific humans: women, slaves, Jews, certain racial groups, the disabled—those who, for one reason or another, were believed unworthy or incapable of rationality and self-governance" (2005, p. 101).

Those belonging to unworthy minority categories have often been defined corporeally, for the purpose of divesting them of moral consideration, for corporeal-bound beings cannot access moral law. Some disabled people, for instance, are

constantly forced to confront their embodiments as vehicles through which they engage with their surroundings. Clare (2007) considers how disability compels both awareness of one's corporeal reality and negotiation with one's surroundings. The author illustrates how he engages the world through a body that trembles and contorts, uncontrollably and even painfully. He is ever present in his body; his body is always reminding him that it is there. His knowledge, experiences, and politics are all mediated through an embodiment of which he cannot be unconscious:

My scars don't come from a surgeon's scalpel, an unusual circumstance for anyone physically disabled since birth. My quad muscles were never cut, sewn back together. Achilles tendons, never severed. Pins, never inserted into hips and knees. The bodies of disabled people so often end up criss-crossed with scars, childhoods punctuated by surgery. But not mine: my skin didn't become a map. For that, I need to go subterranean. Muscles knotted, tendons inflamed, vertebrae too sore to touch (p. 77).

Clare readily admits that he cannot transcend his embodiment. This is not necessarily a problem, not unless you are a Kantian. For, Clare cannot reach the heights of abstraction and objectivity that Kant expects of him. Through the Kantian lens, Clare's cerebral palsy is non-ideal, and it is only through the idealization of the body that theories like Kant's can ignore the body, even cut it away from human consciousness. Wendell (1996) describes this ideal as that which disabled people struggle to approximate:

The ideals change from time to time, but there always seem to be ideals. Body ideals include not only ideals of appearance, which are particularly influential for women (Bartky, 1990), but also ideals of strength, energy, movement, function, and proper control; the latter are unnoticed assumptions for most people who can meet them, but they leap to the foreground for those who are sick or disabled (p. 86).

To the extent that disabled people are ever present in their bodies, theories like Kant's characterize them as lacking in the key markers for personhood, such as "self-

consciousness, rationality, autonomy, and so on” (McMahan, 2005, p. 235); if they are persons at all, they are only marginally so (McMahan, 2005; Vehmas, 2004). When they are thusly marginalized, it is not morally obligatory to treat disabled people with respect, and it is morally permissible to make decisions on their behalf, for their own good.

Wendell goes on to argue that the myth of the normalized body justifies cultural control over those bodies considered non-ideal. Although Clare (2007) does not admit to this being his own experience in the above passage, he indicates, as do other scholars (Asch, 2006; Marks, 1999; Silvers, 1998a), that there exist disabled people whose bodies are medically, even surgically, maintained or repaired because their bodies fall short of a functional or aesthetic ideal.

Women too have historically been considered incapable of transcending their pliant, dirty corporeality:

Women are supposedly rooted in base corporeality. ...And it is this supposed immanence that provides the justification, within the discourse of liberal humanism, for the exclusion of women from the attribute of full rationality, which is one of the essential parameters of moral agency. As a consequence, women are denied control of the very bodies which they have failed to transcend (Shildrick, 1997, p. 81).

In a similar vein, Grosz (1994) describes how women’s corporeal grounding has served as justification for their subordination: “patriarchal oppression...justifies itself, at least in part, by connecting women much more closely than men to the body and, through this identification, restricting women’s social and economic roles to (pseudo) biological terms” (p. 14). Examples of disciplinary practices include the use of cosmetics, hair care, fashion, as well as feminine gestures and manners (Bartky, 1990; Young, 2005). Bartky (1990) discusses how beauty rituals aid in the objectification of women’s bodies, a

process which denies women their subjectivity; when they are objectified, rendered objects, they are thought to be nothing other than bodies: “sexual objectification is a form of fragmentation and thus an impoverishment of the objectified individual; it involves too the implicit denial of those who suffer it that they have capacities which transcend the merely sexual” (pp. 35-36).

Female bodies are not only sexualized through beauty rituals, for maternal bodies are subject to different kinds of control. The social and economic practices identified in Grosz (1994) refer to the tasks of child bearing and rearing, as though all the responsibilities of household maintenance and motherhood are bound to women’s reproductive capacities. Women so defined by biologically limiting roles are also thought to require management, just as disabled bodies have been managed through medication, rehabilitation, surgical correction, and so on. The maternal body disrupts the notion of a unified, ideal, masculine body, for the bleeding, bloating, lactating maternal body is unruly and messy. Kukla (2005) describes the implications: “mothers [have historically been] implored to develop self-control and self-discipline in order to compensate for their vulnerable and poorly bounded bodies” (p. 85). Where to locate reproductive control has historically been at issue because women cannot escape their baser corporeal reality, that is, cannot transcend it to make reasoned, abstract decisions because the messy processes of an embodiment that is impossible to idealize will be constantly reminding the subject that it is there.

### *2.1.2. Personal Autonomy*

#### Overview of Liberal Traditions

Kant's work on autonomy permeated modern Western thought, including its political movements. His moral system translates into political theory in that the categorical imperative involves the honouring of autonomy in other persons (as articulated in the imperative's second formulation); moral beings are thus bound to certain obligations to one another. He also calls for the harmonization of one's maxims with a hypothetical kingdom of ends (as articulated in the third formulation); that is, moral beings must seek to emulate the kingdom of ends by acting autonomously, which means they are legislating moral law in reality. He is advocating a theory that one honours autonomous action via social contract<sup>9</sup> (Kant, 1996).

Social contract theory is a tradition first found in Enlightenment political philosophy, championed by influential thinkers including Hobbes (1985), Locke (1980), and later Rawls (1999). According to the thought experiment typical to social contract theories, human beings are imagined in their hypothetical state of nature (Hobbes, 1985; Locke, 1980) or original position (Rawls, 1999)—that which is logically prior to social positioning. They leave this state by entering into political society, which is built on a contract with one another. This contract is a tacit agreement that human beings will cooperate with one another and abide by laws. The value of this thought experiment is

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<sup>9</sup> Although, Kelly (2005) describes Kant as “only equivocally contractualist” (p. 25) because Kant's model of consent as that which conforms to moral law does not require interpersonal agreement. This means that the social contract Kant envisions is entirely hypothetical, whereas the political theorists after him had concrete notions about political organization (during Kant's time, constitutional monarchies) based on rational consent.

that the state of nature from which human beings develop social contracts is a position that is free from external control. Ideally, then, decisions are made independently and rationally (Gauthier, 1986). Hobbesian (Gauthier, 1986; Hobbes, 1985) social contract theories hold that the motivation for entering into contracts is human self-interest, an interest in self-preservation; while another set of social contract theories (Locke, 1980; Rawls, 1999) draws from Kantian philosophy, according to which human beings are motivated by recognition of and respect for one another's autonomy, the basis for moral consideration (Kelly, 2005).

One influential set of political theories stemming from this tradition is liberalism, according to which liberty or freedom (which Kant (1993) equates with autonomy) is a central political value (Kymlicka, 1996; Lukes, 1973). The legitimate use of political power would involve the promotion or protection of the freedom of citizens (Kelly, 2005). During the Enlightenment, intellectuals concentrated on the contract between citizens and monarchies (Hobbes, 1985; Locke, 1980) while more recent theorists focused on democratically organized societies (Rawls, 1999), but the central premise running through the history of these theories is that a liberal society would not interfere with, but instead would serve the purpose of guaranteeing, the freedom of its citizens.

#### Liberalisms on Autonomy and Freedom

Although the development of liberalisms owes much to Kant, there is a significant point of departure. Kant holds that it is not enough to say that the will acts independently of external influence; the only other motivation for action is a moral imperative, in

principle accessible to all who are capable of rationality. There is no possibility for pluralism, for it is assumed that all rational beings are autonomous only insofar as they are enacting the same law. Disparate conceptions of what is right and actions motivated by one's own welfare (based on interests, values, and so forth) would indicate that the will is heteronomous, not autonomous. A theory that makes room for plurality would have to redefine autonomy or freedom:

Though most or all of the classical conceptions of freedom as autonomy—in the Stoics, Spinoza and in Kant—are in this sense closed conceptions, it may be possible to construct an account of autonomy which does not have the feature of requiring access to a single body of objective moral truths, but instead demands simply the free exercise of the human intelligence (Gray, 1995, p. 58).

Within liberal traditions, theorists considered how political systems might accommodate diverse interests (Dworkin, 1988; Mill, 1978; Rawls, 1999), and theories of this nature are predicated on a different definition of freedom. In these theories, there is often a differentiation between freedom and autonomy, though the concepts are related (Berlin, 1969; Dworkin, 1988). Models of autonomy typically pertain to the states of persons, and their motivations for actions (Dworkin, 1988). What many liberal autonomy models share in common is the marked shift away from Kantian theory such that autonomy is a political rather than moral unit of value (O'Neill, 2002). Personal or individual autonomy is a property of persons that pertains to their motivations to act; they may be motivated by particular interests, purposes, reasons, values, and so forth, but the point is that they are self-motivated, rather than moved to act by external factors or constrained from action by other people. Autonomous will as a mechanism for actions

can be found in Kant, but disparate motivations, plans, and purposes for acting have no place in his philosophy, at least not as an ideal.

Personal autonomy is generally understood to refer to self-rule or self-government, which in turn means authority over oneself (Christman, 1991; Dworkin, 1988; Leino-Kilpi et al., 2000). The term itself derives from the Greek *autos* (self) and *nomos* (government or law). Kantian autonomy also involves a notion of self-governance, but only to the extent that autonomy is the ability to legislate moral law. Self-government in later theories came to entail reflecting on choices and taking action independently (Dworkin, 1988). In his theory of individualism, Lukes (1973) links autonomy (as well as freedom) to self-direction, “according to which an individual’s thought and action is his own, and not determined by agencies or causes outside his control” (p. 52). He goes on:

A person is free in so far as his actions are his own, that is, in so far as they result from decisions and choices which he makes as a free agent, rather than as an instrument or object of another’s will or as the result of external or internal forces independent of his will. His autonomy consists precisely in this self-determined deciding and choosing (pp. 127-128).

Autonomous actions are related to freedom to the extent that autonomy deals with states and motivations involved in choice, while freedom is more generally the ability to make meaningful, independent choices. The concept of freedom itself has multiple interpretations. Freedom may be negatively construed as simply an ability to act unrestrained by human interference. This interpretation of the concept concentrates on the decision-making process rather than the content (reasons, purposes, values) or substantive conditions (oppression) affecting of one’s decision. It is formally the space

needed for making one's own decision. In a seminal work on the concept, Berlin (1969) differentiates between negative and positive freedom, and defines negative freedom as "the area within which a man can do what he wants" (p. 7). A person may be unfree when someone deliberately enters into this area and frustrates his plan. Berlin goes on to explain how a man might see his plans frustrated:

I am normally said to be free to the degree to which no man or body of men interferes with my activity. Political liberty in this sense is simply the area within which a man can act unobstructed by others. ...Coercion is not, however, a term that covers every form of inability. If I say that I am unable to jump more than ten feet in the air, or cannot read because I am blind...it would be eccentric to say that I am to that degree enslaved or coerced. Coercion implies the deliberate interference of other human beings within the area in which I could otherwise act (p. 122).

This definition of freedom as the absence of coercion derives in part from Hobbes:

"Liberty, or freedom, signifieth (properly) the absence of Opposition; (by Opposition, I mean externall Impediments of motion)" (1985, p. 261). Hobbes argued that influence, manipulation, pressure, anything other than coercion as physical force, does not qualify as an impediment to freedom. Hence, in any instance where decisions are made in the absence of coercion, the agent making the decision is autonomous and therefore accountable. In other liberal political theories that employ a negatively conceived freedom, expected state commitments typically pertain to non-interference (Locke, 1980; Mill, 1978). The state's responsibility is simply to ensure no one stands in the way.

In contrast with his definition of negative freedom as "not being enslaved", Berlin (1969) defines positive freedom as "being one's own master" (p. 16). Positive freedom for Berlin, then, is when agents make decisions based on their own motivations—the freedom *to* make a decision, as opposed to freedom *from* coercion. Liberal theories

predicated on negative liberty have been criticized by Miller (1983) and Oppenheim (1961), among others, inasmuch as these theories only account for intended constraints to freedom. Gray (1995) lists other possible impediments to freedom that would not be considered coercion, and he argues that these impediments posit the need for a more comprehensive definition of freedom:

Many modern threats to freedom—propaganda, media manipulation and the tyranny of fashion—can be understood, I think, only by invoking some [new] conception of autonomy. Freedom may be curbed by means other than coercion, and it is a virtue of the idea of freedom as autonomy...that it accommodates this fact (p. 58).

An extension of constraints to freedom may include undue manipulation and pressure to conform that have been internalized, thereby affecting the decisions that persons make.

Christman (1991) illustrates with the following example:

Imagine, for example, a woman who is raised in a culture which fiercely inculcates in her the idea that women should never aspire to be anything but subservient and humble domestic companions to their husbands, no matter how unhappy this makes them or how abusive their husbands are. Imagine further that this person is suddenly placed in a new culture where opportunities abound for women to pursue independent activities. She nevertheless shuns these opportunities and remains married to an oppressive husband from the old culture (pp. 344-345).

The woman in this example is only constrained by her desires, and yet she is unfree because her values were developed in an oppressive context: “for an individual to be self-governing it at least must be the case that she is not moved by desires and values that have been oppressively imposed upon her” (p. 345).

Kymlicka’s (1989, 1996) project is a defence of a model of liberalism that incorporates cultural context, a model which he holds is actually common in liberal

theory. He argues that culture provides the context, the options by which one might make meaningful choice and thereby exercise individual freedom:

How does this [individual freedom] relate to membership in societal cultures? Put simply, freedom involves making choices amongst various options, and our societal culture not only provides these options, but also makes them meaningful to us. People make choices about the social practices around them, based on their beliefs about the value of these practices. ...And to have a belief about the value of a practice is, in the first instance, a matter of understanding the meanings attached to it by our culture (1996, pp. 82-83).

For him, individual autonomous choice cannot happen in a vacuum. Rather, choices are informed by, and actions are motivated by, values that are inscribed by one's culture. He does not think that liberalism has to be isolating because individuals are borne out of and always entrenched in their cultural contexts. Such a theory involves locating meaning production in social situations, rather than in a universal standard that is accessible to rational beings. It is thus conceivable that individual autonomy does not have to entail transcending one's empirical reality.

### Critique of Personal Autonomy

But which (or whose) empirical reality is to be considered? The concept of disability often found in liberal traditions is controversial, and runs counter to Kymlicka's claim that liberalism generally accounts for context. During the Enlightenment, with its focus on science and medicine, the category of disability came under the auspices of the medical field, as a problem to be diagnosed and cured (Oliver, 1990, 1996; Priestley, 1976; Siebers, 2008). Disabilities were individualized, regarded as biologically isolated impediments to fully functioning. Identifying this framing of disability as the Individual

Model, Oliver (1990) argues that this model “locates the ‘problem’ of disability within the individual [caused by] functional limitations or psychological losses” (p. 2). Those incapable of fully functioning in their communities would according to this model be responsible for their inability to participate, or no one is responsible for their tragedy, for their barriers to their fully functioning are natural defects.

For liberal theories that adhere to Berlin’s (1969) classical characterization of negative freedom, there is no recourse for redressing the ways in which a disabled person’s freedom is compromised, for a disability like blindness (an example Berlin raised in his account of negative freedom) is a medical problem. Even critics of Berlin, Miller (1983) and Oppenheim (1961), consider disability to be a natural phenomenon that interferes with a man’s abilities, not his freedom. Even when they argue for extending constraints to freedom, they differentiate between natural and social constraints—being unable versus being unfree—and classify disability as natural, therefore irrelevant to discussions about how freedom might be unjustly blocked. A blind man’s ability to participate in his community is stymied by a physical limitation, and not because he exists in a visual-dominant culture that lacks, for instance, Braille translations. While medical practitioners under the Individual Model are charged with the task of curing people of their disabilities, the implication is that governments have few responsibilities regarding personal medical matters. There is no room in this example for the possibility that the blind man, though uncoerced, would be unduly constrained because he lacks meaningful options in an ableist culture. Even if such a man were resigned to living without accommodations and never bothered to learn Braille when it was introduced to

him, one might still argue that his values and character were forged in a context that lacked meaningful alternatives.

Kymlicka's theory (1996) includes a substantive notion of freedom, one achieved through state obligations to facilitate access to meaningful options. A blind man may be considered unfree when, in the absence of accommodations, it would be impossible for him to pursue an education and certain occupations. He still has the capacity to make decisions, but not decisions among all the options available to other members of his societal culture. His culture would be illiberal to the extent that it failed to promote minority rights, which Kymlicka argues coexist with individual rights: "respecting minority rights can enlarge the freedom of individuals, because freedom is intimately linked with and dependent on culture" (p. 75). Indeed, unlike the liberal theorists who dismiss disability as a natural impediment, Kymlicka identifies disability in his characterization of minority rights, putting the identity on par with gender, race, and so forth.

Nevertheless, Kymlicka's theory, as is common in liberal theories, is predicated on a notion of individualism, which may be complicated by dissonant bodies—bodies that are not only corporeal but intercorporeal, and as such are never fully independent but are interdependent: "the body...is a set of operational linkages and connections with other things, other bodies" (Grosz, 1994, p. 120). A blind man may "see" through the eyes of his guide, for example, and is led by his guide via touch. Navigating inaccessible spaces may happen through connection and communication. That bodies operate in

connection with one another contradicts notions of personal autonomy that are located in the individual whose body boundaries differentiate him from others.

The example of the blind man may be imperfect, for with the right tools and skill set someone who experiences blindness can isolate himself and function independently, at least according to liberal ideological lenses. He might opt for a walking stick rather than a guide, for instance, and claim that in this way he need not rely on others. Intercorporeality in this instance is not inevitable, and indeed, may only be understood as metaphorical. However, there are embodied realities that must be considered quite literally intercorporeal. For example, Dreger (2004) describes how conjoined twins challenge the prioritization of independence and individuality in Western politics and thought:

In the United States, conjoinment might be especially challenging because American culture equates individualism with independence, and interdependence with weakness. ...But even within this context—or perhaps as a result of this context—Americans who happen to be conjoined felt that they, too, are independent individuals. They do not think they need a discrete body to achieve independent status, any more than another person needs to grow her own food, sew her own clothes, and be her own doctor to count as an independent individual (pp. 31-32).

In cases of explicit interdependence, there is no dyad between the individual and her context, for the individual is constituted by, or at least cannot be understood as separate from, interrelations. Dreger makes clear that interdependence is not merely a property of disabled people, for nondisabled people function within relations inasmuch as they too depend on others for food, clothing, and medical care. That their body boundaries are more visibly marked than the boundaries of conjoined twins should not mean that we ignore how nondisabled people survive and thrive through interconnectivity.

In the case of pregnancy, Mackenzie (1995) also invokes the concept of intercorporeality: “[pregnancy] defies a sharp opposition between self and other, between the inside and the outside of the body. From the perspective of the woman, there is no clear-cut boundary between herself and the fetus” (p. 50). That is, the phenomenology of pregnancy poses difficulties for how to account for one’s identity according to body boundaries. The fetus is the woman, and yet is not; she feels something inside her, beneath her very flesh and bones, but there is a qualitative yet difficult-to-discern difference between “the baby kicked” and hunger pangs. The experience of pregnancy cannot be understood according to clear boundaries, for, especially in this case, “the boundaries dividing selves from others are porous and fluctuating” (Donchin, 2009, p. 34). Shildrick (2002) makes a similar claim: “the pregnant female body...speaks to an inherent capacity to problematize the boundaries of self and other” (p. 31). Embodiments that bleed and blend into other embodiments, that are “both one and two” (Karpin, 1992-1993, p. 327), destabilize traditional notions of individualism, and may call for a drastic refashioning of autonomy as something other than a property of individuals.

### *2.1.3. Relational Autonomy*

#### Feminist-Grounded Critiques of Autonomy

Concepts of relational autonomy were developed in feminist theories as alternatives to personal autonomy models, which have been criticized for hinging on atomistic, individualistic agents (Mackenzie & Stoljar, 2000; Wolgast, 1987; Young, 1990). Because relational autonomy developed in response to critiques of autonomy

theory that I have already begun to touch upon in the previous sections, I will begin here with a more in-depth account of feminist criticisms.

Even procedural accounts of autonomy require substantive values to the extent that they include a prescriptive component regarding how a person ought to be conceptualized, and how he ought to conduct himself. Under personal autonomy models, persons are autonomous inasmuch as they are self-sufficient and independent (Code, 1991; Sherwin, 1998). This telos is bound up in “a larger North American cultural ideal of competitive individualism” (Sherwin, 1998, p. 34), indicating that the concepts that have been associated with autonomy have been imbued with meaning through culture and context. That is, these ideas did not materialize in abstraction, as rationalistic philosophers would have us believe, but have a home in Western cultures that prioritize rugged individualism (Basser, 2011; Pateman, 1989; Sherwin, 2011; Smart, 1989).

As discussed, conceptualizations of personal autonomy require that autonomous persons are borne out of causal isolation, that is, that sharp distinctions are drawn between persons so that they might function autonomously (Baier, 1985). Rationality too is a necessary condition to acting autonomously. Even when not directly drawing from Kant (1993)—who grounded autonomy in the rational capacity to recognize universal law—liberal interpretations of the principle have still required that just states be organized such that persons recognize the rationality, and thus the capacity for autonomy, in one another (Locke, 1980; Rawls, 1999). All this means that the notion of personhood undergirding autonomy theories is defined by specific, common characteristics that transcend context (Code, 1991). Although these interpretations are meant to be

compatible with pluralistic societies, individuals so framed are interchangeable. The content of decisions may differ according to individuals' respective aims and values, but a person is autonomous by virtue of a common mechanism by which decisions are made.

These a priori traits that tend to be associated with autonomy within liberal traditions—independence, rationality—have been typically ascribed to able-bodied men. Friedman (2000) identifies reason as a common feature to autonomy concepts found in popular Western culture, in addition to “other masculine-defined traits, for example, independence and outspokenness” (p. 38). She goes on to note that such specific formulations of autonomy only work as long as typically feminine traits are overlooked or effaced: “traits popularly regarded as feminine, by contrast, have no distinctive connection to autonomy—social interactiveness, for example (p. 39). Code (1991) notes how these conceptualizations are male-centric:

Feminists need to understand the androcentricity of malestream epistemology: its near-exclusive concentration on men's experiences, masquerading as 'human' experiences, and counted as the sources of knowledge. If the language is tailor-made to express those experiences, and if women's experiences simply fall through the spaces in that same language, the androcentricity of the theory is scarcely a surprise (p. 60).

It may be that women and disabled people have been bracketed out of the category of autonomous agents because they have more explicitly functioned within social networks rather than as isolated individuals. The above sections discuss the corporeality and intercorporeality of disabled and female bodies—qualities which prevent abstraction and individuation. Disabled people have required varied accommodations depending on their disabilities in order to function. Women have functioned within family and household relationships, and have been socially, politically, and economically rendered dependent

on men. These lifestyles are not strictly defined as independent; conceptually, these (non)persons cannot be radically isolated and reduced to the level of individuality. To the extent that this is the case, many interpretations of autonomy cannot account for how members of these minorities might make decisions autonomously. Instead of continuing to bracket minorities out in order to salvage theory, though, perhaps it is time we reconsider our theoretical priorities.

Individualism requires the erection of metaphysical and political barriers that distance people from one another (Dillon, 1992; Harvey, 1999). Nedelsky (1993) locates personal autonomy within the American philosophical and legal framework of rights as limitations, and criticizes the concept for being individualistic, obfuscating, and alienating. The concept is individualistic in that it is grounded in notions of independence and self-sufficiency: “the essence of autonomy is independence, which thus requires protection and separation from others. My argument is that this is a deeply misguided view of autonomy. What makes autonomy possible is not separation, but relationship” (p. 7). Personal autonomy-based rhetoric obfuscates because it reifies autonomy rights as though they are fixed, transcendent entities rather than products of consensus and context. Finally, Nedelsky finds personal autonomy theories alienating to the extent that they are used to erase relationships: “rights have this distancing effect in part because, as they function in our current discourse, they help us avoid seeing some of the relationships of which we are in fact a part” (p. 17). The implication to liberal theories is that the interrelations that disabled people and women experience act as hindrances to the ability to be autonomous. This association can only happen within a

framework that effaces the relationships that are essential to all persons. For, as Dreger (2004) noted, one need not grow one's own food nor forsake physicians in order to qualify as independent and therefore autonomous; those dependencies are merely overlooked in personal autonomy frameworks.

### Feminisms on Autonomy

The trick, then, is to reorient one's approach to autonomy, such that the concept developed retains the power to diminish oppression "without...its baggage as a concept that sustains the ideals of individualism" (Sherwin, 2011, p. 15). Autonomy must imply agency and control without ignoring relations of power and privilege. There are feminists who have sought to build such a concept, hoping to demonstrate that autonomy as a political and moral tool is salvageable.

Nedelsky (1989) proposes that persons are autonomous not through "isolation, but relationships—with parents, teachers, friends, loved ones—that provide the support and guidance necessary for the development and experience of autonomy" (p. 12). Feminists like Nedelsky, Christman (2004), Code (1991), Downie and Llewellyn (2001), Keller (1985), and Sherwin (1998, 2011), among others, recommend re-conceiving autonomous agents as socially constituted rather than atomistic. Sherwin (1998) explains: "relational selves are inherently social beings that are significantly shaped and modified within a web of interconnected (and sometimes conflicting) relationships" (p. 35). This alternate conception of identity proposes that no person can be reasonably understood as capable of functioning outside relationships. Within interpersonal relations, agents develop

identities that shape their decisions. As such, they only act autonomously within the context of interpersonal relations: “there is no pure, self-determining free will that somehow escapes the operations of power, nor is there a true self, there to be discovered through introspective reflection” (Mackenzie & Stoljar, 2000, p. 11).

When the self is defined as relational, autonomous decision-making must be re-conceived as something other than independent, individualistic, and rational. A re-conceived model of autonomy would require instead that autonomous decision-making be understood as related to the identities and values borne out of connection and communication. Reviewing relational autonomy models, Mackenzie and Stoljar (2000) question whether interpersonal relations play a crucial role in the development of autonomy, or whether autonomy is entirely constituted by these relations, but relational autonomy models all have in common that they make the connection between autonomy and relationships, however that connection is characterized.

Autonomy may also function within a larger context of economic, political, and social conditions that make impacts on the personal sphere of relations (Meyers, 1989; Sherwin, 2002). Says Donchin: “oppressive social conditions privilege the more powerful and interfere with the opportunities of others to develop skills necessary for exercising autonomy. Unjust prerogative marginalizes many women and minorities, depriving them of their fair share of social goods” (2009, p. 34). Relational autonomy models that include such a wide explanatory range can account for how relations of power have played a significant role in enabling autonomy for some and obstructing the development of autonomy in others.

### Self-Trust as an Essential Conceptual Component

Some relational autonomy theories include self-trust. This concept refers to an attitude shaped by one's feelings for and beliefs about oneself (Govier, 1993, 1997; McLeod, 2002; McLeod & Sherwin, 2000). Both self-trust and its correlative, distrust, are relational concepts in that they are constituted or affirmed through interpersonal relations: "they are moulded to a significant degree by the responses of others and by societal norms" (McLeod, 2002, p. 37). Social support can facilitate self-trust such that people are capable of autonomous decision-making; whereas experiences of oppression can be internalized, leading to self-distrust (Harvey, 1999; McLeod, 2009). McLeod and Sherwin (2000) explain how oppression may be internalized:

Oppression can lead to the internalization of a sense of social worthlessness and incompetence that is translated into a lack of self-worth and self-trust. When a group is oppressed, the society at large operates as if that group is less worthy and less competent than others and devalues its members. Members of oppressed groups may then internalize these attitudes; many are inclined to accept society's devaluing of their personal worth on at least an unconscious level and to doubt their own worth and ability to make appropriate choices. This lack of self-worth and self-trust may be devastating to agents' autonomy competency, interfering with their ability to act according to their own interests at all (p. 262)

Harvey (1999) explores how people who are oppressed may be internally blocked from fully functioning as members of a moral community. She raises an example similar to Christman's (1991): denigrated and demoralized, a housewife may lack self-trust because of interpersonal relations with an emotionally abusive husband, but may also be enacting a gender role that has historically weighed on women's opportunities and social conditions. Even if her first husband leaves her, the housewife may decide to be subservient to another man, thus perpetuating the cycle. She may do so because she feels

she does not deserve better, or is incapable of better. Even with other options available, she is capable of no other choice because of the person she became when in an abusive relationship. Says Harvey: “the person lacks appropriate beliefs about his/her proper moral status, and also the person’s moral self is blocked from functioning properly as a member of the moral community—but the block, it seems, has become internal” (1999, p. 113).

Harvey’s notion of the internal block is tremendously important to include in feminist evaluations of autonomy theories that have pushed disabled people and women to the very periphery of personhood itself. Ideology has the power to be applied to economic, political, and social arrangements. Oppressive rhetoric and exclusionary categories can manifest in law, policy, and medicine, as well as personal relationships and casual conversation. Through endorsements of Kantian or liberal traditions, we can convince those with marginal identities that they are unworthy of moral consideration, that they fall leagues short of the ideal embodiment and mental state. We in effect instill distrust and teach (non)persons to lower their expectations for themselves. Even if more conceptual space was allotted to those once historically marginalized so that they might make decisions “freely,” only relational autonomy models can account for why they might still be incapable of autonomous action.

## 2.2. Autonomy in Bioethics and Law

In this section, I will identify autonomy theories in two fields that have tremendous influence over women’s reproductive experiences. I will connect the

concepts explored in the previous section with the autonomy theories found in these fields, and will demonstrate that these concepts carry with them the baggage I previously critiqued. In bioethics, autonomy is a canonical principle, grounded in notions of informed consent and decisional capacity. In Canadian law, autonomy is framed with consent and capacity rhetoric, as well as s. 7 protections of life, liberty, and security of the person.

### *2.2.1. Autonomy in Bioethics: Consent and Capacity*

#### Autonomy in Bioethics

Autonomy, alongside justice and beneficence, is central to bioethical canon (Engelhardt, 1986; Faden, Beauchamp, & King, 1986; Viafora, 1996). The principles are typically portrayed as formal in character, meant to provide a general, flexible moral framework that can be easily applied to various medical situations (Beauchamp & Childress, 2009; Viafora, 1996). According to Beauchamp and Childress (2009), beneficence was once the guiding principle for moral action in medical contexts, beneficence being “a group of norms for distributing benefits, risks, and costs fairly” (p. 12). Autonomy has become increasingly more important over time, however, such that debates revolve around whether the principle takes priority over all the other principles in bioethics frameworks (Beauchamp & Childress, 2009; Faden, Beauchamp, & King, 1986).

The bioethical principle of autonomy has been defined in myriad ways that correspond with autonomy theories. In a work that charts the historical development of

bioethics, Viafora (1996) defines autonomy based on earlier instantiations: “the principle of autonomy prescribes acting in such a way as to treat the patient always as an end and never as a means; that is, according to his nature of autonomous subject” (p. 26). This formulation of the principle adopts Kantian language: respect for autonomy entails recognition of a person’s worthiness of moral consideration. For Beauchamp and Childress (2009), the concept at minimum is similar to the concept of personal autonomy found in liberal theories: “self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (p. 58). They warn against relying on only this minimalist definition because it focuses too narrowly on the subject as independent and rational. For this reason, Beauchamp and Childress conceive of the principle substantively, in such a way that it at least in part relates to the concept of relational autonomy found in feminist theories:

We aim to construct a conception of respect for autonomy that is not excessively individualistic (neglecting the social nature of individuals and the impact of individual choices and actions on others), not excessively focused on reason (neglecting the emotions), and not unduly legalistic (highlighting legal rights and downplaying social practices) (p. 57).

### Grounding Consent in Personal Autonomy

Autonomy is exercised in medical contexts through free and informed consent (Berg & Appelbaum, 2001; Faden, Beauchamp, & King, 1986; Grisso & Appelbaum, 1998; Lindley, 1991; Segest, 1995). Consent has not always been associated with autonomy, however, and so it has not always been necessary that consent be free and informed. Once justified by the principle of beneficence, consent was bound up in the

physician's duties rather than the patient's entitlements, which led to justifications for deception for the purpose of obtaining consent (Sidgwick, 1981)—an idea which predates the field of bioethics. Faden, Beauchamp, and King (1986) describe Percival, who wrote on medical ethics as early as 1803: “he insisted that honesty, including honest disclosure, must be the gentlemanly norm except in emergency situations, terminal situations, and situations where harm would be caused by truthfulness” (p. 69). That is, during emergencies, as long as it was in the patient's best interest to receive medical treatment, and the patient might not arrive at this decision by himself, then the physician was ethically justified in lying about the condition or the effects of treatment options in order to obtain consent. Within these consent models, the patient's best interest could be determined by the physician, and so the physician had moral and medical authority in medical decision-making contexts.

As bioethical discourses developed, they moved away from the idea that consent could be obtained through deception, and consent came to be a matter of respecting and facilitating the patient's ability to decide what is in his best interest: “the practice of free and informed consent is justified both out of respect for the freedom of individuals as well as to achieve their best interests” (Engelhardt, 1986, p. 300). Engelhardt explicitly makes the connection between autonomy and consent: “consent is the origin of authority, and respect of the right of participants to consent is the necessary condition for the possibility of a moral community. The principle of autonomy provides the minimum grammar for moral language” (p. 86). The reworking of the grounding for consent in effect shifts at least some of the authority in medical contexts from physician to patient.

The question remains: how is autonomy being defined in this context? Criteria for informed consent, provided in Faden, Beauchamp, and King's seminal work on the concept (1986), include allusions to personal autonomy in that decisions must be made by an individual, free from external control: "consent must not be controlled by influences that would engineer the outcome" (p. 54). Consent occurs free from influence, manipulation, and coercion. In order for consent to take place, a space must be carved out for the agent such that decisions are not affected by externalities. Additional criteria include the decision being one's own, in the form of permission: "consent must involve the intentional giving of permission for an intervention" (p. 54). These two components indicate that Berlin's (1969) classical autonomy model is expressed in medical contexts through consent, for consent is only given as long as the patient is not being pushed into a decision, and has the ability to take ownership of that decision. In order for consent to be informed, it must be understood, and so Faden, Beauchamp, and King (1986) include a third criterion: "a patient or subject must agree to an intervention based on an understanding of (usually disclosed) relevant information" (p. 54).

#### Condition of Capacity

The conditions of consent—individuality defined by one's separateness from others when making a decision, agency expressed in the ability to make a decision, and understanding of the stakes involved in a decision—imply that only certain persons can provide consent. A child, for instance, may not understand the complexities of a medical decision, and so her guardians make the choice for her; someone in a comatose state lacks

the agency to grant medical permissions required in that moment, and so the physician may seek out the patient's advanced directive or loved one.

Consent can only be given when the patient has decisional capacity, also called competence in bioethics literature. Decisional capacity is determined according to the reasoning process involved in making a decision, rather than the content of the decision (Buchanan & Brock, 1989). That is, those who make what would be considered incorrect decisions or decisions counter to other people's, even their own, values may still have decisional capacity. Capacity is not static; for instance, people who do not understand some complex medical issues might still be equipped to participate in other aspects of decision-making, or might later on in the day or week be lucid enough to make decisions on their own (Beauchamp & Childress, 2009).

Various models of capacity share overlapping elements, including understanding of the facts (Beauchamp & Childress, 2009; Buchanan & Brock, 1989; Grisso & Appelbaum, 1998) and appreciation for the nature of the decision and the stakes involved (Grisso & Appelbaum, 1998). "Reasoning and deliberation" (Buchanan & Brock, 1989, p. 84) entails the rational manipulation and evaluation of information (Buchanan & Brock, 1989; Grisso & Appelbaum, 1998). These conditions might not be satisfied if the person at the heart of a medical decision is a child, has an intellectual disability, or is mad, as examples. One must also be capable of executing or at least communicating the decision (Beauchamp & Childress, 2009; Grisso & Appelbaum, 1998). This condition would be impossible to satisfy if the person is in a coma or incapable of conveying her wishes due to a physical disability. Another, albeit disputed, element has been identified:

“relatively stable values or a conception of the good life” (Buchanan & Brock, 1989, p. 84). This final component is arguable because it speaks to the substance of the decision, while the other components identified pertain to the mechanisms by which decision-making takes place.

Patients may be determined to be incapable because they do not satisfy some of the conditions identified above when a decision needs to be made. In these cases, there are decision-making standards that are meant to uphold the principle of autonomy: “individual autonomy should and may be promoted through respect for the process of substituted judgment” (Kapp, 1999, p. 57). Buchanan and Brock (1989) put forward guiding principles for directing how to make decisions when the patient lacks the capacity to give consent, the first of which involves “implementing an advance directive, such as a ‘living will’ or durable power of attorney, that the patient executed while competent” (p. 88). The next, in the absence of an advance directive, would be “substituted judgment [which is] acting in accordance to what the individual, if competent, would choose” (p. 88). A loved one, for instance, may know which decision the patient would have made if capable, or may at least know personal, cultural, or religious factors that would have influenced the patient’s decision. Finally, when wishes or values are not already known or cannot be inferred, the substitute decision-maker, be it a loved one or the physician (if no one else is available), may invoke a “reasonable person” standard (Buchanan & Brock, 1989; Lazar et al., 1996). This standard is meant to be what an objective, ideal person would do in the given circumstances, where there is

limited information regarding how extenuating, personal circumstances might affect the decision.

### Critique of Consent and Capacity

How is a person determined to be decisionally incapable? That is, who determines when and whether a patient meets the conditions for capacity? Capacity is a phenomenon that may be constructed based on communication between the patient and the physician, and is determined by the latter party (Kerzner, 2006; Stefan, 1993). According to Stefan, “questions of competence arise only as a function of a relationship between one or more people and...this relationship is necessarily a hierarchical one, characterized by dominance and subordination, by power and powerlessness” (p. 766). She describes incompetence, or lack of capacity, as “a characteristic of an individual, brought about by forces internal to the individual” (p. 776), such as madness, intellectual disability, or substance use<sup>10</sup>.

The concept is framed in bioethics and law with the same rhetoric used under the individualist model of disability, with little regard for how capacity is determined through

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<sup>10</sup> “Madness” is a term reclaimed by the psychiatric survivor community, and as such has fewer pejorative connotations than “mental illness”—a term I only use when quoting source material. I choose not to use “psychiatric survivor” because there are clear examples (notably Ashley Smith) of people who did not survive the psychiatric system.

Canadian scholars oft employ “developmental disability” instead of “intellectual disability,” though I prefer the latter because it highlights how people are disabled on the basis of intellectual standards.

Finally, I choose to use the term “substance use” over “alcoholism,” “addiction,” “substance abuse,” or “substance dependency” because this collection of terms over-emphasizes the individual condition and as such may efface stigma.

an interpersonal relationship between the patient and physician, a relationship that we should not assume unfolds on a level playing field, devoid of any power dynamic. Ho (2008) advocates against the use of the individualist model in the context of medical decision-making: “we need to pay attention to the social structure that frames people’s identity and decisions” (p. 194). Indeed, relations of power shape capacity (“identity” for Ho) and determine whether and how consent is freely given (“decisions”). She goes on to argue that the individualistic approach to autonomy in the context of medical decision-making is dyadic, when it should instead be understood within a matrix of social influence: “patients’ decisions are embedded within a complex set of social relations, practices, and policies that structure an individual’s selfhood and can significantly affect people’s ability to exercise autonomy with respect to their choices” (p. 195). As examples, financial positioning and social class (Brody, 1980; Seedhouse, 1992) may play roles in how, and how much, information is transferred between the physician and patient: “physicians provide more information to those in higher social classes than lower social classes” (Leino-Kipli et al., 2000). Elander and Hermoren (1993) also consider whether structural dynamics within hospital settings—the rules and routines, implemented by medical professionals in authority—affect autonomy, such that patients consent to medical treatment because they are eager to behave, or are made to feel as though they should.

Given that consent takes place within this dyadic exchange, the power of the patient to exercise autonomy in medical contexts is reduced to consent. That is, while the grounding of consent in autonomy marked an important paradigm shift, the implication

has been that autonomy is limited to consent. The components of consent include understanding of the information imparted by a physician, and the ability to permit medical intervention. Autonomy as permission is limited, for it occurs within closed contexts based on the information that the physician deems reasonable, and it involves very little agency or open participation. Shildrick (1997) criticizes health care that is built on consent to the extent that the concept “reinforces the intrinsically passive nature of patient ‘participation’” (p. 85). She explains:

The notion of a fully informed consent relies currently not on the patient’s own subjective interests but on what the reasonable (and one might add potentially paternalistic) doctor would judge them to be. The assumption would seem to be that only disinterested rationality is to count fully and that only the professionals are capable of exercising it. It is a case of both privileging rationality and denying it to certain specific groups. For women, that disempowerment is compounded in that in a society based on normative male standards they are not considered fully rational in the first place (p. 85).

For Shildrick, then, consent as the standard for exercising autonomy hems in autonomy by rendering the patient passive in medical exchanges. Patient participation hinges on merely submitting to medical intervention based on physician advice; the extent to which a patient is advised depends greatly on what the physician deems relevant or significant advice. When discussing the physician-patient encounter, Wendell (1996) describes this phenomenon as the cognitive power of medical practitioners “to describe us to ourselves and others” (p. 24). In her example, a patient may consult a physician on symptoms, but is told nothing is wrong when the physician cannot discern a physical cause. In effect, the physician invalidates the pain, the fatigue, the dizziness, and so forth that the patient

has been experiencing. Wendell elaborates on how the patient is disempowered as long as cognitive authority rests in the hands of the physician:

The cognitive and social authority of medicine to describe our bodies affects how we experience our bodies and our selves, how our society describes our experiences and validates/invalidates them, how our society supports or fails to support our bodily sufferings and struggles, and what our culture knows about the human body. It also affects profoundly the relationship of medical providers to patients and the quality of care. The authority of medicine tends to delegitimize our experiences of our bodies as sources of knowledge about them, because the authoritative, that is, the medical and scientific, descriptions of our bodies are third-person descriptions of physical conditions (p. 119).

Medical practitioners are authorities in medical exchanges not only because they constitute the vanguard that determines what and how much information is given to the patient, as well as whether and how the patient is ill, injured, and so forth; but they also have some power in determining whether a patient is decisionally capable of giving consent. They may even serve as substitute decision-makers in the absence of an advance directive or loved one, in which case they employ a reasonable person standard that requires idealized, rational thought. Should patients opt not to give their consent, the medical professional has the recourse of questioning the patient's decisional capacity, for the physician may determine that a decisionally capable person would give consent as long as she understood the information provided. Granted, capacity does not hinge on the content of a patient's decision, but determinations of capacity may be compounded by identity characteristics, such as gender, disability, and various intersections of the two. Someone whose record includes a history of madness, for instance, may be questioned for the decision she makes: someone who experiences post-partum depression, or has a history of alcohol use, or is on anti-anxiety medication may be more heavily scrutinized

should she not consent to recommended medical treatment. Capacity may be reductive, not only because it reduces the patient to a passive role in the decision-making process, but also because it employs a rationalistic standard that someone in authority may determine a patient is incapable of achieving. As Shildrick (1997) and others (Forell & Matthews, 2001; Gilligan, 1982) have pointed out, rationalism has long served as a standard for moral worthiness, a standard that was once and perhaps is still limited to (able-bodied) men.

### *2.2.2. Autonomy in Law: Consent and Capacity*

#### *Starson*

In the case of *Starson v. Swayze* (2003), the Canadian legal model of consent and capacity was examined. Diagnosed as bipolar, Scott Starson (who identified as a Physics Professor) refused treatment “that included neuroleptic medication, mood stabilizers, anti-anxiety medication and anti-parkinsonian medication” (p. 2), although he consented to psychotherapy. His past experiences indicated that medication dulled his senses and affected his research, so he came to the conclusion that all medication had the same negative effect. His attending physician found him incapable of making the decision, based on the criteria stipulated in the 1996 Ontario *Health Care Consent Act* (HCCA). Starson contested to the Ontario Consent and Capacity Board, which upheld the original decision; then to the Superior Court of Justice, which overturned the determination of incapacity. The Court of Appeals and the Supreme Court of Canada

upheld the decision. The Supreme Court majority of six Justices ruled that Starson had the right to refuse medication.

The Court reflected on the HCCA, which presumes a patient's capacity to accept or reject medical treatment, meaning patients are presumed to be decisionally capable until evidence indicates otherwise: "the presumption of capacity can be displaced only by evidence that a patient lacks the requisite elements of capacity provided by the *Act*" (p. 3). The elements of capacity identified in the *Act* are as follows: "a person must be able to understand the information that is relevant to making a treatment decision"; and "a person must be able to appreciate the reasonably foreseeable consequences of the decision or lack of one" (as cited in *Starson v. Swayze*, p. 3). These two components to capacity share minimum overlap with capacity models found in bioethics literature (Beauchamp & Childress, 2009; Buchanan & Brock, 1989; Grisso & Appelbaum, 1998).

The Consent and Capacity Board's sole purpose is to determine capacity by evaluating evidence that might interfere with the two elements of capacity found in the HCCA. The Board determined Starson lacked capacity based on two findings: "that the respondent was in 'almost total' denial of a mental disorder, and that he failed to appreciate the consequences of his decision [to refuse medication]" (p. 3). The Supreme Court of Canada found that the Board's findings lacked basis: "although the patient did not conceive of the condition as an illness, he was quite aware that his brain did not function normally" (pp. 3-4), which indicated that he did indeed understand, but did not frame his condition with the same rhetoric that his physician employed. The Court further ruled that the Board had no basis for speculating that the proposed medication

would “improve his chances at future board meetings” or lead to the “resumption of the respondent’s work as a physicist” (p. 4).

Finally, it was noted in the Supreme Court case that “the Board misapplied the statutory test for capacity” (p. 4). Starson was never asked during the Board hearing whether he understood that his condition may worsen should he refuse treatment, and so the Board would have been unable to determine conclusively whether Starson truly did understand the situation and appreciate the consequences. Further, “although the Board found the respondent failed to appreciate the risks and benefits of treatment, it neglected to address whether the reasons for that failure demonstrated an inability to appreciate those risks and benefits” (p. 4). In other words, capacity cannot be determined based on the content of the decision; the Board never determined whether Starson was able to grasp risks and benefits despite making what the Board would consider an unwise decision: “the Board improperly allowed its own conception of the respondent’s best interests to influence its finding of incapacity” (p. 4).

It was thus ruled that the Board did not have the authority to consider the patient’s best interests when determining capacity. They could not guarantee that medication would be ameliorative. Indeed, Starson refused medication on the grounds that “the medication dulled his mind and diminished his creativity” (p. 9). It would appear that the respondent weighed the risks and benefits; that he made a decision with which his physician disagreed did not necessarily reflect that he was unable to consider consequences, for he acted based on the negative consequences to accepting medication. The physician and the Consent and Capacity Board could not find Starson decisionally

incapable based on the values that served as grounds for his decision, for their prerogative is merely to assess the mechanisms by which decisions are made: “it would be erroneous for a Board to find incapacity simply because treatment is in the best interests of the patient” (p. 33).

### Analysis

The majority decision made in *Starson* represented a departure from traditional interpretations of the HCCA (Roth, Meisal, & Lindz, 1977; Sklar, 2007). The HCCA did not apply a capacity test that required that patients act rationally, although it did regard the patient’s denial of mental illness as central to determinations of incapacity. In this case, the majority drew from Weisstub’s 1990 report written for the Ontario Ministry of Health, which emphasized “allowing individuals the greatest measure of control of their lives [including] the right to act ‘unreasonably’ and to make foolish decisions should they choose” (p. 66). Weisstub argued that patients need not agree with specific diagnoses made by inexact psychiatrists but instead need only understand “the broader manifestations of illness” (p. 250) in order to satisfy the “understanding” element of capacity. The *Starson* case set the precedent according to which the patient’s perceived best interests were deemed irrelevant to capacity determinations.

Sklar describes the fallout from the *Starson* case: “psychiatrists tend to see the legal principle of autonomy, on which the right to refuse is based, as incongruent with ‘true autonomy,’ which, they maintain, involves ‘the choices of the healthier self...and that self’s long-term autonomy’” (Saks, 2002; as cited in Sklar, 2007, p. 2). Chief Justice

McLachlin, who “penned a vigorous dissent in *Starson*” (Wilderman, 2011, p. 265), echoed these sentiments when later publicly criticizing the *Starson* decision, noting that Starson remains hospitalized: “Starson’s ‘liberty to refuse treatment,’ she said, had resulted in the loss of his liberty to be treated and ultimately released from the hospital” (McLachlin, 2005; as cited in Sklar, 2007, p. 6). According to the Chief Justice (2005), the decision made in *Starson* upheld a negative model of autonomy, where psychiatric medication represents interference with autonomous action; when the Supreme Court should uphold an autonomy model that views medication as enabling autonomy by making patients rational.

Liberal theorist Berlin (1969) has cautioned against efforts to uphold autonomy by imagining what a sane, or rational, or healthy person would want for himself. Autonomy conceptually collapses for the philosopher when people uphold the principle by acting in what they believe should be, but is in fact contrary to, a person’s best interests. In sum, positive freedom should stop short of paternalism. The majority of Justices did not see a conflict between negative and positive freedom when excluding value judgments from capacity determinations; forcing unwanted medication would have constituted paternalism. Does this mean that it is possible to justify the *Starson* decision with the principle of liberal autonomy, at least those versions of the principle that include positive freedom? It would seem that the role of positive freedom in liberal theories is in dispute when applied to this case.

By contrast, in her analysis of *Starson*, Wilderman (2011) applies Sherwin’s (2011) version of autonomy, grounded in feminist relational theory. Sherwin criticizes

the reduction of autonomy to uncoerced choice among a range of options: “an individual cannot always improve her degree of autonomy by improving her understanding of the nature of the decision that she is to make or by reducing internal compulsions and external threats” (p. 26). Applied to *Starson*, this means that C.J. McLachlin’s dichotomy is false because relational autonomy challenges the very structuring of decisional capacity: “relational theory releases us...from what may have appeared to be a forced choice between negative freedom and psychiatric paternalism. In place of that forced choice, we are presented with the work of mutual exploration of the conceptual and material bases of decisional capacity” (Wilderman, 2011, p. 280). What are these conceptual and material bases? Wilderman suggests that current medical conditions and power dynamics serve to induce or exacerbate crisis, which have the effect of eroding capacity. A more robust notion of capacity, grounded in relational theory, would work to alleviate crisis and would render medical practitioners responsible for enabling and building capacity: “mechanisms may include deployment of mobile crisis units trained to engage with persons in a respectful manner aimed at de-escalating crisis, and/or availability of short-stay venues such as peer-run safe houses” (p. 271). The *Starson* decision and the resultant public debate over capacity turned on notions of liberal autonomy, but an application of feminist relational theory demonstrates that not nearly enough has been done to ensure capacity is cultivated.

Ashley Smith

*Starson* may function as an important step in mental health law, one which reflects the legal acknowledgement of and respect for the principle of personal autonomy; however, Szigeti (2004) notes that there was a catch:

The Board has interpreted the Judgment in *Starson* as lowering the burden of proof only in relation to matters of capacity. It maintains the 'enhanced' onus is required to be met by physicians who seek to continue a patient's involuntary status (p. 21).

That is, while determinations of capacity may be based on the updated, minimal criteria stipulated in *Starson*, Consent and Capacity Boards still curtail patient autonomy based on the broader criteria used before the *Starson* judgment. A patient may see her involuntary stay in a mental health facility lengthened and treatment continually enforced even when she understands the situation and appreciates the consequences of refusal.

Ashley Smith's experiences within the mental health system make this point clear. In 2002, at fourteen years old, Smith was criminally charged with "offences related to public disturbances, trespass or violence" (Office of the Ombudsman and Child Youth Advocate, 2008, p. 15). She was sentenced to probation for one year and enrolment in a support program, then she was sent to the New Brunswick Youth Centre (NBYC) the following year for breach of probation. She found herself released from and returned to youth correctional facilities for years thereafter. With each incident of noncompliance, additional time was appended to her sentence. As indicated in the Ombudsman Report, these incidents often occurred within the facilities themselves: "most of the disciplinary measures and incidents involving this young person occurred while she was in prison" (p. 18). From 2003 until 2006, the NBYC recorded nearly eight hundred accounts of her

transgressions, many of which were “related to her acting disruptively on a unit and/or refusing staff directives, or to self-harm” (p. 19).

In 2005, Smith underwent a court-ordered assessment at the Restigouche Hospital Center (RHC). The attending psychiatrist concluded that “Ms. Smith clearly understands her responsibilities and their consequences” (p. 19). The assessment was not made for the purpose of finding capacity so that Smith might have a say in what would happen to her, for the court was interested instead in confirming that Smith could be held responsible for her crimes, and punished more severely. Indeed, a determination of understanding and appreciation was used to justify Smith’s involuntary confinement. The RHC findings led to the addition of one hundred, eighty days of incarceration to the sentence she was already serving. While at the RHC, when Smith refused medication, the psychiatrist applied for and was granted “Admission of a Person as an Involuntary Patient” under the *Mental Health Act* in order to have her forcibly medicated.

Disciplinary strategies— isolation, restricted movement— further served to control Smith. As the Ombudsman’s report indicates, “there is a stringent policy on administering discipline for bad behaviour at the NBYC” (p. 20). For two-thirds of her time at the centre, Smith was left in seclusion, in what was called a Therapeutic Quiet unit. Restraints were also frequently employed, including full-body restraints referred to as the “WRAP:”

The ‘WRAP’ consists of applying restraint belts beginning at the inmate’s feet, all the way up to his or her shoulders, ceasing all possibility of bodily movement. Then a hockey helmet is placed on the head which would prevent one from injuring themselves in the event they topple over, and also preventing the subject from biting anyone. After the ‘WRAP’ was applied, Ashley had to be picked up by staff in order to move her to

another location, as all movements, including walking, are impossible (p. 22).

Later punishments in adult correction would involve pain: for example, pepper spray and tasers were used when Smith refused to submit to a mandatory strip search.

The NBYC ultimately decided to transfer her to a provincial adult correctional system when she reached eighteen years of age. Smith was transferred to the Saint John Regional Correctional Centre (SJRCC), and from there she would be transferred to nine different federal and correctional facilities outside New Brunswick. The transfer to an adult facility meant that Smith's charges and sentences would be altered to fit criminal law for adults:

On October 24, 2006, Ashley appeared in Adult Court and was imposed an adult sentence for criminal charges laid while she was still at the NBYC. As a result of the additional 348 days of custodial time added to the already existing 1,455 days, Ashley was to serve the remainder of her sentence in a federal institution due to the fact that this totality exceeded two years.

On October 31, 2006, at the age of 18, Ashley Smith left New Brunswick and was transferred to the Nova Institute for Women in Nova Scotia, a federal correctional facility (p. 29).

In October 2007, at the Grand Valley Institution for Women in Kitchener-Waterloo, Smith hanged herself in seclusion in her cell, suicide functioning as her means of escape. She was nineteen years old (Sapers, 2008).

While transfers are customarily conducted automatically when youths reach twenty years old, Smith's transfer process was applied for, granted, and carried out under s. 92 of the *Youth Criminal Justice Act* (2002). According to s. 92:

When a young person is committed to custody [under specific conditions outlined elsewhere in the *Act*], the youth justice court may, on application

of the provincial director made at any time after the young person attains the age of eighteen years, after giving the young person, the provincial director and representatives of the provincial correctional system an opportunity to be heard, authorize the provincial directory to direct that the young person, subject to subsection (3), serve the remainder of the youth sentence in a provincial correctional facility for adults, if the court considers it to be in the best interests of the young person or in the public interest.

The transfer was carried out against Smith's wishes for substantive reasons: for her own good and for public safety. And more than this, the transfer functioned as further punishment, for the threat of transfer was used until Smith turned eighteen in an effort to keep her in line. In her own words: "I am really scared about the thought of going to an adult facility with dangerous people. It has occupied my mind for a long time. I have wanted to behave to ensure that I would not ever go to adult and was sure that I would succeed" (p. 27).

During the youth transfer hearing, Smith provided a document listing reasons not to be transferred: "in it, Ashley emphasizes the fact that contrary to popular belief, she is incapable of controlling her outbursts and behaviour although she was very conscious of their impact" (Ombudsman, 2008, p. 25). The determination of capacity provided by the RHC did not work in her favour in that it rendered her responsible for her actions and deserving of the consequences. It did not matter that she had been incarcerated as a youth for years, nor that she had been treated poorly throughout her incarceration. Starson fought to have his capacity recognized so that he was entitled to refuse treatment; whereas Smith had no other recourse than to beg to be stripped of a capacity determination just to mitigate her living conditions. The principle of personal autonomy built into mental health policy was applied to this case in such a way that Smith had no

freedom to control the length and quality of her confinement, and yet this was because she was thought decisionally capable, free to choose her actions and behaviours, therefore accountable for her faults. She had no control over her life despite being considered capable of autonomous choice, and instead was subjected to paternalism, masked in beneficence.

### 2.2.3. *Autonomy in Law: Section 7*

#### Overview of Section 7

Legal autonomy is not limited by competence evaluations alone. Autonomy is protected constitutionally under s. 7 of the *Canadian Charter of Rights and Freedoms*. According to s. 7: “everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice”. In *Blencoe v. British Columbia (Human Rights Commission)* (2000)<sup>11</sup>, the Supreme Court of Canada articulated the standard for identifying a s. 7 violation: “in order for s. 7 to be triggered, one must first establish that the interest in respect of which the respondent asserted his claim falls within the ambit of s. 7” (p. 5). Further, if any of the three rights is infringed upon, the infringement must not be in accord with principles of fundamental justice.

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<sup>11</sup> In *Blencoe v. British Columbia (Human Rights Commission)* (2000), Robin Blencoe, a minister of the British Columbia government, had three sexual harassment claims filed against him. Due to delays reaching court, his story was covered extensively in the media, causing the ruin of his career as well as social and psychological hardship for him and his family.

The principles of fundamental justice function as “qualifier[s] of the right not to be deprived of life, liberty, and security of the person, [and as qualifiers], the phrase serves to establish the parameters of the interests” (*Re B.C. Motor Vehicle Act*, 1985, p. 501). The function and criteria “for a rule or principle to constitute a principle of fundamental justice for the purposes of s. 7” (p. 6) were explained in *R. v. Marmo-Levine* (2003)<sup>12</sup>. The Court decided that the values basic to social organization have the power to limit and shape the individual freedoms found under s. 7: “the delineation of the principle of fundamental justice must inevitably take into account the social nature of our collective existence. To that limited extent, societal values play a role in the delineation of the boundaries of the rights and principles in question” (p. 6).

Regarding the conditions which render a principle relevant to fundamental justice, it must firstly “be a legal principle about which there is significant societal consensus that it is fundamental to the way in which the legal system ought fairly to operate” (p. 6). A principle of fundamental justice must be a tenet central to law, but only insofar as society has deemed it to be central. If there is significant disagreement over the nature and importance of the principle, then this principle cannot function as justification for the infringement of autonomy rights: “before a principle can become a principle of fundamental justice, significant public support must have coalesced behind it” (Milton,

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<sup>12</sup> In *R. v. Marmo-Levine* (2003), David Marmo-Levine was charged with marijuana possession for the purpose of trafficking. His organization, the Harm Reduction Club, used the drug to educate users, and provided it at cost. He argued that the harm principle should be considered a principle of fundamental justice under s. 7, such that an element of harm must be part of any criminal charge. The Court determined that the harm principle did not meet the qualifying conditions for it to be a principle of fundamental justice.

1995, p. 132). Moreover, “it must be identified with sufficient precision to yield a manageable standard against which to measure deprivation of life, liberty or security of the person” (*Malmo-Levine*, 2003, p. 6). A manageable standard would involve the translation of a principle into a practical, workable limitation to constitutional rights (Fallon, 2006). It must be possible to devise a clear strategy for implementing a principle in order for that principle to function as a limitation to s. 7 rights.

Liberty: *B.(R.)*

Liberty, one of the three elements found under s. 7, was examined in *B.(R.) v. Children’s Aid Society of Metropolitan Toronto* (1995). Parents who identified as Jehovah’s Witnesses objected to a blood transfusion for their infant, who was born prematurely and had compromised health. The Children’s Aid Society was granted temporary wardship of the infant according to the *Child Welfare Act*: “S.B. received a blood transfusion as part of the examination and operation for the suspected glaucoma” (p. 3). The parents claimed that s. 19(1)(b)(ix) of the *Act* “which defines ‘child in need of protection’, together with the powers in ss. 30(1)2 and 41 and the procedures in ss. 21, 27, 28(1), (10) and (12)” (p. 3) infringed on their s. 7 rights as well as their s. 2 rights to freedom of religion.

The majority of Supreme Court Justices wrote separate rulings; for the purpose of this section, I will focus on the rulings that have bearing on s. 7. The Supreme Court of Canada held that citizens’ liberty interests must be protected from state interference by s.

7 as long as the choice in question is nontrivial, and does not come into conflict with essential societal values:

The liberty protected by s. 7 of the *Charter* does not mean unconstrained freedom. Freedom of the individual to do what he or she wishes must, in any organized society, be subjected to numerous constraints for the common good. The state undoubtedly has the right to impose many types of restraints on individual behaviour, and not all limitations will attract *Charter* scrutiny. On the other hand, liberty does not mean mere freedom from physical restraint. In a free and democratic society, the individual must be left room for personal autonomy to live his or her own life and to make decisions that are of fundamental personal importance (p. 4).

This interpretation is grounded in liberal philosophies, according to many of which a just state must not interfere with human choices as long as those choices cause no harm to others (Locke, 1980; Mill, 1978). Further, liberal philosophical rhetoric associates liberty with self-rule or self-direction, namely the ability to make decisions that pertain to one's life plans and purposes (Lukes, 1973). The Court thus deliberated over whether the decision to refuse a blood transfusion for one's child was a decision of fundamental personal importance, and if that were the case, whether there was a principle of fundamental justice that legitimized state interference.

Four Justices ruled the parents' s. 7 right to liberty had been violated but the violation was in accord with the principles of fundamental justice insofar as this right had to be balanced against the Court's *parens patriae* jurisdiction. They recognized that "the right to nurture a child, to care for its development, and to make decisions for it in fundamental matters such as medical care, are part of the liberty interest of a parent" (p. 5), but "this recognition was based on the presumption that parents act in the best interest of their child" (p. 5). The state may intervene in order to act in a child's best interests,

and can do so by invoking *parens patriae*, which was explained in detail in *E. (Mrs.) v. Eve* (1986)<sup>13</sup>: “the *parens patriae* jurisdiction is...founded on necessity, namely the need to act for the protection of those who cannot care for themselves” (p. 45). *Parens patriae* was identified in *B.(R.) v. Children’s Aid Society* (1995) as fundamental to Canadian jurisprudence: “the protection of a child’s right to life and to health is a basic tenet of our legal system, and legislation to that end accords with the principles of fundamental justice” (p. 6).

Three Justices argued that the exercise of parental liberty in this case fell outside the ambit of s. 7 because the life and health of the child would have been seriously endangered: “the exercise of parental beliefs that grossly invades those best interests is not activity protected by the right to liberty in s. 7. There is simply no room within s. 7 for parents to override the child’s right to life and security of the person” (p. 7). This argument signifies the Court’s interest in protecting the s. 7 rights of the child, rather than the liberty rights of the parents. Given that s. 7 rights are individual rights—“the *Canadian Charter*, and s. 7 in particular, protects individuals” (p. 72)—the interests of one party may conflict with the interests of another. Whereas one ruling in this case limited the parents’ liberty interest with a principle basic to social organization, this ruling limits autonomy rights when the boundaries of those rights push against another rights-bearer’s boundaries.

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<sup>13</sup> In *E. (Mrs.) v. Eve* (1986), Mrs. E. wanted permission to consent to the non-therapeutic sterilization of her intellectually disabled daughter Eve. The Supreme Court of Canada ruled unanimously in Eve’s favour, holding that non-therapeutic, forced sterilization does not fall under the jurisdiction of *parens patriae*.

### Security of the Person: *Rodriguez*

Another right identified under s. 7, security of the person was central to the case of *Rodriguez v. British Columbia (Attorney General)* (1993). Sue Rodriguez was diagnosed with amyotrophic lateral sclerosis (ALS), a progressive, terminal disability. She wanted to end her life once the disability immobilized her, but at that point ALS would render her physically incapable of doing so on her own: “[she] wishes that a qualified physician be allowed to set up technological means by which she might, when she is no longer able to enjoy life, by her own hand, at the time of her choosing, end her life” (p. 3). With one year left to live, she applied to the Supreme Court of British Columbia to have s. 241(b) of the *Criminal Code* struck down on the grounds that it violated s. 7 rights to life, liberty, and security of the person; s. 12 protection against cruel and unusual punishment; and s. 15 right to equality. The Supreme Court found in a five to four ruling that the prohibition of assisted suicide does not violate *Charter* rights.

Again, I will focus on the rulings related to s. 7 rights. Security of the person was so defined by J. Sopinka, who wrote the majority decision: “security of the person in s. 7 encompasses notions of personal autonomy (at least with respect to the right to make choices concerning one’s own body), control over one’s physical and psychological integrity which is free from state interference, and basic human dignity” (p. 5). Security of the person thus involves the right to make fundamental decisions regarding one’s own body and mental state. While liberty more broadly applies to fundamental decisions about one’s life, the security of the person interest more directly relates to corporeal and psychological decisions. Reflecting on the case, Milton (1995) notes that “the sanctity of

life is the overarching principle [fundamental to Canadian society] but on occasion it is subject to exception founded on personal autonomy. As a result, the majority recognized a right of corporeal autonomy” (p. 13). He characterizes corporeal autonomy in the following way:

I am a competent adult. I have a right to autonomy. At the very least, this right confers on me the right to do what I wish with my body provided no one else is harmed. Therefore, I have a freedom to commit suicide. Restrictions on aided suicide impair my freedom, and when I am unable to commit suicide unaided, the ban creates a complete barrier to exercise of my freedom (p. 125).

In the case of disabilities where one experiences corporeal limitations, suicide might only be possible with assistance, such that a physician or loved one acts as an instrument, appendage, or extension of the agent making the decision. At least at the time the case was heard, Rodriguez was capable of making and communicating the decision, although she would eventually be incapable of executing it. While the ability to execute a choice is a component of decisional capacity in some bioethics literature (Beauchamp & Childress, 2009; Grisso & Appelbaum, 1998), Rodriguez made a case for honouring her right to make decisions about her body and her life even when she required assistance to carry out the decision.

The majority found that s. 241(b) of the *Criminal Code* violated Rodriguez’s rights to liberty and security of the person; regarding the latter, the section “deprives the appellant of autonomy over her person and causes her physical pain and psychological stress in a manner which impinges on the security of her person” (p. 4). It was determined, however, that this deprivation “is not contrary to the principles of

fundamental justice” (p. 4). The principle in question was the state’s interest in protecting vulnerable populations who in similar contexts could be taken advantage of:

Given the concerns about abuse and the great difficulty in creating appropriate safeguards, the blanket prohibition on assisted suicide is not arbitrary or unfair. The prohibition relates to the state’s interest in protecting the vulnerable and is reflective of fundamental values at play in our society. Section 241(b) therefore does not infringe s. 7 of the *Charter* (pp. 5-6).

The majority thus ruled that Rodriguez had the right to liberty and corporeal autonomy; she had the right to make fundamentally important decisions regarding her life and body. However, she could not carry out her decision without her physician’s help, and so the Court had to acknowledge that Rodriguez was only capable of acting autonomously in this instance if someone facilitated the decision. The Court could not set a precedent that ran the risk of abuse in other contexts, against vulnerable people.

In a similar vein, bioethicist Callahan (2008) considers how decisions regarding physician-assisted suicide are always social, produced in dialogue between the disabled person and the person assisting. He is wary of the motivations of other people involved in the decision, and whether they are abusing their power, for their involvement might constrain the autonomy of the disabled person whose life is at stake. Harris (1990) and Lindley (1988) hold instead, though, that suicide should not be prohibited when the act maximizes autonomy; it has been proposed that suicide when the alternative is a life with a disability is one such exception to the rule (Hwang, 2007; Powell & Lowenstein, 1996). Some disability rights advocates (Shakespeare, 2006; Silvers, 1998b) even argue that it is problematic to characterize disabled people trying to make end-of-life decisions as vulnerable. Says Hwang: “among disability activists, supporters of physician assisted

death assert that emphasizing vulnerability contradicts the goals of the independent-living movement by promoting the image of people with disabilities as a weak class incapable of full self-determination” (2007, pp. 20-21). Perhaps part of self-determination is the decision to die.

Or, it is possible that this ruling overlooked that end-of-life decisions are not always autonomously made, especially given that ableist contexts may produce pressures to end one’s life (Asch, 2005; Shakespeare, 2006). Ho (2008) argues:

Without addressing the social context within which people may find no feasible option but to seek death, the autonomy argument for assisted death reinforces the status quo by not questioning whether imposition of isolation, abandonment, and lack of support and opportunity make life seem not worth living to people with impairments (p. 203).

The majority ruling reinforced the individualistic spirit of s. 7, in that it acknowledged Rodriguez’s freedom to make an end-of-life decision, without acknowledging how ableist societal attitudes might be internalized and incorporated into end-of-life decisions. The cases discussed in this section reflect a specific notion of autonomy that does not incorporate context and relations. Such a formulation of the concept has implications for autonomy jurisprudence, implications which are also made manifest in relation to reproduction.

### 2.3. Reproductive Autonomy

The following section will grapple with how autonomy theories have been applied to reproductive decision-making. It will begin with a consideration of how reproductive autonomy is explained in bioethics literature, especially relative to maternal-fetal

connections. The next sub-section will present the relevance of and implications to *R. v. Morgentaler* (1988), which grounded reproductive rights in the s. 7 right to security of the person. I will demonstrate that security of the person relates to reproductive autonomy, and I will evaluate whether this right can adequately protect and facilitate reproductive decision-making.

### *2.3.1. Reproductive Autonomy in Bioethics*

#### Personal Reproductive Autonomy

Reproductive autonomy concerns a range of decisions pertaining to women's procreative events or activities, including contraception, impregnation, abortion, as well as pre-implantation, prenatal, and postnatal technologies (McLeod, 2002; Roberts, 1997). McLeod (2002) makes a case for expanding the definition to such a wide range, when reproductive autonomy has historically tended to refer only to abortion decisions:

Although reproductive autonomy is often understood narrowly in terms of women's civil rights of access to abortion and reproductive technologies, surely the concept should have wider application. For example, if little respect is given to women's autonomy once they gain access to reproductive technologies, they will lack control over how they reproduce or attempt to reproduce (p. 2).

The concept generally refers to a woman's entitlement to determine and control her reproductive activities and to make choices related to her reproductive system. Examples range from the choice to use birth control to protection from involuntary therapeutic sterilization; from the use of assistive reproductive technology to the refusal to ever bear children; from the decision to carry a pregnancy to term to the decision to terminate; from access to diagnostic technologies to the right not to know.

The concept of reproductive autonomy has been legally integrated into Canadian law in recent decades, reflecting the theoretical work of liberal scholars. As Glendon (1987) notes, “fundamental change...occurred in [the area of reproductive rights, specifically abortion] all over the Western world in a relatively short period of time” (p. 10). Her assessment is based on legal reforms in twenty Western countries (including Canada) beginning in the 1960s through the 1970s—shifts in law and policy that came to the defence of women’s entitlement to reproductive control. Glendon speculates over the ideological underpinnings to these shifts, holding that “much of family law is no more—and no less—than the symbolic expression of certain cultural ideals” (p. 10). The cultural ideal to which she is referring (and which she, standing in opposition to reproductive rights, condemns) is personal autonomy: “I would say to my pro-choice friend...please consider what a set of legal arrangements that places individual liberty or mere life style over innocent life says about, and may do to, the people and the society that produces them” (p. 62).

Glendon is using the rhetoric of a rights conflict to frame abortion, and the lens is not uncommon. Indeed, she is referencing scholars of the 1970s, among them feminists, who championed women’s reproductive rights by seeking to resolve a conflict between woman and fetus. Jarvis Thomson (1971) and Overall (1987) argue that the fetus has no claim to occupying a woman’s womb despite any moral standing to which it might be entitled, and for this reason women’s right to bodily autonomy overrides the interest the fetus has in living. A woman who opts to have an abortion, in this light, is not violating the fetus’s right to life, but is only denying the use of her body, for she is not morally

required to offer her body at great cost to herself: “having a right to life includes having a right to be given at least the bare minimum one needs for continued life. But suppose that what in fact is the bare minimum a man needs for continued life is something he has no right at all to be given?” (Jarvis Thomson, 1971, p. 3).

According to an extreme liberal position taken on abortion rights, the fetus has no moral standing, that is, does not qualify as a person. If not a person, it lacks competing legal, or at least moral, interests. A position of this sort may be defended by identifying criteria to personhood that the fetus cannot meet. Singer (1979) and Tooley (1972), as examples, argue that personhood begins with self-awareness, which develops months after birth. Tooley notes that ascribing value at any point during a pregnancy, including conception (fertilization of the ovum), quickening (fetal movement detected by the pregnant woman), and viability (the ability to survive on its own despite still being in utero), would only be arbitrary: “in the case of abortion a number of events... might be taken as cutoff points, and it is easy to overlook the fact that none of these events involves any morally significant change in the developing human” (p. 38).

Warren (1973) originally held that the decision to terminate a pregnancy is entirely a matter of a woman’s right to bodily autonomy because the fetus has no rights, for it does not qualify for membership in the moral community until long after birth<sup>14</sup>.

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<sup>14</sup> Warren (1973) concedes that her position on abortion also supports infanticide (a practice historically associated with the birth of disabled newborns), in cases where the infant has not developed the criteria that would render it a member of the moral community: “a man or woman whose consciousness has been permanently obliterated but who remains alive is a human being which is no longer a person; defective human beings, with no appreciable mental capacity, are not and presumably never will be people; and a fetus is a human being which is not yet a person” (p. 6). She challenges infanticide on

She cites five conditions to membership in the moral community, or “traits which are most central to the concept of personhood” (p. 5): consciousness of objects and pain, reasoning capacity, self-motivated activity, communication, and self-awareness. Without these characteristics, the fetus has no entitlement to life. Critiquing Jarvis Thomson, Warren indicates that abortion is not a “morally serious and extremely unfortunate, even though sometimes justified act” but might instead be a “morally neutral act, like cutting one’s hair”<sup>15</sup> (p. 4). Steinbock (2011) explains Warren’s position: “actions have moral significance only if they harm or wrong persons. If the fetus is not a person, then the decision to abort it is not a moral one” (p. 53).

### Critique

Warren’s position fell in line with those myriad positions taken by liberal (sometimes feminist) scholars, positions which were undergirded by the rhetoric of rights and entitlements. Warren (1989) defends making use of these concepts: “respect for rights provides a moral floor—a minimum protection for individuals which remains morally binding even where appropriate caring relationships are absent or have broken

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consequentialist grounds, but she is clear about her determination of personhood, and who is excluded from the category. Tooley (1983) also grants that his position on abortion is a position in favour of infanticide, and consequentialist Singer (1979) defends infanticide in the case of disabled newborns.

<sup>15</sup> Regarding the comparison of terminating a pregnancy to cutting one’s hair, Steinbock (2011) says of Warren: “Warren later repudiated this analogy in conversation. Her book, *Moral Status: Obligations to Persons and Other Living Things* [1984], while denying moral standing to fetuses, gives a more nuanced view of the morality of abortion than her 1973 article” (footnote 55). I will discuss Warren’s later position, but thought it prudent to include her seminal 1973 work when discussing early liberal positions on reproductive autonomy.

down” (p. 47). She goes on to explain that rights discourse is compatible, not in competition, with feminist ethics:

But is the concept of a moral right necessarily incompatible with the social nature of human beings? Rights are indeed individualistic, in that they can be ascribed to individuals, as well as to groups. But respect for moral rights need not be based upon an excessively individualistic view of human nature (p. 47).

There is certainly a practicality to the arguments outlined above in that they speak the language of law, invoking a specific kind of autonomy—autonomy that is personal, liberal, belonging to individuals (Gavigan, 1992). Personal reproductive autonomy is predicated on the individuation of parties with potentially competing interests. The framing of reproductive matters in this way is not new, for discourses on abortion long before feminist activism understood the woman and fetus to be deadlocked in a rights conflict, only the fetal interest in life was understood to possess more moral weight than a woman’s interest in corporeal control (Glendon, 1987; Marquis, 1989). Early defences of reproductive autonomy sought to negate or outweigh the moral standing of the fetus, but held much of the conceptual presuppositions of the opposition to be true.

Conceptual individuation has gained much more traction due to a reproductive technology that has become “one of the most common rituals of pregnancy in the late twentieth-century urban North America” (Mitchell, 2001, p. 3). Karpin (1992-1993), Mitchell (1994, 2001), and Petchesky (1986, 1987) claim that the fetal imagery produced via ultrasound technology has captured the imagination of our visual-dominant culture. More than that, interpretations of this imagery have shaped the cultural imagination for fetal-maternal identities and relationships. The tool may be used to render that which is

private, public: “the technological removal of the fetus from the ‘secrecy of the womb’ through ultrasound and other prenatal procedures gives the fetus social recognition as an individual separate from the mother” (Blank, 1993, p. 73). The relationship that the prospective mother forges with the fetus is cultivated through the technological medium that makes it possible for mother to meet fetus, for it sharpens the focus between the two.

For example, in the work featured in the 1965 *Life Magazine* cover and photo spread as well as the book *A Child is Born* (1986), Scandinavian artist Lennart Nilsson took pictures of fetuses in utero. Katz Rothman (1987), Mitchell (2001), and Stabile (1992) describe the pictures’ dark background, sometimes depicting outer space, replacing the uterus in which the fetus is actually situated. Stabile (1992) argues that this background, as well as the captions discussing the thriving child, have had the effect of disappearing the mother: “both visually and textually, the embryo-fetus enjoys a thoroughly autonomous status” (p. 187). Images like these have functioned as tools used to “personify” (Kukla, 2005) the fetus and to render the female body hostile: the fetus is “active, virtually autonomous...trapped in its mother’s womb, begrudgingly serving a nine-month sentence of confinement” (Gavigan, 2009, pp. 131-132). The pregnant woman’s role in fetal development has been erased through the production of fetal identity, such that the woman, far from facilitating fetal development, has come to be regarded as potentially standing in the way; the relationship between woman and fetus has therefore come to be framed as adversarial:

The potential cultural and political successes of the fetal rights movement, then, lie in its ability to both capture the imagination and tap the anxiety of people who are receptive to the notion that pregnant women are capable of extreme acts of selfishness and irresponsibility. The fetus is presented as

helpless and vulnerable, the most innocent of innocent victims. Again, what is striking is that this campaign has been so successful without significant support in Canadian law for its fundamental underlying premise: that the fetus is a person with legal rights (p. 132).

Although the use of the technology during pregnancy is meant to “reduce maternal anxiety and to stimulate the parents’ emotional ‘bond’ to the fetus” (2001, p. 4), Mitchell describes the effect of ritualizing ultrasound procedures: “it offers a means for influencing women into complying with prenatal care recommendations about food, cigarette, alcohol and/or drug intake” (p. 4). Kukla (2005), too, explains how reproductive rituals like ultrasound have helped shape both fetal identity and the mother’s role, which in turn affect the politics of abortion: “as a shared pregnancy narrative becomes canonized, and the inside of the pregnant body is transformed into a public arena, the individual outsides of pregnant bodies are rendered permeable and transparent” (p. 122). Ritual legitimizes the cultural understanding of the fetus as fragile and vulnerable, and renders the uterus either protective or dangerous for fetal development, depending on the mother’s compliance. The bifurcation of woman and fetus has thus led to personification of the fetus, as well as dehumanization of the woman when her interests collide with fetal health, that is, when she is unable or unwilling to maintain and discipline her body for the sake of the fetus.

Katz Rothman (1990) considers the ideological underpinnings that shape motherhood and pregnancy, among them technology and patriarchy. These ideologies have the power to frame identities and relationships to the extent that they are internalized, becoming “part of common sense” (p. 27); and as argued earlier in this study, the internalization of oppressive ideology has a deleterious effect on reproductive

decision-making. She explains how individuation has been accomplished through the use of reproductive technology in a culture that inferiorizes women: “in patriarchy, the sense of separation of the fetus and mother was already there as a concept; the new technology allows the separation to be reified” (p. 158). That is, the reification of this idea that woman and fetus are separate entities, even entities at odds with one another, serves the interests of patriarchy. Maternal responsibility, dedication to pregnancy monitoring and maintenance, might appear to be autonomously carried out, but instead happen as a result of the internalization of ideological systems that seek to control reproduction.

It would seem, then, that Warren (1989) was wrong about the compatibility of liberal defences of abortion with feminist ethics, at least the feminist ethical theories of later years. Personal autonomy cannot do the work needed to counter discourses that would seek to limit women’s reproductive control, for personal autonomy requires that the experience of pregnancy be refashioned as a conflict, whether between persons, or person and nonperson. This conflict, predicated on the conceptual separation of woman and fetus, does not properly convey what the experience of pregnancy is like, but instead reflects the effects of technology and patriarchy—ideologies that have become ingrained in public consciousness such that they have set the terms of the moral disagreement.

### Feminist Reproductive Autonomy

While Warren (1989) held that a liberal position on abortion is compatible with feminist ethics, even she conceded that not all feminists would agree. Wolgast (1987) rejects rights discourses because they require that persons be atomistic and self-

interested, in competition with others. Gilligan (1982) and Noddings (1984), too, stress the value of interpersonal relationships over moral entitlements, seeking to build codes of ethics along lines of relations rather than according to distribution to individuals. Should the concept of reproductive autonomy be compatible with these feminisms, it cannot be a concept derived from liberal ideologies.

When analyzing those early feminist perspectives on reproductive autonomy as outlined above, Colker (1992) criticizes the tendency on both sides of the old abortion debate to assume that women and fetuses can be understood separately:

Feminist pro-choice litigators attempt to argue that we should consider the woman's right to autonomy in isolation from the state's interest in protecting life. Instead of seeing pregnant women as having an implicit connectedness to the fetus, and thus a responsibility to the well-being of that fetus, pregnant women are described in isolation from that fetus. Pro-life advocates do no better. As Rosalind Petchesky has pointed out, they try to remove fetuses from women's bodies, and pretend that we can protect fetal life without controlling women's lives. Their concern for the autonomy or well-being of fetuses causes them to disregard women's lives (p. 85).

For her, discourses on abortion too often fail to account for the necessary connection between fetus and mother. This "imperative to describe the mother and fetus as either one being or two, but not both one and two", Karpin (1992-1993) argues, "indicates the limitations of logocentric and phallogocentric discourse" (p. 327), when women's bodies are in reality "least able to conform to an optics of the skin, particularly in the context of pregnancy" (2005, p. 195). Katz Rothman (1990) holds that the experience of pregnancy challenges arguments rooted in personal autonomy:

We have motherhood, the physical embodiment of connectedness. We have in every pregnant woman the living proof that individuals do not enter the world as autonomous, atomistic, isolated beings, but begin

socially, being connected. And we have in every pregnant woman a walking contradiction to the segmentation of our lives: pregnancy does not permit it. In pregnancy the private self, the self, familial self, announces itself wherever we go. Motherhood is the embodied challenge to liberal philosophy, and that, I fear, is why a society founded on and committed to liberal philosophical principles cannot deal well with motherhood (p. 59).

Mackenzie (1995), too, argues that while many feminist perspectives on reproductive autonomy acknowledge that fetal existence and welfare cannot be understood as separate from the pregnant woman, they fail to account for the implication that liberal interpretations of reproductive autonomy also require that the woman and fetus be understood as separate and in conflict. The erection of borderlines around the woman, and the continued characterization of the maternal-fetal relationship as oppositional, runs counter to the phenomenology of pregnancy. The fetus could have moral value, then, not due to abstract notions of individualism, but instead as a result of being “related to the human community in and through the bodies of the women who gestate them” (Tong, 1997, p. 151).

In her later work, Warren (1989) refines her analysis, arguing that birth, rather than simply qualifications for membership into the moral community, is a morally significant event that should have bearing on the question of reproductive rights. In her own words:

Birth is morally significant because it marks the end of one relationship and the beginning of others. It marks the end of pregnancy, a relationship so intimate that it is impossible to extend the equal protection of the law to fetuses without severely infringing women’s most basic rights. Birth also marks the beginning of the infant’s existence as a socially responsive member of the human community. Although the infant is not instantly transformed into a person at the moment of birth, it does become a biologically separate human being (p. 480).

Recall that earlier in this chapter, it was noted that the experiences of pregnant and some disabled bodies as explicitly and profoundly intercorporeal challenge liberal interpretations of autonomy. These bodies may serve as entry points into theoretical work that needs not be predicated on individual bodies with isolated entitlements. Indeed, consider in the above passage that Warren is not saying that birth marks the individuation of persons; she is not recommending a new cut-off point for assigning moral significance, alongside viability, self-awareness, and the like. She is instead arguing that birth marks a transition in relationships, a shift from the profoundly intimate bond between woman and fetus, two bodies as one, to engagement with others within a greater network of, if not intercorporeality, at least interconnectivity. Price and Shildrick (2002) highlight the importance of interconnectivity, using disability as their entry point and postmodern language to frame their theory:

Against an ingrained tendency for disability activists and scholars to claim a clear set of identities as disabled people, the trajectory within postmodernism has been to fragment the concept of identity in general and to substitute a fluid, shifting notion of a process of becoming that defines neither its own corporeal boundaries nor a fixed context. In suggesting such a radically different approach, our purpose in part is to open up the ethical agenda to encompass not just the liberal humanist pursuit of rights, interests or even individual moral flourishing—all of which presuppose identity—but the post-conventional concerns with encounter, with relationship and becoming-in-the-world-with-others (p. 62).

When we introduce notions of relationships and responsibility to pregnancy, we may well be painting a more accurate picture of women's experiences, thereby erasing the body boundaries that are foundational to rights conflict rhetoric, but do these notions so complicate reproductive autonomy as to render the principle useless? Donchin (2009) argues that, to the contrary, reproductive autonomy can be refashioned such that it

includes connectivity and community: “a relational perspective can weave its way through shifting relationships and novel reproductive arrangements without jeopardizing the reproductive autonomy of the individuals involved” (p. 34). The intercorporeal phenomenology of pregnant bodies should disrupt conceptions of self such that we no longer limit autonomy analysis to the sphere of individuals, for instances of intercorporeality should deconstruct, rather than simply be understood as exceptions to, normalized embodiments. With this frame of reference in mind, we can more readily account for how reproductive decision-making happens within a vast context of interrelations:

Advocates of relational autonomy highlight the ways in which interpersonal connections and influences from intimates can enable rather than present obstacles to an individual’s autonomy. If our selves are connected in this way, the requirements for autonomy cannot simply exclude the needs and interests of our loved ones from influencing our decisions. Though relational autonomy theorists can recognize that the influence of some intimates can present obstacles to autonomy...they also argue that supportive personal relations provide the conditions under which autonomy is even possible (Goering, 2009, p. 12).

When identity is no longer understood to be singular, when boundary lines between persons blur, decision-making becomes more nuanced and collaborative, where autonomy is borne out of the support and advice of loved ones (Jackson, 2001).

Grandmother raised me Catholic, and an abortion would break her heart; my mother is ecstatic, even offered to move in and help; my boyfriend and I are just not ready to settle down yet; my wife and I have been trying to have a baby for years: the concept of relational autonomy makes these concerns, these other people, much more relevant to decision-making. Such a perspective, too, can identify other influences, perhaps those

that are unwelcome: namely, the ideologies of technology and patriarchy that are internalized and incorporated into reproductive decisions.

### 2.3.2. *Reproductive Autonomy in Law*

#### *Morgentaler*

These considerations have not entered into reproductive autonomy jurisprudence, for the landmark case in Canada, *R. v. Morgentaler* (1988), upheld the body-defined boundaries between rights-bearers. In this case, Drs. Henry Morgentaler, Leslie Frank Smoling, and Robert Scott were charged with illegally inducing miscarriages at a Toronto clinic, thus violating s. 251(4) in the *Criminal Code*. Under the *Criminal Code*, abortion was considered an indictable offense unless it was performed in a hospital by a doctor, and was approved by a committee of physicians who determined that the medical treatment would serve the purpose of saving a pregnant woman's life. Initially, the appellants argued that the *Criminal Code* was "inconsistent with s. 1(b) of the *Canadian Bill of Rights*" (p. 3), but as their cases proceeded the *Charter of Rights and Freedoms* was introduced into Canadian jurisprudence. The Supreme Court of Canada considered whether s. 251 infringed on s. 2(a) freedom of conscience; s. 7 rights to life, liberty, and security of the person; and s. 12 right not to be subject to cruel and unusual punishment. The Supreme Court majority of five to two agreed that s. 251 infringed on women's s. 7 right, and the deprivation of this right was not in accord with the principles of fundamental justice. It was also determined that the violation did not satisfy s. 1 of the *Charter*.

Introduced by then Justice Minister Pierre Elliot Trudeau in 1969, the amendment to the *Criminal Code* was progressive for its time, for it paved the way for the decriminalization of abortion. Previously an offense for which women could receive life imprisonment, abortion came to be legal as long as a committee comprised of at least three medical professionals could determine that the pregnant woman's physical, mental, or emotional health was endangered by the pregnancy: "[abortion was possible if] the continuation of the pregnancy of such female person would or would be likely to endanger her life or health" (s. 251, 4c). Morgentaler and his associates violated the *Criminal Code* by setting up "a clinic to perform abortions upon women who had not obtained a certificate from a therapeutic abortion committee of an accredited or approved hospital" (*R. v. Morgentaler*, 1988, pp. 2-3). They did so because, as indicated by their public statements, they questioned "the wisdom of the abortion laws in Canada and [asserted] that a woman has an unfettered right to choose whether or not an abortion is appropriate in her individual circumstances" (p. 3).

Those in the Supreme Court majority wrote three different rulings. Accompanied by J. Lamer, C.J. Dickson wrote that s. 251 "forces women to carry a foetus to term contrary to their own priorities and aspirations and which imposes serious delay causing increased physical and psychological trauma to those women who meet its criteria" (p. 63). Justice Beetz, with whom J. Estey was in agreement, wrote that by amending s. 251 in 1969, Parliament had acknowledged that "the objective of protecting the foetus is not of sufficient importance to defeat the interest in protecting pregnant women" (p. 126); s. 251 was "manifestly unfair" (p. 11) because it failed to meet Parliament's objective.

According to J. Wilson<sup>16</sup>, s. 251 violated s. 7 rights to security of the person and liberty; she explained the violation of liberty in the following way: “liberty in a free and democratic society does not require the state to approve the personal decisions made by its citizens; it does, however, require the state to respect them” (p. 167). She further argued that the decision to terminate a pregnancy was “essentially a moral decision, a matter of conscience” (p. 175) and thus s. 251 also violated the *Charter’s* s. 2(a) freedom of conscience.

Justice Wilson cited autonomy when ruling that s. 251 violated the right to liberty: “the right to ‘liberty’ contained in s. 7 guarantees to every individual a degree of personal autonomy over important decisions intimately affecting their private lives” (p. 37). For her, every right and freedom in the *Charter* is underpinned with the idea that “the state will respect choices made by individuals and, to the greatest extent possible, will avoid subordinating these choices to any one conception of the good life” (p. 37). According to her interpretation of the *Charter*, every right and freedom, including s. 7, to some degree is designed to respect autonomous decisions, as long as autonomy is understood as self-direction, the condition by which people make choices freely. By J. Wilson’s logic, then, reproductive decision-making should in part be grounded by the principle of personal autonomy.

Granted, the other Justices in the majority did not argue that s. 251 of the *Criminal Code* violated the *Charter’s* s. 7 right to liberty, nor did they argue that the s. 7

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<sup>16</sup> Justice Wilson was the only female Supreme Court Justice presiding over the case. When it comes to the question of the moral permissibility of reproductive rights, there is value in considering who—which gender—grants the permission.

right to security of the person should be interpreted so widely as to include the promotion of personal autonomy despite the argument made by the defence. *Rodriguez* (1993) associated security of the person with corporeal autonomy, but *Morgentaler* happened long before *Rodriguez* set the precedent. In *Morgentaler*, the appellants' counsel Mr. Manning had used American constitutional theory to argue their case: "[section 7] is a wide-ranging right to control one's own life and to promote one's individual autonomy. The right would therefore include a right to privacy and a right to unfettered decisions about one's life" (p. 51). Manning was referring to the landmark American case on abortion rights, *Roe v. Wade* (1973), in which it was ruled that under the Fourteenth Amendment's Due Process Clause, women are entitled to privacy in reproductive contexts, at least until the fetus becomes viable at twenty-eight weeks of pregnancy. In response to counsel, C.J. Dickson cautioned against interpreting s. 7 through the lens of American theories: "we would, in my view, do our own Constitution a disservice to simply allow the American debate to define us, all the while ignoring the truly fundamental structural differences between the two constitutions" (p. 53).

Indeed, it would be problematic to draw a one-to-one comparison between security of the person found in the Canadian *Charter* and privacy protections from the American Constitution. Within the *Roe v. Wade* (1973) ruling, privacy was linked to "personal liberty embodied in the Fourteenth Amendment" (V). Although the term is not explicitly found in the Constitution, "the Court...recognized that a right of personal privacy, or a guarantee of certain areas or zones of privacy, does exist under the Constitution" (VIII). This was possible because the right to privacy was understood to

have broad applications: “the Constitution nowhere mentions a specific right of personal choice in matters of marriage and family life, but the ‘liberty’ protected by the Due Process Clause of the Fourteenth Amendment covers more than those freedoms explicitly named in the Bill of Rights” (I). The concept of privacy has historically related to self-disclosure: “common law secures to each individual the right of determining, ordinarily, to what extent his thoughts, sentiments, and emotions shall be communicated to others” (Warren & Brandeis, 1980; as cited in Leino-Kilpi et al., 2000, p. 80). Broadly, at least in the US, the principle has been applied in an effort to protect individuals from interference when making decisions. In Canadian law, security of the person has a more specific application, grounded in the protection of persons from physical and psychological harm:

The appellants submitted that ‘security of the person’ protected by the *Charter* is an explicit right to control one’s body and to make fundamental decisions about one’s life. The Crown contended that ‘security of the person’ is a more circumscribed interest and that, like all of the elements of s. 7, it at most relates to the concept of physical control, simply protecting the individual’s interest in his or her bodily integrity (*R. v. Morgentaler*, 1988, p. 54).

Despite C.J. Dickson’s caution, s. 7 can still be understood as a set of rights that upholds reproductive autonomy. Canadian theorist McLeod (2002) discusses the effect of interference with reproductive autonomy: “if little respect is given to women’s autonomy...they will lack control over how they reproduce or attempt to reproduce.” (p. 2). She thus links autonomy with reproductive control. Indeed, reproductive decisions are necessarily grounded in women’s bodies and reproductive capacities, and how freely made those decisions are has a tremendous impact on the physical and psychological

hardship a woman might endure. Purdy (2006) explains the significance of ensuring women control their own bodies: “autonomy is particularly important for women...because reproduction still takes place in women’s bodies, and because they are generally expected to take primary responsibility for child rearing” (p. 287). If a woman lacks access to abortion services, she must carry a pregnancy to term, resulting in a drastic transformation of her body and a lack of control over what happens to her body. Women may experience these hardships because, as C.J. Dickson held, the criminalization of abortion ran contrary to women’s priorities and aspirations. The Chief Justice acknowledged that in reproductive matters, reproductive control involves a degree of self-direction, of acting in accordance with one’s own values. Therefore, even a narrow definition of the right to security of the person is framed with concepts associated with autonomy, such as self-direction.

### Analysis

While the 1988 *Morgentaler* case marks an historic victory for reproductive rights in Canada, the decision framed reproductive decision-making as strictly a medical issue, one which unfolds between a woman and her physician: “the victory was...contradictory in that the Court reinforced the notion that abortion is a medical matter” (Gavigan, 1992, p. 222). While *Morgentaler* has served as a cultural icon and champion for reproductive rights since this first case and many more thereafter, this case questioned the guilt of physicians involved in performing abortions, not the women seeking abortions out. The decision rendered was meant to protect not only women but also physicians.

This decision reflects how intimately involved physicians are in reproductive decision-making processes. They need not be since they have not always been; as Katz Rothman (1991) notes, “the transition from almost all births taking place at home to almost all births taking place in the hospital took just over two generations. In those two generations, birth changed from being an event in the life of a family to being a medical procedure” (p. 29). Pregnancy has come under the auspices of the medical field, and as such has been ideologically reshaped: “the primary characteristic of the modern medical model of health and illness in general is that it is based on the ideology of technology, that appropriate to the technological society, with its values of efficiency and rationality, practical organization, systematizing, and controlling” (p. 34). When reproductive practices are medicalized, women are understood to enact reproductive autonomy by consenting to or refusing treatments, by choosing to heed or to neglect physician advice, by availing themselves of or declining healthcare services.

When reproduction becomes entirely a healthcare issue, the pregnant woman is by implication removed from family contexts where she once, historically, would make decisions regarding her pregnancy. In medical contexts, the pregnant woman is an individual patient, and her entitlements in such an exchange are individualized. The resultant “rights-based, neo-liberal, privatized argumentation that characterizes Supreme Court jurisprudence on reproductive autonomy” (Rodgers, 2006, p. 275) has not gone without criticism.

It should be said though: the emphasis on individualism in rights discourse, at least in the Canadian context, does not lead to the individuation of the fetus for the

purpose of ascribing it rights. A comparison might be helpful. In the US, the woman's right to privacy is balanced against the state's interest in protecting viable life, when the fetus is "potentially able to live outside the mother's womb, albeit with artificial aid" (Hellman & Pritchard, 1971; as cited in *Roe v. Wade*, 1973, IX). The Supreme Court of Canada does not recognize viability, and so a woman's right to security of the person is not limited by any state interest in protecting viable life. In *Tremblay v. Daigle* (1989), for example, physically abusive Jean-Guy Tremblay sought an injunction against a pregnant Chantal Daigle, who had ended her relationship with Tremblay and was seeking an abortion; Tremblay held that he was protecting his unborn child's right to life. It was determined that the fetus had no legal status—relegating questions of biological and human status to the realms of philosophy, theology, and linguistics—and so *Charter* rights did not apply. It is clear that Canadian jurisprudence is not interested in balancing fetal and maternal rights.

Even so, *Morgentaler* (1988) and subsequent rulings have been predicated on the isolation of the pregnant woman as rights-bearer. In her analysis of *Morgentaler*, Rodgers (2006) holds that reproductive control ought to be grounded in the rights of women as a marginalized minority: "we must continue to place emphasis on the nature of reproduction as 'social' reproduction, not individual liberty" (p. 289). Gavigan (1992) argues that Canadian case law on reproductive rights belies a formulation of autonomy that is associated with individualism, and this rhetoric is inconsistent with the language taken up within the feminist movement:

The language of the *Morgentaler* judgments of the majority was a ringing restatement of an *individual* right to life, liberty, and security of the person

and is thus consistent with the emphasis on abortion as a private and individual matter. While this reflects the language of lawyers and judges, it has not been the characterization of Canadian pro-choice and feminist activists, who have consistently framed abortion as an issue of equality and access (p. 222).

There are important implications to characterizing reproductive rights as individual rights to be fulfilled only in medical contexts. According to Dunsmuir's (1998) analysis of J. Wilson's decision: "the state is required only to respect such decisions [to terminate pregnancies], or to refrain from interfering with them, not to approve or facilitate them" (unpaginated). That is, in the case of reproductive rights, s. 7 protections cannot guarantee positive state obligations that would provide the resources women need in order to make reproductive choices. Section 7 has no power to protect women from the "creeping privatization" (Gilmour, 2002, p. 267) of healthcare, the effect of which has been that abortion is at risk of being quietly removed from our list of medically necessary (and therefore covered) health services. Some provinces have entered into agreements promising to cover some or all of the costs associated with abortion procedures, but these arrangements remain complex and confusing, far from uniform (Downie, 2011). As demonstrated in the previous chapter, abortion access is already varied depending on the province or territory due to this lack of regulation and administrative clarity.

According to Gilmour (2002), the Health Services Restructuring Committee (HSRC) poses another impediment to abortion access given its role in advising the Minister of Health on which hospitals to close: "in some instances in Ontario, HSRC decisions resulted in the 'winning' hospitals (the survivors) being those with Roman

Catholic affiliations” (p. 287). She cites the merger of Pembroke Civic Hospital with Roman Catholic Pembroke General, and the redirecting of funds from the closed Wellesley General Hospital to Saint Michael’s Hospital. As a result, “access to a number of reproductive health care services previous available at the Wellesley [has been eliminated]” (p. 288). In effect, women have the right to reproductive control but lack options, and reproductive choices should at minimum be facilitated by meaningful options provided within one’s social context. They might also be facilitated if reproductive autonomy was understood to function within relations, and pregnancy was not understood to be entirely a health matter, to be undermined whenever healthcare policy is adjusted in the interest of tightening budget lines. Decisions that favour Catholic hospitals in the restructuring of healthcare not only limit women’s options, but also express a judgment about abortion which may be internalized:

[These institutional policies] carry with them an inherent judgment, the judgment of a publicly funded institution charged with carrying out government policy to provide comprehensive health care, that those seeking such services—primarily women—are also morally in the wrong, or at best misguided. That is not a silent presence but an active judgment with real consequences and ramifications (p. 288).

For Jackson (2001), the state is responsible for facilitating reproductive choice by providing access to the necessary services. She holds that this responsibility is consistent with reproductive autonomy, and she fashions the principle with the use of feminist advocates of relational autonomy: “autonomy is... ‘a capacity that requires ongoing relationships that help it flourish” (Nedelsky, 1993; as cited in Jackson, 2001, p. 6); “Young’s participatory model of empowerment...emphasizes the social constraints upon the options from which an individual is able to choose” (Young, 1997; as cited in

Jackson, 2001, p. 6). Such a reworked principle accounts for how reproductive decisions can be made freely when communities provide valuable options. Respect for autonomy thus requires not merely the removal of barriers, but the active facilitation of choice and the disruption of influences, overt and systemic, that undercut the authenticity of choice: “[the principle] should sharpen society’s responsibility to ensure that each pregnant woman has...a range of valuable options from which to choose” (p. 115). Jackson’s work points to the inadequacies inherent in reproductive protections in Canada, for our current notions of reproductive autonomy have been ill-equipped to handle provincial efforts to curtail abortion access and the pervasive religious framing of pregnancy in terms of the individuated fetus and irresponsible mother. The *Morgentaler* (1988) decision triggered what Petchesky (1987) has described in the US as a “rightward drift” (p. 57) of public opinion, or at least of a vocal minority, fuelled with powerful imagery like Nilsson’s photography (1965, 1986). This movement has operated effectively outside the courts to chip away at abortion access in both the US and Canada. Says Gavigan:

The legalization of abortion contributed to the ascendance of an aggressive antiabortion movement, one that has continued to organize in the churches and religious schools. Their discourse of the unborn child has become a dominant ideology of our time. Their ability to present all pregnant women as risky, possibly irresponsible, always potentially hostile to their own pregnancies, has in my view become pervasive and I believe socially shared (2009, p. 32).

#### 2.4. Reproductive Autonomy and Disability De-Selection

This chapter will conclude with an analysis of how reproductive technologies designed to de-select fetal impairment affect the autonomy principle framing

reproductive decision-making. Maternal-fetal relationships and all their constituent maternal responsibilities are produced or at least sharpened through the use of technology, and how these relationships and responsibilities are constructed vary depending on what is identified through the technological lens. That is, when a diagnosis is rendered, the conversation around reproductive decision-making changes, and the principles grounding that conversation are used differently.

This section will begin with a presentation of how scholars have addressed the introduction of technologies into reproductive decision-making; I will consider specifically whether they enhance or hinder autonomy. I will then consider legal cases that shape the parameters of responsibility: *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)* (1997), where the Supreme Court of Canada explored the implications to detaining a pregnant woman for treatment against her will; and *Arndt v. Smith* (1997), a suit where a mother was not financially compensated for wrongful birth because, according to the Court's analysis, she would not have terminated her pregnancy even if informed of impairment-related risks.

#### *2.4.1. Reproductive Autonomy and Disability De-Selection in Bioethics*

##### Reproductive Autonomy Model

According to a common theme in bioethics, reproductive autonomy is enhanced through the use of technologies that might identify impairments, for they enable potential parents to make better informed decisions:

One of the principal values that is offered in support of prenatal screening is autonomy. The value of autonomy, often framed in terms of women's

choice, is widely recognized by those who fund, research, develop, and implement prenatal screening and is central in obstetrics and genetics departments and public information pamphlets (Seavilleklein, 2009, p. 69).

Buchanan and colleagues (2000) as well as Lippman (1993) refer to this justification for the use of reproductive technologies as the reproductive autonomy model: “prenatal diagnosis is presented as a means of giving women information to expand their reproductive choices” (Lippman, 1993, p. 22). As an example, Ruddick (1988, 2000) implicitly endorses the reproductive autonomy model when he argues that prenatal disability de-selection is a decision that should be left to the pregnant woman to make, for the difficulties that prospective mothers might encounter when raising a disabled child are significant factors to consider in the decision-making process; technologies that can identify or rule out fetal impairment risks can thus empower her by informing her. Autonomy is facilitated through better informed decision-making, specifically through an agent understanding her situation and options.

There are nevertheless tensions between the promotion of reproductive technology as a means of enhancing autonomy, and the “degree of autonomy available to a woman regarding [its] use” (Sherwin, 2004, p. 369). As McCoyd (2007) argues, the provision of technologies is not neutral, but ambivalent:

Prenatal diagnostic techniques both enable and force women and couples to make decisions about whether to continue a pregnancy where the fetus has an anomaly. These decisions are considered individual, yet they are made in a medical culture that pushes for the most sophisticated diagnosis and treatment (p. 37).

Hubbard (1982), Katz Rothman (1987), and Rapp (2000) concur; says Katz Rothman: “new technology...offers new choices, but it also creates new structures and new

limitations on choice” (1987, p. 14). It is my hope that this section explores this ambiguity, which complicates efforts to promote reproductive technologies on autonomy grounds alone.

While ultrasounds, genetic screening and testing, and pre-implantation genetic diagnosis are designed for the purpose of providing more information, it may be that women are misinformed regarding the employment of these tools. That reproductive technologies have been featured in pregnancy rituals and routines in such a prominent way has led to pregnant women assuming that their use is standard, even compulsory (Lippman, 1993; Tremain, 2006; Vassy, 2006). Recall that in the previous section, Kukla (2005) and Mitchell (1994, 2001) were noted for discussing the ritualization of these procedures, meaning that their necessity is constructed. Further, information derived from reproductive technologies is framed with the language of “risks and likelihoods” (Kerr & Shakespeare, 2002, p. 132), and thus should not be trusted as a guarantee for the outcome of a pregnancy or a predictor of the specifics of an impairment (Goodling et al., 2002; Parens & Asch, 2000; Shakespeare, 2005).

What is the function of this misinformation regarding reproductive technologies and their diagnoses? For McDonough (1990; as cited in Masden, 1992), contained within diagnoses of impairment risks is an “action imperative” to terminate or to avoid the pregnancy. Testing and screening tend to take place in cases of wanted pregnancies, when prospective parents take every precaution to guarantee fetal health; but many of those pregnancies are transformed when risks are identified, and the decision-making shifts to questions around termination and de-selection (Asch, 2001; de Melo Martin,

2006; Parens & Asch, 2000). This shift indicates that the diagnosis delivered is not neutral, but instead carries with it social expectations: “a woman’s decision to abort a fetus after a particular prenatal diagnosis is not taken in a vacuum, and may be shaped by both society’s attitudes to disability, and by medical advice” (Jackson, 2001, p. 98). Framing a pregnancy as risky has the power to move prospective parents along in their decision-making process, not to more available options, but to specific questions around disability de-selection.

The reproductive autonomy model may still appear persuasive despite misinformation regarding whether technology use is compulsory or diagnoses are ironclad. The action imperative implicit in the provision of reproductive technologies is not tantamount to Hobbesian coercion (1985). A woman may refuse the technologies in Canada without legal consequence: “in most nations, no laws forbid or mandate ultrasound for pregnant women. No woman is explicitly coerced by her physician or anyone into accepting ultrasound; rather, most pregnant women are eager for the opportunity” (Sherwin, 2004, p. 369). Alternatively, she may decide on her own volition—based on other factors besides medical advice—that she would like to have an ultrasound or amniocentesis; she might also, upon discovery that her pregnancy is risky, opt to terminate because she does not want to raise a disabled child, again, for reasons that exist outside medical advice (Baily, 2000). The choice is hers to make, which seems consistent with the argument that reproductive technologies enhance women’s autonomous decision-making, as long as autonomy is understood to be unimpeded choice—an interpretation of autonomy that has been promoted in liberal theory (Hobbes,

1985; Locke, 1980; Mill, 1978). When considering how reproductive technologies complicate decision-making, it is not enough to say that a woman is simply deceived, or that her hand is forced.

### Unpacking the Action Imperative

It is my contention that the use of reproductive technologies not only misinforms, but also reshapes a woman's reality, given the ideological motivations to offering and ritualizing the technologies. In the previous section, I explained through Gavigan (1992, 2009), Kukla (2005), Mitchell (1994, 2001), and Petchesky (1986, 1987) that visual culture has made a public spectacle of the womb and has elevated the status of the fetus. The fetus is culturally rendered not only a person, but a vulnerable one, at the mercy of its carrier's whims (MacDonald, 1994). That the mother might have a relationship with her offspring, a relationship constituted by two individuals, legitimizes pregnancy management because she must rely on technology wielded by medical professionals to facilitate introductions and interactions, and technology provides evidence that she is responsible for the care of another: "ultrasound windows are influential in shaping the social relationships of pregnancy, including medicine's claim of authority over the management of pregnancy and the relationship between a pregnant woman and her fetus" (Mitchell, 1994, p. 147).

Ultrasounds are only effective as ritual insofar as they produce imagery that is universal and publicly recognizable (Kukla, 2005). The normalized experience of pregnancy includes obtaining the same picture every other pregnant woman has received

of her fetus: “our pleasure in these first ‘encounters’ with our ‘baby’ is inextricably bound up with our pleasure in the conformation of our experience to the shared norm” (p. 116) This can only happen when the fetus lives up to health expectations, where health is the absence of disease and disability (Katz Rothman, 1987; Mykitiuk & Nisker, 2010; Roeher Institute, 2002; Tremain, 2006). According to Taylor and Mykitiuk:

Biology and medicine equated the ‘normal’ with the study of health. The normal healthy state was thought to exist in opposition to the pathological. As such, health was theorized as the mean between excesses and deficiencies in the body. Deviations from the normal state of health were construed as abnormal and as ‘disease.’ Falling squarely within the category of those considered to be abnormal and of ill health were ‘the disabled’ (2001, p. 2).

In the case of impairment diagnoses, the ultrasound ritual deviates, for when the fetus cannot be idealized the experience is no longer about facilitating the relationship between mother and child. Reproductive technologies as a component of overall maintenance of pregnancy are used for the purpose of producing normalized children and avoiding disability: “the theory is that if normal physiology is subjected to rigorous control, pathological deviations from the norm can be minimized” (Jackson, 2001, pp. 119-120).

Outlined by Mykitiuk and Scott (2011), there are many ways in which medical practitioners and social media recommend a woman manages her pregnancy, or has her pregnancy managed, to minimize the risk of disability and disease. She might carefully control her diet: caffeine has been known to cause miscarriages (Munson & Gutfield, 1994); fish consumption is controversial, condoned for the benefits of omega-3 fatty acids and condemned for traces of mercury (Health Canada, 2009a; Murphy, 2002). She might take supplements, including folic acid to prevent neural tube defects (Health

Canada, 2009b), and iron lest iron-anaemic women give birth prematurely (Health Canada, 2009c). Especially frowned upon are alcohol, for causing fetal alcohol syndrome; and smoking, the effects of which include stillbirth, cancer, and learning disabilities (March of Dimes, 2010). Mykitiuk and Scott (2011) note: “women who smoke or drink alcohol during pregnancy are subject to intense public scrutiny, as they are constantly judged by family, friends, and strangers, in a transformation of pregnant bodies into objects of public concern” (pp. 319-320). These practices of regulating pregnancy are meant to safeguard fetal health:

We demand that mothers regulate the natures of their offspring with precision, and we hold them responsible for failure to maximize their chances for fetal perfection where there exist public knowledge and personal disciplinary practices whose invocation might increase these chances (Kukla, 2005, p. 126).

When a normalized pregnancy is impossible to achieve, the responsibilities of the mother change such that she is expected not to nurture and protect her offspring, not to ensure it is healthy, but to abandon the pregnancy. That is, responsibilities shift to disability de-selection: not pursuing pregnancy in the case of genetic screening and pre-implantation genetic diagnosis, and abortion when fetal impairments are diagnosed in utero. Some scholars have gone so far as to consider whether it is morally wrong to reproduce or to refuse to access reproductive technologies when the risks for a genetic disease or disability are high (McMahan, 2002; Purdy, 1996; Rhodes, 1999, 2006).

Purdy (1996), for example, argues “it is morally wrong to reproduce when we know where there is a high risk of transmitting a serious disease or defect” (p. 41). She makes an argument for why termination would be at least morally acceptable: since

women are still largely and unduly responsible for raising children, they should not be further expected to take responsibility for the complications associated with raising a disabled child. In her own words: “caring for a child with serious health problems can add immeasurably to a mother’s burden” (p. 83). Her argument is reasonable even if the characterization of disability as burden is not well received in disability theory.

Economic, political, and social conditions continue to pin the responsibilities for child rearing on mothers<sup>17</sup>; expecting women to further take responsibility for disability may well be too much to ask. Being morally excused from one set of obligations, however, is not identical to being morally responsible to another set, for Purdy is arguing that women are morally obligated to avoid disability. She specifically analyzes Huntington’s Disease, a late-onset genetic condition that shortens life expectancy and results in the loss of mobility and cognitive abilities. The likelihood of inheriting the disease can be identified via genetic screening technologies prior to birth, even prior to pregnancy. Purdy claims that women have the responsibility to make use of these technologies and to terminate

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<sup>17</sup> Women face myriad obstacles when they raise children—obstacles which are amplified for single mothers, who are reportedly poorer compared to dual income households and single fathers (Gaszo & McDaniel, 2010; Gurstein & Vilches, 2010). These obstacles, this lack of a safety net or support system, are grounded in a (liberal) ideology that assumes mothers, or at least parents, should take financial and social responsibility for their own children. For example, “in both [Canada and the US], lone mothers’ experiences of poverty were attributed to their individual failings through the rhetoric of dependency” (Gazso & McDaniel, 2010, p. 373), and this misattribution has justified income support claw-backs and welfare-to-work requirements built into policy, as seen in Alberta (Baker & Tippin, 1999) and British Columbia (Gurstein & Vilches, 2010). The message is that the state will not finance child-raising. Nor will the state subsidize childcare when mothers need to return to work but can only access low-paying jobs: “in Canada there is no coherent system for childcare services. ...Childcare costs are seen as a private parental responsibility, except where parental incomes are so low that payments are not feasible” (Mason, 2003, p. 44).

pregnancies when the risk for impairment is high, on the grounds that prospective parents owe their children minimally satisfying lives, with “health as a prerequisite” (p. 45).

Women who refuse to participate in this practice of disability de-selection run the risk of being considered irresponsible for not doing everything within their power to promote fetal health (Blank, 1993; Lemke, 2002; McDonnell, 2003; Overboe, 2007). Sherwin (2004) argues that while women are not coerced into consenting to ultrasounds, “it is so commonly used and so generally valued that it is difficult for anyone to resist its use without being judged irrational and irresponsible” (p. 369). Questioning a woman’s understanding of the situation and appreciation for the stakes, casting into suspicion her rational evaluation of her pregnancy—these are concerns which call into question a woman’s very capacity to make decisions and to give consent. Lemke (2002) fears that the institutionalization and routinization of reproductive technologies means women may find it is increasingly more difficult to justify their refusal: “the use of genetic diagnoses is not up to individual freedom or personal choice. The will not to know about your genetic make-up or risk profile could be regarded as no will at all: the sign of a deficient or illegitimate will, or even (why not?) the first symptom of a genetic ‘disorder’” (p. 287). How can we say that reproductive technologies enhance autonomy when the refusal to use them is fast becoming a non-option? That is, how are women acting autonomously when social pressures render alternative choices difficult, if not impossible, to choose?

### Public Health Model

There is another justification for the promotion of reproductive technologies, an alternative to the autonomy model which might better account for instances of maternal responsibility; this is called the public health model (Buchanan et al., 2000; Lippman, 1993). According to this model, women are responsible with making use of reproductive technologies in order to prevent the production of disability and disease: “prenatal diagnosis is presented as a way to reduce the frequency of selected birth defects” (Lippman, 1993, p. 22). Use of technology would therefore be a moral and civic responsibility, and less so a way of informing decisions and maximizing autonomy.

Peters and Lawson (2002) discuss the implications: “under the public health model, the routinized use of testing comes the potential to cast women as the genetic gatekeepers of society, not only responsible, but also accountable for the birth of disabled children” (p. 3). Women serve as gatekeepers by barring the entry of disabled persons into society, preventing their very coming into existence through disability de-selection and abortion. Mykitiuk (2002) also considers the theme of woman as gatekeeper: “since women’s bodies are the predominant site of prenatal genetic testing and screening, the process of biological production will likely render women the principal gatekeepers of ‘social cost’” (p. 324). There is a social cost to the production of disability because pregnancy is classified as a health matter, and our current health paradigm “assumes that *to be disabled is to be unhealthy*” (Taylor & Mykitiuk, 2001, p. 67). Within this paradigm, disability presents as a social burden, as a threat to public health, for disability deviates from that which is considered normal or ideal. Women as gatekeepers safeguard

and maximize public health by denying passage to identifiable impairments, to deviations from the ideal. They are responsible for preventing, and thus to blame and at fault for reproducing, disability.

Maternal responsibility is conceived in a context that medicalizes both disability and pregnancy. For instance, the rituals thus far outlined are built around the framing of pregnancy as risky: take folic acid to decrease the risk of defect; terminate pregnancy when at risk for reproducing disabled infants. A pregnancy may be classified as high risk if a woman deviates from a seven to nine and a half pound weight gain, if she is thirty-five years or older, “if she is too young, had no children or had too many, even if she is simply poor” (Katz Rothman, 1991, p. 132). Katz Rothman goes on: “even if a woman does have all the healthy characteristics medicine can ask for, she still won’t be called healthy, or even normal. She will be classified ‘low risk’” (p. 132). Pregnancy is the very purpose of female reproductive anatomy, and yet it is treated as a contagion in need of medical management. The result is the prioritization of health maximization, where health is a hegemonic standard that excludes and regulates pregnant and disabled bodies, those bodies that fall short of the ideal. The language of risk has ideological grounding, for the co-optation of pregnancy and disability under the healthcare model has served to reify and call by another name what was once reproductive control under patriarchy. Only under this model, women are thought radically responsible for reproductive decisions, and by extension, health maximization; liberal reproductive autonomy aids in justifying these subtler instantiations of reproductive control.

Mykitiuk (2001) explains why women are more than ever making use of reproductive technologies, the means by which they might identify impairments: “as patients are exhorted to take greater responsibility for their own health, they are demanding more information on which to base their decisions” (p. 324). With the increasing privatization of healthcare and the continued offloading of responsibilities for child-rearing onto women, women are left with the costs—emotional, financial, medical—of a disabled child, should they so choose to produce one, because their cultural context largely deals with disability by offering only the means by which it might be avoided: “fault and blame...are cast onto the woman, as the responsibility for the health of her future child becomes privatized” (Mykitiuk & Scott, 2011, pp. 329-330). Far from enhancing reproductive decision-making, technologies aid in social efforts to paint women into corners; they become an ever increasing necessity as women scramble to consider whether they could handle a disabled child with very little support, and how they might answer to social pressures to prevent disability (Lippman, 1993; McDonnell, 2003; McDonough, 1990; Shrage, 2003).

#### *2.4.2. Reproductive Autonomy and Disability De-Selection in Law*

##### *G. (D.F.)*

Maternal responsibilities may not directly translate into legal sanctions against reproducing disability. Since *Morgentaler* (1988), abortion decisions have been federally protected. SOGC (2007) guidelines outline why reproductive technologies should be offered to women—in order to enhance their decision-making—and these technologies

have been rendered more available, though not mandatory: “it is our belief that to deny women access to any information about the health or development of their child, when this information is readily available, is wrong and a disservice to Canadian women and their families” (unpaginated). Nonetheless, there have been legal discussions around responsibility and the extent to which the state should intervene.

In *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)* (1997), a young Aboriginal woman called D.F.G. continued her habit of sniffing glue even while pregnant, although doing so can potentially damage the fetal nervous system. She had already given birth to three children, two of whom were disabled as a result of her substance use and had become wards of the state: “two of her previous children were born permanently disabled and are permanent wards of the state” (p. 2). The organization Winnipeg Child and Family Services had the Manitoba Court of Queen’s Bench order that G. be placed in custody “and detained in a health centre for treatment until the birth of her child” (p. 3), a decision which was appealed. She gave birth shortly thereafter, but the case still went to the Supreme Court of Canada. The Supreme Court upheld the appeal, according to which “the existing law of tort and of *parens patriae* did not support the order and, given the difficulty and complexity entailed in extending the law to permit such an order, the task was more appropriate for the legislature than the courts” (p. 3).

The Court had to explore two issues: tort law and *parens patriae* jurisdiction. The first question they asked was as follows: “does tort law, as it exists or may properly be extended by the Court, permit an order holding a pregnant woman against her will in order to protect her unborn child from conduct that may harm the child?” (p. 14). Tort

law is a body of law that compensates for civil wrongs occurring within contractual obligations: “the essential purpose of tort law...is to restore the plaintiff to the position he or she would have enjoyed but for the negligence [or action] of the defendant” (*Athey v. Leonati*, 1996, p. 14). A person may sustain a tort or legal injury due to a breach in the duty of care she is owed. Tort law applies in instances where duty of care is built into a relationship between two legally recognized persons, and there has been a breach in duty of care, either by an act or by negligence, that can be shown to cause injury (Kerr, Kurtz, & Olivo, 1997). Gilmour (2006) articulates the criteria for finding negligence in tort law:

A plaintiff must prove on a balance of probabilities that: (i) the defendant owed him or her a duty of care; (ii) the defendant breached the standard of care established by law; (iii) the defendant’s breach caused injury or loss to the plaintiff; and (iv) the plaintiff’s injuries are not too remote to be recoverable in law (p. 56).

The majority in *G. (D.F.)* (1997) determined that revising tort law to detain and treat G. would require a drastic change in legal principles, for Canadian jurisprudence would have to legally recognize the unborn child in order to posit duty of care as well as its breach: “once a child is born, alive and viable, the law may recognize that its existence began before birth for certain limited purposes. But the only right recognized is that of a born person. Any right or interest the fetus may have remains inchoate and incomplete until the child’s birth” (p. 3). Judicial change is not meant to be drastic, but incremental: “judicial change to common law principles is confined to incremental change based largely on the mechanism for extending an existing principle to new circumstances” (p. 3). The extension of tort law, because it would require such a radical shift in legal principles, would have “complex ramifications impossible for a court to fully assess” (p.

4), such as incarcerating pregnant women in order to protect fetal life. Other speculated implications included the disproportionate effect on pregnant women in lower socio-economic categories; the policing of pregnant women by their own loved ones; and pregnant women avoiding medical treatment for fear of legal consequences, thus endangering their own health. Extending liability to pregnant women would undermine women's autonomy "because the fetus is physically located inside the body of the pregnant woman, indeed, it is part of the body of the pregnant woman, and because the pregnant woman can never be alone" (Mykitiuk & Scott, 2011, p. 342). If liability were established, every action conducted by a pregnant woman in relation to her own body would be subject to scrutiny and grounds for liability, thereby undercutting her right to autonomous decisions and bodily integrity.

Further, the Court considered whether to rule in favour of the appellant agency by extending *parens patriae*:

Does the power of a court to make orders for the protection of children (its *parens patriae* jurisdiction), as it exists or may properly be extended by the Court, permit an order detaining a pregnancy woman against her will in order to protect her unborn child from conduct that may harm the child? (*G. (D.F.)*, 1997, p. 14).

As already explained, *parens patriae* is legal intervention in order to protect those who lack capacity in decision-making scenarios where it is found that their caregivers are not acting in their best interest: "the *parens patriae* jurisdiction is...founded on necessity, namely the need to act for the protection of those who cannot care for themselves" (*E. (Mrs.) v. Eve*, 1986, p. 45).

In *G. (D.F.)*, in dispute was whether the respondent had a mental illness, for the trial judge had established *parens patriae* jurisdiction based on her mental health. That is, this judge determined that G. had a mental disorder, and ordered her supervision and treatment under Manitoba's *Mental Health Act*: "the trial judge ordered the respondent detained for treatment as she was suffering from a medical disorder within the meaning of the Manitoba *Mental Health Act*...and second on the court's *parens patriae* power that permits it to act in place of the parent for the protection of a child" (*G. (D.F.)*, 1997, p. 48). As articulated by the Supreme Court of Canada, "the Court of Appeal held that the evidence did not establish incompetency under the *Mental Health Act*. The trial judge had wrongly relied on the court's *parens patriae* jurisdiction of lunacy" (p. 13). *Parens patriae* did not apply because, firstly, there was no evidence to suggest that G. was mentally ill, and secondly, the jurisdiction does not extend to unborn children. On this latter point, the Supreme Court of Canada was concerned that the extension of *parens patriae* would lead to the violation of women's liberty interests, because until the child is born it is corporeally inseparable from its mother:

A pregnant woman and her unborn child are one and to make orders protecting fetuses would radically impinge on the fundamental liberties of the mother, both as to lifestyle choices and how and as to where she chooses to live and be. ...Extension of the *parens patriae* jurisdiction of the court to unborn children has the potential to affect a much broader range of liberty interests since the court cannot make decisions for the unborn child without inevitably making decisions for the mother herself (p. 4).

Writing the dissenting opinion, J. Sopinka discussed the state's interest in intervening when the pregnant woman in extreme cases conducts herself irresponsibly:

When a woman chooses to carry a fetus to term, she must accept some responsibility for its well-being and the state has an interest in trying to ensure the child's health. Since the pregnant woman has the right to decide her lifestyle, a court's ability to intervene to protect the fetus must be limited to extreme cases where her conduct has, on proof to the civil standard, a reasonable probability of causing serious irreparable harm to the unborn child (pp. 5-6).

He noted that the potential mother has the right to forfeit responsibility by having an abortion, but should she so choose to carry through with the pregnancy, she ought to commit by conducting herself appropriately, such as ceasing substance use. It would appear, then, that reproductive autonomy serves an important function in the rhetoric taken up by at least the minority ruling in this case. An autonomy framework can render women responsible for the decisions that they make; a woman who opts not to terminate her pregnancy in effect chooses to commit to it.

### Analysis

Although J. Sopinka was in the minority, his ideas still resonate in theory; reflecting on the case, Turk and Koren (2007) explain (and endorse) the position that "women's choice to have a baby, in and of itself, justifies restricting her actions for the welfare of the baby" (p. 1). While Turk and Koren's biases are laid bare inasmuch as their article is published in a journal entirely devoted to ending fetal alcohol abuse, Mackenzie's (1995) approach is subtler. Mackenzie argues that a woman values her pregnancy once she decides to carry through with it; inasmuch as she makes that decision, the implication is that she is responsible for upholding it: "there is a genuine

moral requirement upon a woman to protect and nurture a fetus once she has assumed parental responsibility for its future well-being” (p. 49).

Vehmas (2002) also discusses “standards for parental autonomy and responsibility” (p. 47), asking “do parents have an indisputable right to autonomous reproductive choices despite the possible unfortunate outcomes for their future children?” (p. 47). In response to literature which pins on potential parents the moral responsibility to avoid reproducing disability, Vehmas argues instead: “parents should commit themselves to the project of parenthood if and when they decide to procreate and...at the same time, they should undertake obligations which are inseparable from that project” (p. 53). His response addresses arguments made by those in agreement with Purdy (1996) and proponents of the public health model; and given his work in disability theory Vehmas might well find *G. (D.F.)* problematic for building a component of disability avoidance into maternal responsibility. Nonetheless, Vehmas is interested in defining parental responsibility as that which parents should accept when they decide to reproduce. Even though he and J. Sopinka might disagree on the substance of the responsibilities, they are both arguing that responsibility materializes with the choice not to terminate. Despite the tension between the two positions of disability advocacy and disability avoidance, there is agreement regarding when maternal responsibility begins: with autonomous choice (as though reproductive decisions can always be so freely made).

Should we be so quick, in theory and law, to deem the mother irresponsible based solely on her substance use? Setting aside the discrimination inherent in deeming

substance users prima facie irresponsible, even incompetent in the case of the original trial<sup>18</sup>, I would hold that to the contrary, the respondent in this case had in fact attempted to demonstrate responsibility according to even J. Sopinka's standards. It was noted in the case that G. had in fact sought treatment at a stage in the pregnancy when substance use would have affected the fetal nervous system, but was turned away due to lack of facility capacity:

The respondent points out that damage to the fetal nervous system occurs in the early stages of pregnancy long before the order was sought or made, that at an earlier stage of her pregnancy she had voluntarily sought treatment but had been turned away due to lack of facilities, that when asked to take treatment she agreed and only later refused because she had fallen into a state of intoxication, and that once taken to hospital, she remained until discharged, although the custodial order requiring her to remain had been stayed (*G. (D.F.)*, 1997, p. 12).

This is an important point to note, for G. did what was within her power to comply with and conform to social expectations of pregnant women. She was five months pregnant by the time she was taken to court. It was long after all else had failed, and the window for the substance use to have an effect had passed, when the appellant agency thought to step in. Questions around detainment and coerced treatment would not have been raised

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<sup>18</sup> Although I am setting this point aside for the sake of argument, a footnote is in order. Fullilove, Lown, and Fullilove (1992) identify types of trauma that substance-dependant women (specifically dependant on crack cocaine) experience: "(1) a trauma that predated the...onset of crack use (e.g., being injured in a traffic accident); (2) trauma that were the direct sequelae of crack use (e.g., being raped or having one's children taken); or (3) stigma trauma (being regarded as a crack 'ho' or as an inadequate mother by members of the community)" (p. 284). In a study conducted by Reid, Greaves, and Poole (2008), women who identify as mothers challenged by substance use discuss how they have internalized social stigma. In addition to stigma related to substance use, women experience subtler forms of discrimination based on their race and class. Mykitiuk and Scott (2011) note that expectations of pregnant woman disregard racial and class considerations given that those from disadvantaged minority groups may lack the wherewithal to engage in pregnancy regulation rituals, least of all to quit substance use.

in the Canadian Supreme Court, at least this case might not have come to pass, if the agency or similar social structures had initially provided support.

The Supreme Court of Canada ruled in favour of the respondent, but cases in the US have had different outcomes. Hewson (2001) discusses American cases in which pregnant women who regularly used drugs were prosecuted: “in South Carolina and California, drug-addicted pregnant women attending antenatal clinics have been arrested and charged with criminal offences, after they tested positive for drugs whilst pregnant” (p. II13). It was not until 2001 that testing pregnant women in South Carolina for drugs covertly, without their knowledge or consent, was ruled unconstitutional. In *Whitner v. State* (1997), Cornelia Whitner, indicted for cocaine use while pregnant, was convicted of criminal child neglect for failing to provide proper medical care, and was sentenced to eight years of imprisonment. She appealed on the grounds that her counsel was ineffective, though the Supreme Court upheld the original ruling.

Pollitt (1994) explores the legal preoccupation with the substance use of pregnant women, and how this preoccupation is an inroad for fetal rights: “drugs and alcohol are only the latest focus of a preoccupation with the fetus and its ‘rights’ that has been wandering around the zeitgeist for the past decade” (p. 291). She argues that the application of “duty of care” to pregnancy reflects pro-life movement principles, which pit the fetus and woman at odds with one another and characterize the woman as “selfish, confused, potentially violent, and incapable of making responsible choices” (p. 295). Pollitt goes on to question this focus when there are so many other conditions which are necessary for healthy pregnancies, conditions outside a pregnant woman’s realm of

control: “why does maternal behaviour, a relatively small piece of the total picture, seem such an urgent matter, while much more important factors—that 1 in 5 pregnant women receive no prenatal care at all, for instance—attract so little attention?” (p. 292). She further argues: “although duty of care theorists would impose upon women a virtually limitless obligation to put the fetus first, they impose that responsibility only on women [while placing] no corresponding duty upon society” (p. 299). As we see in the Canadian case, G. was brought to court for the purpose of detainment and forced treatment, on the grounds that she was too irresponsible—and for the trial judge too incompetent—to nurture her pregnancy on her own. The time window for the effect of substance use had long passed before she would be remanded into custody and treated, and she was turned away when she initially sought assistance, yet Winnipeg Child and Family Services thought her complicit in the possible reproduction of disability. Women in similar situations in South Carolina could face legal punishment for what is considered failing in their responsibilities, not upholding their duty of care. These cases push fetal rights in through the back door of court systems, for demands of pregnant women correspond to fetal entitlements.

In this particular Canadian case, the Court ruled that it would not intervene, a victory for women’s reproductive rights, but important support systems like drug rehabilitation programs continue to provide inadequate services. Further, women from Aboriginal communities continue to experience high levels of substance use, which have been linked to poor healthcare and a dearth in educational opportunities (Neil, 2003). The rationale for the ruling was that Canadian law protects women’s rights to make

decisions regarding their pregnancies and bodies (and so the establishment of fetal rights would represent a drastic change in jurisprudence), thereby isolating women as rights-bearers, shielding them from interference. It does not always serve in the woman's best interest to be so isolated. In G.'s case, she gave birth to her fourth child, possibly a third child in need of complicated and potentially expensive accommodations that she would be responsible as caregiver for providing (or else she would lose her child to the state, another method of intervention that is far harsher than building preventative measures and social supports). She also gave birth while still struggling with substance use, because she was turned away when she sought to enroll in a rehabilitation program. The Court may have ruled in G.'s favour, but its ruling was in essence to stand down, not to intervene, when there are methods of intervention which may support women's reproductive choices and activities.

### Arndt

That same year, the Supreme Court of Canada heard the suit *Arndt v. Smith* (1997). In this suit, Carole Arndt gave birth to a child with congenital varicella syndrome, the result of maternal chicken pox. She sued her physician Dr. Margaret Smith for not informing her of the more serious, though less frequent, risks to having chicken pox while pregnant: "she contended that had [Smith] properly advised her of the risk of injury to her fetus, she would have terminated the pregnancy and avoided the costs she now incurs" (p. 1). Smith's defense was that Arndt "would not have terminated the pregnancy even if she had been fully advised, and therefore asserted that the loss claimed

was not caused by the failure to advise risk” (pp. 1-2). The judge at the original trial ruled in favour of Smith, as explained in the Supreme Court case:

Evaluating her testimony at trial that she would have had an abortion against the fact that she desired a child, that she was skeptical of ‘mainstream’ medical intervention, that an abortion in the second trimester held increased risks and that an abortion would have required the approval of a committee on health grounds, the trial judge concluded that [Arndt] would not, on a balance of probabilities, have aborted the pregnancy (p. 2).

In the Court of Appeal, the judge “held that the trial judge had applied the wrong test” (p. 2). The Supreme Court of Canada dismissed Arndt’s case after applying the modified objective test for causation and determining that Arndt would have opted to give birth regardless of medical advice.

This case is an example of a wrongful birth suit, a kind of suit in tort law which is pursued in order to hold physicians responsible for negligence that results in birth. Negligence may manifest in nondisclosure; relevant to this study, nondisclosure includes the failure to inform of risks of fetal impairment (*Arndt v. Smith*, 1997), or of technologies which may identify fetal impairment (*Mickle v. Salvation Army Grace Hospital*, 1998; *R.H. v. Hunter*, 1996). Information provision is both part of the physician’s duty of care and a condition for patient consent, and so failure to disclose robs a patient of fully informed consent. Originally a mechanism in tort law for dealing with, as examples, botched abortions (*Cherry v. Borsman*, 1992) or sterilizations (*Cataford et al. v. Moreau*, 1978) that resulted in birth, wrongful birth in recent years has become an avenue for dealing with the progress of reproductive technologies: “the rapid pace of technological innovation in the area of genetic testing...has forced courts, willingly or otherwise, to respond to cutting-edge issues striking at the core of the

disability rights movement” (Hensel, 2005, p. 150). The plaintiff in *Arndt* argued that she was unable to make a fully informed decision regarding her pregnancy due to her physician’s failure to provide sufficient medical advice. Whether Arndt would have made the decision to carry through with the pregnancy regardless of medical advice was thus in question.

The modified objective test used in this case is designed to strike “a reasonable balance, which cannot be obtained through either a purely objective or a purely subjective approach” because “a purely subjective approach fails to take into account the inherent unreliability of the self-serving assertion of a plaintiff, while the purely objective standard might result in undue emphasis being placed on the medical evidence” (p. 3). That is, the plaintiff’s subjective position could change after consent was given, due to the unforeseen results of the medical treatment (self-deceit and self-revision of the narrative); it could also change in court to suit the plaintiff’s argument (lies impossible to invalidate because the matter is so personal). Further, while the physician’s medical advice constitutes the reasonable course of action (for, the physician’s duty of care entails providing reasonable medical advice regarding specific risks associated with treatment options), the Court had to acknowledge that particular patients would weigh that advice against other personal factors when making the decision to consent to or to refuse treatment. The modified objective test was developed in *Reibl v. Hughes* (1980)<sup>19</sup>, to

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<sup>19</sup> John Reibl had a stroke during surgery to treat severe migraines, after which he was impotent and partially paralyzed. He no longer qualified for the pension he was eighteen months away from receiving at the time of the surgery. In *Reibl v. Hughes* (1980), Reibl accused his surgeon, Dr. Robert A. Hughes, of negligence and battery for implying the risks to not having the surgery outweighed the risks to having the surgery. Reibl claimed

determine causation in cases of potential medical malpractice. In this earlier case, the Court set the precedent to ask when applying the test what a “reasonable person in the plaintiff’s position” (p. 882) would do. Subjectivity is incorporated into the question, and the baseline of the question is objective. Subjectivity is thus the modification. The Court further explained in *Reibl*: “although account must be taken of the patient’s practical position, a position which will vary with the patient, it must be objectively assessed in terms of reasonableness” (p. 900).

When *Arndt* (1997) reached the Supreme Court of Canada, the crucial question examined was whether Arndt would have had an abortion had she been informed of risks associated with her contracting chicken pox during pregnancy. Upon application of the modified objective test, the Court found the following:

While [Arndt] did make a very general inquiry concerning the risks associated with maternal chickenpox, there was nothing to indicate to the doctor that she had a particular concern in this regard. Further, factors such as [Arndt’s] desire for children and her suspicion of the mainstream medical profession can be taken into consideration when determining what a reasonable person in her position would have done if informed of the risks. As found by the trial judge, the failure to disclose some of the risks to the fetus associated with maternal chickenpox did not affect [Arndt’s] decision to continue the pregnancy to term (p. 3).

The Court determined that the physician’s failure to disclose would not have affected Arndt’s decision not to terminate. That is, a reasonable person in Arndt’s position would have carried through with the pregnancy regardless of the advice Smith could have given. Given the information withheld was moot, Smith was not liable for wrongful birth.

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that he had not given informed consent for the surgery, for he would have at least delayed the surgery in order to qualify for his pension. Hughes was found guilty of negligence.

## Analysis

Wrongful birth suits shed some light on the legal framing of responsibility.

Firstly, these suits help explain medical pressure to diagnose and de-select disability, for they have the power to render physicians financially liable for the births of disabled children. Duty of care now includes SOGC (2007) recommendations to make disability de-selective technologies available to all women. The guidelines were designed to facilitate reproductive autonomy, but the effect has been that the guidelines become a physician's responsibility; indeed, this expansion of responsibilities under duty of care means that physicians promote these technologies for fear of civil suits. The promotion of reproductive technologies takes place in physician/patient relationships, though, where there is a clear power dynamic, a trust based on the physician's supposed superior knowledge about pregnancy, and this aids in the routinization of the technologies as well as the value judgments underlying their use: "the availability of prenatal screening and the fact that it is being offered by a physician, carries normative implications about the desirability of prenatal screening" (Pioro, Mykitiuk, & Nisker, 2008, p. 1028).

Secondly, elements of maternal responsibility are identifiable. The argument made in *Arndt* (1997) demonstrates that the mother's decision to terminate pregnancy is a necessary criterion to satisfy in order to justify wrongful birth: "wrongful birth...claims do not compensate every individual who is deprived of the ability to make an 'informed' reproductive choice" (Sheth, 2006, p. 666). Lacking information is therefore not the sole basis for wrongful birth claims, because a plaintiff must also argue that had she been fully informed, she would have opted for an abortion: "it is not lost choice in the abstract that

is actionable, but the lost opportunity to abort the impaired child or to prevent conception” (Hensel, 2005, p. 167). Indeed, if the harm were simply the lack of reproductive choice, then it would not matter what the choice was.

Some theorists (Akazaki, 1999; Andrews & Hibbert, 2000; Hull, 2006) hold that wrongful birth suits involving disability contain a devaluing of disability, a framing of disability as an injury or burden for which someone must be held liable. This framing is consistent with Oliver’s (1990) individualistic model of disability, according to which the “problem” of disability is individually allocated; this has the effect of excusing legal, political, and social institutions of any responsibility for creating the conditions which disable people. Hahn (1994) articulates the problem in the following way: “the notion that a disability is unique and personal...implies that it is an essentially private problem to be resolved, conquered or overcome by individual effort rather than by public policies or social services” (supra note 19). Hensel (2005) notes the discomfort discernible in the rhetoric employed by trial judges who presided over wrongful birth cases involving disability. There was hesitation in these cases, including *Arndt* (1997), to make any pronouncements regarding the quality of life for someone who is disabled. Nevertheless, belying the case, and belying wrongful birth suits of this nature, was a legal practice of localizing the responsibility for disability. Arndt was seeking financial compensation from someone she blamed for the birth of her child. The case pertained to holding someone liable for the birth of a disabled child.

Wrongful birth, though, may be one of few recourses women have to drum up financial support should they find themselves raising a disabled child. Households that

include disabled children have been shown to be economically disadvantaged (Emerson, 2003). Disability supports are inadequate, while the costs of raising a disabled child include myriad accommodations. In *R.H. v. Hunter* (1996)<sup>20</sup>, a wrongful birth suit the plaintiff won, the sum total of financial compensation physicians had to pay approximated three million dollars. While the breakdown of costs included controversial components such as pain and suffering, more practical concerns included medical needs, daily living, accommodations, attendant care, education, professional services, respiratory assistance, transportation, and vocational work. Such a breakdown should make clear how extensive the costs of care for a disabled child can be. Since policies that would aid parents are being reined in, or have never been offered adequately, laying blame may be one of few ways to guarantee that the costs of care are covered.

The set of wrongful birth suits relevant to this study may offer one of few avenues for covering the costs of care, but inasmuch as they operate within an ableist climate, liability can only be established if the plaintiff can convince the court that she would have chosen to terminate her pregnancy: “no matter how compelling the need...no assistance will be extended to the family who would have chosen to embrace or simply accept the impaired child prior to his birth” (Hensel, 2005, p. 172). Whether the consent given was fully informed is irrelevant as long as the decision made matches the decision that would have been made. This means that ultimately, women still function as the gatekeepers for disability production. If they choose to grant passage, to compromise public health, then

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<sup>20</sup> In *R.H. v. Hunter* (1996), physicians were found negligent for failing to inform prospective parents of the availability of prenatal screening technologies, which would have identified the risk of muscular dystrophy; as well as genetic counselors, who based on the diagnoses would have recommended abortion.

the burden is theirs to bear, however more complicated or expensive a disability can render child-rearing. Wrongful birth is meant to safeguard and promote reproductive autonomy by ensuring that consent is fully informed, that the choice to carry through with a risky pregnancy entirely belongs to the pregnant woman to make, but this autonomy framework has disastrous implications for women who would choose disability. Our reproduction industry, built on the assumption that its tools will aid in disability avoidance, has become so prominent that it is included in a physician's duty of care; physicians must discuss the available technologies for fear of a legal suit being brought against them. Women who do not avail themselves of these tools are made responsible for the consequences. Autonomy as it is currently conceived in law and medicine has therefore had the effect of doing harm to women, for it localizes responsibility for disability. The rhetoric of responsibility masks the insidious ways in which women internalize discrimination and are directed when making very personal decisions about their own bodies and their plans for parenthood.

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## Chapter 3: Equality

This chapter entails the evaluation of equality as either an alternate or supplementary principle for grounding reproductive decision-making. Of particular interest is whether and which tensions exist between concepts of equality and autonomy, especially in reproductive contexts involving disability. The chapter will commence with theories of equality, including critiques from feminist disability discourses. Equality theory will then be situated in bioethics (in association with the principle of justice); and jurisprudence (under the *Charter's* s. 15). I will examine the case made for reproductive equality, and will outline how reproductive autonomy grounded in s. 7 has not done the work that s. 15 could: to promote reproductive access, especially to members of disadvantaged minority groups. I will finally consider what equality means when reproductive decision-making revolves around the question of disability avoidance, for some key disability critiques of selective abortion indicate that these practices express ableist attitudes. Is there a conflict between women's reproductive autonomy, even their reproductive equality, on the one hand, and disability equality on the other?

### 3.1 Theories of Equality

This section will explore key advances in equality theory. Elements of the Aristotelian interpretation of formal equality are still relevant to contemporary concepts of equality. Since there have been myriad models of equality developed since, as well as many interpretations of each model, I will focus on developments that have bearing on

current formulations in medicine and law (how they have bearing will be considered later in the chapter). Equality of opportunity, grounded in concepts of luck and merit, borrows rhetoric from liberal autonomy theories; these models have become increasingly more substantiated, but continue to divide social and natural conditions in problematic ways, and still operate within distributive frameworks. There are feminisms which have suggested that equality is substantive, grounded in notions of oppression and subjugation rather than the distribution of resources. My purpose in this section is two-fold: I will present the conflicts and compatibilities between concepts of equality and autonomy; further, I will draw from feminist disability theory to engage each concept of equality critically.

### *3.1.1. Formal Equality*

#### Overview of Aristotelian Theory

Formal equality finds its roots in Aristotle, a classical Greek intellectual whose work in philosophy and science tremendously influenced both the ancient and medieval civilizations of Western history. He is largely attributed with developing natural rights theory, the conceptual framework Kant (2002) much later resisted:

“commentators...celebrate Aristotle as ‘the philosophic founder of authentic natural law,’ for whom natural rights represents ‘the eternal laws of morality’ and an ‘immutable’ standard of justice” (Trude, 1955; as cited in Yack, 1990, pp. 141-142). The attribution may be anachronistic, however. Stoics of the Hellenistic Period (Epictetus, 1972) and Christians of the Middle Ages (Aquinas, 1964) interpreting Aristotle may have lumped

him in with natural rights theorists like his own teacher Plato, but doing so requires that one overlook the disagreements and differences between Platonic and Peripatetic teachings (Jaffa, 1952; Yack, 1990, 1993).

Plato argues in *The Republic* (1991) and *The Crito* (2007) that human laws are approximations of the form of Law, a perfect idea which transcends our reality, accessed via abstract thought. Aristotle may hold that law derives from both nature and convention, but he also argues that both types of law vary according to place and time: “while with us there is something that is just even by nature, yet all of it is changeable” (*NE*, 5.7). Yack (1990) argues that Aristotle’s characterization of natural law as mutable defuses his “predecessors’ strongest objection to the naturalness of justice: that standards of justice, unlike natural things, differ from place to place and time to time” (p. 218). That is to say, Aristotle deviates from Platonic legal theory in that he grounds natural law in reality rather than abstractions; by natural, Aristotle means biological<sup>21</sup>, not divine. His project in the *Nicomachean Ethics* is to investigate human causes, including *telos*, meaning the thing’s purpose or design. Natural things change, but not because they are falling in and out of their approximations of the form of the Law. Rather, built into every existing thing is a teleological cause, a purpose that the thing is working to actualize; “tree” is the *telos* built into an acorn, for instance. So too in ethics, every human action has a purpose meant to be realized: “for example, health is the end of medicine, the vessel of shipbuilding, victory of generalship, and wealth of estate management” (*NE*, 1.1).

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<sup>21</sup> This biological grounding is further complicated, though, by the Aristotelian idealization of human beings: male, white, nondisabled, rational, and so forth. Aristotle’s ethics is certainly abstract, even if his theory of natural law is not grounded in the divine, as posterity would later misinterpret.

Aristotelian teleology grounds ethics in human matters, and in so doing eschews Platonic forms. For Aristotle, we are not working to approximate something outside our reality, but are actualizing purposes inherent within us. His theoretical framework is thus meant to concretize ethics, that is, to make ethics meaningful for human affairs.

Within such a framework, justice must be politically relevant. Indeed, Aristotle situates justice within human relations: “justice exists between men whose mutual relations are governed by law” (*NE*, 5.1). Justice as lawfulness implies good order, for right reasons. The principle is enacted so as to ensure the happiness of those individuals constituting a political community. Happiness is the telos for all human activity, the ultimate end or purpose in all that we do. Health as the object of medicine and victory as the object of generalship, as examples, are instrumental goods; we pursue particular, instrumental goods in order, ultimately, to be happy. Since “man is naturally a political animal” (*Pol.* 1.2), his purposes are best realized within a political context that facilitates his most promising opportunities for personal growth. Indeed, it is only through community and cooperation that one might practice medicine or pursue a military career, for the institutions of medicine and the military do not exist outside human society. These institutions must be just, or lawful, so that men might perform the activities they would like to do and are best suited to do. A man cannot carry out his intended pursuits when injustices stand in the way: he may be jailed, for example, for insufficient reasons, or barred from participation because positions are distributed based on nonsensical criteria.

### Aristotle on Equality

Equality plays an important role in the Aristotelian theory of justice. Because standards of justice are subject to change, even improvement, equality serves a corrective function: “the equitable is just, but not the legally just but a correction of legal justice. ...And this is the nature of the equitable, a correction of law where it is defective” (*Pol.* 3.10). In order to expand on how equality is corrective, I must explain the two types of equality found in Aristotle. One type is formal in character. By formal, I mean lacking in substantive moral content (Westen, 1982; Williams, 2005). The principle structures political relations, not prescribing any particular treatment but recommending only the consistent application of treatment deemed to be moral or just. According to this principle, “things that are alike should be treated alike, while things that are unlike should be treated unlike in proportion to their unalikehood” (*Pol.* 3.9). In other words, those who are similar in a relevant moral and legal respect are entitled to the same application of law. Westen (1982) explains:

To say that people who are morally alike in a certain respect ‘should be treated alike’ means that they should be treated in accord with the moral rule by which they are determined to be alike. Hence ‘likes should be treated alike’ means that people for whom a certain treatment is prescribed by a standard should all be given the treatment prescribed by the standard. Or, more simply, people who by a rule should be treated alike should by the rule be treated alike (p. 547).

The principle of formal equality structures distributive relations. Aristotle is credited with developing a concept of distributive justice, according to which property, rights, opportunities, and so forth may all be meted out by the institutions of a political community to its citizens. How might goods be distributed, then? The ancient

philosopher suggests two ways, beginning with numerical distribution, according to which every person within the polis is indistinguishable from the other. In other words, everyone receives the same quantity regardless of merit, need, or any other way in which we might differentiate between persons. This form of equal distribution makes no room for the possibility that differential treatment is just, but as Aristotle has stipulated in the corollary to his definition of formal equality, unlike things should be subject to a different rule or form of treatment. Further, numerical equality is impractical in the case of scarce resources.

Aristotle proposes instead that proportional equality frames distribution, which would allow for just inequalities. Proportional equality requires that persons be treated in relation to their due—what they merit or deserve: “all men agree that what is just in distribution must be according to merit” (*NE*, 5.3). Westen (1982) notes that Aristotle’s concept of proportional equality implies formal equality: “to say that ‘every person should be given his due’ means ‘persons who are alike should be treated alike’ and ‘persons who are unlike should be treated unlike’” (p. 556). In other words, those who are considered alike fall under a standard of justice; formal equality demands the consistent application of this standard, while proportional equality ensures that those who are subject to this standard deserve to be so. Standards of justice may change over time or depending on the politics of a place, but equality serves a corrective function by framing these standards, and by course-correcting when it can be shown that someone does not deserve the treatment to which he is subjected.

A mechanism is needed by which persons might be classified as alike, as subject to the same moral or legal treatment. The mechanism Aristotle identifies, according to Frank (1998), is merit:

A distribution will be just if the difference in the amount allocated to the parties to the distribution is in proportion to some relevant difference between them. It is the difference between parties, measured in terms of some particular quality (which Aristotle calls desert or merit)...that shows the parties to be unequal for the purposes of the distribution, that is necessary for Aristotle's understanding of equality proper (p. 787).

What constitutes Aristotelian merit? While Nussbaum (1982) suggests that need is related to the concept, other scholars (Fleischacker, 2005; Frank, 1998; Woldron, 1995) would disagree: "Aristotle allows the meaning of 'merit' (*axia*) to vary quite widely...but it always describes something good about a person, something that that person, and others, can value about him- or herself. No one, including the needy person him- or herself, values neediness" (Fleischacker, 2005, p. 14). Frank (1998) argues instead that excellence is a requirement for merit. By excellence or virtue—the terms are interchangeable—Aristotle basically means that an activity is performed well (you are not praiseworthy if you perform an activity poorly), and voluntarily (there is no moral responsibility or praise for involuntary acts). In other words, virtue requires skill and choice<sup>22</sup>.

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<sup>22</sup> Free will and autonomy are inventions which were developed long after Aristotle, but we might understand Peripatetic choice to be something like autonomy. I would hold that choice is at least a precursor to later, more sophisticated theories of freedom. This is important to note because later egalitarian theories grounded in a condition of merit very much so rely on autonomy language, and in so doing echo Aristotle.

### Critique of Formal Equality

Merit determines proportions within a distributive justice framework, and excellence determines merit; such a set-up could lead to vast differences in how rights, goods, and opportunities are parcelled out. This is certainly the case for Aristotle, who develops different standards of justice according to the gender, racial, and class fault lines running through his antiquated culture. Regarding slaves, he argues "there will be different kinds of justice appropriate to a ruler and the justice appropriate to the ruled" (*Pol.* 3.4). This is acceptable because slaves are better disposed for physical labour than intellectual pursuits, and so they are naturally, biologically built to serve: "that which is able to plan and to take forethought is by nature ruler and master, whereas that which is able to supply physical labour is by nature ruled, a slave to the above" (*Pol.* 1.2). Women, too, are unlike men (considered at the time to be deformed versions of men, in fact), and equal treatment entails that those who are unlike ought to be subject to differential treatment in proportion to their unlike-ness. In this case, differential treatment entails subjugation: "as regards male and female, the former is superior, the latter inferior; the male is ruler, the female is subject" (*Pol.* 1.5). These are lawful relations between persons and nonpersons, as defined by what each deserves, desert here being grounded in intelligence or other such qualities thought to be biologically endowed. While it is a common mistake to assume that by formal equality Aristotle means same treatment across the board, we should instead be wary of the implications to the differential treatment he would sanction.

Indeed, thousands of years later, Westen (1982) makes this point all too clear in his defence of equality as an empty concept:

Consider how one would go about deciding whether monstrously deformed neonates or human embryos<sup>23</sup> or stroke victims in irreversible comas should be treated as 'persons' for purposes of the right to respect. In trying to make the decision, one gets nowhere by intoning that all persons are equal, because the very question is whether the three candidates are indeed 'persons' within the meaning of the rule. Nor does it do any good to saying that likes should be treated alike, because the very quest is whether the three candidates are indeed alike for purposes of human respect. Rather one must first identify the trait to ascertain empirically whether the trait appears in one or more of the three candidates (p. 549).

Westen is arguing that equality only functions to frame justice, only forces the consistent application of law, but the blanks, like "personhood," must first be filled in or else equality means nothing. The implication belying his argument is that "monstrously deformed neonates" or "stroke victims in irreversible comas" may not qualify as persons, that is, may not be members of the category entitled to the respectful treatment meant for persons. At least, their status as persons is in question. Depending on how Westen would see the concept substantiated, Aristotelian formal equality could justify the classification of those disabled as nonpersons. Long since Aristotle, civil rights and feminist movements have fought for the inclusion of racialized persons and women, respectively, within the category of personhood, so that they might be treated equally. At least by legal standards, racialized persons are no longer regarded as intellectually

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<sup>23</sup> While two of Westen's (1982) three examples pertain to disability, it is interesting to note that the third example implies that Westen questions the personhood of embryos, in which case, he might endorse some of the theorists found in this study who defend women's reproductive autonomy by radically individualizing the woman and dehumanizing that which she carries.

inferior, and women are no longer medically understood to be deformed versions of men. Part of the work to include them under the banner of personhood has been to negate all associations with disability. It should come as little surprise, then, that efforts to include those with disabled embodiments or mental states have been less successful.

### *3.1.2. Equality of Opportunity*

#### Formal Equality of Opportunity

Modern egalitarian models—egalitarianism involving an exclusive focus on the principle of equality—continue to borrow Peripatetic concepts of formalism, distribution, and desert. Central to many egalitarian theories is equality of opportunity, a concept situated within distributive justice models that have been married to free market economies (Nozick, 1974). The principle is designed to be corrective or redistributive insofar as it provides a strategy for equalizing unjustly hierarchical politics. Egalitarian theories must account for just inequalities, or at least account for what to do about scarce resources, and many do so by supposing that a just society is liberal and competitive, where some goods must be earned (Dworkin, 1981b; Nozick, 1974; Rawls, 1999). Equalized opportunity, at least formally defined, means that everyone in a society may apply for scarce social goods—a luxury, an employment position—and the best or most deserving wins those goods. Says Jacobs:

Equality of opportunity as a regulative ideal focuses on the fair use of competitive procedures as a means for achieving an egalitarian distribution of some scarce resources or goods. Competitive procedures mean that, as in most games, there are winners and losers. Winners enjoy the resources or goods at stake; losers either do not enjoy them at all or only in much more limited ways than winners (2004, p. 13).

Equality is meant to keep the competition fair, but how so? According to formalistic interpretations of the principle, equality of opportunity requires an element of procedural fairness, a focus on the rules which, when consistently practiced, apply to everyone (Cohen, 1989; Jacobs, 2004; Joseph, 1980; Rioux, 2003). A just society makes opportunities available to all by keeping the rules of the game fair. Put another way (with Aristotelian language), everyone within the game is subject to the same standards, or is treated alike by virtue of their entitlement to like treatment.

#### Substantiated Equality of Opportunity

Such a narrow conceptualization of the principle may be insufficient given that despite investment in and attention to procedural fairness, inequalities may still exist between the players in the game. Key egalitarian theorists (Arneson, 1989; Dworkin, 1981b, Rawls, 1999) would explain these inequalities by differentiating between goods endowed by luck and circumstance, such as "physical health or lack thereof, intelligence, and imagination" (Rawls, 1999, p. 54); and those acquired by choice, including "liberties, opportunities, income, and social bases of self-respect" (p. 54). The former are distributed disproportionately according to a hypothetical birth lottery or auction. This means that it is by sheer luck and circumstantial conditions that one inherits natural advantages and disadvantages, and resultant inequalities produced are unearned, or undeserved. Inequalities can be compensated for through redistribution of social goods until equilibrium is achieved, or until those least advantaged, the worst off, are envy-free (Dworkin, 1981b).

These ideas can be traced back to Rawls, whose “legacy is one of the most significant contributions to contemporary theories of equality” (Malhotra, 2006, p. 70). For Rawls (1999), social and economic inequalities are just in a liberal society when they satisfy two conditions. Firstly, they must be “attached to offices/positions open to all under conditions of fair equality of opportunity” (p. 42). Fairness requires that background conditions are taken into account (Jacobs, 2004) and natural competitive advantages, those advantages bestowed by virtue of luck, are counter-balanced. Secondly, the “greatest benefit [must be allotted to] the least advantaged members of society (the difference principle)” (Rawls, 1999, p. 43). The difference principle ensures that those with the fewest natural privileges have a leg-up in the competition. These two conditions have the effect of levelling the playing field, an illustrative term often invoked in reference to equality of opportunity (Arneson, 1989; Cohen, 1989; Dworkin, 1981b; Roemer, 1995, 1998). A race is fair not only procedurally, not only when the rules are applied consistently, for contestants enter with different inherited advantages and disadvantages; they all have different starting points. A just society redistributes resources in order to ensure that the only advantages that matter are those which are chosen, not those which are the product of circumstance. When this happens, in the metaphor, the competitors are all brought to the same starting line, then the best runner wins the race, not the competitor with a head-start.

Liberty is therefore essential to just distribution: “justice [for Rawls] requires that liberty may only be limited for the sake of liberty and not for the sake of other social and economic advantages” (Hart, 1989, p. 61). An opportunity is the means by which one

might pursue one's own purposes or interests. The prize made available by the opportunity can be neither conferred nor imposed; it must first be chosen, and ultimately won. Under models where equality and liberal autonomy are interwoven, a person has the freedom to choose his life course, but with that freedom comes the personal responsibility to rise to the occasion. Therefore, an additional, related condition of merit is built into equality of opportunity models (Miller, 1999; Nozick, 1974; Rawls, 1999). Kymlicka (1990) explains: "in a society that has equality of opportunity, unequal income is fair, because success is 'merited', it goes to those who 'deserve' it" (p. 56).

Is equality of fair opportunity enough to correct unjust inequalities, and legitimize merit-based inequalities as just? Williams (2005) criticizes at least formal equality of opportunity when he discusses a hypothetical example of a warrior class where membership depends on physical skill and birthright. This society might change the rules in order to open membership up to every citizen across class lines, and in so doing maintain procedural fairness. Despite reform, however, those members of the supposedly defunct pedigree possess the wealth and privilege to develop their physical advantage, and so they continue to be the most qualified for the position:

The wealthy families still provide virtually all the warriors, because the rest of the populace are so under-nourished by reason of poverty that their physical strength is inferior to that of the wealthy and well nourished. The reformers protest that equality of opportunity has not really been achieved; the wealthy reply that in fact it has, and that the poor now have the opportunity of becoming warriors—it is just bad luck that their characteristics are such that they do not pass the test (p. 110).

Rawlsians may have the answer to the problem: a more substantiated principle of equality of opportunity can redress the problem of natural inequalities. The warrior society may

be rendered fairer by ensuring that the poorest citizens are well fed so that they might qualify for membership to the class. The example illustrates how the strategy of redistributing social resources brings opportunities within reach for those who are otherwise barred due to circumstance.

### Critique of Equality of Opportunity

The solution, though, requires that we treat some inequalities, such as talent and intelligence, as native, and divided up by luck. When advantages are so conceived, there is neither acknowledgment nor analysis of which skills and intelligences are socially valued. For example, historical proponents of innate intelligence once used standardized tests measuring logic and mathematics to rank racialized, impoverished, as well as intellectually and learning disabled persons as intellectually (as well as morally) inferior<sup>24</sup> (Burt, 1935; Goddard, 1912; Herrnstein & Murray, 1994). The authors cited valued particular intelligences and assumed that these intelligences were inherited by particular persons: typically white, wealthy, and nondisabled persons.

To explore Williams's example (2005) further, suppose that instead of a warrior caste, our hypothetical society is ruled by an intellectual trust: academics, experts, and philosopher kings. Intelligence is the condition for entry into this class. If a man born into this society cannot perform well on qualifying examinations, he will be understood to be naturally disadvantaged, as though disability is an internal setback. The opportunity to join may be available to him, along with myriad educational opportunities. Perhaps he

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<sup>24</sup> While standardized tests ostensibly no longer serve this purpose, they are still used as a way of quantifying and ranking intelligence within current Western education systems.

does not avail himself of these opportunities, or perhaps he does and yet he still falls short on testing day. The fault lies with him because for all the social advantages at his disposal, he is simply unable to overcome his natural condition.

The language here is anathema to disability rights activists and theorists, but appropriate, for redistribution serves the purposes of correcting and overcoming what has been deemed innate disadvantage: “[the model] presumes that the natural characteristics of people with disabilities can somehow be overcome, when in fact this is neither possible...nor in many cases desirable” (Rioux & Valentine, 2006, p. 54). Indeed, Rawls (1985) believed there were some conditions that were impossible to overcome. His theory of justice is primarily concerned with equality for citizens, those cooperating, contributing members of the community; and he excludes from the definition of citizen those who are disabled so severely “as to prevent persons from being normal and fully cooperating members of society in the usual sense” (p. 233). People who score low on intelligence tests might not be considered contributing members of a community that highly values (what has been defined and reified as) intelligence. Reflecting on the implications, Anderson (1999) notes that equality of opportunity “disparages the internally disadvantaged and raises private disdain to the status of officially recognized truth” (p. 306).

Malhotra (2006) seeks to salvage Rawlsian theory by erasing the distinction between natural and social goods: “a rejection of the distinction between social primary and natural primary goods leads directly to a substantive duty to accommodate in order to overcome the effects of arbitrary barriers created by social institutions” (p. 80). Silvers

(1998), too, believes that an equality of opportunity model, even formally framed, can be used to dismantle barriers to access for disabled persons: “formal equality requires sameness of opportunity in respect to securing equitably effective instrumentalities” (p. 127). She explores the social model of disability in order to demonstrate that redistribution of resources is a strategy that can redress social conditions affecting disabled people’s access to opportunities:

Disability is not a ‘natural kind’, nor is the disadvantage attendant on it an immutable fact of nature. None of this is to deny that, in the main, disablement correlates with anomalous, nonideal, or troubling biological conditions. But once it is recognized that no biological mandate or evolutionary endorsement warrants the dominant group’s fashions of functioning as being optimally effective or efficient, we can see that the main ingredient of being (perceived as) normal lies in being in social situations that suit one—that is, in a social environment accustomed to people like oneself (p. 76).

However, removing external barriers will not ensure equalized access as long as “we are concerned about access to the means of satisfying an individual’s interests” (Mahowald, 1998, p. 269). That is, an egalitarian model that is only concerned with levelling the playing field may overlook what the particular goals are for all the players. The substance of the model is at risk of being loaded with normative assumptions about what ought to be valued.

Merit is an excellent example of a normative assumption that complicates equality theories. A society can legitimize inequalities by framing justice as distributive and competitive, such that there are winners and losers, the deserving and the undeserving. MacLeod (2005) argues that there are clear counter-examples that complicate, if not render absurd, such a model. He discusses those convicted of crimes, often popularly

understood to be undeserving: “what is presumably intended...is that they ‘deserve’ the punishments meted out by the law for the offenses they have committed” (p. 424). Yet, they are still legally protected from police beatings (even if this protection is abstractly conceived and inconsistently enforced): “the protections afforded the members of a just society by the ideal of equality under the law—and many rights that are plausibly subsumable under the ideal—are not desert dependent” (p. 424). People requiring financial support are often judged as undeserving of social welfare or a passerby’s spare change because they did not earn, that is, did not work for, the money. Although a proponent of equality of opportunity and sympathetic to ideas about desert, Arneson (1997) is critical of its practicality, holding that current social institutions, including social assistance, do not actually operate according to this standard:

Given that we do not in fact care enough about deservingness to scrap the market [based on supply and demand principles] and reshape the family [which offers care according to blood and marriage ties] in order to try to tailor individual good fortune to individual deservingness, why does this issue suddenly loom in importance when we are discussing social welfare policies that address the alleviation of poverty? (p. 350).

In other words, our social institutions do not determine resource distribution according to whether the recipient is deserving, although there is a strong theoretical and populous attraction to determining distribution in this way. When explaining the ideology of desert, Arneson notes that those considered deserving of a broader range of social supports are often disabled, while “assistance to the able-bodied, non-aged poor should be offered only in the form of opportunities to work...and never in the form of cash supplements” (p. 337). Disabled people may be further divided into deserving and undeserving categories according to, as examples, how socially inconvenient the

disability is or how the impairment was acquired. The effect is that people are instrumentalized, that is, valued according to their social contributions, weighed against the various and arguably arbitrary ways in which their contributions are limited.

As seen in these examples, the equalization of opportunities reinforces old hierarchies because it does not address why certain kinds of people are under-resourced. Under the standard of desert, some inequalities are naturalized as unfortunate happenstance; even if Malhotra (2006) and Silvers (1998) can fix this problem, the inequalities that arise from their corrections under an equality of opportunity model are thought to be due to, in large part, personal failing. What is missing from these models is the ways in which value systems and ideologies play a significant role in not only who is naturally unfortunate, who loses out in the birth lottery, but also who ultimately wins the game.

### *3.1.3. Feminist Theories on Equality*

#### Feminist-Grounded Critiques of Distributive Justice

Underpinning the equality concepts discussed is a distributive justice framework: equality functions as a regulative ideal overseeing resource distribution, and inequalities are resolved by adjusting distribution patterns. As already indicated, however, ideological organization plays a key role in equality matters. Anderson (1999) explores what equality models (equality of opportunity, specifically) are missing:

There must be a better way to conceive of the point of equality. To do so, it is helpful to recall how egalitarian political movements have historically conceived of their aims. What have been the inegalitarian systems that they have opposed? Inegalitarianism asserted the justice or necessity of

basing social order on a hierarchy of human beings, ranked according to intrinsic worth. Inequality referred not so much to distributions of goods as to relations between superior and inferior persons (p. 313).

Inegalitarianism may more broadly pertain to the subordination of persons within relationships of power. These relations may produce disproportionate resource distributions, as poor income distribution and limited employment opportunities may certainly be symptoms of inequality. The remedy, however, is not simply to redistribute those goods, because not all manifestations of subordination can be understood to be resources. The aim of egalitarian justice is, arguably, "to end oppression [and] to create a community in which people stand in relations of equality to others" (pp. 288-289). Inequality limited to resource distribution fails to redress the ways in which people are rendered unequal within relations of power.

Granted, within some feminist theories, power is treated as a resource, and its redistribution is proposed as a solution to oppression. Olkin (1999), for instance, argues that the institutions of marriage and the family are unjust due to the unequal distribution of "critical social goods [between husband and wife, such] as work (paid and unpaid), power, prestige, self-esteem, opportunities for self-development, and both physical and economic security" (p. 136). Her solution is to reorganize how the goods associated with these institutions are parcelled out. Feminisms interested in developing a standard of rights often operate within the same sort of distributive framework (MacKinnon, 1987; Wollstonecraft, 2004). Rights distribution has the effect of isolating rights-bearers inasmuch as rights are not articulated as manifesting and functioning within relationships

between persons (Davis, 2006; Dillon, 1992). Women's rights are associated with freedoms, such as freedom from violence and reproductive control, and freedom to control property, as examples. Indeed, rights so framed are themselves property, their ownership in dispute.

Young (1990) has been critical of defining power as a distributable resource, "something identifiable and assignable" (p. 23), "possessed by individuals in greater and lesser amounts (p. 31). When power is understood in this way, it separates individuals from one another, for they only function in dyadic relationships with the institutions providing goods, and power has no role to play within wider contexts of relations: "in the distributive logic...there is little room for conceiving persons' enablement or constraint as a function of their relations to one another" (p. 23). Power cannot be properly understood, however, outside a vaster context of relations, for it exists in actions rather than as a tangible, substantive entity (Harvey, 1999; Young, 1990). Further, distributive justice models of power are often employed to correct the disproportionate assignment of power, that is, the high concentration of power in upper classes of people to the detriment of everyone else. However, power is diffuse, reaching and affecting the most intimate interpersonal relations.

#### Feminisms on Unequal Power Relations

How can power be so diffuse? Smith (2005) discusses ruling relations, or "forms of consciousness and organization that are objectified" (p. 13), that is, external to consciousnesses and bodies. Ruling relations function as tacit ideology, socially

organizing knowledge and producing values to regulate other consciousnesses (Smith, 1990, 2005). These relations coordinate everyday life, as people internalize how defective they feel in contrast with that standard external to them. Their identities are produced relative to this standard, through discursive power differentials. The category of femininity, for instance, has been associated with empathy and the capacity for interpersonal relationships, among other qualities (weakness, sentimentality, irrationality). The category is reinforced through interpersonal and institutional expectations. There are feminisms that have even embraced some of these characteristics as essential, natural, feminine markers, thereby perpetuating the stereotype (Gilligan, 1982; Lorde, 1980). Resisting essentialism, Young (1990) argues that some identities, femininity being an example, are produced via power relations. She suggests that women are members of a social group, or a collective “of persons differentiated from at least one other group by cultural norms, practices, or way of life. Members of a group have a specific affinity with another because of their similar experience or way of life” (p. 43). A social group may come together based on shared experiences of oppression, or their identification with one another produced via oppressive relations.

Not all women’s experiences of oppression are uniform, because ruling relations target other identity characteristics. Indeed, a key internal criticism of feminist theories has been that women experience overlapping membership to other social groups, and as such experience different kinds of oppression. When feminisms overlook overlapping experiences of oppression, they tend to protect only certain categories of women: white, wealthy, nondisabled, with a heteronormative orientation. A tool was introduced to

feminist theory, called intersectionality (Crenshaw, 1998; Davis, 2008; Yuval-Davis, 2006), to highlight “silences, tensions, and failures within identity based movements” (Cole, 2008, p. 445). Initial proponents of intersectionality were interested in the integration of class and colour into feminist analysis (Collins, 1990; Crenshaw, 1991; Fuss, 1989; hooks, 1982; Walker, 1995). Their purpose was to criticize those theories which objectify and privilege only certain women’s experiences, and in effect naturalize the feminine identity such that some women inevitably fall short of the standard: “intersectionality theory examines the social divisions, identifications and power relations that structure people’s lives, particularly those people deemed to be marginalized” (Cronin & King, 2010, p. 879). These feminisms are largely grounded in monolithic categories that have been produced by ruling relations.

Intersectionality disrupts the standard by which equality, at least formally characterized, is so often measured because the identities by which people might be determined to be alike are “unstable, multiple and contextually produced” (Cronin & King, 2010, p. 877). Says Jhappan: “instead of making the old formal equality argument that women are essentially similarly situated, in effect, women now argue that they are not similarly situated because of their socially constructed inequality” (1998, p. 74). The theoretical work underlying intersectionality further challenges equality of opportunity models that would seek to naturalize some inequalities. Shared identities are not grounded in happenstance, but are constructed based on internalized oppressive ideology and shared experiences of subjugation. The correction of “natural” inequalities through

redistribution is a superficial fix, for it does not identify or redress the ways in which people are rendered unequal.

What is needed is a relational theory of equality, and a restorative theory of justice. Llewellyn (2011) calls for such a theory of justice, one which seeks to redress oppression, only it does not do so through redistribution of goods. Rather, restorative justice seeks equality of relationship, taking “the fact of relationship, of connectedness, as our starting point” (p. 90). In contrast with liberal theories of justice, relational theories do not study inequalities in isolation and can account for the affects of power. Kogge (2011) explains:

A relational approach [to equality] (1) is contextual in that it allows us to attend to the details of the lives of those affected by various kinds of unequal and oppressive relationships—relationships that are in turn shaped by particular social practices and political contexts; (2) uncovers the governing norms and practices that sustain various inequalities for those who are powerless and disadvantaged; and (3) reveals the importance of the perspectives of those adversely affected by relationships of power as sources for learning about various kinds of inequalities and the structures that sustain them (p. 74).

To see these tenets of relational theory brought to life, it is helpful to turn to Young’s (2000) analysis of systemic oppression. Young lists and explains manifestations of oppression, the ways in which categories of persons are devalued and mistreated. These manifestations include marginalization, which involves the deprivation of material resources, a problem resolved through redistributive efforts; but marginalization is also “unjust because it blocks the opportunity to exercise capacities in socially defined and recognized ways” (p. 41). She cites as an example liberal frameworks according to which “all rational autonomous agents [are entitled] to equal citizenship” (p. 41). The

definition marginalizes, or excludes, people considered to be too dependent: “poor people, women, the mad and the feebleminded, and children were explicitly excluded from citizenship, and many of these were housed in institutions modeled on the modern prison: poorhouses, insane asylums, schools” (p. 41). Those equality models grounded in liberal ideals are by virtue of those ideals not fully inclusive, but create demarcations by which inequalities might be deemed justifiable.

Another face of oppression, exploitation entails “a steady process of the transfer of the results of the labour of one social group to benefit another” (Young, 1990, p. 49). It is through exploitation that inequalities are structured and rendered possible, as some social groups gain privileges by profiting from the fruits of the labour of other social groups. For example, within heteronormative, patriarchal marriages, men have historically benefitted from women’s labour without bothering with remuneration; that is, men might explore career opportunities more freely because women have been historically relegated to the supportive work of maintaining the household and raising the children (Delphy, 1984; Kingston, 2005). Another example of exploitation, this time in the context of race, is when racialized persons are understood to be well suited for, and forced to perform, menial labour: “in our society there remains strong cultural pressure to fill servant jobs—bellhop, porter, chambermaid, busboy, and so on—with Black and Latino workers. These jobs entail a transfer of energies whereby the servers enhance the status of the served” (Young, 2000, p. 40). Menial labour thus functions as a modern manifestation of slavery, a practice justified under the Aristotelian equality model. Exploitation is unjust because it “consists in social processes that bring about a transfer of energies from one

group to another to produce unequal distributions, and in the way in which social institutions enable a few to accumulate while they constrain many more" (p. 41). The injustice can only be corrected through institutional reorganization and structural change.

Finally (for the purpose of this section, although Young lists five faces of oppression), oppression is made manifest in systemic violence, "the knowledge that [members of some groups] must fear random, unprovoked attacks on their persons or property" (p. 46). Violence becomes systemic when the practice targets people by virtue of their membership to social groups: women have been targeted for rape; racialized persons have come to expect harassment; members of the LGBT community have experienced assaults (Young, 2000); disabled people have been subject to physical, sexual, and verbal violence and abuse as well as neglect (Roche Institute, 1995). Young (2000) considers violence to be unjust because social context renders violence possible, even tolerable. She points out that "violence is a form of injustice that a distributive understanding of justice seems ill equipped to capture [which may be] why contemporary discussions of justice rarely mention it" (p. 47).

These examples of oppression are structural, found in institutions and ideologies that frame or facilitate inequalities by sanctioning domination and subordination. While distributive models have lost their veneer in light of their inability to redress these kinds of oppression, is autonomy still a useful concept to link to equality? Indeed, as seen, autonomy has been central to many egalitarian models that have been developed in the context of liberal politics and capitalist markets, and yet liberalism is targeted by Young

as an ideology that marginalizes, and capitalism as a system that legitimizes exploitation. The autonomy of distributive models comes to be as untenable as corrective distribution.

However, feminist notions of justice are compatible with autonomy as long as autonomy is relational, borne out of discursive relations of power. How free a person is greatly depends on the sorts of privileges and oppressions she faces by virtue of her membership to various social groups. The systemic privileging of one social group over another has the effect of disempowering the dominated, that is, of depriving them of their agency, of their ability to pursue their interests, and even of their self-respect. Someone who is marginalized, for instance, is excluded from resources and opportunities; someone targeted by systemic violence may be prevented from pursuing a life project, and may even avoid the pursuit because of fear. This fear, while not equivalent to direct Hobbesian coercion, still limits autonomous actions. Indeed, the concept of ruling relations helps to explain self-trust and lack thereof: some social groups internalize oppression, their identities the result of internalized standards, and are internally blocked from fully functioning within their communities.

### 3.2. Equality in Bioethics and Law

This section will consist in the application of equality theories to the two fields of interest to this study. Alongside autonomy, justice is a canonical principle often grounding bioethics, and there are clear associations with formal and distributive notions of equality. Canadian equality jurisprudence has varied interpretations, beginning with the use of Aristotelian rhetoric to interpret equality rights under the *Canadian Bill of*

*Rights* (1960); equality rights are currently protected under s. 15 of the *Charter of Rights and Freedoms* (1982), and *Charter* interpretation has built gradually through case law.

This section will include both the explication of equality theories in medical and legal discourses and their associations with autonomy formulations.

### 3.2.1. *Equality in Bioethics*

#### Formal Equality in Bioethics

Justice is central to principle-based bioethics, and is generally defined as resource allocation according to standards of desert, or what is owed: “the terms fairness, desert (what is deserved), and entitlement have been used by various philosophers in attempts to explicate justice. These attempts interpret justice as fair, equitable, and appropriate treatment in light of what is due or owed to persons” (Beauchamp & Childress, 2009, p. 241). By equitable, Beauchamp and Childress refer to the way in which distributive justice might be structured, and in so doing they appeal to a formal notion of equality, or consistent application of a rule: a person is owed a resource by virtue of membership to a group that is owed the resource.

Nozick (1974) employs an empty or formal notion of equality in his entitlement theory: “the entitlement conception of justice in holdings makes no presumption in favor of equality, or any other overall end state” (p. 233). When no one conception of the good, even in healthcare, is enforceable, “the state does not coercively take anyone’s personal property to benefit another” (Beauchamp & Childress, 2009, p. 246). Nozick’s notion of just healthcare involves the freedom of providers to set prices and to agree to

services, as well as the freedom of patients to seek insurance plans that best suit them. While his concept of equality employs a standard of desert more closely resembling Aristotelian merit (in that merit involves skill and choice), Beauchamp and Childress, Daniels (1995), and Williams (2005) discuss desert in relation to need. Nozick is critical of characterizing need as the driving internal goal of medicine, citing and evaluating Williams's position:

Leaving aside preventative medicine, the proper ground of distribution of medical care is ill health: this is a necessary truth. ...When we have a situation in which, for instance, wealth is a further necessary condition of the receipt of medical treatment, we can once more apply the notions of equality and inequality: not now in connection with the inequality between the well and the ill, but in connection with the inequality between the rich ill and the poor ill. ...This is an irrational state of affairs (Williams, 2005; as cited in Nozick, 1974, p. 233).

Nozick (1974) argues in response that no other profession (a barber, for instance) requires that the practitioner be limited in pursuing his own goals: "why should *he* [a medical practitioner] bear the costs of the desired allocation, why is he less entitled to pursue his own goals, within the special circumstances of practicing medicine, than everyone else?" (p. 234). Daniels (1995) considers approaches like Nozick's to be untenable because they leave needs unmet. When need qualifies desert, autonomy—at least in the strictest of liberal terms—becomes problematic when packaged with a healthcare model that strives to be just: "it is the belief of many that health care is special which forces us to examine the reasons we have for extending to providers their traditional autonomy and power" (Daniels, 1995, p. 16).

### Equality of Opportunity in Bioethics

Daniels (1995, 2008) proposes that the Rawlsian (1999) theory of justice be applied to healthcare, which would take the shape of a two-tiered system: in the first tier, everyone has access to basic healthcare; in the second tier, privatized options are made available to those who can afford to go above and beyond basic care. The model is just as long as fundamental needs are met for even those who are worst off. Once those needs are satisfied, more limited, less necessary resources are open to choice, and can be provided according to wealth. Beauchamp and Childress (2009) call this threshold the decent minimum standard:

The moderate egalitarian point of view requires equal access only to fundamental health care and health-related resources. ... The decent-minimum approach entails acceptance of a two-tiered system of health care: enforced social coverage for basic and catastrophic health needs (tier 1), together with voluntary private coverage for other health needs and desires (tier 2) (p. 260).

Daniels (2008) connects Rawls to healthcare by expanding the notion of opportunity: “my claim about the relationship between health and opportunity...provides a way of extending Rawls’s theory to address the inequalities created by disease and disability, a key issue that Rawls had deliberately avoided” (p. 21). He does so by defining health as functional: the absence of those disabilities, diseases, and injuries that would limit functioning and render various opportunities impossible to choose. Functional health is normative, allowing for “an explanation of disease in relation to value-judgments” (Schramme, 2007, p. 124). According to a normative account of health, being unhealthy is a condition that would not have been chosen, and is undeserved. Rioux (2003) notes that a functional approach to disability grounds the

cause for disability in individual deficit, just as seen in a biomedical approach, except here the condition is understood in terms of its impact on functional capacity: “the ways of treating or addressing the functional incapacity are broader and include both ameliorating the condition and developing ways to enable people to develop their own potential” (p. 330).

One such ameliorative strategy is healthcare, the means by which one might overcome or manage those obstacles to social functioning (Matcha, 2000; Parsons, 1951). A functional approach to health thus justifies entitlements under a distributive framing of healthcare. This is because normative health “acts not only to describe and explain, but also to enjoin to action [by indicating] a state of affairs as undesirable and to overcome” (Engelhardt, 1975, p. 127); and distributive justice provides the tools for overcoming undesirable states of affairs. Schramme (2007) explains the egalitarian justification for healthcare: “differences in these circumstances should ideally result only from autonomous choices. Since disease is usually a matter of brute bad luck, ill people have a justified claim on health care resources” (p. 125). That is, the purpose of health resource allocation is to cure, to fix, or at least to manage disability, disease, and injury: “health needs are those things we need in order to maintain, restore, or provide functional equivalents (where possible) to normal species functioning” (Daniels, 2008, p. 42).

Granted, Daniels (2008) opposes a strongly normative conceptualization of health, pointing to notable exceptions where the onset of disability merely instigates functional changes in a value-neutral way: “some of our most important goals are not necessarily undermined by ill health or disability. Moreover, many people adjust their goals to fit

better with their dysfunction or long-term disability” (p. 35). Khushf (2007) and Schramme (2007) describe the debates around normative and naturalistic accounts of health as indeed contentious. Nonetheless, Daniels (2008) ultimately argues that people tend to prefer “normal functioning” (p. 41), achieved at peak health, and when healthcare provisions that facilitate normal functioning are denied, a normative element to health develops: “we may still be able to improve the situation—by curing the condition or moderating its outcomes and its effects. ...We should not allow misfortune to beget injustice” (p. 13). Should distributive justice shape healthcare provisions, then, the standard of entitlement to unequal provisions requires a conceiving of disability, disease, and injury as functional limitations to opportunity. People only need and thus deserve a disproportionate allocation of healthcare provisions when their condition is functionally problematic, in that it interferes with opportunity maximization, that is, with how they would choose to live their lives.

Poor health is undeserved because it would not be chosen, and it interferes with life choices. Inasmuch as this is the case, personal responsibility creeps into the notions of desert central to egalitarian healthcare models, and is raised as a deciding factor for resource allocation when needs are many and resources are scarce. Examples include activities that induce high blood pressure, tobacco use, and obesity (Sharkey & Gillam, 2010). According to Moss and Siegler (1991), and Thornton (2009), in the name of fairness (a Rawlsian condition to opportunity provision) alcohol related End Stage Liver Disease (ARESLED) should be grounds for prioritizing liver transplantation, given that the resource is limited and the procedures are expensive. That is, those who reach ESLD due

to alcohol rather than a more natural circumstance should be de-prioritized on the liver transplantation list, because they chose substance use and could have therefore chosen to stop using the substance affecting their livers:

In view of the distinctive circumstances surrounding liver transplantation, we propose as a general guideline that patients with ARESLD should not compete equally with other candidates for liver transplantation. ...We propose that a priority ranking be established for the use of this dire, absolutely scarce societal resource and that patients with ARESLD be lower on the list than others with ESLD (Moss & Siegler, 1991, p. 1296).

In response to the objection that alcoholism is a chronic disease, they and Glannon (1998) maintain that like diabetes mellitus, "alcoholism requires the patient to assume responsibility for participating in continuous treatment" (Moss & Siegler, 1991, p. 1296). Beauchamp and Childress (2009) qualify the condition, arguing that prioritization of organ transplantation should be grounded in the failure to take personal responsibility for maintaining the organ. This would mean that people with ARESLD should not drop in the priority list of organ transplantation recipients unless they refused to improve their condition:

Examples of conditions under which personal responsibility should affect priorities and lead to a lower rating are the following are the following: (1) The alcoholic who fails to seek effective treatment for alcoholism and develops alcohol-related ESLF [end stage liver failure] should receive a lower priority, but unlike Moss and Siegler, we do not view a diagnosis of alcohol-related ESLF as itself categorically sufficient for a lower priority score. (2) A transplant recipient who through personal negligence does not take sufficient immunosuppressant medication, causing the transplant to fail, should be given a lower priority or be rejected for a second transplant (pp. 263-264).

### Feminist Approaches to Bioethics

Questions around the role of personal responsibility indicate that bioethics discourses have taken a sharply liberal turn since early associations with feminist theory. The feminist movement developed alongside, and had early influences on, bioethics, as initial intellectual currents in bioethics focused on the health concerns of marginalized groups; but feminists have noted that this focus has gradually been pushed to the peripheries of bioethics discourses (Holmes, 1999; Purdy, 2001; Shildrick, 2004). While bioethics continues to deal with the normative imperatives to healthcare, these imperatives are all too often oriented toward ameliorating natural conditions and competitive disadvantages, and such an orientation tends to overlook those with chronic conditions, as well as conditions that are “chosen.” Purdy (2001) and Sherwin (1992) express concern for the focus of “mainstream bioethics...on specific issues, narrowly defined, and, for analytic convenience, accompanied by minimal consideration of the broader social context” (Purdy, 2001, p. 129). That bioethics is no longer committed to ending oppression is an indication that “most of the writings of contemporary medical ethics must be judged as lacking from the perspective of feminist ethics” (Sherwin, 1992, p. 84).

Feminist bioethics reorients toward justice by dealing more readily with healthcare issues in relation to subordination and oppression (Colker, 2009; MacKinnon, 1989), and by concretizing bioethics problems. Early instantiations of bioethics (Caplan, 1980; Christie & Hoffmaster, 1986; Engelhardt, 1986) were clear about not overly relying on theoretical principles: “the principles of moral philosophy are simply too abstract and too formal to

contribute to the resolution of concrete cases” (Christie & Hoffmaster, 1986, p. xv).

Currently, Beauchamp and Childress (2009) are leading authorities on bioethics, and their seminal work outlines the canonical principles used to frame healthcare.

How might bioethics be re-concretized? How might justice be social, rather than abstract? Shildrick (2004) points the way, clarifying what feminisms can bring to bioethics discourses:

That assumption of a given sovereign subject whose agency precedes and acts on particular contexts, rather than emerging from and being immersed in them, has been successfully challenged by feminist bioethics. That emphasis has been redirected to the specificity of the needs and desires of each person, to the mutuality of the biomedical encounter, and to an ethics of interconnection and care which deliberately extends the focus of bioethics to encompass everyday issues of bodily well-being as well as the more dramatic scenarios of life and death (p. 150).

The approach she recommends moves away from the biomedical focus on patient pathology, and would not posit that the driving purpose behind healthcare is to ameliorate those conditions that impact functional capacity. With a focus on connectivity, there is room for Wendell’s (1996) theory on the construction of disability, built within medical contexts by physicians. Wendell’s work points to an injustice within the context of healthcare itself—an instance of a ruling relation within which the physician subordinates the patient. Shildrick’s characterization of feminist bioethics has the capacity to identify and condemn such a relation.

With an emphasis in bioethics on cultivating interconnectedness, care may figure more prominently into healthcare models and notions of justice. Indeed, Wendell (1996) notes that feminists have been grappling with how medical contexts should incorporate notions of care, despite the focus in bioethics discourses on distributive healthcare

models, on the dyadic relationship between individual, isolated persons and the healthcare system. That healthcare services do not focus on care has led to an offloading of care-giving responsibilities onto the mothers of children with complex medical needs (Hillyer, 1993). From the perspective of those who are cared for, ideas of privacy, individualism, and liberal autonomy may be internalized as impossible standards, and may produce feelings of shame (Wade, 1994). The denigration of care and connectedness has been done in the name of pursuing cures to disabilities, diseases, and injuries, leading to a lack of investment in and commitment to facilitating health through access to stable living conditions, decent food, and job security; through preventing the poor health that is the result of poverty, unstable political conditions, and violence, as examples (Raphael, 2006). In Wendell's (1996) own words:

Few of us would criticize someone who sought a lung transplant for emphysema caused by air pollution, or spinal cord regeneration (a long-promised development) for paraplegia caused by an automobile accident, but the fact remains that such 'cures' function not only as benefits to individuals, but also as ways of depoliticizing health, safety, and ability for those who are privileged enough to have access to high-technology medicine. The very existence of 'cures' which are available to a few people places some onus on individuals to buy solutions to problems that have social causes and could have social solutions (p. 161).

### 3.2.2. *Equality in Law*

#### Formal Equality in *Bliss*

In *Bliss v. Canada (Attorney General)* (1979), equality jurisprudence drew from a formal notion of the principle. Stella Bliss challenged the constitutionality of the *Unemployment Insurance Act*. Section 46 of the *Act* guaranteed fifteen weeks of

unemployment insurance benefits to pregnant women (eight weeks prior to giving birth and six weeks after). Those who qualified had to satisfy the conditions under s. 30: they had to carry out insurable employment for at least ten weeks prior to the employment interruption. Bliss left work abruptly due to her pregnancy (she gave birth four days later), then applied for unemployment insurance six days after giving birth. Her claim was denied because she did not meet the qualifying condition in the *Act*, that is, she had not completed ten weeks of insurable employment. She had to wait six weeks before she was entitled to insurance.

Bliss argued that the *Act* violated s. 1(b) of the *Canadian Bill of Rights* (1960), which read: “in Canada there have existed and shall continue to exist without discrimination by race, national origin, colour, religion or sex...the right of the individual to equality before the law and the protection of the law”. She held that she had been denied equality before the law:

[Section] 46 denied ‘equality before the law’ for the period therein specified to pregnant and child-bearing women who failed to fulfil the conditions required by s. 30(1) because it denied them the benefits available to all other claimants both male and female, who had eight weeks of insurable employment and who were capable of and available for work (p. 184).

The phrase “equality before the law” refers to identical treatment regardless of the characteristics specified in the *Bill*. Equality thus required that people be similarly situated, entitled to like treatment by virtue of belonging to a like category: Canadian citizen, all those protected by the *Bill*. Bliss alleged that she was discriminated against by virtue of her sex, a characteristic specified in the *Bill*.

The Supreme Court of Canada ruled unanimously that the *Bill of Rights*' provision of equality before the law had not been violated. There was determined to be no discrimination on the basis of sex because under the *Act*, the qualifications for unemployment insurance pertained to the claimant's pregnant condition rather than her sex. Any sex-based inequality in the area of pregnancy "is not created by legislation but by nature" (p. 184). Cited in the Supreme Court's ruling, J. Pratte from the Federal Court of Appeal found the *Act* did not discriminate on the basis of sex and so was not in violation of the *Bill of Rights*:

Assuming the respondent to have been 'discriminated against', it would not have been by reason of her sex. Section 46 applies to women, it has no application to women who are not pregnant, and it has no application, of course, to men. If section 46 treats unemployed pregnant women differently from other unemployed persons, be they male or female, it is, it seems to me, because they are pregnant and not because they are women (as cited in 1979, p. 190).

In Young's (2006) words: "*Bliss* remains tagged as an artefact of equality days gone by, of an earlier overly formal and thin equality *zeitgeist*" (p. 50). Equality as understood under the *Bill* was formal in character, according to which law was applied to both men and women in equal measure, the same manner; legislation was equal for those who were similarly situated, while differences like pregnancy could be attributed to nature and were thus not grounds for legal intervention. Boyd and Sheehy (1989) note that liberal feminist scholars were critical of "the Supreme Court of Canada's abysmal record of women's equality claims under the *Canadian Bill of Rights*" (p. 2), a record which included this case. These early scholars still used the Court's formal language to describe equality, arguing along with *Bliss* that women were entitled to like treatment

regardless of the natural conditions that characterize their sex. These early arguments sought to expand protections against unequal treatment, so that pregnancy could not be used to mark women as different. Whether these arguments were effective or cogent is suspect, given that a “problematic aspect of equality as consistency is its treatment of difference. Only ‘likes’ qualify for equal treatment; there is no requirement that people be treated appropriately according to their difference” (Fredman, 2011, p. 13). It would be more effective to critique the concept applied in *Bliss*, not whether it was applied appropriately.

This case may also be critiqued from the perspective of equality of opportunity, and indeed, the rhetoric of equality of opportunity would be taken up later in case law critiquing *Bliss* (1979). The case demonstrates that the principle of formal equality cannot produce gender-specific legislation because formal equality is a negative concept, one which does not lead to the amelioration of disadvantage, such as those disadvantages women experience when pregnant (Porter, 2006). As long as liberal feminists critical of the case are interested in maintaining that equality is formal and calling merely for a category expansion, their argument deflates in the face of instances where women are no longer similarly situated. The biological differences between men and women should not be ignored, for pregnancy puts women at a competitive disadvantage, especially in the workplace. Equality of opportunity ensures that those who are naturally disadvantaged might have “a legitimate claim to compensation—in such forms as affirmative action and employment equity—to enable them to start in a relatively similar position as others” (Rioux, 2003, p. 299). Unemployment insurance that discriminates on the basis of

pregnancy misses the point, for unemployment insurance should in part be designed to redress the inequalities that result from pregnancy. Legislation is meant to level the playing field that has been rendered rocky by natural conditions, to smooth over the uphill climb some face by virtue of circumstance.

#### Rejection of Formal Equality in *Andrews*

In *Andrews v. Law Society of British Columbia* (1989), *Bliss* was criticized and equality legislation shifted in light of the replacement of the *Bill of Rights* with the *Charter of Rights and Freedoms*. In *Andrews*, Mark David Andrews, a British citizen and permanent resident in Canada, argued against citizenship as a requirement for qualification for the provincial bar. The Supreme Court of Canada ruled that s. 15(1) of the *Charter* had been violated and could not be saved by s. 1. This became a landmark case for s. 15 interpretation.

The *Charter of Rights and Freedoms* replaced the *Bill of Rights* in 1982 and served as a redress for some of the shortcomings in equality legislation. Equality rights are protected under s. 15 of the document:

15(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

In *Andrews* it was noted that *Charter* equality rights have broader application than those found in the *Bill of Rights*, which only covered equality before the law. The *Charter* expanded the scope of equality to the following: “(1) the right to equality before the law; (2) the right to equality under the law; (3) the right to equal protection of the law; and (4) the right to equal benefit of the law” (p. 30). Equality before and under the law means that Canadians are subject to the same entitlements; an individual or group is neither privileged nor disadvantaged in contrast with other Canadians as a result of laws that would unfairly discriminate on the basis of the identity characteristics identified or read into the section. Section 15(1) protects Canadians from unjustly discriminatory laws and ensures Canadians are all entitled to the same beneficial results of these laws. Subsection 2 ensures that it is possible to design legislation that benefits an already disadvantaged group so that conditions preventing people from enjoying the protections and benefits enjoyed by other members of society may be redressed.

During *Andrews*, the Court rejected the “similarly situated” test used in early interpretations of s. 15 (*Reference Re Family Benefits Act*, 1986; *Reference Re Use of French in Criminal Proceedings in Saskatchewan*, 1987; *Smith, Kline & French Laboratories Ltd. v. Canada (Attorney General)*, 1987; *R. v. Ertel*, 1987; as cited in *Andrews*, 1989). The test was explained by J. McLachlin in the Court of Appeal: “the essential meaning of the constitutional requirement of equal protection and equal benefit is that persons who are ‘similarly situated be similarly treated’ and conversely, that persons who are ‘differently situated by differently treated’” (as cited in *Andrews*, p. 26). This rhetoric was used long before early *Charter* interpretations, found in *Bliss* to justify

the *Unemployment Act*. The Court traced the formal concept of equality invoked here to Tussman and tenBroek (1949), and originally to Aristotle's *Nicomachean Ethics*.

In *Andrews* (1989), it was found that "the 'similarly situated should be similarly treated' approach will not necessarily result in equality nor will every distinction or differentiation in treatment necessarily result in inequality. The words 'without discrimination' in s. 15 are crucial" (p. 3). A new test was needed, with discrimination serving as the key condition for determining inequality, because discrimination could be the result of similar treatment. In *Bliss*, for instance, the *Unemployment Insurance Act* applied to men and women in equal measure, and this resulted in inequality because the similar treatment was discriminatory. It was acknowledged by the Court in *Andrews* that "every difference in treatment between individuals under the law will not necessarily result in inequality and, as well, that identical treatment may frequently produce serious inequality" (p. 25). Justice Kerans was quoted from *Mahe v. Alberta (Government)* (1987):

The test accepts an idea of equality which is almost mechanical, with no scope for considering the reason for the distinction. In consequence, subtleties are found to justify a finding of dissimilarity which reduces the test to a categorization game. Moreover, the test is not helpful. After all, most laws are enacted for the specific purpose of offering a benefit or imposing a burden on some persons and not on others. The test catches every conceivable difference in legal treatment (p. 244).

The *Andrews* test was developed in order to identify s. 15 violations. It asked whether the law made a distinction based on any of the enumerated and analogous characteristics protected under s. 15; and whether the distinction resulted in discrimination. Justice McIntyre defined discrimination in the following way: "a

distinction...which has the effect of imposing burdens, obligations, or disadvantages on such individual or group not imposed upon others, or which withholds or limits access to opportunities, benefits, and advantages available to other members of society” (p. 34).

This definition marked a shift away from *Bliss*, for it redressed the problems inherent in a formal formulation of equality. Indeed, the rhetoric of undeserved disadvantage and denied opportunity more closely resembles Rawlsian models of equality.

#### Equality Jurisprudence after *Andrews*

The concept of equality employed in this case was comparative, “the condition of which may only be attained or discerned by comparison with the condition of others in the social and political setting in which the question arises” (p. 25). The basis for Andrews’s claim was that he was discriminated against as a non-citizen, as compared to citizens. Underscoring comparative equality are categories of entitlement. One must identify with a group and claim that this group is discriminated against in contrast with another group. The concept moves away from formal notions of equality in that entitlement does not necessarily entail being treated alike, for similar treatment may result in discrimination. The concept was not only comparative but compensatory for its focus on identifying and remedying discrimination. The implication was that equality protections should involve positive action with the purpose of erasing disadvantage:

The Supreme Court of Canada’s approach to the constitutional right to equality, because it is based on remedying disadvantage rather than treating likes alike, means that laws that have not benefited disadvantaged groups must now do so. The justice system must provide adequate protection against sexual assault and racial violence, women must not be

disadvantaged by reproductive capacity, society must be reorganized to allow full participation of disabled people (Orten, 1990, p. 302).

Nonetheless, Porter (1998) questions whether *Andrews* did enough to move away from formal equality, noting that no framework was established for positive action:

Such an approach [in *Andrews*] may ensure that positive measures addressing particular needs arising from disability, pregnancy or systemic discrimination will not be found to be discriminatory, but does not establish the framework for establishing when such positive measures are required. There is a significant further step involved between rejecting a 'same treatment' model of equality and accepting needs arising from the distinctive or pressing needs of disadvantaged groups protected by section 15 (p. 73).

In his review of case law after *Andrews*, he demonstrates that "the relatively open-ended comments in *Schachter* and *Haig*<sup>25</sup> with respect to the broader ambit of positive obligations were replaced by comments suggesting that the issue of positive obligations had somehow been decided in the negative" (p. 74). As examples, he quotes J. L'Heureux-Dube in *Thibaudeau v. Canada* (1995)<sup>26</sup>: "although s. 15 of the *Charter* does not impose upon governments the obligation to take positive actions to remedy the symptoms of systemic inequality, it does require that the government not be the source of further inequality" (p. 446); and C.J. Lamer in *Egan v. Canada* (1995)<sup>27</sup>: "it is clear that

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<sup>25</sup> In *Schachter v. Canada* (1992), Shalom Schachter challenged the *Unemployment Insurance Act* for denying paternity benefits to an adoptive parent on the basis that he was not available for work. The Court in this case reaffirmed that s. 15 entailed both negative and positive rights. The same interpretation of s. 15 was reiterated in *Haig v. Canada* (1993), which concerned Graham Haig's ineligibility to vote in the Charlottetown Accord due to his moving out of the province.

<sup>26</sup> In *Thibaudeau*, the *Income Tax Act* was challenged for requiring that alimony payments be included as a woman's taxable income. The Court determined that the *Act* was not in violation of s. 15.

<sup>27</sup> In *Egan*, James Egan and John Norris Nesbit, who were in a long-term relationship, challenged the *Old Age Security Act*, which did not include spousal benefits for spouses

Parliament does not have any constitutional obligation to provide benefits” (p. 596). The concept of equality was to be substantiated, but the substance remained vague.

In *Law v. Canada (Minister of Employment and Immigration)* (1999)<sup>28</sup>, a further explanation of s. 15 was attempted: “to prevent the violation of essential human dignity and freedom through the imposition of disadvantage, stereotyping, or political or social prejudice” (p. 88). The term “dignity” refers to an inalienable attribute to human beings, something worthy of esteem (Basser, 2011, p. 17). Fredman (2011) describes dignity as “valuable in underscoring the role of equality in situations in which there is no obvious comparator, making it impossible to demonstrate the demand of formal equality” (p. 22).

She discusses the example of sexual harassment:

Because sexual harassment is uniquely bound up with sex, there is no easy answer to the question of whether the harasser would have treated a man in the same manner. Substantive equality does not require a comparator in the same way: it simply prohibits sexual harassment because it is inconsistent with respect for a woman’s basic dignity and humanity (p. 22).

The concept of human dignity may solve the problem of tricky comparisons, but it moves further away from the framework for positive action recommended by Porter (1998). In and for some time after *Law*, the process for determining a s. 15 violation required not only that discrimination or disadvantage be found, but that it be found to undermine human dignity. The move to regard human dignity as “an independent element in

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of the same sex. Although their appeal was dismissed, this was a landmark case for establishing that sexual orientation was an analogous prohibitive ground for discrimination under s. 15.

<sup>28</sup> In *Law*, thirty-nine-year-old widow Nancy Law challenged the *Canada Pension Plan* on the grounds that she was denied survivor benefits due to her age. The Court determined that there was no violation under s. 15.

discrimination law” (Fredman, 2001, p. 23) translated into extra work for those claiming *Charter* violations (Fredman, 2001; Fyfe, 2007). This standard was associated with freedom—the freedom to make decisions and determinations unburdened by legal constraints. Lawrence (2003, 2006) argues that the rhetoric of freedom found in *Law* was used to the detriment of the larger scope that s. 15 was meant to encompass:

The Supreme Court has said that the interests protected by human dignity relate to the realization of personal autonomy and self-determination, self-respect, and physical and psychological integrity and empowerment. This statement of purpose tends to obscure the possibility that section 15 is meant to prevent the subordination of groups, whether through systemic or other forms of discrimination (2006, p. 117).

She goes on to critique the liberty paradigm: “it does not simply thwart the claims of equality seeking groups—it actively retrenches societal mechanisms which serve to support inequalities, whilst detaching these inequalities from plausible claims of discrimination” (p. 132). Systemic disadvantage, manifest in Young’s (2000) faces of oppression, fall the wayside because they cannot be accounted for with the language of personal autonomy used to articulate the human dignity standard. Legal equality requires comparatives; the comparison should be between subordinate and dominant groups, rather than a formalistic ideal (MacKinnon, 1989; McIntyre, 2006; Pothier, 2006; Reibetanz Moreau, 2006).

#### Substantive Equality in *Kapp*

In *R. v. Kapp* (2008), the Supreme Court of Canada reinforced the formulation of equality put forward in *Andrews*, and paved the way for a more concrete account of positive legal obligations to redressing inequalities. In this case, a communal fishing

license was granted exclusively to Indigenous people; commercial, mainly non-Indigenous fishermen contested the license when they were arrested for fishing at a time prohibited by the license. At trial, “they argued that the communal fishing license discriminated against them on the basis of race” (pp. 5-6). The Court ruled that the license was not a violation of equality rights because s. 15(2) enables governments to create programs that are meant to ameliorate situations for disadvantaged groups: “the government program at issue here is protected by s. 15(2) of the *Charter*. The communal fishing license was issued pursuant to an enabling statute and regulations and qualifies as a ‘law, program or activity’ within the meaning of s. 15(2)” (p. 7).

The Court examined and revised the s. 15(1) test developed in *Law* (1999). It was acknowledged that *Law* had unified “what had become, since *Andrews*, a division in this Court’s approach to s. 15” (p. 28). This was accomplished by reiterating that the principle of equality would be substantive, not formal; would entail positive obligations to facilitate equality, and not just negative obligations to protect against inequalities. Nonetheless, the establishment of human dignity as a standard and legal test was criticized:

Human dignity is an abstract and subjective notion that, even with the guidance of the four contextual factors<sup>29</sup>, cannot only become confusing and difficult to apply; it has also proven to be an *additional* burden on equality claimants, rather than the philosophical enhancement it was intended to be. Criticism has also accrued for the way *Law* has allowed for formalism of some of the Court’s post-*Andrews* jurisprudence to

<sup>29</sup> Those four contextual factors were as follows: “(1) pre-existing disadvantage, if any, of the claimant group; (2) degree of correspondence between differential treatment and the claimant group’s reality; (3) whether the law or program has an ameliorative purpose or effect; and (4) the nature of the interest affected” (*Law*, 1999; as cited in *Kapp*, 2008, pp. 27-28).

resurface in the form of an artificial comparator analysis focused on treating likes alike (*Kapp*, 2008, pp. 28-29).

The purpose of s. 15(1) was thus restated in such a way that it reaffirmed the *Andrews* ruling: “preventing governments from making distinctions based on enumerated or analogous grounds that have the effect of perpetuating disadvantage or prejudice or imposing disadvantage on the basis of stereotyping” (*Kapp*, 2008, p. 6). It was further determined that the purpose of s. 15(2) was to enable “governments to pro-actively combat discrimination by developing programs aimed at helping disadvantaged groups improve their situation” (p. 6).

*Kapp* reaffirms Canada’s commitment to substantive equality, a notion of equality which involves the acknowledgement that resources and opportunities are not already distributed equally, and equal treatment thus sometimes entails treating groups differently in order to redress disadvantage. In the words of Hughes (1999), substantive equality is “a form of equality which is satisfied only if policy or law is made meaningful for all members of society, including those who have been racialized or systemically defined by gender, sexuality, or disability or similar characteristics, as well as intersecting identities” (note 1). Quoting Raphael (1976), she describes Canadian equality jurisprudence with the familiar rhetoric found in equality theory:

The recognition that ‘certain basic capacities and needs are possessed by all’ led (eventually) to a concomitant principle to respond to the inability of everyone to enjoy those needs because of natural inequalities. Some reconciliation between liberalism’s equality of opportunity (underlying its economic strand) and the reality of both conventional and natural inequalities was needed. If people were to enjoy commonly recognized needs and were to realize an equal opportunity for self-development which was at the heart of the evolving liberalism, some account must be taken of different needs. As Raphael points out, everyone needs food, but a

diabetic needs insulin; every child needs education, but visually impaired children require 'special, more costly facilities'" (Hughes, 1999, p. 18).

She lauds this shift, arguing along with others (Minow, 1991; Rioux & Valentine, 2006) that modern inequalities tend to be systemic rather than overt or ostensible, the result of the failure to recognize difference: "in this sense, the concept of 'substantive equality' is a major value in the organizing of Canadian society" (Hughes, 1999, p. 22).

Hughes criticizes, however, the Court's reliance on identity categories to determine inequalities, a practice carried out because legal equality is a comparative concept. The categories used are not only socially produced (Smith, 1990, 2005; Young, 1990), but are also reductive. Those persons who have overlapping membership to several categories may have very different experiences of inequality, according to intersectionality theory (Crenshaw, 1998). Their experiences may therefore be inexplicable relative to the categories framing legal inequality: "it is impossible to dissect an experience such as gendered disability discrimination into neat, separate categories of gender and disability, just as it is impossible to dissect the claimant into neat, separate components of gender and/or disability" (Sampson, 2005, p. 45). Says Hughes:

A fully realized substantive equality concept requires an appreciation of the flexibility and overlapping nature of identity and of the distinction between an externally imposed and an internally derived identity. Here the structure of section 15 and its roots, through wording and interpretation, in human rights or anti-discrimination jurisprudence make it less useful as a guide (1999, p. 43).

Not only is equality law category-specific, but it is site-specific in that it advocates an "individual approach to redressing inequality (this person was refused accommodation or a job or denied a promotion)" (p. 43). Inasmuch as this is the case, the substance of

equality still largely draws from equality of opportunity models and more liberal approaches that take an individualist focus, and that stress competition and responsibility (Rioux & Riddle, 2011). A more robust substantive equality would draw more readily from feminisms to account for systemic inequalities, that is, the production of social categories via ruling relations (Smith, 1990, 2005) and the manifestations of entrenched oppression (Harvey, 1999; Young, 2000).

*Bliss* went awry because social practices and legal policies have historically subordinated women based on their reproductive capacities, pushing them out of the workplace due to a failure to respect and an effort to control women, not because a natural condition put *Bliss* at a competitive disadvantage. How the subordination of women is grounded in reproduction will be elaborated on in the next section, but the point to be made here is even a substantiated notion of equality does not fully address the injustice that *Bliss* experienced.

### 3.3. Reproductive Equality

In the next section I will apply the principle of equality to reproductive decision-making contexts. I will begin by situating reproductive equality in bioethical discourses, considering the tensions between Rawlsian and feminist health models. I will then determine how s. 15 has been applied to *Doe et al. v. The Government of Manitoba* (2004). This section explores the tensions between reproductive autonomy and reproductive equality, specifically addressing how inequalities undermine autonomy

rights, as well as how some concepts of autonomy can complicate and compromise equality jurisprudence.

### *3.3.1. Reproductive Equality in Bioethics*

#### Formal Equality Applied to Reproduction

Interpretations of reproductive equality, and the effectiveness of each interpretation, vary depending on the formulation of equality employed. To begin, Daniels's healthcare model (1995, 2008), framed as an expansion of opportunity, is not easily applied to reproductive health. He is relying on the work of Rawls, a philosopher who did not himself tackle healthcare, although in *Political Liberalism* (2005, originally published in 1993) he did consider abortion as an example of a political problem—a moral disagreement in the public arena. Interpreting Rawls, Gutmann and Thompson (1997) classify abortion as a non-deliberative moral disagreement, irresolvable “because the best moral understanding that citizens can muster does not show them which position should be rejected” (p. 74). Claims made in these disagreements “cannot be defended except by appeal to principles drawn from what [Rawls] calls ‘comprehensive doctrine’” (George, 1997, pp. 1390-1391). By comprehensive doctrine, he means ideology, both secular and religious, rooted in culture and context rather than reason: “background culture is the culture of the social, not of the political. It is the culture of daily life, of its many associations: churches and universities, learned and scientific societies, and clubs and teams, to mention a few” (Rawls, 2005, p. 468).

For Rawls, in a just (read, liberal) society, political decisions are not made based on background conditions. George (1997) explains:

To analyze the problem of abortion in Rawlsian terms, people who believe that abortion is wrongful killing (and as such a violation of human rights)...should...desist from the exercise of political power to secure legal protection for abortions' unborn potential victims. As a violation of the liberal principle of legitimacy, advocacy and action to restrict abortion are contrary to political justice and, in that way, unreasonable (pp. 1391-1392).

In other words, positions taken against abortion violate a principle that is foundational to liberal society. The liberal principle of legitimacy justifies the exercise of power over citizens, and is read as follows: "our exercise of political power is fully proper only when it is exercised in accordance with a constitution the essentials of which all citizens as free and equal may reasonably be expected to endorse in the light of principles and ideals acceptable to their common human reason" (Rawls, 2005, p. 393). Rawls believes a just society can be built on procedural, formal principles to which all persons, ideally, find reasonable. Rather than appeals to the substantive particulars of a moral problem, these principles inform policy-making.

The philosopher advocates a reasonable balance of the values at stake in the disagreement, and in the context of abortion, "any reasonable balance of these three values [respect for life, the ordered reproduction of political society over time, and equality of women as equal citizens] will give a woman a duly qualified right to decide whether or not to end her pregnancy during the first trimester" (p. 243). He holds the opinion that a liberal society would permit abortion because there are no legitimate, or reasonable, grounds for limiting women's equality, at least early in the pregnancy. Any

balance of the three values that would lead to anti-abortion legislation might be not only unreasonable but also "cruel and oppressive" (p. 243). There may be dissentients whose comprehensive doctrines are incompatible with abortion provisions, but "this does not mean that they must reject the political legitimacy of the law or of the constitution" (Freeman, 2007, p. 409). Wherever a person might stand in the moral disagreement, that background culture informing his position has no place in political decision-making.

Rawls only invokes abortion as an example to illustrate political decision-making, and does not discuss what should follow from the point of permission. That is, he does not specify how one might strike a reasonable balance between equality for women, respect for life, and a social responsibility to manage reproduction and the family (read, the point at which women's equality may be reasonably limited by fetal life and social control). Nor does he justify these three values in the footnote where this discussion is found. In a follow-up to the footnote, he writes that he did not intend to argue for the right to abortion; he is not even willing to say with certainty that the right to abortion ought to be granted in a liberal society. He explains further:

I used three political values (of course, there are more) for the troubled issue of the right to abortion, to which it might seem improbable that political values could apply at all. I believe a more detailed interpretation of those values may, when properly developed at public reason, yield a reasonable argument. I won't say the most reasonable or decisive argument; I don't know what that would be, or even if it exists (1997, p. 140).

By stopping at (or perhaps just shy of) permission, he cannot elaborate on how abortion provisions ought to be distributed in order to further facilitate equality; and indeed, as an empty concept, one which cannot recommend positive action, formal equality may have

nowhere to go beyond the granting of permission. Further, Rawls explores the example of abortion by first presupposing that society is “well-ordered” and that the women seeking abortions are “mature” and “adult” (2005, p. 243). He considers equality for women only in the context of an example involving a certain kind of woman.

#### Equality of Opportunity Applied to Reproduction

In order to better understand how reproductive health provisions might be distributed under a Rawlsian model, we return to Daniels (1995, 2008), who appeals to a more substantiated notion of justice in order to work out the more practical details involved in healthcare: equality of fair opportunity. To review, according to this model, healthcare is an entitlement in a just society because it redresses the functional limitations of disability, disease, and injury; curing or at least managing these conditions ensures that people do not miss meaningful social opportunities. Does the condition of pregnancy, which is by Daniels’s own admission “not a disease” (2008, p. 42), not complicate the characterization of health as a normative lacking?

While women seeking to terminate unwanted pregnancies might not consider pregnancy to be pathology, they do frame their condition in terms of functional limitations. That is, an unwanted pregnancy presents as an obstacle in the way of one’s full range of opportunities: “when women seek to terminate unwanted pregnancies, whether through a morning-after pill or an abortion, ...[they and the medical professionals treating them] view unwanted pregnancies as the result of normal—perhaps all-too-normal—functioning” (p. 41). Prohibiting abortion would serve as an

unreasonable limit to a woman's freedom to determine her life course, and inasmuch as this is the case it may be analogous to disability, disease, and injury.

A distributive model of healthcare must also account for wanted pregnancies, which are not ostensibly framed as unhealthy or undeserved. What would then account for women's entitlement to healthcare resources? As Daniels notes in the case of disability, not all conditions need to be characterized as normative lacking. Like chronic illness, pregnancy is managed in order to minimize risk, in the case of the latter risk to the pregnant woman and developing fetus. Provisions may include, as examples, myriad gynaecological appointments, dietary recommendations, or prenatal vitamins, all of which are designed to stave off complications and reduce risk. The point is not to cure but to maintain and prevent. Justice (so framed) demands this sort of resource distribution in order to facilitate a woman's liberty.

However, through resource distribution we have not merely expanded opportunity, but we have also constructed pregnancy as a medical matter, and pregnant women's bodies as in need of medical attention. There are implications to likening pregnancy to disability, and indeed, to medicalizing both phenomena. While healthcare provisions are offered on the basis of need, the language of risk in association with pregnancy constructs women's need, and builds a relationship of dependency on medical professionals (Lippman, 1991). Those professionals, propped up as authorities over medical matters (Kukla, 2005; Wendell, 1996), offer advice and services in order to maintain women's "vulnerable and poorly bounded bodies" (Kukla, 2005, p. 85).

### Feminist Approaches Applied to Reproduction

While Rawlsian healthcare is rooted in correcting “natural conditions” and fulfilling “medical needs,” it fails to account for how the condition of pregnancy is at the root of patriarchal politics. There is little consideration over which material disadvantages and oppressions might render healthcare provisions necessary. Feminisms deal more readily with these considerations. Sherwin (1997), for instance, prioritizes the background culture Rawls rejects, arguing that feminist ethics is not concerned with resolving the moral intricacies of the grand abortion debate. She instead assumes that there are myriad reasons to terminate a pregnancy, many of which are tied to oppression on the basis of sex; women are therefore in the best position to make decisions about their own reproductive health, and ought to make those decisions in order to avoid further subjugation:

Feminists recognize that women have abortions for a wide variety of reasons. Some women, for instance, find themselves seriously ill and incapacitated throughout pregnancy; they cannot continue in their jobs and may face enormous difficulties in fulfilling their responsibilities at home. Many employers and schools will not tolerate pregnancy in their employees or students, and not every woman is able to put her job, career, or studies on hold. Women of limited means may be unable to take adequate care of children they have already borne and they may know that another mouth to feed will reduce their ability to provide for their existing children<sup>30</sup> (p. 320).

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<sup>30</sup> It is worth noting (though its relevance will arise more so in the next section) that Sherwin (1997) continues listing reasons, and her latter set pertain to disability, located both in the pregnant woman and the fetus: “women who suffer from chronic disease, or who feel too young, or too old, or who are unable to maintain lasting relationships may recognize that they will not be able to care properly for a child at this time. Some who are homeless, or addicted to drugs, or who are diagnosed as carrying the AIDS virus may be unwilling to allow a child to enter the world under such circumstances. ... Some women have learned that the fetuses they carry have serious chromosomal anomalies and

Colker (1992) elaborates on why the decision belongs to women: "it is because women are saddled with virtually all of the expenses of pregnancy and childbirth, as well as the costs of childcare, that we must insist women be allowed to choose the conditions under which they become pregnant" (p. 85). Not merely a biological condition that gets in the way of functioning, pregnancy has historically been used as grounds for social subordination.

Sherwin (1997) goes on to say that there are ways in which healthcare provisions (whether there is an overabundance or a lacking) can render women's choices authentic or otherwise: "feminist ethics directs us to look at abortion in the context of other issues of power and not to limit discussion to the standard questions about its moral and legal acceptability" (p. 325). A lack of abortion services, for instance, can serve as a hindrance to facilitating reproductive health. Abortion policy framed simply as permission involves a negative right, where governments agree not to regulate. This dearth of regulation leads to inadequacies in services. The services that are more uniformly made available in the Canadian reproductive health context pertain to women opting to carry through with their pregnancies. Pregnancy management is a manifestation of social inequality in that women have been historically disadvantaged by socially produced responsibilities associated with pregnancy and parenting, which include the responsibility to make use of the provisions made available: make your appointment, take your vitamins, listen to your doctor. The guise of responsibility has shrouded the ways in which reproductive

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consider it best to prevent them from being born with a condition bound to cause suffering" (p. 320).

capacities have been taken up as justification for subordination (Metzger, 2007; Rodgers, 2006c).

For Colker (1992, 2009), autonomy and equality are indivisible principles in the context of reproductive decision-making to the extent that social inequalities work to render choices inauthentic, not autonomous. Critical of literature on abortion for predominantly focusing on individuating the woman or the fetus, she argues that reproductive issues should be grounded instead in equality theory because equality theory stresses connectivity:

And equality perspective, by contrast, does not rely on such assumptions about lack of connectedness. Equality doctrine, at its core, requires that people be treated with equal respect, irrespective of group status. Thus, equality doctrine...insists that women be allowed to choose to have abortions because of women's position in society—the roles and responsibilities of women in society in relation to others (1992, p. 85).

Colker focuses on a specific notion of equality, arguing that an anti-subordination approach to equality, as opposed to an anti-differentiation approach, best meets the needs of women making reproductive decisions. Her understanding of the two approaches corresponds with the conceptual division of formal and substantive equality. Anti-differentiation, or formal equality, protects individual interests regardless of presenting characteristics (think of the Rawlsian position on abortion—reasonable, bereft of contextual considerations). She considers this perspective problematic because it “focuses on the motivation of the individual institution that has allegedly discriminated, without attention to the larger societal context in which the institution operates”; further, it “focuses on the motivation of the specific effect of the alleged discrimination on discrete individuals rather than on groups” (p. 87). An anti-subordination approach, by

contrast, "seeks to eliminate the power disparities between men and women, and between whites and nonwhites, through the development of laws and policies that directly redress those disparities" (p. 87); in so doing, this approach "focuses on society's role in creating subordination" and "on the ways in which this subordination affects, or has affected, groups of people" (p. 88).

Subordination can lead to self-fulfilling prophecy, where women lack the faith in self to resist reproductive control. As explained in relational autonomy theories (Govier, 1993, 1997; McLeod, 2002; McLeod & Sherwin, 2000), self-trust is a vital component to autonomous reproductive decision-making. Self-trust is difficult to cultivate in situations of inequality, where ruling relations are internalized and enacted. As an example, McLeod (2002) describes Lee, a nurse and counsellor who "entered an infertility program feeling confident about where her boundaries lay in terms of how much she was willing to go through emotionally, spiritually, and physically in trying to become pregnant" (p. 2). Lee left the program feeling "powerless and objectified" (p. 3) because she had little bodily control, due to the team-based approach that made no guarantees regarding who would examine the patient, and left for little room to develop relationships with the medical practitioners. In a letter Lee later wrote to a physician who performed her hysteroscopy, she describes problems with care:

When you did the informed consent over the phone, I specifically asked you how many people would be in the O.R. [operating room] suite. You told me there would be three people—the anesthetist, the circulating nurse, and yourself. This was a very important issue for me because of my past history of trauma. ...When I was wheeled into the room I counted eight people (men and women) there cleaning instruments, laughing and showing no signs of finishing up before you got started (with my entire lower body fully exposed and my legs in stirrups). I looked at you to help

me in this and to try to honor my need for control and personal dignity, and you responded in defense of the staff that were cleaning instruments rather than on my behalf. I still remember crying and begging the anesthetist to knock me out because what I was feeling at that moment was unbearable. ...It was another episode where I felt objectified (p. 4).

McLeod notes that Lee was unable to leave on her own, and instead turned to a medical authority for help. Although not coerced into staying in the operation room, she remained because she lacked the confidence to leave. McLeod is careful to explain the ways in which Lee was made to feel throughout her time enrolled in the program that she lacked control, arguing that these conditions led to Lee's inaction. This narrative illustrates the "many obstacles that oppression can pose to the ability of patients to trust themselves" (p. 5). It also speaks to the ways in which autonomy cannot be exercised in a context where the agent is disadvantaged.

### *3.3.2. Reproductive Equality in Law*

#### *Doe et al.*

An attempt to ground reproductive rights in s. 15 was made in *Doe et al. v. The Government of Manitoba* (2004), although the way in which equality was framed is worth consideration. This case went to court because, firstly, Jane Doe 1 "personally paid the cost of [her] abortion in the sum of \$375" (p. 2). She did so because she was told by the Health Services Centre, a Winnipeg hospital, that the wait time for an abortion procedure would be six to eight weeks, when she was seven and a half weeks along at the time of her diagnosis of pregnancy. She understood that the hospital would have paid for her procedure if she could wait, and that she would have to pay out of pocket if she had the

abortion at the Morgentaler Clinic. Her decision to use the clinic's services rested on the following reasons: "having to wait six to eight weeks would be stressful for her, both physically and emotionally. Jane Doe 1 was also aware of the increased health risks associated with a delay in having an abortion" (p. 3).

Another claimant in this case, Jane Doe 2, was also pregnant and had been informed that her procedure, if conducted at the Health Sciences Centre, would be delayed by four to six weeks and would require three appointments. She was on social assistance at the time, and when she expressed concern that a delay would "cause her severe emotional stress and increased physical risk" (p. 4), her case worker helped her obtain an appointment at the Morgentaler Clinic. The province paid a substantial amount of her fee for the procedure, which according to the case transcript was "a most interesting fact especially in light of the position taken by the Government that it will not fund abortions at the Morgentaler Clinic" (p. 4).

Jane Doe 1 and Jane Doe 2 challenged s. 2(28) of the *Manitoba Regulation 46/93* and ss. 116(1)(h) and 116(2) of Manitoba's *Health Services Insurance Act*. Section 2(28) "excludes as a benefit under the Plan a therapeutic abortion that is not performed in a hospital" (p. 5). Denied or limited access to safe and timely abortions, the claimants argued, violated their *Charter* rights to s. 2(a) freedom of conscience, s. 7 security of the person, and s. 15 equality. The Court determined that s. 2(28) of the *Regulation* as well as ss. 116(1)(h) and 116(2) of the *Act* "are of no force and effect insofar as they pertain to therapeutic abortions because they are in violation of the rights and freedoms as guaranteed by sections 2(a), 7 and 15 of the *Charter*" (p. 24), and could not be saved by

s. 1. This judgment has been set aside, however, and the decision has not served as a precedent for subsequent cases pertaining to reproductive rights (Richer, 2008).

Section 2(a) freedom of conscience was invoked by J. Wilson in her dissenting ruling in the 1988 *Morgentaler* decision. The claimants in this 2004 case argued that their right to s. 2(a) was violated because the *Regulation* “interferes with a woman’s ability to make a moral or ethical decision as to whether or not she wishes to terminate a pregnancy” (p. 11). Regarding s. 7, they relied on the precedent set in *Morgentaler* (1988), in which C.J. Dickson (as noted in *Doe et al.*, 2004) held that “state interference with bodily integrity and state-imposed psychological stress infringed the right of women to security of the person as guaranteed by s. 7 of the *Charter*” (p. 9). With respect to s. 15, Jane Doe 1 and Jane Doe 2 claimed that “because women are the only persons who can access abortion services, any legislated restrictions on women’s ability to access abortion services uniquely affects women as opposed to the general population” (p. 10). In other words, current policies on abortion provisions violate women’s substantive equality, the right to differential treatment.

Their argument, however, was complicated by what equality jurisprudence was at the time, for *Law* (1999) set the standard. In order to meet the conditions for an equality violation, the claimants argued that the “right to reproductive freedom is central to a woman’s autonomy and dignity as a person [and] the ability to assert that autonomy and to exercise self-determination regarding one’s own body is fundamental to the preservation and protection of women’s dignity” (*Doe et al.*, 2004, pp. 10-11). Rhetoric from *Law* manifested in the judge’s ruling as well: “Judge Oliphant tethered his equality

rights analysis to a conception of dignity rooted in liberty-based values of reproductive freedom, autonomy, and self-determination” (Erdman, 2007, p. 1100).

### Analysis

This account of equality is rooted in an autonomy that has liberal associations. This interpretation of equality affects the relationship between state and citizen, for the state’s interest in equality remains negative, a matter of non-interference. In general, Judge Oliphant understood *Charter* protections to serve as a shield rather than a sword, that is, as a collection of negative rights instead of positive obligations: “a narrow interpretation of constitutional rights in the health care context is routinely defended by evoking fears of judicial meddling in the complexities of health budgeting and allocation” (Erdman, 2007, p. 1115). Such an interpretation has been long criticized for its implications in the context of reproductive health: “the experience of the Canadian abortion legislation illustrates both the very real limitations of formal equality and the very real need to continue to defend and extend women’s legal rights” (Gavigan, 1987, p. 279).

Ordolis (2008) notes the problems inherent in the Canadian legal concept of reproductive equality—the crucial missing elements—when comparing Canadian and Colombian rulings on reproductive rights. Standing in stark contrast with the history of Canadian jurisprudence on reproductive health from *Morgentaler* (1988) to *Doe et al.* (2004), the Constitutional Court of Colombia struck down the complete prohibition of abortion on equality grounds, recognizing “the connections between discrimination and

lack of access to abortion, [and] emphasizing the disproportionate impact of forced pregnancy and unsafe abortion on adolescent, poor, rural, and indigenous women, and displaced victims of internal conflict” (Ordolis, 2008, p. 264). Here we see far more so than in Canadian claims to substantive equality that equality must meet the needs of persons disadvantaged on the basis of overlapping, intersecting memberships to social groups. It is not enough to say that women are entitled to bodily control when barriers to access continue to exist, and are more prominent for women who are marginalized on other grounds. Further, equality requires structural change rather than merely distribution, for Ordolis also notes that the Colombian Court “highlighted the systemic aspect of unsafe abortion, outlining intersecting forms of discrimination that place certain women in positions of greater vulnerability” (p. 269), as well as the structural connections between sexual violence and the need for available, safe abortions. This case outlined Colombia’s positive obligations to facilitate reproductive options, as demanded by international law—a commitment Canada has failed to make. Ordolis explains the Canadian context in contrast:

While Canadian feminists and intervenors such as the Women’s Legal Education and Action Fund have argued for an equality-based understanding of reproduction, the courts have failed to adopt such an analysis. Despite legal victories in relation to the decriminalization of abortion, Canadian feminists have strongly criticized the ‘rights-based, neo-liberal, privatized argumentation that characterizes Supreme Court jurisprudence on reproductive autonomy’. More specifically, it has been suggested that the focus on liberty has led to a failure to recognize the multiple and systemic forms of discrimination that limit women’s access to abortion in Canada (Rodgers, 2006b; as cited in Ordolis, 2008, p. 281).

The concept of equality used in *Doe et al.* (2004) may have changed since *Kapp* (2008); human dignity no longer functions as a standard in determinations of s. 15

violations. Nevertheless, as Stang Dahl and Snare (1978) indicated long before the introduction and interpretations of the *Charter*, “law reforms have to be accompanied by a ‘delivery system’ which in essence means a political and economic reorganization of society” (p. 14). *Doe et al.* (2004) is merely a late development in a long history of Canada’s inadequate delivery system. Rodgers (2006a) elaborates on this gap between legislation and delivery:

Discriminatory delivery of medically necessary health services needed only by women is clear sex discrimination. Where discriminatory delivery of medically necessary services disproportionately impacts racialized, immigrant, aboriginal, and poor women it violates s. 15 of the *Charter* on the grounds of race and citizenship (p. 121).

She goes on to conclude:

Despite *Charter* protections, access to abortion services has proved elusive at best for Canadian women. The costs, delays and lack of public funding to advance further legal challenges to inadequate services, and the limited impact of the victories that have been achieved, suggest that it is women who will continue to bear law’s limitations despite their right to law’s protection. For women who find themselves pregnant, access delayed is justice denied (p. 122).

Indeed, despite Morgentaler’s victory in 1988, there have been many shortcomings related to abortion administration. In response to Morgentaler’s announcement that he would open an abortion clinic in Nova Scotia, the province prohibited abortions outside hospitals, and denied funding for abortions performed in clinics. In court, he challenged the newly passed legislation, and it was duly struck down in a unanimous Supreme Court of Canada ruling, the legislation found to be *ultra vires*, or beyond the provincial mandate (*R. v. Morgentaler*, 1993). In *Morgentaler v. New Brunswick* (1994), he again challenged and won against provincial law, this time the *New*

*Brunswick Medical Act*, which characterized abortion in a non-hospital setting as professional misconduct. In 1995 (*Morgentaler v. Prince Edward Island*), Morgentaler applied to have a regulation under Prince Edward Island's *Health Services Payment Act* declared *ultra vires*. According to this regulation, abortions would be paid for only if performed in a hospital and if the Health and Community Services Agency deemed it medically necessary. The application was granted, although as indicated earlier in this study, access to abortion provisions remains limited on PEI. As recently as 2008, Morgentaler challenged New Brunswick law again: the *New Brunswick Medical Services Payment Act* excluded abortions performed in non-hospital settings from the definition of "entitled services." He claimed the regulation violated the *Canada Health Act* as well as *Charter* ss. 7 and 15; the case has not yet proceeded (Richer, 2008).

It would seem, then, that Morgentaler's cause requires a life-long commitment. This set of cases demonstrates that the legal protection of reproductive health has been insufficient. One could claim that these insufficiencies are due to the current grounding of the right to terminate in personal autonomy; however, appeals to equality might not adequately redress problems with delivery to the extent that the substance of Canadian legal equality is kept vague, or is coloured with personal autonomy rhetoric. This is not to say that equality jurisprudence should be devoid of autonomy considerations, especially since women's inequality has been historically rooted in who controls their reproductive abilities (Cook & Howard, 2007; Metzger, 2007). Says Rodgers:

Reproductive autonomy is key to women's equality and essential to women's full and constitutionally protected membership in the Canadian state. ... Women's reproductive capability, the biological ability to conceive, to carry and to birth children and the socially assigned obligation

to nurture and to care for them to maturity, has been and remains a primary location for the subordination of women (2006c, pp. 1-3).

The concepts are connected, for reproductive autonomy has been impossible to achieve in any authentic way because of inequalities. These inequalities have not been redressed because the concepts have been framed in unhelpful ways: autonomy as personal, liberal decision-making; equality as negative, formal non-interference.

### 3.4. Reproductive Equality and Disability De-Selection

This section will consider whether there are tensions between reproductive autonomy and reproductive equality in relation to disability diagnostic technologies. I intend to explain how distributive justice models (grounded in either formal equality or equality of opportunity) apply to defences of disability de-selective reproductive technologies. Specifically, I will consider the seminal work *From Chance to Choice: Genetics and Justice* (2000), in which Buchanan and colleagues analyze genetic technologies through a liberal lens. To problematize their framework, I will explore how the technologies are made available especially on the basis of race, class, age, disability, and other such characteristics, and why this uneven distribution happens. I will further explore how geneticization has been built into the provision and promotion of reproductive technologies. My purpose here will be to consider tensions between reproductive autonomy (and in some cases equality) on the one hand, and disability equality on the other. Finally, through an analysis of *E. (Mrs.) v. Eve* (1986) I will uncover how involuntary sterilizations have affected legal equality for both women and disabled people.

### 3.4.1. Reproductive Equality and Disability De-Selection in Bioethics

#### Access to Services

In *From Chance to Choice* (2000), four internationally renowned bioethicists consider the advent of what they call the new genetics: recent developments in technologies that can identify risks for or diagnose instances of genetic impairments before birth, even before conception. The new genetics are explored through a Rawlsian lens, with a reliance on concepts of distributive justice and equality of opportunity. Specifically, co-author Daniels's (1995, 2008) interpretation of Rawls is used, according to which health is defined as species typical functioning; healthcare prevents, cures, or manages impediments to this standard. Kirby and Sherwin (2003) elaborate on the use of Daniels's theoretical work: "they [Buchanan et al.] advocate promoting justice through systematic attempts to help all individuals achieve a state of 'normal species functioning' in order to enable them to be effective participants in society's cooperative scheme" (p. 209).

This concept of species typical functioning means that genetic impairments are impediments to equal opportunity and full functionality. By aiding in the prevention or de-selection of genetic impairment, reproductive technologies foster greater equality of opportunity:

Recently...some theorists, including Ronald Dworkin and John Roemer, have suggested that justice requires redistributing social goods in order to compensate those with less desirable natural assets. But they have not considered the possibility that justice might sometimes require altering the natural assets themselves, perhaps for the simple reason that until very recently this has been unthinkable (Buchanan et al., 2000, pp. 63-64).

Redistribution of resources facilitates justice by adjusting conditions for those who are worst off from the birth lottery. Buchanan and colleagues argue that advancements in genetic technologies revolutionize goods redistribution because these technologies have the power to affect natural goods.

This is not to say that there is no longer a need for redistribution of social goods, only that we ought to strike a balance between inclusivity (the social response to disability) and maximization (directly affecting natural conditions rather than socially compensating for them), both of which are morally legitimate interests. This balance is required because genetic technologies cannot—*yet*, Buchanan et al. hold—guarantee the elimination of all instances of disability. Genetic technologies aid in this maximizing interest: “see genetic technologies as resolving the problem of inclusion by finding ways to avoid the very existence of (or to fully restore to ‘normality’) those who might be difficult to include in important social structures” (pp. 209-210). Unless or until technological advances can fully maximize health (read, fully eliminate disability), inclusivity remains important in the interest of justice; that is, inclusivity functions as an alternative interest only because total maximization is impossible (although it may not always be) with the current tools at our disposal: “at present...biomedicine’s powers of prevention are very limited. The requirement that workplaces be modified to accommodate persons with disabilities is a reasonable response to the inadequacy of the preventative strategy” (p. 292).

The maximization of health is not merely an entitlement, but is also an obligation: “new knowledge about the risk of genetic transmission of diseases and other harmful

conditions will give individuals both the opportunity and the responsibility to choose whether to transmit such harms to their offspring or to risk doing so” (p. 204). Genetic technologies represent first an opportunity in that a just Rawlsian society is liberal, and technologies inform decision-making, thereby increasing autonomy:

Among [the grounds Buchanan et al. provide for reproductive freedom] are the claims that reproductive freedom contributes to individual happiness and well-being, and that reproductive control encourages the equality of men and women. But their most powerful argument is that reproductive freedom is a particular expression of the political value of personal liberty (Scully, Banks, & Shakespeare, 2006, p. 28).

Seeing no incompatibility with this autonomy ground, the authors of *From Chance to Choice* also provide grounds for the framing of genetic technologies as morally obligatory: “parents are regarded as having permission, and some would say an obligation, to [make the choices that] produce the ‘best’ children they can” (Buchanan et al., 2000, p. 156). A liberal society does not only preserve the liberty of women, but also requires that the potential liberty of the developing fetus be considered. Its right to an open future, one that is not hindered by disability, requires that women make use of technologies that might identify and eliminate disability. Equality of opportunity thus operates in such a way that it must balance the liberty interests of discrete, competing parties. Kirby and Sherwin (2003) explain:

The only constraints proposed are that the child’s ‘right to an open future’ is respected and ‘the potential advantage’ so gained is, by Rawls’ difference principle, to the benefit of the least well off in society (e.g., the productive earnings of ‘the enhanced’ are redistributed to the disadvantaged through government taxation) (p. 210).

### Ideological Framing of Distribution

Buchanan et al. (2000) admit that reproductive technologies should be available to all, but what happens when technologies are pushed onto specific populations, or policy on their distribution overlooks the different impacts that the technologies have on different social groups? Kirby and Sherwin (2003) are critical of *From Chance to Choice*'s premises that justice is distributive, and equality a matter of opportunity. They argue that the appropriate justice model would "take more seriously the impact of genetic technologies on existing patterns of oppression involving gender, race, class, sexuality, and disability" (p. 210). They go on:

The injustice created by existing biases against vulnerable social groups is likely to be exacerbated, not diminished, by a program that attends only to conditions of choice and re-distribution of wealth. Social justice involves more than the proper distribution of material resources; it also requires appropriate mechanisms for valuing the humanity of all types of citizens (p. 210).

Previous chapters have already demonstrated that reproductive access remains a theoretical and legal problem; nonetheless, some segments of the population must contend with not only a dearth in services related to reproductive health, but also the overabundant provision of certain reproductive technologies that might lead to selective abortion. Rodgers (2009) describes reproductive health provisions, and how they are not evenly distributed:

There was documentation of racist delivery of abortion and reproductive health care services and of imposed contraception and sterilization. The young, the poor, women with disabilities and aboriginal women, refugees and women of colour were noted as being particularly mistreated. There was documented evidence of pressure to terminate a pregnancy or to use permanent forms of contraception such as sterilization or Depo-Provera for some women (p. 26).

The assumption belying these uneven distribution patterns is that some women more than others, some with certain intersecting identities, might be at risk for producing children with undesirable characteristics. Those women are targeted due to a tacit social mandate to prevent the reproduction of disability.

Consider the historical treatment of racialized minorities: the Aboriginal women, refugee women, and women of colour Rodgers mentions. Davis (2001) and Roberts (1994) discuss the birth control movement of the 1970s, spurred by the invention of a contraceptive pill to prevent pregnancy as well as positive changes in abortion law. This movement heralded technological advancements and legal reform for facilitating autonomy, but overlooked the social inequalities between women that still hinder reproductive control:

The birth control movement has seldom succeeded in uniting women of different social backgrounds, and rarely have the movement's leaders popularized the genuine concerns of working-class women. Moreover, arguments advanced by birth control advocates have sometimes been based on blatantly racist premises (Davis, 2001, p. 453).

Davis goes on, echoing Rodgers: "the movement, for example, has been known to advocate involuntary sterilization—a racist form of mass 'birth control'" (p. 454).

Racialized persons were historically subjected to sterilization procedures because low intelligence was associated with race, as well as class and immigrant status. For Burt (1935), Goddard (1912), and Herrnstein and Murray (1994), low intelligence was thought to be a genetically inheritable trait, passed down to people of inferior moral fibre.

Herrnstein and Murray (1994) associated cognitive class with the following range of social behaviours: poverty, unemployment and idleness, welfare dependency, and crime.

Scientists have since discounted the theoretical links forged between intelligence, minority status, and moral character (Gardner, 1994; Gould, 1996; Kamin, 1995), but the geneticization of intelligence led to policies on reproductive control for the purpose of minimizing disability (DAWN-RAFH Canada, n.d.; Park & Radford, 1998).

Although sterilization is no longer the primary mechanism employed in Canadian contexts for the purpose of reproductive control, other technologies are arguably promoted for the purpose of reducing disability, this mandate evident in the groups targeted for the use of these technologies. The conditions for risky pregnancies earlier discussed concern risk for disability; potential parents who are disabled or whose genetic makeup might result in disability may be warned through the use of reproductive technology. Even those women who are outside the ideal maternal age see their pregnancies classified as risky for the possibility that they might produce a child with Down Syndrome. Grant's study in *Canada's Royal Commission on New Reproductive Technologies* (1993) concludes that the increased availability of technologies for women of advanced maternal age has changed their utilization patterns. While the women who participated in the study did not claim they were coerced, they did say they felt at least covert pressure to diagnose disabilities and to terminate pregnancies. This pressure is the result of a system of relations that devalues disability and constructs maternal need: women need ultrasound technology, they need amniocentesis, they need physician advice, until they reach the point where they need to terminate (Lippman, 1986, 1991, 1993). A Rawlsian healthcare model may on its face further opportunity and fulfill medical needs, but within this model equality of opportunity amounts to little more than

liberal rhetoric used to gloss over who truly has reproductive control, as well as how racist, classist, and especially ableist medical discourses have framed, even created, needs for the medical field to fulfill.

### Geneticization

Underscoring this deliberate targeting of women with intersecting marginalized identities is the trend toward geneticization, or the reduction of persons to their genetic codes<sup>31</sup> (Lippman, 1991, 1993; Rapp, 2000; Rose, 2007). Certain women have been targeted and encouraged, even forced, to submit to technological surveillance and intervention due to ideas around the inheritability of disability. According to Rapp, “geneticization is an historically consonant ideology linking individual attributes and social problems as if they could be effectively reshaped or eliminated only in the realm of biomedicine now reduced to genetic diagnosis” (2000, p. 215). Gould (1996) calls this phenomenon biological determinism, or a theory of limits, which rests on fallacies of reification: “tendency to convert abstract concepts into entities”; and ranking: “propensity for ordering complex variations as a gradual ascending scale” (p. 24). That is, geneticization hinges on abstract formalism and hierarchical thinking.

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<sup>31</sup> Reproductive technologies may identify non-genetic disabilities. The previous chapter explored ultrasound technology in great detail, for instance, and ultrasound may identify physical anomalies that have no genetic basis. Further, not all disabilities have a genetic basis. Disabilities may be the result of delivery, as an example, or of injury. Literature nevertheless points to the medical ambition to ground as many human differences as possible in genetic causes, and often focuses on genetic technologies as the means by which disability might be prevented.

Like the ultrasound ritual discussed in an earlier chapter, geneticization yields visual representations. Extracted chromosomes are taken to be identical throughout a biological entity, and so those chromosomes build a karyotype profile (Martin, 2002). These profiles may be limited because firstly, the technologies developed to date remain and may always be (despite Buchanan et al.'s assurances) imprecise (Hubbard & Lewontin, 1996; Marshall, 1995); and secondly, they are reductive when one considers all that human identity entails: "the human at the level of the species as well as that of the individual person, while in co-evolution and co-adaptation with nature, is more than the sum total of biological or prosthetic components" (Knoppers, 2006, p. 9). And yet, the pictures that are produced mark "the body from which the cells were extracted...by difference" (Martin, 2002, p. 15). Fyfe and Law explain how imagery has a naturalizing effect:

A depiction is never just an illustration. It is the material representation, the apparently stabilised product of social difference. To understand a visualisation is thus to inquire into its provenance and into the social work that it does. It is to note its principles to exclusion and inclusion, to detect the roles that it makes available, to understand the way in which they are distributed, and to decode the hierarchies and differences that it naturalises (p. 1).

What then, is being naturalized? Genetic information aids in the construction—what Scully (2008) calls the essentialization and reification—of a species typical functioning. Taylor and Mykitiuk (2001) criticize associations of health with normalcy, and disease with genetic failings: "when genetic mutations are implicated in the development of our knowledge of disease, our understanding of health risks becomes effectively geneticized. Genetic knowledge incorporates and builds upon the concept of

normalcy" (pp. 4-5). This concept effaces any social inequalities disabled people experience. With the rise of technological innovation, "more and more human variation is attributed to genetic difference", and so "it becomes easier to foreground the biological and background the social, as if they were separable, reproducing and sustaining classic nature/culture dichotomies" (Rapp, 2000, p. 215). Recall that this is precisely Buchanan and colleagues' (2000) project: to see technological advances increase so that disability might be eliminated, at least cured; and social accommodations come to be eclipsed, and supposedly unnecessary. Taylor and Mykitiuk (2001) explain how geneticization legitimizes equality of opportunity models that disempower disabled people:

The assumption that we should strive to remove the barriers to opportunity that arise due to diseases is being fuelled by geneticization. Traditional notions of equality of opportunity, based on socio-economic standing, race or ethnicity, are being expanded by genetic knowledge to include genetic makeup, viewed as a social asset that determines one's ability to compete for resources (p. 3).

### Tensions between Activisms

Disability critiques have been mounted against de-selective reproductive technologies. These critiques often hold that reproductive technologies yield information that expresses a devaluation of disability and a discriminatory attitude against disabled people (Amundson, 2005; Kerr & Shakespeare, 2002; Melo-Martin, 2006; Parens & Asch, 2000; Saxton, 2000). The decision to terminate based on a diagnosis of fetal impairment has more social meaning than termination on some other basis because there is "professional support for testing and abortion" (Asch, 2001, p. 307) in the case of the former. Termination on the basis of disability indicates "that one cannot accept and

welcome the opportunity to nurture a life that will have a potential set of characteristics—impairments perceived as deficits and problems” (Asch, 1989, p. 82). While Herissone-Kelly (2007) and Wolbring (2003) compare disability de-selective abortion and sex selective abortion, the literature still demarcates between terminating due to a devalued identity characteristic and terminating because of life circumstances (a woman being too young, too poor, not ready, unwilling).

Buchanan et al.’s (2000) recommendation that a balance be struck between genetic technologies and social accommodations is controversial in bioethics discourses that aim to further disability rights. Steinbock (2000), for example, holds that reproductive technologies can be developed as long as the social context does not discriminate against disability: “there is no reason why society cannot both attempt to prevent disability and to provide for the needs of those who are disabled. As a matter of fact, the rise of prenatal screening has coincided with more progressive attitudes toward the inclusion of people with disabilities” (p. 121). Asch (2003) claims, in contrast, that promoting technologies for the purpose of de-selecting disability and building an inclusive society are fundamentally incompatible goals:

Is it possible for the same society to espouse the goals of including people with disabilities as fully equal and participating members and simultaneously promoting the use of embryo selection and selective abortion to prevent the births of those who would live with disabilities? As currently practiced and justified, prenatal testing and embryo selection cannot comfortably coexist with society’s professed goals of promoting inclusion and equality for people with disabilities. Nonetheless, revamped clinical practice and social policy could permit informed reproductive choice and respect for current and future people with disabilities (p. 315).

These discourses concern how reproductive technologies affect disability equality, and although Asch (1989) and Rioux (1996) explicitly hold that disability equality-based critiques are compatible with women's reproductive rights, conflicts nevertheless exist. Steinbock (2000) argues that if abortion is morally permissible for the purpose of "avoiding other unwanted consequences (having a child too young, having to give up school, a job, etc.)" (p. 110), disability is just as morally permissible a reason for termination. Sharp and Earle (2002) caution that there are tensions between women's reproductive autonomy and disabled persons' equality in that rendering abortion morally permissible means that women cannot be questioned for their decision to terminate regardless of their reasons. They hold that the two movements are fundamentally incompatible as a result, and designed in such a way that bridging the gap would be impossible.

The document *Bridging the Divide: Disability Rights and Reproductive Rights and Justice Advocates Discussing Genetic Technologies* (Generations Ahead, 2009) was the result of focus group discussions on this tension. These discussions yielded a characterization of how the goals of the two movements, disability rights advocacy and reproductive rights advocacy, diverge:

For disability advocates, concerned with challenging structural oppression facing people with disabilities and advocating for their increased social access, genetic testing has proved worrisome in its potential for selecting out fetuses based on disability. For reproductive rights advocates, the affirmation of reproductive autonomy is paramount, and genetic technologies are generally supported for increasing reproductive options for women and families (p. 1).

This conflict seems to reflect a conflict of principles: disability equality and reproductive autonomy. The conflict only holds as long as the concepts invoked are grounded in liberal ideologies, rather than theories involving relations of power and support.

Should the two movements be each grounded in theoretical models other than liberalism, they might share important common goals. For disability rights advocacy, the social model of disability—explained in a previous chapter—locates disability in social inequalities and policies and practices of exclusion rather than genetic variance (or defect, depending on the model). Feminist reproductive justice counters the traditional grounding of reproductive rights in personal, legal rights, instead using “an intersectional analysis that recognizes the multiple factors that affect people’s lives and offers an understanding of the intersectional nature of economic, social and political forces that shape the lives of women, their families and communities” (p. 5). What they share in common is as follows:

Both recognize the relationship of individual lives to larger social, political, and economic factors, and the intersectional and contextual nature of individual and family decision-making. They appreciate that the difficult decisions that women and people with disabilities make must be understood in terms of structural and pervasive inequality, mistreatment and bias (p. 5).

Alliance building, or at least conflict resolution, would require the recognition of a woman’s right to reproductive control and a dismissal of the devaluation of life with disability. Working together might concretely entail “securing the financial resources and social support to raise children and care for family members with disabilities” (p. 7). Consider that the geneticization of disability not only naturalizes disabled people’s inability to participate in exclusionary contexts, but also overlooks the responsibilities

with which mothers are saddled when they birth disabled children to a world that has absconded all social responsibility to accommodate difference. In this light, reproductive autonomy is not in conflict with equality, but rather, cannot be understood without equality. The feminist model of relational autonomy requires an understanding of relations of power, and of overlapping interests in social equality.

### *3.4.2. Reproductive Equality and Disability De-Selection in Law*

#### *Eve*

The intersectionality approach aids in a refashioning of reproductive equality: “the necessary rethinking of equality requires that unintended pregnancy and its consequences be approached from the perspective of not only women in general, but of different subgroups of women, particularly those who are marginalized due to income, age, or race” (Cook & Howard, 2007, p. 1056). Intersectionality analysis is important because barriers to reproductive health provisions more significantly affect “socially vulnerable women—the young, less well educated and newcomers to Canada” (Badgley, 1977, unpaginated).

This phenomenon is demonstrable in the case of *E. (Mrs.) v. Eve* (1986), in which Mrs. E. from Prince Edward Island was concerned that her intellectually disabled daughter Eve might “innocently become pregnant” (2). Eve’s disability was described thusly: “Eve...suffers what is described as extreme expressive aphasia. She is unquestionably at least mildly to moderately retarded. She has some learning skills, but only to a limited level” (p. 9). Expressive aphasia is “the inability to communicate

outwardly thoughts or concepts which she might have perceived" (p. 9). Eve struck up a friendship with a boy from school and he spoke of marriage. The school convinced the boy to abandon the pursuit, but "the situation naturally troubled Mrs. E." (9). A twenty-four-year-old Eve was described as "attracted and attractive to men" (9). Her mother feared her daughter would become sexually active when not under supervision. Mrs. E. explained that she would have to take responsibility for Eve's child and she could not do so as a widow nearing sixty years of age.

She applied for "(1) a declaration that Eve was mentally incompetent pursuant to the *Mental Health Act*; (2) the appointment of Mrs. E. as committee of Eve; and (3) an authorization for Eve's undergoing a tubal ligation" (p. 2). A tubal ligation procedure would have constituted non-therapeutic sterilization. Eve was appointed a guardian while the case was litigated; during the appeal process, the Supreme Court of Prince Edward Island "ordered that Eve be made a ward of the Court pursuant to the *Medical Health Act* solely to permit the exercise of the *parens patriae* jurisdiction to authorize the sterilization" (p. 3), a decision which was appealed at the level of the Supreme Court of Canada.

The Supreme Court ruled unanimously that non-therapeutic, forced sterilization does not fall under the jurisdiction of *parens patriae*:

Sterilization should never be authorized for non-therapeutic purposes under the *parens patriae* jurisdiction. In the absence of the affected person's consent, it can never be safely determined that it is for the benefit of that person. The grave intrusion on a person's rights and the ensuing physical damage outweigh the highly questionable advantages that can result from it (p. 4).

*Parens patriae*, as characterized in this case, is “founded on necessity, namely the need to act for the protection of those who cannot care for themselves” (p. 45). Provincial courts may intervene and supplant guardians to make decisions that are “in the ‘best interest’ of the protected person, or again, for his or her ‘benefit’ or ‘welfare’” (p. 45), and it can be determined that the guardian is not acting in that person’s best interest.

The case revolved around who ought to make the decision on Eve’s behalf, based on who had Eve’s best interest in mind. Eve could not make the choice to either consent to or to refuse sterilization because “choice presupposes that a person has the mental competence to make it” (p. 55). The Court acknowledged that they could not guess what Eve’s choice would have been had she met Canadian competence criteria to make it, and cited *Eberhardy* (1981) to establish a best interest standard:

We conclude that the question is not choice because it is sophistry to refer to it as such, but rather the question is whether there is a method by which others, acting on behalf of the person’s best interests and in the interests, such as they may be, of the state, can exercise the decision. Any governmentally sanctioned (or ordered) procedure to sterilize a person who is incapable of giving consent must be denominated for what it is, that is, the state’s intrusion into the determination of whether or not a person who makes no choice shall be allowed to procreate (as cited in *E. (Mrs.) v. Eve*, 1986, pp. 55-56).

While its scope is deliberately left vague so that it may be broadly applied, there are clear limitations to the jurisdiction: “a court can act not only if injury has occurred but also if it is apprehended” (p. 3). The respondent in the Supreme Court case could not demonstrate that Eve had been or was guaranteed to experience injury, and so there were no grounds to intervene. Examples of justification, or proposed injuries, such as the trauma of birth, lack of fitness as a parent, and hygienic problems, were dismissed: “the justifications

advanced are the ones commonly proposed in support of non-therapeutic sterilizations. ...Many are demonstrably weak” (p. 50).

While the Court was able to settle on a common law basis, *Charter* applications were considered. According to the argument made by Mrs. E.’s counsel, women have the fundamental right “to choose not to have children and to implement that choice by means of contraception” (p. 56). A violation of that right would constitute a violation of the s. 7 right to liberty. Eve’s counsel also invoked s. 7, noting that Eve would not be making the choice to be sterilized, and so the decision to sterilize would violate rather than uphold her entitlement to procreate: “a court-ordered sterilization of a mentally incompetent person, by depriving that person of the right to procreate, would constitute an infringement of that person’s rights to liberty and security of the person under s. 7” (p. 56). These arguments expand reproductive rights to encompass not only termination but also procreation and contraception. More than that, though, they problematize legal autonomy when the woman whose reproductive rights are being scrutinized is deemed incapable of making the decision on her own.

In response to the appellant’s s. 7 argument, Mrs. E.’s counsel invoked s. 15: “the most appropriate method of ensuring the mentally incompetent their right to equal protection under s. 15(1) is to provide the mentally incompetent with a means to obtain non-therapeutic sterilizations” (p. 56). That is, the denial of a medical procedure on the basis of disability when such a procedure is otherwise offered to nondisabled women would constitute unequal treatment. The argument revolved around the right to access

reproductive services, and noted how access differs according to minority categories.

The counsel for the Public Trustee of Manitoba was quoted:

Denial of [a mentally incompetent person's] right to have his or her case presented by a guardian *ad litem* to a Court possessing jurisdiction to give or refuse substituted consent to a non-therapeutic procedure such as sterilization, would be tantamount to a denial to that person of equal protection and equal benefit of the law. Such a denial would constitute discrimination on the basis of mental disability, which discrimination is prohibited by Section 15 of *The Canadian Charter of Rights and Freedoms* (p. 57).

### Analysis

The Supreme Court of Canada chose to avoid this debate between autonomy and equality, between the right to procreate and the right to access reproductive technologies that would prevent procreation:

[The duty to protect those who are unable to take care of themselves] must not, in my view, be transformed so as to create a duty obliging the court, at the behest of a third party, to make a choice between the two alleged constitutional rights—the right to procreate or not to procreate—simply because the individual is unable to make that choice" (p. 57).

In so doing, the Justices overlooked how central inequality was to Eve's reproductive rights and abilities, and indeed, how autonomy and equality are not in conflict, but are interdependent.

The equality analysis employed by the respondent implied formal equality, where services ought to be distributed evenly and consistently, regardless of one's identity characteristics. And yet, identity characteristics had been targeted by historical sterilization programs. Alberta's *Sexual Sterilization Act* of 1928 justified the systematic, involuntary sterilization of people diagnosed as disabled until its repeal in 1972.

Christian (n.d.) describes the practice as “the institutionalization of racial and puritanical prejudice under the guise of beneficent science” (pp. 122-123). Park and Radford (1998) explore the case files from 1929 to 1972, written up by the Alberta Eugenic Board: a panel of four (some medical experts, others laymen) who were responsible for mandating sterilization procedures. Upon analysis, the case files revealed telling reasons for sterilization: “behavioural difficulties”, “deprivation of family support”, “impoverished family environment”, “precondition to institutional release”, and “parental request” (p. 326). People lacking economic support from their families were sterilized, for instance, as were women who experienced sexual assaults. Here we see a collision of racism, classism, sexism, and ableism, where social behaviours that were deemed deviant and medically deficient were used to justify the denial of reproductive control.

The reasons often provided for sterilization—the guise of beneficent science— included “danger to the transmission of the progeny of ‘mental disability’ or ‘mental deficiency,’ and the danger that the exercise of the power of procreation may involve risk of mental injury either to the patient or to her progeny” (p. 325). Long after the repeal of the *Act*, this rhetoric was latent in *Eve*: the fear of the inheritability of disability, and the paternalist protection of women thought unfit to mother.

Alberta policy was resisted in *Muir v. Alberta* (1996), in which Leilani Muir filed a law suit years after having been sterilized in the Provincial Training School for Mental Defectives (PTS). She argued that a later intelligence examination demonstrated that she was mentally competent, which meant that she had no disability to pass along to offspring, and she was fit to mother. The Court ruled that Muir had been wrongfully

sterilized and her confinement at PTS resulted in “loss of liberty, loss of reputation, humiliations and disgrace, pain and suffering, loss of enjoyment of life, loss of normal developmental experiences, loss of civil rights, loss of contact with family and friends [and] subjection to institutional discipline” (p. 2). In *Muir* we see the language of liberty, but there is no tackling of the issue of discrimination on the basis of disability, for her confinement and loss of reproductive freedom were wrongful only because she could demonstrate she did not have below-average intelligence. Without any acknowledgment that discrimination on the basis of disability has happened, what is to happen to future Eves?

Although the Court ruled in Eve’s favour, and ground their decision in common law, Rodgers (2006c) contends that the decision recognized her equality rights, but used equality rhetoric to reinforce ableist social inequalities:

The impact of [the] decision is to allow Eve’s (assumed) physiological capacity for pregnancy to prevent her broader engagement with her community. [The] reliance on overstated respect for women’s reproductive role effectively precludes Eve from engaging in a sexual life because of fears that her sexuality might result in a child alleged by others not to be in her interest—nor in theirs. Here... apparently equality enhancing recognition of reproductive capacity is used to the anti-egalitarian effect of denying Eve a full life (p. 14).

The Court opted not to intervene, when the case transcript already indicated that Eve had been separated from her friend, and possibly her lover. Her mother and school denied her a sexual life for fear that sexuality equated with procreation. Eve already existed within power relations that disadvantaged her. Even if she wanted to bear a child, her reproductive rights were bound up in a responsibility to care for the child herself, or the responsibility of her mother to do so. The services to support her and her mother should

she want to reproduce were inadequate or nonexistent. The Court may have saved Eve from sterilization by choosing not to intervene, but they failed to address the ways in which inequality renders it impossible for Eve to live as a full citizen, to participate fully in her community.

### Policy

While sterilization has been an overt, violent medical recourse for de-selecting disability, this study has explored subtler technological advances. To review, recent SOGC (2007a) guidelines recommend “all pregnant women in Canada, regardless of age, should be offered, through an informed consent process, a prenatal screening test for the most common clinically significant fetal aneuploidies in addition to a second trimester ultrasound for dating, growth, and anomalies” (p. 49). The guidelines mark a revision of the SOGC’s original position, which was to recommend only pregnant women of advanced maternal age be provided with genetic testing.

They give the following reason for their recommendation: “it is our belief that to deny women access to any information about the health or development of their child, when this information is readily available, is wrong and a disservice to Canadian women and their families” (SOGC, 2007b, unpaginated). The appeal to reproductive access is reminiscent of a formalized, liberal notion of equality, such that historical and current professionally supported disability de-selection is not acknowledged. Equality is here synonymous with access to a wide range of options or opportunities, for the purpose of furthering autonomy (though, note that autonomy is furthered only through the narrow

window of informed consent). Although these guidelines appeal to the principle of equality and are dealing readily with disability, there is no discussion around how to respect the equality entitlements of disabled persons, nor those of women who opt not to avail themselves of technologies to diagnose or de-select disability. Says Miceli (2007) of the 2007a guidelines:

The SOGC...noted in their tenth recommendation that 'screening programs should show respect for the needs and quality of life of persons with disabilities. Counselling should be nondirective and should respect a woman's choice to accept or to refuse any or all of the testing or options offered at any point in the process' (p. 154). Unfortunately, there is no information in the document as to how the screening programs would show respect towards persons with disabilities, leading one to speculate that such a sentence is merely a throwaway line, devoid of any real substance (p. 6)

In this case, the gaps in the discussion are especially important. The policies are meant to uphold equality and autonomy, and yet no mechanisms are put into place to safeguard against routinization and ritualization of the recommended procedures, nor is there an acknowledgment of how technologies function in social contexts rife with inequalities. Key stakeholders are missing. Moreover, while the framing of equality remains rooted in formalistic, liberal concepts, the principle still only lurks in the background of reproductive issues, while autonomy remains the primary principle grounding reproductive health policy. Canadian law and policy will continue to struggle with how to frame reproductive equality if there is no discussion on equality, no recognition that inequalities affect, and are central to, reproductive control.

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#### Chapter 4: Respect for Difference

In this chapter I introduce the principle of respect for difference. I will begin with a review of liberal traditions, and from a postmodern<sup>32</sup> feminist perspective I will critique their assumed premises about what persons hold in common. I will next examine what it would mean to respect difference in bioethical and legal contexts, considering specifically the potential of and limitations to the s. 15 right to equality, and more generally how our medical and legal systems are structured according to ideals about human sameness. Respect for difference, I will show, is of tremendous importance to reproductive health, even if theoretical and legal discourses fall short of honouring the principle, as is evident in examples of sterilization abuses and controversies around sex selective abortion. Finally, I will consider how respect for difference factors into a comprehensive conceptual framework when one reflects on the use of reproductive technologies to increase, rather than to decrease, the likelihood of disability. I am interested in whether there is an assumption in bioethics and law that reproductive technologies should be used for the purpose of disability de-selection, and whether this (either implicit or explicit) bias reflects tension between reproductive autonomy and equality on the one hand, and respect for difference on the other.

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<sup>32</sup> Throughout this study I have claimed to be engaging postmodern theory. I recognize that the terms “postmodernism” and “post-structuralism” tend to be erroneously conflated in rhetoric and literature, and that this chapter makes use of philosophers who have identified or been identified as post-structuralist. My choice to use “postmodern” is deliberate, for this chapter especially discusses theory in response to modernity.

#### 4.1. Respect for Difference in Theory

The introductory section to this chapter will provide an account of the traditions that feature personal autonomy and egalitarianism—theories I have considered in the previous chapters. These traditions, I will go on to demonstrate, are rooted in assumptions about what human beings hold in common. This starting point reflects a hegemonic standard that excludes myriad identities associated with gender, class, race, sexual orientation, and disability. Drawing from postmodern feminist and disability theory, I will argue that we are in need of a politics of difference, that is, a conceptual model that anticipates and respects variations in the human condition. Such a model makes use of the principle of respect for difference to contextualize and enhance both relational autonomy and restorative justice.

##### *4.1.1. Liberal Traditions and the Foundation of Sameness*

###### The Autonomous Self

Autonomy has become integral to political philosophies since Kant introduced the concept and liberal traditions expanded its meaning. Recall Kant characterized autonomy as “the only original right belonging to every man by virtue of his humanity” (1996, 6.237), and in so doing he declared that autonomy is an essential component to the human condition. The property was central to his ethics, qualifying human beings as deserving of respect, respect equating to non-interference: “act in such a way that you treat humanity...as an end and never merely as a means” (1993, 2.429).

Liberal theories broke away from Kantian philosophy by associating autonomy not with a moral doctrine but instead with personal intentions. Kant's concept of autonomy was moral in character, and was realized when man acted according to reason, a universal will, rather than external motivations. Liberal versions of autonomy posit the possibility for plurality, that is, for multiple, varied reasons for choosing or acting. What they retain from Kant is only the mode by which man might govern himself: "a person is free in so far as his actions are his own, that is, in so far as they result from decisions and choices which he makes as a free agent, rather than as an instrument or object of another's will" (Lukes, 1973, pp. 127-128).

This move toward personal, pluralistic autonomy has led to associations with rugged individualism; autonomous choice belongs to the radically isolated agent, he who is marked with self-sufficiency and rationality. The right to autonomy requires that one satisfy the conditions for membership to this identity (Locke, 1980; Rawls, 1999). In this way, liberal models of autonomy still rely on the Kantian dichotomy between the subject and object—he who acts and that which is acted upon: "rational beings are called persons inasmuch as their nature already marks them out as ends in themselves" (Kant, 1993, 2.428). So while autonomy might involve myriad intentions, preferences, or reasons—many substantive motivations for acting—the mechanism by which one might make autonomous decisions is what subjects must hold in common.

### Their Kingdom of Ends

Presuppositions about what it means to have subjectivity have factored into models of egalitarianism. To review, these models reflect the antiquated conception of equality as formal, or as sameness: “things that are alike should be treated alike, while things that are unlike should be treated unlike in proportion to their unalikehood” (Aristotle, *Pol.* 3.9). The principle was built into Aristotle’s account of proportional equality, which for him frames distributive relations between men. Goods are to be distributed according to desert or merit: “all men agree that what is just in distribution must be according to merit” (*NE*, 5.3). In turn, merit is determined by excellence: when an act is voluntarily chosen and performed well.

Choice and skill continue to belong to the subject under egalitarian models, and serve as justification for inequalities. That is, an equality model may legitimize goods distribution patterns by appealing to the recipient’s membership to the category of autonomous agency, subjectivity, or personhood; while those historically considered nonpersons have been marked as unlike or different, and therefore undeserving.

Consider how these implications arise even in many liberal egalitarian models that came long after Aristotle. Rawls (1999) performed a thought experiment in which he imagined how a society would be built by and for people who live behind a veil of ignorance. This veil, or the original position, is a hypothetical starting point for humanity, one devoid of social knowledge or standing: “no one knows his place in society, his class position or social status; nor does he know his fortune in the distribution of natural assets and abilities, his intelligence and strength, and the like” (p. 137). The

purpose of this experiment is to determine how resources ought to be distributed, and consequently, how social justice might be achieved. Rawls means to construct an ideal society, a utopia for the best in men, or that which men hold in common. His theoretical society is not constructed in such a way that human differences would be acknowledged, accepted, or accommodated, for Rawls is interested in what renders men the same (Roemer, 2002).

Difference is understood by Rawls (1999), among others (Arneson, 1989; Dworkin, 1981), in two ways. Firstly, traits such as “physical health or lack thereof, intelligence, and imagination” (Rawls, 1999, p. 54) are natural advantages or disadvantages, the result of circumstance or the birth lottery. The disadvantages function as obstacles to be overcome. Equality operates as a tool that levels the playing field, or renders those who are naturally different, essentially the same (Arneson, 1989; Cohen, 1989; Dworkin, 1989; Roemer, 1995, 1998). A Rawlsian egalitarian system would redistribute goods until natural inequalities are compensated, such that those least advantaged are without envy, for they would have the minimum goods necessary to act freely (Dworkin, 1981).

Secondly, once natural differences are remedied, any other differences may be attributable to choice, and thus are understood to be deserved. They might include “liberties, opportunities, income, and social bases of self-respect” (Rawls, 1999, p. 54). Equality models thus use autonomy, and the accompanying notions of personhood, to justify inequalities—those anomalies that might be shaken loose from ideal theories (Miller, 1999; Nozick, 1974; Rawls, 1999). Liberty may be employed to explain why for

all the opportunities made available, there are people who have yet to correct their shortcomings and rise to the standard (Hart, 1989).

It would appear, then, that modernity has not developed a concept of difference that would be worthy of respect. Respect is earned, according to these theories, for reasons of sameness, or compliance with a particular standard: sharing decision-making mechanisms in common, overcoming disadvantage, choosing right courses of action. To find anything like a call to respect difference, we must look elsewhere, beyond the modern age, to postmodern critiques.

#### *4.1.2. Postmodern Critiques of Liberal Traditions*

##### Modernity

There are philosophers, oft called postmodern, who are critical of these liberal theories. Lyotard (1984) calls this process, this “incredulity toward metanarratives” (p. xxiv), the postmodern condition, by which the ideologies of modernity are challenged. By modernity, he means liberalism to which the Enlightenment gave rise; and by metanarrative he means concepts that have been taken for granted as true but that all along have been built, and used to structure our theories, our societies, and our lives. They are the themes running through our theoretical models, the principles taken for granted as true. Although Derrida and Foucault do not identify as postmodernist, they nevertheless conduct projects that involve critiquing the theoretical work produced by or within the Modern Age. Their understandings of modernity may stretch further back than the 1700s: “for Derrida, Western philosophy is the product of...the metaphysical tradition

in philosophy, from Plato to Hegel” (Noonan, 2003, p. 11). While this section focuses on liberalisms, which remain definitive for current political philosophies and relevant to my work, this study in general acknowledges that philosophers of antiquity (Aristotle, for example) made significant contributions to building the great myths of modernity.

Modernity is rooted in classificatory thinking—the separation of the subject from the object, the self from the others, the persons from the things, as seen in the metanarratives on autonomy developed since Kant. It has been shown throughout this work that the primacy of selfhood has underscored dominant theoretical accounts of humanity as well as recommendations for social and political organization. The category of personhood comes with conditions for membership, such as competence, reasoning skills, independence, and the like.

As Noonan (2003) explains, the identity of personhood can only be forged if differences are excluded: “the real goal of [category] thinking and the politics that follows from it is to eliminate differences, either absolutely or by reducing differences to inessential moments of an underlying essential identity” (p. 23). Consider what becomes of differences in egalitarian theories such as Rawls’s (1999) so outlined above—differences are overcome, or excused as the product of poor choices. The focus remains fixed on what might be the same. Rawls sought to correct some differences, to write others off, and even admits that his theory of justice does not include consideration of disabled people because they are simply too different, too far away from his essential premises about the human condition. He chooses to focus instead on those persons who are not prevented from acting as “normal and fully cooperating members of society in the

usual sense" (1985, p. 234). His standard excludes people with "permanent physical disabilities or mental disorders", rather than people who experience disease and injury "to be expected in the ordinary course of human life" (p. 234), as though it is possible to separate out kinds of difference: the normalized and the deviant sorts, the excusable and the excludable. Difference as disability is unacceptable when it affects the capacity to have "a particular conception of the good that they try to achieve" (p. 234). If someone is incapable of perceiving a worthy good, and incapable of striving for that good on his own, he cannot be understood to be free and equal, which are moral conditions for membership in a just society.

### Differance

The postmodern condition challenges the assumptions and metanarratives about selfhood: "postmodern knowledge...refines our sensitivity to differences and reinforces our ability to tolerate the incommensurable. Its principle is not the expert's homology, but the inventor's paralogy" (Lyotard, 1984, p. xxv). In science, homologous characteristics derive from the same ancestor; what Lyotard means is that those responsible for reinforcing a hegemonic standard equate this standard with what they are, what they take to be, or what they aim to acquire as, their own characteristics. Paralogy, in the context of Lyotard's interpretation of the postmodern condition, is variation from the standard, or more precisely, a break from the long-standing reasoning for maintaining this standard. He argues that difference is what counters modernity's dominant

narratives. All those exceptions to the rule eventually cannot be ignored, and it is at this point that the rule can be challenged, perhaps transformed.

Consider further Derrida's (1972) work on differance, that which "makes possible the presentation of the being-present" (p. 6). Differance is a non-concept, meaning it follows a neither/nor structure, while concepts take an either/or format. That is, concepts are understood in light of what they are not (it is either this or that), while differance has no opposite that might explain its meaning. It is all that has been excluded from a concept and that has yet to be classified, but it is required so that classifications are possible. That is, differance ensures that concepts have meaning or presence to the human mind, because a concept can only have meaning if it relates to that which is absent from its meaning. While concepts can only be expressed in light of the play of differences that brings them about, it is recognition of this play, this differance, that exposes and opens up conceptual limitations. Differance is both the condition for the possibility of meaning and the productive force by which meaning is eventually deconstructed or broken down. Again, exceptions transform the rule.

Derrida compares differance to the sheaf that binds wheat, or an assemblage that "has the complex structure of a weaving, an interlacing which permits the different threads and different lines of meaning...to go off again in different directions" (p. 3). His purpose for employing this imagery is to avoid describing differance as a concept that moves through history, for differance is other to historical development. It is instead the context in which concepts are situated and foregrounded, and the space that makes their presence to mind possible.

Put another way, classificatory language for Derrida (2002) requires that there be an Other: "differance marks...a relation to alterity, to the singularity of the other" (p. 93). The complexity and irreducibility of meaning is impossible to contain within the boundary lines of definitions, concepts, and theories, and so these attempts to enclose meaning must eventually break down in the face of all that exists beyond them, all those differences that had been excluded or regulated for the purpose of producing meaning. The Other calls to the subject, and calls for openness rather than the imposition of conceptual frameworks. Recognition of the Other, of those excluded from the standard, of the possibility for human difference, "ushers in an impetus to the re-conceptualization of the self [that] is based upon the primary care of the other" (Elliot, 2002, p. 191). In other words, to be open to others beyond and unlike oneself displaces the self. Selfhood, at least for a time, comes to be constituted by relations to people rather than (necessarily and inevitably) problematic metanarratives.

#### Managing Differance

Rare is the occasion that the call of the Other is answered in such a way. More commonly, according to Derrida, we do violence to the Other by imposing and managing specific identities and notions of the ideal self. In his own words:

The rapport of self-identity is itself always a rapport of violence with the other so that the notions of property, appropriation, and self-presence, so central to logocentric metaphysics, are essentially dependent on an oppositional relationship with otherness. In this sense, identity presupposes otherness (as cited in Kearny, 1984, p. 117).

Derrida describes the imposition of identity as violent because what a person can be or become is limited considerably. When one must “give an account of everything, and only thematically” (1992, p. 25), the range of life projects and possibilities diminishes, and persons are silenced, adjusted, and regulated to fit the themes or roles that have been taken to be their totality. Says Noonan (2003) of Foucault’s work, which also concerns the oppressiveness of thinking in terms of totalities: “the category of totality structures all contradictions and struggles according to [given theoretical] assumptions” (p. 18).

The management and effacement of difference happens within relations of power that Foucault (1977) describes as subtle and diffuse. While Derrida uses the term “violence” in a specific, metaphorical way, Foucault considers how subjection can be accomplished through means other than “the instruments of violence or ideology” (p. 26). In his own words: “[power] may be calculated, organized, technically thought out; it may be subtle, make use neither of weapons nor of terror and yet remain of a physical order. ...It cannot be localized in a particular type of institution or state apparatus.” (p. 26). Power functions not as a possession to be distributed but as a strategy to be implemented, and when implemented it is internalized such that we enact and reinforce totalizing theories by regulating one another and ourselves. Bartky (1990) describes this phenomenon, comparing the regulatory mechanisms of everyday life to a prison structure:

The project of control has brought into being a new individuality. In fact, Foucault believes that the operation of power constitutes the very subjectivity of the subject. Here, the Panopticon returns: knowing that he may be observed from the tower at any time, the inmate takes over the job of policing himself. The gaze which is inscribed in the very structure of the disciplinary institution is internalized by the inmate (p. 79).

Power, manifest in the machinery of modernity, operates as a strategy that disciplines bodies: “even if they do not make use of violent or bloody punishment, even when they use ‘lenient’ methods involving confinement or correction, it is always the body that is at issue” (Foucault, 1977, p. 25). Differences are managed in material, physical ways such that the bodies that modernity produces are rendered docile. Foucault invokes the example of the soldier: “by the late eighteenth century, the soldier has become something that can be made; ...posture is gradually corrected; a calculated constraint runs slowly through each part of the body, mastering it, making it pliable, ready at all times, turning silently into the automatism of habit” (p. 135). He elaborates on the implications:

The human body was entering a machinery of power that explores it, breaks it down and rearranges it. A ‘political anatomy’, which was also a ‘mechanics of power’, was being born; it defined how one may have a hold over others’ bodies, not only so that they may do what one wishes, but so that they may operate as one wishes, with the techniques, the speed and the efficiency that one determines. Thus discipline produces subjected and practised bodies, ‘docile’ bodies. Discipline...dissociates power from the body (p. 138).

The manipulation of bodies renders people the same, in conformity with the standard established within our metanarratives: the rugged individualism of autonomy theories, the sameness built into equality models. Differences might have transformative power when they are used to challenge entrenched metanarratives, but our theories persist because differences are ironed out through the systemic manipulation and production of the body.

#### *4.1.3. Postmodern Feminisms*

##### Intercorporeal Embodiment and the Interruption of the Autonomous Self

The postmodern condition has bearing on some feminist critiques of the management of gender. Bartky (1990) takes up such a task of incorporating postmodernism into her analysis, noting that Foucault's work on docile bodies could be (and should have been) applied to the category of woman:

Foucault treats the body throughout as if it were one, as if the bodily experiences of men and women did not differ and as if men and women bore the same relationship to the characteristic institutions of modern life. Where is the account of the disciplinary practices that engender the 'docile bodies' of women, bodies more docile than the bodies of men? (p. 65).

Bartky points to the difference of gender and how it might serve to deconstruct even Foucault. That is to say, the experiences women have of bodily treatment complicate assumptions made by Foucault about a unified, or at least similar, experience of body management for both men and women. Female bodies especially have been produced, manipulated, and rendered docile. Gender binaries—man and woman—often run along the fault-lines of subject and object, autonomous and dependent, rationality and corporeality. Female bodies are managed to reinforce these conceptual binaries.

How is this accomplished? The body serves as a cultural medium: "it is the surface on which prevailing rules of a culture are written. ...Cultural rules are not only revealed through the body; they also shape the way the body performs and appears" (Gimlin, 2001, p. 3). This is especially the case within the context of patriarchy, where social rules are inscribed upon the bodies of women. Under patriarchy, meaningful rituals associated with the female body include weight management, make-up

application, careful attention to clothing and hair care, and so on (Bartky, 1990; Wolf, 1991). Beauty rituals function to produce an ideal femininity by engaging in an “art of disguise” (Bartky, 1990, p. 71): routines work to cover or change that which renders women different, where difference is associated with ugliness and lack of worth. The woman’s body is produced as Foucault’s soldier’s body has been.

Woman has undergone a process of objectification, a separating out of her subjectivity from her body as an object. Within patriarchal ruling relations, her value is attached to her body, specifically her beauty, beauty equating to success at ensuring her body approximates the idealized standard of femininity. This standard is understood to be what the heteronormative man would prefer or find desirable; the heteronormative male gaze has thus been compared to the panopticon—the prison structure Foucault (1977, 1980) describes as maintaining social control. Power acts as a strategy, as a subtle set of prescriptions for how to manipulate one’s body in order to enact the ideal (Garland-Thomson, 1997). Women’s objectification, their reduction to mere bodies in contrast with the heteronormative male subject, occurs through the internalization of patriarchal narratives of gender.

As already explained in detail earlier in this study, women are also objectified—reduced to objects rather than subjects, bodies rather than minds—in reproductive contexts. When a woman is understood to be nothing more than her body, her purpose may come to be seen as solely reproductive. Her messy, leaky, pregnant body calls for management (Kukla, 2005; Shildrick, 1997). The differences that mark women and

hence constitute the gender divide justify medical and legal control over reproductive functions.

Corporeal differences must often be regulated, and persons may be objectified under hegemonic standards on the grounds of their differences, but these differences also have the power to render our standards unstable: “the security of binary differences is constantly undermined by irreducible difference—the refusal of the self/other relation—of the disabled [and I might add, female, at least pregnant] body” (Shildrick, 2009, p. 40). Differences constitute the condition for the possibility of normative theories and politics, for how would a dominant group become dominant without others to control; how would such a group be characterized without a contrast? And yet, even as the condition for the possibility of current traditions, differences might still challenge those traditions and point to a new way. The instability of different embodiments acts as “a device for destabilising all categories of identity” (Berube, 2002, p. x).

How is this so? Lyotard (1984) describes why he is incredulous toward current metanarratives about the self-sufficient autonomous agent: “no self is an island; each exists in a fabric of relations that is now more complex and mobile than ever before” (p. 15). Discussed at length already, intercorporeality, the condition of being bodily connected and dependent, is understood within liberalism to be a weakness. Long associated with the characteristic of intercorporeality, disabled people and women have often been marked as inferior, non-ideal, and have been managed. Shildrick (2009) describes the phenomenon:

Where physical and mental autonomy, the ability to think rationally and impartially, and interpersonal separation and distinction are the valued

attributes of western subjectivity, then any compromise of control over one's own body, any indication of interdependency and connectivity, or of corporeal instability, are the occasion—for the normative majority—of a deep-seated anxiety that devalues difference (p. 2).

There is a discomfort with intercorporeality, and rightly so, for the condition contradicts, perhaps even transforms, what it means to be human. No longer do we qualify as fully functioning members of our communities, not in the usual sense, when we are too readily dependent on and connected to others. Shildrick goes on to say that “at the same time that the modernist focus on the boundaries of bodily difference gives way to a full recognition of the dimensions of embodiment...corporeality itself segues into the notion of intercorporeality” (p. 18). The totality of our corporeal experiences cannot be explained with the theories we predominantly use. They cannot account for important differences: for the material reality of pregnancy, where one becomes two; or for how independent living for some physically disabled people requires attendant service providers to aid in feeding, catheterization, even intimacy; or perhaps even a difference as trivial as our reliance on others to offer aid, advice, or support when we make decisions, acquire food, seek pleasure. The explicitly intercorporeal being complicates our theories of selfhood, breaks them down and opens them up so that we might account for how human beings cannot simply be conflated with the isolated individual or the abstract agent.

### Intersectionality and the Deconstruction of Identity

Classificatory thinking, theorizing about the autonomous self, functions as a central component to equality models, and thus brings to those models the pitfalls noted

by postmodernists. For instance, the Rawlsian veil of ignorance depends on constructed bodies and presumptions of subjectivity. Recall that Rawls (1985) found those disabilities he deemed permanent and severe to be too inconvenient to include in his theorizing about the ideal society, for those disabilities impair an individual's capacity to have in mind a worthy good, as well as the capacity to make use of those opportunities that might enable him to reach that good. An ideal society, such as the society Rawls conceived, is only successful, only possible to imagine, if constituted by certain subjects, those who are understood to be free and equal. Kittay (1999) says the following about the idealization built into Rawlsian theory:

It puts too much distance between the 'normal functioning individual' and the person with special needs and disabilities. Not a single citizen approaches the ideal of full functioning throughout a lifetime. The idealization, in contrast, suggests that those who are not fully functioning are relatively few, and that consequences of special needs is brokered only in monetary terms (p. 88).

Rawls, among others (Dworkin, 1981; Harsanyi, 1953), built a theory based on what would best suit man from behind his veil of ignorance, and the theory only works if the condition behind the veil, understood to be empty, excludes certain anomalies. Belying even this seemingly vacuous starting point, then, are substantive assumptions about personhood (Roemer, 2002). Being the same in some meaningful way hinges on the exclusion of difference; having subjects to situate in distributive justice frameworks requires objectification of the Other.

This critique was already explored in a previous chapter through a feminist lens. Feminisms have pointed to the difference gender poses to conventional politics and theories, and even within feminist circles differences have been invoked for the purpose

of internal critique. Intersectionality complicates experiences of oppression, for people with overlapping memberships to various minority groups can claim to have different experiences. There is an interplay built into their identities that produces something new. Says Knudsen: "intersectionality points towards the critical view on becoming 'the other' in a normative setting" (2007, p. 62). Social groups are the result of a binary relationship between the ideal and the non-ideal, and yet the binary is not enough to account for the inexhaustible experiences yielded by combinations of differences.

Knudsen goes on to discuss the centrality of relationships to intersectional analysis:

Intersectionality implies more than gender research, more than studying differences between women and men, and more than diversities within women's groups or within men's groups. Intersectionality tries to catch the relationships between socio-cultural categories and identities. ...Gender, race, ethnicity, disability, sexuality, class and nationality are categories that may enhance the complexity of intersectionality, and point towards identities in transition (p. 61).

The concept of intercorporeal embodiment might be described as one such identity in transition. The pregnant woman and what she is carrying is/are in a state of becoming, as an example. As Knudsen argues, this lens of analysis focuses not merely on combinations of identity, monoliths that themselves need to be deconstructed, but on the relations and connections moving between, reproducing, and sustaining identities.

The concepts discussed here might be foundational to a politics of difference. Such a politics would anticipate and accept difference as "basic to the world" (Noonan, 2003, p. 23). Such a politics would be open to otherness, meaning that infrastructure would be built according to particular needs. Social and political organization would

develop in response to difference, with a goal to include difference, rather than on the basis of a standard that necessarily excludes and regulates difference. Noonan elaborates:

If universal definitions of human nature are always the products of the exercise of power, if every universal definition is made possible by the forcible exclusion and subordination of nonconforming differences, then it follows, postmodern political theory argues, that a radical politics must somehow do away with the idea of human nature. There is simply no underlying identity shared by all human beings. That identity...is an illusion whose real function is to justify the remaking of the world according to the definition of human nature that suits the ruling power. Only by breaking with the belief that all human beings share an essence can differences speak in their own voice (pp. 4-5).

Can this be done practically? That is, can a politics of difference be codified into law, or made manifest in medical contexts? Derrida (1972) argues that we need categories to enable human understanding. Even after deconstruction, what is built will be doomed to be broken down in the future. Does this mean that the critique and dismantling of current systems of power inevitably leads to more of the same, some new method of classificatory thinking that will inevitably do violence to some unanticipated Other? We will see in the sections that follow whether openness to the Other is pragmatically, politically possible.

#### 4.2. Respect for Difference in Bioethics and Law

This section will explore how difference is accounted for (or not) in medical and legal contexts. Beginning with bioethics, based on work accomplished in the previous section, I will develop the components that a principle of respect for difference would include, then I will consider why no such principle can be found in work on bioethical principles. The principles that do exist and are prominent in bioethics, and thus this

work—autonomy and equality—rely on narratives that do not reflect efforts to respect difference. I will review these narratives, beginning with consent and capacity standards that promote and privilege a particular kind of autonomous person. For the second, I will explore how the othering of disability with the use of functional frameworks of health is foundational to equality models.

In the realm of law and policy, I will present where we might find respect for difference in international documents, and will consider whether policy offers a foundation upon which we might develop a framework for respect for difference. In case law, we last analyzed the shortcomings to the Canadian juridical equality model, and I intend to continue the story in order to determine whether respect for difference is ever accounted for, if not called by name. I will examine *Eldridge v. British Columbia (Attorney General)* (1997), which characterized disability as a social phenomenon and paved the way for considerations of context in equality jurisprudence. I will move on to the cases that have followed, examining whether difference has been respected in *Auton (Guardian ad litem of) v. British Columbia (Attorney General)* (2004), and how context has been integrated into equality analysis in *Withler v. Canada (Attorney General)* (2011). Throughout I will question whether equality rhetoric does the work needed to account for difference.

#### *4.2.1. Respect for Difference in Bioethics*

##### Defining Our Terms

A principle of respect for difference requires an understanding of the concept of difference as all differences, including those that are foundational to current oppressive practices and those not yet anticipated. Derridean difference might best account for the sort of difference imagined, and thus might point the way to how we frame strategies by which we might make respect for difference possible. Recall that difference for Derrida (1972) represents all that is other to categories and classifications. That which is outside our current ideas around the self in effect displaces the self, for difference functions as its condition for possibility and the catalyst for its critique.

What I mean to say is that exceptions to our standards, all those who are othered by or absent from theoretical and legal benchmarks, challenge those standards, and a principle of respect for difference might aid us in recalibrating our systems, rather than acting as a method of including people within those systems. The concepts we have been using carry with them the baggage of liberal theory and classificatory thinking, but the call to be open to and respecting of difference has the force to reorient our concepts and challenge their embedded narratives. My concern, then, like Shildrick's (2002), is to "uncover the extent to which the western notion of the sovereign self, and of the bounded body, is, in general, both guaranteed and contested by those who do not, indeed cannot, unproblematically occupy the embodied subject position" (p. 5).

Perhaps the principle of respect for difference is not a principle at all, as long as principles are understood to be abstract, general rules. Difference requires an

understanding of concrete particulars, and thus requires a contextual approach. General rules of action prove ineffective, for they inevitably engage in a process of othering. Their establishment requires conceptual boundary markers, and so some other must exist outside their meaning. Instead, respecting difference might more so resemble justice as corrective critique, or reflective response.

Such a concept is not found in modern theory, for, as I have outlined, modernity consists of philosophies and politics of sameness. Principle-based bioethics, which saw its rise during the modern age, makes few explicit references to anything like respect for difference. Recall that the canonical principles of bioethics are autonomy and justice, beneficence and non-maleficence; there is no place in bioethics foundations for the concept just described, and there is little accounting for difference that is even implicit in the theoretical work that has developed around the existing principles. I have shown that theories of personal autonomy tend to posit a particular sort of person capable of autonomous choice and action, a particular sort of person capable of expressing autonomy through consent. Further, justice as distributive—so justice as formal equality, even equality of opportunity—in the context of health requires assumptions around the standards of health to which people on unequal footing are meant to be elevated. These metanarratives—consent and capacity work, and functional health paradigms—underlie our standards for the Rawlsian free and equal person, he who has entitlements in bioethics discourses. Metanarratives have the effect of distancing us from context, abstracting problems so that general, principle-based strategies might fit as solutions. They are purported to be theories of totalities, even if some other, some difference,

inevitably exists outside the totality. To understand what it means to be the subject, the free and equal person capable of consent and seeking to restore his status as disembodied, we must account for those standards by which nonpersons are excluded, and what it means to be different from and deviant to our standards.

This section's analysis will thus begin with capacity determinations, returning to earlier work done on capacity in this study. I mean to demonstrate that not enough work is being done to respect difference, and to consider how the call to respect difference could potentially change our theoretical and legal discourses.

#### Discursive Relations of Power and the Consenting Self

As already argued, capacity determinations are rendered within relations of power, where medical and legal professionals are accrued authority (Stefan, 1993; Wendell, 1996). The cult of subjectivity has been central to capacity standards, such that only those who share in common the indications of a decision-making mechanism qualify as decisionally capable. Those indications include rationality, independence, individualism (Buchanan & Brock, 1989; Faden, Beauchamp, & King, 1986; Grisso & Appelbaum, 1998)—the properties of the subject borne out of liberal theories.

The subject is disembodied, that is, the concept of the subject is abstracted from the body as object, because the identity of the subject requires a binary in order to be meaningful. The meaning production happening within the power relations of medical contexts is grounded in a dyadic understanding of the subject that acts and the object that is acted upon. The body is objectified, marked by docility and passivity, subjected to

examination, interpretation, and manipulation: "a body is docile that may be subjected, used, transformed and improved" (Foucault, 1977, p. 136). Shildrick (1997) considers this divide, and the importance of critiquing the abstraction of the body:

The issue revolves round two seemingly disparate loci: first, the notion of what it is to be a moral agent at all, which devolves on questions of subjectivity; and second—and this is particularly relevant to health care—what relationship exists between the 'I' who makes choices, who consents, and the body of that agent. Clearly any critique of consent which takes health care as its substantive field must inevitably come up against the materiality of the body (p. 81).

Foucault (1980) describes how the body is objectified due to the institutionalization of the medical gaze. Power is invested in the body, operating continuously with minimal cost, meaning that subjects interiorize standards of normalcy and take on the responsibility of body management: "an inspecting gaze, a gaze which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself" (p. 155). The panoptic medical gaze consists of recommendations and expectations that the patient takes for granted as imperative. The strategy has proven so effective that medicine has come to assume "an increasingly important place in the administrative system and the machinery of power" (p. 176).

Decisional capacity thus acts as a tool for managing bodies in at least two ways. Firstly, those determined to lack decisional capacity see medical decisions made for them, on their behalf. Shildrick (1997) notes that categories of people historically thought to lack capacity are also corporeally grounded: "women are both clearly identified with their bodies, and are paradoxically denied the capacity to exercise moral

agency over their bodies" (p. 81). Autonomy is diminished for those who are determined to lack the mechanism for decisional capacity, that is, for those who cannot be abstracted from their bodies.

Secondly, decisional capacity can be used to justify disproportionate resource distribution in the context of healthcare, where those who experience illness due to their own choices rather than circumstance do not qualify for organ transplantation, as Beauchamp and Childress (2009) as well as Moss and Siegler (1991) discuss in the context of alcohol related End Stage Liver Disease. The consequence is rooted in a notion of justice: justice in the face of resource scarcity in this example. Justice can also manifest as punishment, as seen in the case of Ashley Smith (Ombudsman, 2008, p. 25), whose incarceration and treatment were in response to the diagnosis that she was decisionally capable, and therefore responsible for her actions. Here autonomy is diminished for those who share the mechanism in common but the content of their decisions is not in compliance with social order. The subject is not merely free to make decisions, but is responsible for making the right one, or at least responsible for the consequences of deviation.

Consent and capacity standards are built on a conception of self that excludes certain kinds of people. Those who are different must be excluded, for they are the condition for the possibility of the capable and consenting, and thus autonomous, subject. Further, those who are different, either because they cannot be shown to have the mechanism for decision-making or the content of their decisions does not comply with standards for right or rational choice, are managed such that people are only considered

autonomous when they are in some sense the same. It is in this way that consent and capacity standards, and by implication autonomy theory work, promote and reproduce status quo.

Respect for difference calls for a reorientation. A focus on treatment of those who are different opens up the standards by which people who fall short are managed. Perhaps a reorientation could make use of conceptual work developed around relational autonomy, for the interdependent, intercorporeal other, I have argued, renders explicit how decision-making operates within context. However, it might not be enough to re-conceptualize autonomy so that it is more inclusive; respect for difference should entail critique of systems of power that are eventually, inevitably exclusionary.

#### Disembodied Health and Equality Models

In the context of medicine, the body as object is assumed to be fixed: “some kind of stable and unchanging given, differentiated simply by its variable manifestation of the signs and symptoms of health or disease, ability or disability, normality or abnormality” (Shildrick, 1997, p. 15). That is, until disability disrupts, differentiates, and draws attention, the body is understood to be stable and as such can be forgotten, relegated to the background; if the body is disabled, the assumption is that it should be fixed. It is described to us with medical rhetoric, which is “a language of distance” (Halifax, 2009, ft. 2) to the extent that having our bodies described to ourselves distances subject from object, active from passive, foreground from background. Our identities as subjects are defined in relation to that from which subjectivity has been abstracted—that materiality

of embodiment that serves as grounds for our existence and yet is bracketed out for the sake of meaning production.

This distancing has aided in the personal and social conceptualization of the body as absent. Gimlin (2006) explains how various bodily phenomena are taken to be absent:

Regions involved in perception and action are largely absent from awareness...and those that remain unused recede into the corporeal background. Within the body's depths, internal structures too are largely inaccessible; neither organs nor physiological functioning is readily available to observation or control (p. 701)

Gimlin is recounting work done by Leder (1990) on the absent body. Leder considers how despite the absence of the body, there are experiences that make us conscious of our bodies, or make the body dys-appear. The term dys-appearance derives from the Greek *dys*, meaning "away, apart, asunder" (p. 87). The body appears through what is understood to be disruption and obstacle, at least in contrast with how we expect our bodies to behave: "when the body [is] brought into the foreground by demands (pregnancy, fatigue, hunger, as well as states of illness), we are aware of demands made upon us: feed me, sleep. The dys-appearance of the body occurs when bodily demands require our attention" (pp. 167-168). Dys-appearance may be a complex experience, impossible to localize or to understand as fixed. Hunger, for example, "is a complex nexus of heaviness, exhaustion, conative urges, and discomforting sensations that, while gathering into notes of crystallization, ambiguously inhabits the entirety of the corporeal field" (p. 42).

Disability, disease, and injury especially are "typified by complex patterns of dysfunction" (p. 81). The body can no longer be absent with such a drastic disruption.

Recall Clare (2007), whose body is always present because his engagement with the world is punctuated by “muscles knotted, tendons inflamed, vertebrae too sore to touch” (p. 77). Shildrick (1997) notes “the body is curiously absent to us during health, and it is only in sickness that it makes itself fully felt, and then as that which unsettles the sense of self” (p. 10). That is, when the body does not function as a properly absent object, it unsettles abstracted subjectivity by interrupting and reshaping active engagement.

Shildrick (1997) and Scully (2008) suggest this means we should take the materiality of bodily difference as a starting point for bioethics. Shildrick advocates reshaping bioethics into “not so much a feminist reconstruction of the general principles or rules of behaviour, as an ethic in which differences are acknowledged, respected and allowed to flourish as the very basis of moral discourse” (p. 6). What we have instead, much more predominantly, are health models that are motivated by dys-appearance to manage difference, and push it back into the stage scenery: “one’s ‘whole being is forcibly reoriented’ towards a new goal: to rid ourselves of bodily intrusion by whatever means necessary” (Leder, 1990; as cited in Gimlin, 2006, p. 701). Concepts of functional or normative health characterize difference as deviation, that which needs to be corrected. Equality comes to be a matter of managing difference, restoring the dys-appeared body back to the ideal standard so that it can again be forgotten. It is for this reason that “medicine has played an increasingly important role in the construction and regulation of ‘normal’ subjects” (Marks, 1999, p. 75).

Foucault (2003) notes that the language of medical management does the best it can to classify difference, regardless of how complex dys-appearance can be. Similarly

to the manifestation of hunger, disability and disease appear in varied combinations of symptoms throughout the body, subject to transformation over time. And yet, fixed labels are necessary for diagnosis and treatment, so “the space of configuration of the disease and the space of localization of the illness in the body have been superimposed, in medical experience” (p. 3). He goes on: “the medical gaze, open to these fine qualities, necessarily becomes attentive to all their modulations; the decipherment of disease in its specific characterizations is based on a subtle form of perception that must take account of each particular equilibrium” (p. 14). What he means is that medicine is framed with classificatory language to define and manage the complex and complicated ways in which the body materializes.

Medical understandings of the body’s equilibrium and dysfunction, as well as the medical goal to erase and render absent dys-appeared bodies are particularly problematic for those populations whose corporeal associations are entangled in social inequalities. Those bodies that are doomed never to comply or conform with the standard of the absent, functioning body are subject to heavy medical scrutiny and management: “normalizing individuals by imposing the standard of species-typical functioning may itself disadvantage...any population that already has been made vulnerable because its members do not function in the normal, typical, or customary way” (Silvers, 1998, p. 65). Leder (1990) considers how social, rather than simply bodily, phenomena can produce dys-appearance, that is, can foreground the body:

In social dys-appearance, this split [of the body away, apart, asunder from itself] is effected by the incorporated gaze of the Other. But not just any gaze will bring about such a rupture; it is the objectifying gaze that refuses contrasensence. As long as the Other treats me as a subject—that is,

experiences with me to the world in which I dwell, mutual incorporation effects no sharp rift. But it is different when the primary stance of the Other is highly distanced, antagonistic, or objectifying. Internalizing this perspective, I can become conscious of my self as an alien thing (p. 96).

The medical industry responds to dys-appeared bodies by offering management and curative strategies, and it is in this way that bodies marked by differences such as gender, disability, race, and sexuality, are disproportionately targeted and pushed to be docile when subjected to the leveling medical gaze. Says Dolmage: “the alien body could be publicly stigmatized and displayed, or removed to the back rooms...for further medical inspection, or passed along, yet always formatively imbued with the spirit of the investigation and the power of the gaze” (2011, p. 36).

Medical models have objectified and decontextualized the body (Halifax, 2009), and disruption of these efforts only leads to more forceful strategies to reorient and render absent; legal approaches to difference in large part rely on these models and are therefore also complicit in rendering bodies absent. Mykitiuk (1994) discusses how legal reasoning is a kind of classificatory thinking, “all about categorizing, characterizing, sorting and fitting complex social phenomena and relations into pre-existing legal pigeon holes” (p. 67). The category taken to be the benchmark is the liberal self, with a normal body (Karpin & Mykitiuk, 2008, 2011). Such a self can only serve as a benchmark when abstracted from the body or else it would be all too clear the particular body in which the liberal self is grounded. According to Mykitiuk: “at the center of liberal, legal discourse we find not an absent body, but a particular body, one who is white, male, heterosexual, able bodied, young, adult, and it is this body which has been generalized as the normative body of liberal discourse” (1994, p. 80). Discourses that reflect a politics of sameness

require that a specific sort of body be privileged as worthy of equal standing. The sort of body just described can only pass as the condition for the liberal subject because it “has accrued sufficient social, economic, cultural, and political resources to minimize the impact of its dependency and interconnection with others” (Karpin & Mykitiuk, 2011, p. 121).

To have a standard implies that those who are other to that standard need to be managed. Drawing from postmodern theory, Shildrick (2005) argues: “law is never impartial but always caught up with strategies of power and with a discursive violence that seeks to grasp and domesticate the troublesome other” (p. 31). She holds that even while this is the case, those who are other to the liberal self “not only escape the instrumental structure of the law, but radically disturb the very framework under which the juridical operates” (p. 39). She uses the Derridean Other, or “dispersed and undecidable subjectivity” as her entry point into a new legal approach, one which “might give way to an embrace of difference that was celebrated precisely in its uncertainty, its fluidity and its interconnections” (p. 39). A legal approach that embraces alterity would respond to difference rather than classify difference in advance. Pronger (2002) elaborates:

The ethics of inclusion, which tries to bring otherness into a system while requiring it to manifest itself within the structure of the system, appropriates otherness, making it conform to the system. The ethics of alterity, in contrast, works not by inclusion, but by openness—openness to otherness in a way that allows the other to deconstruct the system to call into question the system’s limits (p. 17).

Are we moving toward anything like such an approach in Canadian law and policy? We see legal work to develop a concept of respect for difference more so than we see in

bioethics, and yet are these developments promoting a shift in the structure of our legal approaches?

#### *4.2.2. Respect for Difference in Law*

##### The CRPD: Respect for Difference and Supported Decision-Making

The United Nations Convention on the Rights of People with Disabilities (2006b), or CRPD, was ratified in Canada in 2010. Estey (2011) provides a more detailed account of the process:

In December 2006 the United Nations adopted the Convention on the Rights of Persons with Disabilities. On March 30, 2007, the government of Canada was one of the first countries to sign. The Convention became international law with respect to ratifying states on May 3, 2008, when 20 member states of the United Nations ratified the Convention. On March 11, 2010, Canada became the 82<sup>nd</sup> country to ratify it (unpaginated).

In the CRPD (2006b) eight principles are recommended for codification into law.

Included in these principles is respect for difference, defined in the following way:

“respect for difference and acceptance of persons with disabilities as part of human diversity and humanity”. The Law Commission of Ontario (LCO)’s Project on Disability Law Reform (2012a, 2012b) takes a principle-based approach that adopts the CRPD’s framework, and has thus reflected on what it means to respond to diversity in human abilities:

This principle requires recognition of and responsiveness to the reality that all people exist along a continuum of abilities in many areas, that abilities will vary along the life-course, and that each person with a disability is unique in needs, circumstances and identities, as well as to the multiple and intersecting identities of persons with disabilities that may act to increase or diminish discrimination and disadvantage (2012b, p. 17).

The LCO goes on to say: “persons with disabilities are not ‘the other’, but are part of the range of human experience” (p. 17). Disability as an identity is by no means homogeneous, covering a vast range of disabilities, and the experience of disability changes in relation to other identity categories. Respect for diversity entails not redressing disability as a shortcoming, but acknowledging that abilities exist on a spectrum—as opposed to within a hierarchy. Differential treatment in such a context is not necessarily ameliorative but entails a valuing of and openness to all persons.

Also of interest are the controversies surrounding the development of Article 12, according to which, “State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law”. Specifically, the Article calls for recognition of “legal capacity on an equal basis with others in all aspects of life” and the obligation to “provide access by persons with disabilities to the support they may require in exercising their legal capacity”. Reservations to Article 12 have been noted by some state parties that have adopted the CRPD. These reservations have posed the following questions: “how has legal capacity been constructed in the CRPD? Does it include both the capacity to have rights and the capacity to act? If yes then has this legal capacity been extended to all persons with disabilities or have certain persons been excluded?” (UN, 2008, p. 1). In response, the UN declared that “a reservation on article 12 is antithetical to each of [the principles listed in the CRPD]” (p. 3), including equality, non-discrimination, respect for dignity, and autonomy. Rather than demarcating between persons, the CRPD advocates a supported decision-making model that highlights the contexts and relations within which decision-making takes place (Dhanda, 2006-2007).

The UN (2007a) identifies the province of British Columbia as “one of the leading jurisdictions in incorporating supported decision-making into law, policy and practice” (p. 90). In British Columbia, under this model, a person in need of support when making decisions may enter into a representation agreement with a support network. This agreement is a legal document that authorizes members of the support network to assist the individual or to act on her behalf (Nidus, n.d.). This arrangement is laid out in the 1996 BC *Representation Agreement Act*, the purpose of which is cited under s. 2:

- (a) To allow individuals to arrange in advance how, when and by whom, decisions about their health care or personal care, the routine management of their financial affairs, or other matters will be made if they become incapable of making decisions independently, and
- (b) To avoid the need for the court to appoint someone to help adults make decisions, or someone to make decisions for adults, when they are incapable of making decisions independently.

Under s. 3.1 of the *Act*, decision-making capacity is presumed: “until the contrary is demonstrated, every adult is presumed to be capable of (a) making, changing or revoking a representation agreement, and (b) making decisions about personal care, health care and legal matters and about the routine management of the adult’s financial affairs”. The UN (2007a) has referred to the supported decision-making model as an innovative alternative to traditional guardianship laws, hence its incorporation into the CRPD.

Even so, the wording in Article 12 has been left ambiguous, and its ambiguity reflects a history of difficult discourses around its development. During the early stages of writing the Convention, a footnote was included in Article 12: “in Arabic, Chinese and Russian, the term ‘legal capacity’ refers to ‘legal capacity for rights,’ rather than ‘legal

capacity to act” (UN, 2006a). The footnote was meant to draw a distinction between recognizing disabled persons as persons, and recognizing them as possessing the capacity to act. A disabled person may still be entitled to rights, except for those that require consent, should she be diagnosed as lacking in capacity. This distinction would justify legal systems continuing to employ paternalistic models of guardianship, where guardians substitute in their judgment in the best interest of disabled persons who have been declared incompetent or incapable. Dhanda (2006-2007) notes that “the introduction of this distinction between legal capacity for rights and legal capacity to act was strongly questioned by representatives of civil society and non-governmental organizations” (p. 443).

The Article certainly promotes supported decision-making, although it leaves open the possibility that member states adopting the CRPD may continue to endorse a substituted decision-making model. The Coalition of Individuals, Organizations and Agencies of the People for the People and by the People with Disabilities in Eastern Europe (2003) proposed that an early draft of the Article include the clause: “where as a person with intellectual disability is not able to exercise this right, the legal guardians of that person shall be entitled to exercise the right on behalf of and in the interests of, that person” (Art. 25(3)). The non-governmental organization Inclusion International objected to “the introduction of any reference to paternalistic guardianship laws in the Convention” (Dhanda, 2006-2007, p. 439). Debate over the language of the Article continued into the Seventh Session on the development of the CRPD, during which time modified text was proposed in an attempt to “combine some of the safeguards required

for guardianship with some of the standards desired for supported decision-making” (p. 450).

This text was accepted, and stands as the language currently found in the CRPD under Article 12, meaning that although the Article advocates supported decision-making, and although this was reiterated in the UN response to recent reservations, Article 12 “does not prohibit substituted decision-making” (p. 439). Indeed, when Canada adopted the CRPD, it took the position that “the article only requires that denial of capacity should not happen on a discriminatory basis” (p. 455-456). The Canadian statement made on the adoption of the Convention reads as follows” “[the Article] is not a prohibition on substitute decision-making regimes [although] it does place particular emphasis on the importance of supported decision-making” (UN, 2007b, unpaginated).

So Article 12 leaves the door open for substitute decision-making models, which are built upon determinations of incapacity. This is a problem because with such a model disabled people begin at a starting point where their capacity is questioned and tested. Their status as consenting selves can be called into question. A substitute decision-making model requires state investment in mechanisms for determining in/capacity, for differentiating between persons with and without capacity. A supported decision-making model, in contrast, accounts for a wide range of persons with a variety of needs, and assumes that capacity is not a qualification for the enjoyment of rights or recognition, but a capability that varied supports cultivate:

If support was to be provided proportionately to the actual needs of the person with disability, then it would encompass the entire range of support, from the lowest to the highest level of support. The fact that a

person requires high support was not a reason to surmise absence of capacity (Dhanda, 2006-2007, p. 445).

The Convention does indeed embrace a progressive model, one that reflects respect for difference. However, there is prudence in acknowledging the history of Article 12, as this history demonstrates that the rhetoric is open enough to function as a sort of back-door for substitute decision-making—a model that reorients our approach to disability in such a way that does not signify respect for difference. Already we can see how despite the adoption of the CRPD, countries can justify problematic positions on disability through wider interpretations of Convention language.

#### Respect for Difference in Other UN Instruments

The CRPD is one of several themed covenants that have been written since the 1960s to address how “distinct groups of people in the global community [are] not able to enjoy their rights in the same way as others” (Estey, 2011, unpaginated); examples of distinct groups include racialized and Indigenous persons, and women. We might look to instruments of this sort to determine where in policy a principle of respect for difference has been articulated or implied.

For example, in the UN Declaration on Race and Racial Prejudice (1982), despite beginning with an appeal to commonality—“all human beings belong to a single species”—article 2 claims that “all individuals and groups have the right to be different, to consider themselves as different and to be regarded as such”, and further, “the diversity of life styles and the right to be different may not, in any circumstances, serve as a pretext for racial prejudice”. Contained within this article is recognition of racial diversity. A

commitment to non-discrimination should not be reduced to inclusion as assimilation; it should entail an openness and flexibility to human difference.

As another example, the UN Declaration on the Rights of Indigenous Peoples (2007c) affirms “that indigenous peoples are equal to all other peoples, while recognizing that right to all peoples to be different, to consider themselves different, and to be respected as such”. The preamble goes on to affirm “that all peoples contribute to the diversity and richness of civilizations and cultures, which constitute the common heritage of humankind”. A framework for addressing the oppression that Indigenous people have experienced and continue to experience cannot stand on a foundation of sameness when that oppression is rooted in colonialist strategies of aggressive assimilation, displacement, and effacement. Recognition of sovereignty entails recognition of the entitlement of a civilization or a people to be different.

Further, the Convention on the Elimination of All Forms of Discrimination against Women (1979) recognizes differential impact, even if only implicitly. The Convention recognizes that some freedoms and protections must be tied to reproductive function, and so these entitlements must be designed differently compared to the entitlements men enjoy. For instance, article 11 recognizes the “right to protection of health and to safety in working conditions, including the safeguarding of the function of reproduction”, and article 12 declares that “State Parties shall ensure to women appropriate services in connection with pregnancy, confinement, and the post-natal period”.

Of note, however, is that throughout the Convention on the Elimination of All Forms of Discrimination against Women, the rights put forward seem to be designed for the purpose of leveling that playing field, elevating women to the same plane men occupy. According to the preamble, human beings are entitled to rights and freedoms “without distinction of any kind, including distinction based on sex”. The very real, bodily distinction of reproductive capacity may thus be framed not as a difference to be respected, but a disadvantage to be redressed and overcome.

Indeed, the UN policies outlined here, despite paying heed to difference, all ground entitlement in our common humanity. Respect for differences in culture and gender is justified by an essential sameness, which indicates that our standards still hold even when framing respect for difference in policy. Space can be made for acknowledgment of difference, but the imagination for and anticipation of difference remains limited because international policy contains necessarily empty concepts, yet to be filled, applied, and enforced at the time of drafting. We are entitled to respect because we qualify as members of the human race—which remains an Aristotelian category, and a classification invented within the context of modernity. That is, we are entitled to respect for our differences, but only because we as human beings, as persons, are essentially all the same. It is not enough to speak of respect for difference in the abstract, when the principle has the force to challenge and critique the pitfalls to abstraction. It is not enough to ground respect for difference in modern classificatory justifications and appeals to essential commonalities as though differences are mere attributes, when

respect for difference could instead be grounded in concrete particulars, nuanced contextualization, and transformative postmodern politics.

### Eldridge

If we are to search for where difference is respected in Canadian law, we might consider how the principle is implicitly present in equality analysis, where s. 15(2) is designed to allow for positive action, or ameliorative differential treatment. As explained in the previous chapter, however, allowing for positive action does not mean that the *Charter* requires it, and this gap is highly problematic. Also of note, positive programs and policies are meant to be corrective (*R. v. Kapp*, 2008) so that people who are disadvantaged rise up to a standard; this rhetoric does not necessarily imply that differences are respected as central to the human condition, only that differences can be overcome. This approach does not properly reflect a politics of difference, which would involve the acknowledgment, accounting for, and celebration of diversity.

Might there be some other track to take regarding respect for difference in equality analysis? Might we use a robust concept of equality, one sufficiently distanced from equality of sameness, even equality of opportunity, to assert a politics of difference? I will pick up where I left off in the story of equality jurisprudence, considering what has come of the more rigidly defined, category-dependent concept of intersectionality.

In *Eldridge v. British Columbia (Attorney General)* (1997), Robin Susan Eldridge, along with John Henry Warren and Linda Jane Warren (the latter two a married couple), were each born Deaf and preferred sign language as their primary means of

communication. Eldridge was hiring interpreters for important medical appointments, but alleged that she could not afford to bring her own interpreters for every appointment. These visits without interpretation she found to be “very stressful and confusing” (p. 17) due to communication barriers with her medical providers. Her physician, too, found communication “inhibited and frustrating” (p. 17). Linda Warren’s physician testified that communication by handwritten notation was “time consuming, impractical and has the potential to result in harm in some circumstances” (p. 17). In the Warrens’ case, communication was especially essential for Ms. Warren’s reproductive health since she had given premature birth to twins:

Adequate communication...is particularly critical for childbirth. If the doctor<sup>33</sup> can communicate with the patient so that the patient is able to help with the delivery...complications are less likely to occur and the patient is less apt to have a traumatic birth. In [the physician’s] view, writing notes is not effective in these circumstances; an interpreter is necessary for proper communication (pp. 17-18).

While the trial was taking place, Ms. Warren was pregnant again, and could not afford the hire an interpreter for the delivery, “or for other visits to their doctor” (p. 18).

British Columbia funds medical services under the *Hospital Insurance Act*, which grants hospitals as private corporations discretion with delivery; and under the *Medical Services Plan*, when benefits are core medically required services. Eldridge and the Warrens challenged the leeway given to hospitals under ss. 3, 5, and 9 of the *Hospital Insurance Act* to determine provision and delivery of services. These sections, they claimed, failed “to require that hospitals provide medical interpreter services for the deaf” (p. 3). Further, they challenged the definition of “insurable benefit” under s. 1 of the

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<sup>33</sup> Midwives could have also been identified in this passage.

*Medical Services Plan* for “failing to include medical interpreter services for the deaf” (p. 3). They claimed that these provisions were in violation of s. 15 of the *Charter*. They held that the absence of sign language interpreters “impairs their ability to communicate with their doctors and other health care providers, and thus increases the risk of misdiagnosis and ineffective treatment” (p. 2). The Supreme Court ruled unanimously that s. 15 should be expanded to apply to hospitals, and that sign language interpretation is a core medically necessary service. The failure to provide interpretation services violated s. 15(1) and could not be saved by s. 1.

Regarding the *Hospital Insurance Act*, the Court determined that discrimination against the claimants was “intimately connected to the medical service delivery system instituted by the legislation” (p. 6) in question. That hospitals were not required to offer interpretation was found to be in violation of equality rights. Social services like sign language interpretation are a necessary component to healthcare delivery, and an obligation that hospitals must meet inasmuch as healthcare is a legislative mandate:

The Legislature, upon defining its objective as guaranteeing access to a range of medical services, cannot evade its obligations under s. 15(1) of the *Charter* to provide those services without discrimination by appointing hospitals to carry out that objective. In so far as they do so, hospitals must conform with the *Charter* (p. 6).

Regarding the *Medical Services Plan*, during the original trial, interpretation services were defined as ancillary and therefore nonmedical; and nonmedical services would not qualify as an insurable benefit. This approach to the service led to a grave mischaracterization of “the practical reality of health care delivery” insofar as

“miscommunication can lead to misdiagnosis or a failure to follow a recommended treatment” (p. 54).

The rhetoric of equality of sameness could not account for the discrimination, for the Canadian healthcare system could claim to be treating Deaf and hearing populations alike by offering the same services to both. It was argued instead that a general application of law can result in adverse effects discrimination, and the failure “to provide benefits...without ensuring that disadvantaged members of society have the resources to take full advantage of those benefits bespeaks a thin and impoverished version of s.

15(1)” (p. 8). The ruling goes on:

Even in imposing generally applicable provisions, the government must take into account differences which in fact exist between individuals and so far as possible ensure that the provisions adopted will not have a greater impact on certain classes of persons due to irrelevant personal characteristics than on the public as a whole (pp. 51-52).

The approach taken does use language associated with equality of opportunity, where disadvantaged people are brought up to an equality standard. Though rejecting equality of sameness, or general rule application equality, as thin and impoverished, the Court did not take that further step toward substantive equality, leaving aside the possibility that sign language interpretation qualifies as a positive obligation to treat differentially: “the question raised in this case is of a wholly different order. This Court has repeatedly held that once the state does provide a benefit, it is obliged to do so in a non-discriminatory manner” (p. 56). Sign language provisions were understood only to be a resource necessary to access a good that should be available to all.

The Supreme Court considered the relevance of adverse effects discrimination for disabled persons especially:

This historical disadvantage [disabled people experience] has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the 'equal concern, respect and consideration' that s. 15(1) of the *Charter* demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been condition upon their emulation of ablebodied norms (p. 47).

It was acknowledged that Deaf persons experience disadvantage as a result of social barriers to communication, and these barriers are based on the assumption that everyone can communicate orally. The case involved recognition that disability is a social phenomenon, that is, that people are disabled by social conditions; the ruling thus acknowledged the amelioration of disability-related disadvantage and the full inclusion of Deaf persons into our society require that the law respects the very different ways in which Deaf persons may communicate. Cornish and Faraday (1998) reflect on the ruling:

The obligation to prevent adverse effects discrimination is especially relevant to the disabled as the Court noted that discrimination often arises not from singling out the disabled for special treatment, but from the exact reverse—the government's failure to understand and address the adverse effects on the disabled caused by laws of general application (p. 4).

The Court applied a social model of disability, one which understands disability as entirely imposed by external forces that uphold standards of normativity (Oliver, 1990, 1996; Priestley, 1976; Siebers, 2008). This marks a significant step forward in jurisprudence on disability.

Of note, however, is that the classic social model of disability fails to account for the phenomenology of embodiment, the possibility that experiences of pain, immobility,

madness, or learning frustrations are meaningful and impactful. Deaf advocates (Crouch, 1997; Lane & Grodin, 1997) often characterize Deafness as a linguistic and cultural minority rather than identifying with disability models (to be discussed further in a later section), so they too might overemphasize external disadvantage, but it would be folly to continue to erase how disadvantages are intimately and importantly tied to embodiment. Dolmage (2011) says of the social model, in an effort to locate bodies at its centre: “bodies...are undeniably material, yet they are also undeniably rhetorical” (p. 28); even when exploring the social constructions of disability, then, he acknowledges materiality, corporeality, bodily presence. We can look to how bodies are shaped and transformed by social forces, and how they respond and resist.

### Auton

The work accomplished in *Eldridge* was allegedly undone in *Auton* (*Guardian ad litem of*) v. *British Columbia (Attorney General)* (2004), although the allegation necessitates further examination of the way in which *Auton* interpreted disability and equality. Parents of Connor Auton sought funding for Applied Behavioural Analysis (ABA) or Intensive Behavioural Intervention (IBI) therapy when they could no longer afford the treatment. They and four sets of parents with autistic children challenged the refusal on the part of British Columbia’s provincial government to fund ABA/IBI, invoking s. 15(1).

The Supreme Court of Canada determined that s. 15 had not been violated, a ruling that was based on two premises. Firstly, “the claim for discrimination is based on

the erroneous assumption that the [*Canada Health Act*] and the relevant British Columbia legislation provided the benefit claimed” (p. 9). The trial judge characterized ABA/IBI as a core medically necessary service. As such, the service must be made available with costs covered in order for provincial governments to qualify for federal healthcare funding (Finley, 2005). The Supreme Court of Canada determined that the treatment is not a core medically necessary service, and as such would be delivered according to the province’s discretion:

The legislative scheme does not promise that any Canadian will receive funding for all medically required treatment. All that is conferred is core funding for services provided by medical practitioners, with funding for non-core services left to the Province’s discretion (*Auton*, 2004, p. 21).

Secondly, “on the facts here and applying the appropriate comparator, it [was] not established that the government excluded autistic children on the basis of disability” (p. 10).

The trial judge accepted the claimants’ comparator, used to demonstrate that denial of a medically necessary service to a disadvantaged group constitutes discrimination: “by denying a ‘medically necessary’ service to the disadvantaged groups (autistic children, a subset of the mentally disabled), while providing ‘medically necessary’ services to non-autistic children and mentally disabled adults, the government discriminated against autistic children” (p. 13). The Court of Appeals upheld the judgment, drawing a broader comparison with all members of the provincial *Health Services Plan*. However, the Supreme Court of Canada found that the comparator was problematic:

An overly technical approach to s. 15(1) is to be avoided. In *Andrews...McIntyre J.* warned against adopting a narrow, formalistic analytical approach, and stressed the need to look at equality issues

substantively and contextually. The Court must look at the reality of the situation and assess whether there has been discriminatory treatment having regard to the purpose of s. 15(1), which is to prevent the perpetuation of pre-existing disadvantage through unequal treatment (p. 17).

The Supreme Court rejected the comparators used and supplanted the following comparator instead: “non-disabled people or people suffering from disabilities other than mental disabilities seeking or receiving funding for a non-core therapy important for health, which is emergent and only recently becoming recognized as medically required” (p. 28). This comparator was built because comparators “must be like the claimants in all ways save for characteristics relating to the alleged ground of discrimination” (p. 28).

Eberts, a Friends of Children with Autism representative who testified during the case, held that the Supreme Court decision had “torn the guts out of s. 15” (as cited in Finley, 2005, p. 236). The ruling has been criticized for contradicting *Eldridge* (1997) by interpreting equality narrowly (Cousins, 2009; Finley, 2005). In the earlier case a service for disabled people was characterized as a core medically necessary service, part of and essential to a complex healthcare delivery system, and as such could not be left to provincial discretion. In *Auton*, a service for disabled people was not classified as a core service, and so whether it would be insured remained a matter for provinces to decide.

Cousins (2009) explains the contrast between the two cases:

In *Eldridge*...the Supreme Court held that a failure to provide sign language interpretation where this was necessary to ensure equal access to health care was in breach of the equality provisions in section 15(1) of the *Charter*. However, in the subsequent case of *Auton*...the Court rather narrowly circumscribed the limits of this approach (p. 717).

Called into question is the type of equality analysis employed. Cousins characterizes the contrast between *Eldridge* and *Auton* as swinging “between interventionist and non-interventionist policies” (p. 717). Leaving the decision to fund ABA/IBI to provincial governments arguably points to the shortcomings of s. 15, that is, the way in which equality rights function as a shield rather than a sword, a negative rather than a positive entitlement. Though the *Eldridge* ruling suggested that jurisprudence was moving in the direction of substantive equality, *Auton* has been framed as a throwback to the formal interpretation of equality found as far back as 1979 *Bliss* (OJEN, n.d.). Finley argues: “though the Supreme Court has repeatedly pledged itself to a substantive approach to equality, the reasoning in *Auton* reflects a formal definition of equality” (2005, p. 224).

Perhaps worthy of note is why ABA/IBI was not classified as a core medically necessary service. The behavioural therapy, targeting children between the ages of three to six, involves “the repetitive use of stimuli and emphasized cues” (p. 10). The method is “intensive and therefore expensive”, and that intensity consists in “crude and arguably painful stimuli” (p. 10). Its success rates are marginal: “the trial judge found only that in ‘some cases’ it may produce ‘significant results’” (p. 10). Perhaps more important than its results is its purpose: “changing the child’s mind and personality” (p. 10). Indeed, the urgency behind targeting children at such a young age has to do with changing behaviours, even identities, during formative years.

A self-advocate, or an activist who identified as autistic, testified during the appeal to argue against the therapy. This self-advocate was not alone. Baker notes:

“some members of disability groups fundamentally objected to the creation of an environment in which the right to ABA could be promoted because of their tendency to equate autism with disease and to emphasize the suffering of individuals with autism” (2008, p. 579). The therapy is an example of an effort to cure or normalize autistic people. A ruling in favour of the petitioners, at least in regard to this first premise, might have further sanctioned the medicalization of disability, the work to erase difference.

Critics also target the second ground for the *Auton* ruling—the work around comparators. According to Gilbert and Majury: “the contextual analysis, which would consider unfairness in a more nuanced and sophisticated way, is lost, in favour of an analysis that says that the claimants must find a group to whom they could belong but for the personal characteristic that separates them” (2006, p. 130). This “but/for” framework harkens back to the condition of being similarly situated: “this is the essence of the critique of the ‘but/for’ approach—that it precludes complexity, intersectionality or any analysis of layers of oppression” (p. 130). All “similarly situated” can truly mean is “like the dominant group,” the group with privilege or status. Disabled person must compare with the supposed counter-part, the non-disabled person in the same situation. Gilbert and Majury elaborate:

Equality, as an inherently comparative concept, confirms dominant groups as the standard for comparison and essentializes the grounds upon which comparisons are made. From this perspective, equality’s comparative nature renders it extremely limited and limiting, as a tool and as an aspiration. Essentialism and the imposition of dominant standards are unquestionably some of the risks that arise from the use of the concept of equality in trying to address oppression (pp. 112-113).

So given the complications built into the *Auton* ruling, we might conclude that if we were to look for an entry-point for the principle of respect for difference into equality analysis, we must look elsewhere.

### Withler

In *Withler v. Canada (Attorney General)* (2011), Hazel Ruth Withler and Joan Helen Fitzsimonds were widowed by spouses whose occupations were in the Civil Service and the Canadian Armed Forces, respectively. They both saw reductions in their federal supplementary death benefits—a lump sum payment provided for deceased members' beneficiary—due to the ages at which their husbands died. Withler and Fitzsimonds contested the reduction of the Supplementary Death Benefit by 10% “for each year by which the plan member exceeded a prescribed age” (p. 4). That is, the reduction was the result of the ages at which their husbands died, past sixty (the limit in the *Public Service Superannuation Act*) and sixty-five (the limit in the *Canadian Armed Forces Superannuation Act*). The age restrictions were challenged on the basis of s. 15. It was ruled that there was no violation.

The Supreme Court of Canada determined that comparators constituted an inappropriate approach to equality analysis. Marking an important step for this study, it was legally acknowledged that comparators run the risk of formalizing equality:

The ‘minor comparator group’ analysis may become a search for sameness, may shortcut the substantive equality analysis and may be difficult to apply. ...A minor comparative approach can fail to identify...the discrimination at which s. 15 is aimed. What is required is an approach that takes account of the full context of the claimant group’s situation, the actual impact of the law on that situation, and whether the

impugned law perpetuates disadvantage to or negative stereotypes about that group (pp. 4-5).

The doing away with comparators “provides the flexibility required to accommodate claims based on intersecting grounds of discrimination” (p. 5). This can be done because monolithic identity categories no longer function as a standard. It might well be possible to legally conceive of identity as overlapping and fragmented. Without such a conceptualization of identity, some forms of discrimination fall through the cracks, because “discrimination...is neither reducible to a single inequality nor simply additive” (LEAF, 2010, unpaginated). Overlapping memberships to various sorts of identities may yield different kinds of oppression. Says Pothier: “people at the intersection of grounds are not just more vulnerable to discrimination, they also experience discrimination in different ways and/or in such a different context as to add an entirely new dimension to the problem” (2001, p. 62).

The Supreme Court determined that the purpose of equality jurisprudence has been to build a “substantive and contextual approach and a corresponding repudiation of a formalistic ‘treat likes alike’ approach” (*Withler*, 2011, p. 5). The ruling elaborates:

Whether the s. 15 analysis focuses on perpetuating disadvantage or stereotyping, the analysis involves looking at the circumstances of members of a group and the negative impact of the law on them. The analysis is contextual, not formalistic, grounded in the actual situation of the group and the potential of the impugned law to worsen their situation (p. 24).

This approach enables the courts to account for, perhaps eventually require, differential treatment for the purpose of redressing the systemic discrimination permeating one’s context:

The focus of the inquiry is on the actual impact of the impugned law, taking full account of social, political, economic and historical factors concerning the group. The result may be to reveal differential treatment as discriminatory because of prejudicial impact or negative stereotype. Or it may reveal that differential treatment is required in order to ameliorate the actual situation of the claimant group (p. 25).

Bay reflects on the importance of this landmark case: “complexity...is what is needed. It is the recognition of how power relationships interplay and inequalities co-exist simultaneously that provides real insight into disadvantage and discrimination” (2011, p. 3). Indeed, with *Withler* we see a contextualization and substantiation of identity and equality, a recognition of the interplay of inequalities and oppressions.

The ruling is fresh, though. Despite showing much promise, a contextual approach has not yet been applied to healthcare. In the sections that follow I will consider how such an approach might take shape, specifically in the case of reproductive health, keeping in mind Shildrick’s (1997) call to avoid general principles and to instead render contextualized, material embodiment central.

#### 4.3. Reproductive Justice

In this section I will consider the importance of acknowledging difference and recontextualizing embodiment. The experience of pregnancy is rooted in very clear biological differences between men and women<sup>34</sup>—differences which have served as the

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<sup>34</sup> This section moves into an analysis of gendered difference with a focus on the man/woman dichotomy that has been historically established and oft-discussed. I will be concentrating on the oppression of women through the construction of gender and the discounting of their reproductive bodies; I do so for the purpose of remaining within the scope of this study. I acknowledge, though, that work has been done to complicate and redefine the male/female divide with the introduction and analysis of transgendered

grounds for interpretative, ideological work to construct gender-based inequalities.

Through an investigation of context, I will claim that reproductive justice can accomplish what principles with a liberal gloss have failed to effect. When considering law and policy, I will review case law on reproductive autonomy and equality, and I will investigate sex selective abortion in the context of Canadian policy, healthcare delivery, and public opinion.

#### *4.3.1. Reproductive Justice in Bioethics*

##### Reproductive Difference and the Impossibility of the Autonomous Subject

Beauvoir (1956) considers how women are othered by virtue of biological difference. For her, gendered differences are rooted in the bodily differences between the sexes. This occurs in the case of menstruation: “it is during her periods that she feels her body most painfully as an obscure, alien thing; ... woman, like man, is her body but her body is something other than herself” (p. 57). Invoking language already used in this study, we might characterize the phenomenology of menstruation as the body dys-appearing, or being torn apart and asunder, brought to the foreground of consciousness (Leder, 1990).

This experience of dys-appearance also manifests during pregnancy:

It is especially noteworthy that the pregnant woman feels the immanence of her body at just the time when it is in transcendence; it turns upon itself in nausea and discomfort; it has ceased to exist for itself and thereupon becomes more sizable than ever before. The transcendence of the artisan, of the man in action, contains the element of subjectivity; but in the

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reproductive bodies (AHRA/LGBTQ Working Group, 2008; Brothers & Ford, 2000; De Sutter, 2001; Jones, 2000).

mother-to-be the antithesis of subject and object ceases to exist; she and the child with which she is swollen make up together an equivocal pair overwhelmed by life (Beauvoir, 1956, pp. 477).

Beauvoir's characterization of pregnancy is meant to challenge concepts of self that have been critiqued throughout this chapter. The notion of the independent agent is annihilated in the context of pregnancy (Young, 1984), such that "it is not too clear when the new individual is to be regarded as autonomous: at the moment of fertilization, of birth, or of weaning" (Beauvoir, 1956, p. 50).

There is a gendered<sup>35</sup> differentiation of the roles men and women play during the reproductive process (O'Brien, 2007). Whereas the alienation of woman from fetus-turned-infant is mediated by labour, men are separated from their seed in such a way that they might legitimize concepts of individuation: "the sperm...becomes a stranger to him and separates from his body; so that the male recovers his individuality intact at the moment when he transcends it" (Beauvoir, 1956, p. 50). O'Brien (2007) explains:

Men are free in both the sense of freedom which liberal thought has developed: there are positive and negative aspects of paternal freedom, freedom from and freedom to. Men are aware of parenthood but free from reproductive labour. They are also free to choose paternity, or, as they have liked to put it, to 'acknowledge' the child as theirs (p. 74).

Although there are clear biological differences between men and women in reproductive contexts, gendered differentiation requires interpretive work, that is, work to fit these differences into particular narratives. Already we see that the interpretation of the role men play suits liberal theories of personhood. Men are understood to be free in all the liberal senses throughout the reproductive process, situated at a distance and

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<sup>35</sup> O'Brien (2007) uses the term "genderic."

afforded some choice in acknowledging paternity. Beauvoir (1956) contends that women enjoy no such freedom, and this cannot be explained by simply appealing to biology, even if biology serves as our starting point.

### Woman as Other, Object, and Slave

Woman comes to be understood as the inessential Other because of the interpretive work invested in her reproductive capacity: “women are controlled by lashing us to our bodies” (Rich, 2007, p. 64). That is, she comes to be reducible to her body, an object bereft of subjectivity: “the Other [is] regarded as the object in the eyes of the subject” (Beauvoir, 1956, p. 161). Beauvoir grounds this subject/object dichotomy in the Hegelian master/slave dialectic. According to Hegel’s (1977) analogy, the master and the slave represent two extremes that “are opposed to one another, one being only recognized, the other only recognizing” (pp. 112-113). The master as subject does the active work of recognizing, while the slave as object—as body only—is passively recognized. The identity of the slave is defined relative to the master, until it is sublated or consumed: “on approaching the other it has lost its own self, since it finds itself as another being” (p. 111). Applied to gender dynamics, women as metaphorical slaves are recognized while men as masters do the recognizing, and consequently, the defining. The relationship is doomed to be unequal, and efforts to challenge or transform the relationship are met with interpretive resistance. Even when a woman seeks to redefine her body or to cast it to the background, her identity and acts are translated in relation to the master status:

Neither the 'pure' nor the 'lascivious' woman, neither the so-called mistress nor the slave woman, neither the woman praised for reducing herself to a brood animal nor the woman scorned and penalized as an 'old maid' or a 'dyke,' has had any real autonomy or selfhood to gain from this subversion of the female body (and hence of the female mind) (Rich, 2007, p. 21).

There are feminists who have advocated for gender neutrality. Wittig (1992), for instance, seeks to universalize the Hegelian subject in an effort to eliminate the slave status and elevate women to the status of master alongside men. Butler (1999), too, argues that gender differences are bound up in the subject's act of recognition, and thus should be set aside: "there is no reason to divide up human bodies into male and female sexes" (p. 143). Beauvoir (1956) herself, whose position for a time defined the liberal feminist approach to reproductive rights, argued that women should be liberated from their reproductive roles: "[feminists since Beauvoir often assume that] women are naturally trapped in the childbearing function. Therefore the liberation of women depends on their being freed from this trap" (O'Brien, 2007, p. 49).

O'Brien describes this position as retaining the premise of the master/slave dialectic "but alter[ing] the conclusion" (p. 49). By taking the Hegelian premise for granted, we continue to miss the mark; universalization of the subject simply entails subsuming the slave, or effacing all of the slave's differences. Chandler (2007) instead challenges the primacy of subjectivity, holding that supposed gender neutrality only masks privilege: "my concern is that in destroying the categories of sex and gender, what is created is a separated autonomous subjectivity as the only acceptable conceptions of selfhood. ...The self as in-relation will become further marginalized" (p. 533). She readily admits that during pregnancy women lose their sense of self, their agency, but

“the problematic lies not in the equation of motherhood with non-subjectivity”; instead, it exists “in the privileging of an emancipated individuated subjectivity” (p. 535). She goes on: “the mistake lies not so much in equating motherhood with a loss of freedom and autonomy, but rather in adopting autonomy as an ideal” (p. 536). So gender neutrality goes astray for its reliance on the narrative of the subject. Women cannot liberate themselves or be liberated from the status of the Other by seeking elevation to the status of the One, not when the dichotomy itself—and the polemics that constitute it—is problematic.

This phenomenon, according to Jhappan (1998), is an equality pit. The problem with feminists seeking equality without questioning the liberal interpretation of equality is that their purposes come to be bound up in becoming Beauvoir’s One, Hegel’s master, or the autonomous subject. She grounds this argument in MacKinnon, who claims: “being the same as men or being different from men are just two ways of having men as your standard” (as cited in Finley, 1986, p. 1156). Feminists should be challenging their standard rather than seeking elevation to it. This latter strategy is ineffective for several reasons, according to Jhappan (1998). Firstly, it presents “an essentialist and gender-neutral model of the liberal citizen who, as it turns out, is an essentialized man” (p. 69). Secondly, “gender is not irrelevant; it is deeply relevant although in varying degrees, depending on context” (p. 69). And finally, assumptions are made about the category of woman, such that differences in class, race, sexual orientation, disability, and so forth, are overlooked.

### Reproductive Context

We have seen already how equality models go astray when they take as their standard the quintessential man; how, then, is gender differentially impacted depending on context? Mahowald (2000) contends: "because of unchangeable biological differences, women experience burdens and risks that men do not experience in reproduction and genetics, and those burdens and risks are not equal" (pp. 70-71). Women are not afforded distance from reproduction, such that the conditions of pregnancy are manifest in and on their bodies. Gender cannot simply be neutralized within reproductive contexts, for women are unavoidably, differentially impacted by reproductive decisions when pregnant. Complications to and conditions of pregnancy are theirs to bear.

Jhappan (1998) spoke of a third way in which liberal equality theories miss the mark, and this critique has been raised earlier in this study: namely, that there is no universal category of woman, that woman as Other represents a vast range of identities and experiences. In the context of race, Mahowald (2000) notes: "if respect is to be tendered to both autonomy and cultural differences [the principles are] incompatible" (p. 113). Many equality models struggle to move away from same treatment, and same treatment is bound up in notions of that autonomous subject, that essentialized, individuated normate. Within such models, differences do not belong.

And yet, "for Native American, African-American, Hispanic, and Asian-American women, motherhood cannot be analyzed in isolation from its context" (Hill Collins, 2007, p. 311). Central to debates around intersectionality, Black feminists (Hill

Collins, 2007; hooks, 2007) argue that we need to move away from the traditional feminist call to liberate women from reproductive roles, because this supposed liberation would be irrelevant to the struggles that racialized women face. Their concerns differ greatly from the concerns of the woman serving as standard, she who best approximates the One: “had black women voiced their views on motherhood, it would not have been named a serious obstacle to our freedom as women. Racism, availability of jobs, lack of skills or education...but not motherhood” (hooks, 2007, p. 145). Indeed, far from needing to be liberated from motherhood, women marked by difference (whether that difference is race, class, sexual orientation, or disability) have encountered challenges to reproducing. Those challenges include sterilization abuse, sub-par reproductive healthcare, and the criminalization of parenting (Hill Collins, 2007; hooks, 2007; Roberts, 1999; Salmon, 2007).

The overemphasis in liberal theories on choice requires that women be “deemed legitimate choice-makers” (Smith, 2005a, p. 128). Smith goes on to explain, citing an historical example:

In 1960, Planned Parenthood commissioned a study which concluded that poor and working-class families lacked the rationality to do family planning, and that this lack of ‘rationality and early family planning as middle-class couples’ was ‘embodied in the particular personalities, world views, and ways of life’ of the poor themselves (Rainwater, 1960; as cited in Smith, 2005a, p. 128).

Here we see a notion of subjectivity that suits only a certain sort of woman, while all other women—their otherness the result of their deviations from this standard—are not deemed to have equal moral worth. Struggles for reproductive rights, for personal autonomy and liberal equality, have too often only involved the elevation of some women

to the status of the subject; the struggle has been abstracted, oversimplified, decontextualized, and as a result our theories have proven ill-equipped to contend with variations in reproductive injustice.

If autonomy and equality theories have proven ineffective, where do we go from here? Roberts (1999) claims the experiences of racialized women point the way to the social transformation of liberty and equality. Jhappan (1998), however, cautions against a framework making use of principles that have been ideologically constituted in problematic ways. The purpose of her critique is to point to how “the essentialist definition of the ‘problem’ of gender (race, sexual identity, or disability) as an equality/inequality problem constrains the search for broader remedies to injustice” (p. 65). She holds that an alternative approach would be to recast “the issues in a justice frame” (p. 65). Theories of justice have been historically conflated with equality, but they do not have to be; indeed, when teased out of equality models, justice might better frame oppression within context (Young, 1990). Honouring context requires that theories adjust to differences in culture, class, gender, sexual identity and orientation, and so on.

Applied to reproduction, Smith (2005a, 2005b) and West (2009) suggest that an approach rooted in abstract principles of autonomy and equality has not served women well, not when these principles are entrenched in ideologies that individuate persons and justify inequalities on the basis of notions of worth. An alternative approach exists in reproductive justice, which “recognizes that reproductive oppression is the result of the intersection of multiple oppressions and is inherently connected to the struggle for social justice” (Mendez, 2006, unpaginated). Reproductive justice is contextual rather than

rights-based, with a social rather than individual focus, and can account for—instead of effacing, overlooking, or even essentializing—differences.

Might we then locate respect for difference in discourses on reproductive justice? Proponents of reproductive justice frame their work in ways that account for variations in identities, experiences, and oppressions. They draw attention to concrete particulars and contextual conditions that complicate reproductive decision-making. If we intend to salvage autonomy and equality, perhaps to reframe the concepts with feminist language, we must account for how they function within relations of power that influence freedom of choice and determine whether one has equal moral worth. This network of power relations acts as the sheaf that binds the wheat, or the context that invests meaning in differences—privileging some, managing others. Feminist justice has critical and corrective force because it is sensitive to difference.

#### *4.3.2. Reproductive Justice in Law*

##### Case Law Review

Can reproductive justice be accomplished, even acknowledged, in Canadian law? Hard to say, when no legal case has reached this point. Recall that our benchmark can be found in *R. v. Morgentaler* (1988), which grounded reproductive rights in the s. 7 right to security of the person. Section 7 was described as “a more circumscribed interest [that] at most relates to the concept of physical control, simply protecting the individual’s interest in his or her bodily integrity” (p. 54). Gavigan (1992) calls this rhetoric “a ringing restatement of an individual right...and is thus consistent with the emphasis on

abortion as a private and individual matter” (p. 222). This limiting of abortion rights to bodily integrity and control requires that we understand the body to be a static object to be managed. The body is framed as an entity in isolation, its skin serving as the boundary markers for personhood. Reproductive rights have come to be hemmed in, narrowly defined as individual, and grounded in the assumption that as long as the state withdraws, deregulates, and vows non-interference, the decontextualized woman will be liberated and in control.

Gavigan (1987, 1992) and others (Erdman, 2007; Ordolis, 2008; Rodgers, 2006a, 2006b, 2006c) see more promise in reproductive equality, although legal attempts to make this connection have fallen flat. Recall that in *Doe et al. v. The Government of Manitoba* (2004), despite appeals to the s. 15 right to equality, the argument made included a notion of personal autonomy: “the right to reproductive freedom is central to a woman’s autonomy and dignity as a person” (p. 10). This grounding renders the concept of equality applied formal, negative, and useless in light of the challenges women face in reproductive contexts. Granted, *Doe et al.* made use of now outdated equality jurisprudence. *Withler v. Canada* (2011) represents the latest evolution in our narrative of equality, and promises the acknowledgment of context. Will this new precedent eventually make a difference for reproductive health? Can it effect some approximation of reproductive justice?

### Speculations on the Potential of Equality

What would such a reframing look like? We might turn to the Women's Legal Education and Action Fund (LEAF) for insight into the direction a contextual approach to equality analysis should take in future case law. This organization has intervened in *Andrews v. Law Society of British Columbia* (1989), which marked a turning point for equality jurisprudence, as the Supreme Court of Canada rejected the previously employed formal model in favour of a more substantive version of equality; and *Eldridge v. British Columbia (Attorney General)* (1997), another important milestone, foundational to the contextual approach taken in *Withler* (2011).

Jhappan (1998) praises LEAF for "a considerably more sophisticated and historically grounded understanding of inequality as being rooted in gendered social relations, not in women's similarity to, or difference from, men" (p. 72). In a LEAF publication on substantive equality, Sampson (2006) criticizes formal versions of equality for not accounting for "the ways in which different groups in society have experienced systemic disadvantages" (p. 246). She instead endorses the following:

Through a contextualized approach, equality claimants can educate the judiciary about their actual experiences, contributing to the broadening of the theoretical base of the legal concept of equality, and providing for improved legal reasoning on more informed understandings of experiences of discrimination (p. 247).

A contextualized, relationship-grounded approach avoids the pitfalls to which some equality approaches fall prey when autonomy is used to justify inequalities: "choice limited by a context of inequality; coercion labeled as choice; choice restricted by access

to money, resources, and education; qualified choice as part of a struggle for emancipation—these are women’s choices” (Majury, 2006, p. 218).

How would such an approach be applied to reproductive health? Cook and Howard (2007) try to carry out some of this work, characterizing the problem of abortion as “societies’ inability to accommodate women’s biological differences and to redress the social discrimination women face based on those differences” (p. 1040). For them, reproductive equality necessarily involves respecting—and not simply overcoming—difference: “accommodating differences in the abortion context requires learning how to reframe law and policies to construct an inclusive standard of equality that values sex and gender distinction” (p. 1040). They go on: “women’s equality requires both the acknowledgment and accommodation of women’s actual differences, as well as the elimination of discriminatory treatment based on gender stereotypes” (p. 1044). What they are advocating for is a positive concept of equality that can respect without essentializing difference, and can redress the ways in which difference is socially othered. These differences are not just gender-based, but are also cultural, class-based, and rooted in disability and sexuality: “the necessary rethinking of equality requires that unintended pregnancy and its consequences be approached from the perspective of not only women in general, but of different subgroups of women, particularly those who are marginalized due to income, age, or race” (p. 1056).

Nevertheless, Jhappan (1998) remains wary of the equality pit, holding that the framework of the *Charter* requires comparison, even when case law and legal analysts seek to reinvent equality: “equality means always having to say who you are equal to,

always comparing one group against another, almost invariably on one axis, and, for this reason, it will not let claimants out of the similarly situated, likes alike, sameness/difference traps, regardless of the new language used” (p. 74). The identity categories written and read into s. 15 are identities that mark difference relative to a standard. It may prove difficult to move a contextual approach forward within a legal framework that has historically relied on abstract principles and comparisons against normative, privileged standards. Jhappan questions feminists who “have almost invariably attempted to squeeze all issues into the equality box, even when equality is not necessarily what is missing or wanted and even when it has meant distorting the concept beyond recognition” (p. 82). Applied to reproductive health, Smith (2005a) and West (2009) argue that reproductive justice is not simply an upgraded model of legal equality, but is more broadly an economic, political, and social project. While some feminists have worked to repackage the principles of autonomy and equality, respect for difference may yet be the key ingredient missing in a comprehensive, effective approach to redressing disparities in the context of reproductive health.

#### Policy on Sex Selective Abortion

Respect for difference is not itself entrenched in Canadian law but is in some limited way bound up in substantive equality (or, we might say, has fallen into the equality trap). Further, as I have indicated, given the dearth in case law, we can only speculate on how to take a contextual approach to reproductive health. There might be value at this point in turning to Canadian policy. Where case law provides a form of

redress, dependent on particular cases that point to problems within the legal system, policy offers the promise of Canadian commitments. Further, it has only been in policy at the international level that we have seen the explicit use of the term respect for difference, even if I argued that it is not enough to speak of difference in abstraction.

Perhaps policy is doomed to abstraction as long as it finds no application. In an example then, Canada has encountered controversy around sex selective abortion. A recent study (Almond, Edlund, & Milligan, 2009), based on the 2001 and 2006 Canada Census long-form questionnaires, presented a higher incidence of first and second born births being boys for families of Indian and Asian origin, and speculated that this was the result of sex selective termination. In another study that reviewed singleton live births in Ontario 2002-2007, Ray, Henry, and Urquia "found a significantly higher male:female ratio among infants of multiparous women originally born in Indian than among infants of multiparous women born in Canada" (2012, p. 2). The two studies target Indian and Asian immigrant populations because these cultures are identified as showing a "strong son-preference" (Rogers, Ballantyne, & Draper, 2007, p. 520).

Ray, Henry, and Urquia (2012) recommend that disclosure of the sex of the fetus be withheld until later in the pregnancy, when abortion comes to be unavailable. This recommendation might already be in effect: of the sixteen major hospitals in the Greater Toronto Area that offer prenatal ultrasounds, six do not disclose sex, or are not forthcoming until disclosure is requested. Yang (2012) notes: "whether by coincidence or by design, all six hospitals are located in or near areas with high concentrations of

South Asian immigrants—one of the ethnic communities at the centre of a mounting concern over female feticide” (unpaginated).

The variation in hospital practices can be explained by the open-ended approach the SOGC has taken to disclosure of fetal sex. The SOGC opposes sex selective abortion, and recommends that ultrasounds be used only for health diagnoses (except in those cases where sex can be tied to greater likelihood of a genetic condition): “the SOGC also strongly opposes the non-medical use of ultrasound to view or photograph the fetus or for the sole purpose of determining fetal sex when there is no medical indication to scan” (2007b, p. 1). However, the organization leaves the decision to disclose to the discretion of health professionals, either because those professionals are more acutely aware of the context and conditions their patients face, or due to the authority vested in physicians: “a small number of pregnant women may consider abortion when the fetus is the unwanted sex; however, this is best addressed by the health professionals who are providing care for these women” (2007a, p. 1).

While the SOGC takes a stand against sex selective abortion, it does not prohibit disclosure of sex, in part for patient-centred reasons. They cite *McInerney v. MacDonald* (1992). In this case, a physician refused a patient’s request “to produce copies of consultants’ reports and records she had received from other physicians who had previously treated the patient” (p. 2). She held that the records “were the property of those physicians and that it would be unethical for her to release them” (p. 2). The Supreme Court of Canada determined that the relationship between physician and patient is “fiduciary in nature” (p. 2), meaning held in confidence. The physician has the

fiduciary duty “to grant access to the information used in administering treatment...grounded in the nature of the patient’s interest in the medical records” (p. 2). Granted, the Court ruled that this right to access records is not absolute: “if the physician reasonably believes it is not in the patient’s best interests to inspect the medical records, the physician may consider it necessary to deny access” (p. 3). Based on this case, the SOGC concludes on the topic of disclosing fetal sex: “it is legally difficult to defend nondisclosure. Disclosure of fetal sex upon request respects a woman’s rightful autonomy over personal health information” (2007a, p. 1); though a physician has the leeway to refuse to disclose if she feels doing so would be in the patient’s best interest.

While the right to know is left up to the physician’s discretion, and the right to terminate remains sacrosanct, Canadians lack the right to make use of reproductive technologies such as pre-implantation genetic diagnosis for the purpose of selecting a particular sex. According to the *Assistive Human Reproduction Act* (2004), use of reproductive technologies for this purpose is prohibited. Under s. 5(1)(e), the *Act* prohibits citizens from the following:

Knowingly...for the purpose of creating a human being, perform any procedures or provide, prescribe or administer anything that would ensure or increase the probability that an embryo will be of a particular sex, or that would identify the sex of an in vitro embryo, except to prevent, diagnose or treat a sex-linked disorder or disease.

Thiele and Leier (2010) note that this policy pertains to producing sex rather than terminating pregnancy once sex is discovered, but they hold that the next step is logical, and needed: “although this policy concerns the creation of embryos rather than their termination, it is not unreasonable to assume that the values that drive the prohibition of

sex selection are addressing the goal of sex selection itself, rather than the technical means to achieve that end” (p. 55).

Rogers, Ballantyne, and Draper (2007) argue that sex selective abortion is not morally justified, and should be prohibited in Canada. Drawing from conceptual work reminiscent of feminist relational autonomy models, they hold that choice is inauthentic when made in oppressive contexts: “broader accounts of autonomy place less emphasis upon specific choices, but rather examine the wider context of a person’s whole life situation” (p. 521). They argue that sex selective abortion reflects discrimination against women:

SSA [sex selective abortion] reinforces discrimination against women by explicitly perpetuating two views. The first is that women are valuable only as the mechanisms for producing sons, such that absent a son, a woman is of no value; and second, that female children are such a worthless burden that their births should be prevented. As such, SSA is a particularly discriminatory and oppressive practice that fails to accord women the respect they deserve as ends in themselves (p. 522)<sup>36</sup>.

Further, they hold, should this supposed trend toward sex selective abortion continue, the resultant gender imbalance will eventually lead to too few women available to marry men, depriving men of opportunities for partnerships and family-building—opportunities which constitute a “fundamental good, enshrined as a right in the *Universal Declaration of Human Rights*” (p. 522)<sup>37</sup>. In the final leg of their argument, they claim that abortion when not autonomously chosen constitutes assault.

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<sup>36</sup> Note that Rogers, Ballantyne, and Draper, despite their attempt to ground their work in relational autonomy, invoke Kantian language when they call for women to be respected as ends in themselves.

<sup>37</sup> This argument requires a heteronormative lens, and there is no indication that this social practice would hold should there be a shortage of women. Katz Rothman (1987)

Is the solution to deny women the use of reproductive technologies for the purpose of selecting sex? Consider that concerns centre around racialized persons. As mentioned, Mahowald (2000) wrestles with how to temper autonomy with respect for cultural difference, and how to reconcile the conflicts between the two principles. Work of this sort is criticized in Vogel:

Some physicians are uncomfortable wagging a finger at their patients' cultural practices, explains Bowman. 'We're given very strong messages in Canada that we need to be as respectful to people's cultural differences as possible, and the risk with trying very hard to accommodate those differences is that we can overlook something that's largely unethical' (Bowman; as cited in Vogel, 2012, p. 164).

Herein lies the crux of our supposed rights conflict: can we simultaneously respect cultural and gender differences; and can respect for difference reconcile the right to autonomous choice with gender inequality?

It may be that rights conflicts are resolvable when contextualized—or, perhaps rights rhetoric proves ineffective when applied to context. In this example, assumptions are being made around who deserves the right to choose. Racialized communities and their supposedly backwards ideas about gender are targeted in the studies cited. To suppose that cultural and gender differences are locked in conflict is an overgeneralization, given how women are differentially impacted in reproductive contexts, and how racialized women have experienced all the barriers to reproduce listed

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argues that a gender imbalance would not actually result in a shortage because "a 'shortage' is social defined" (p. 135). She goes on: "if for example a 'shortage' of women were to make male homosexuality and female prostitution more socially acceptable...then the fact that there would not be enough women to be distributed in heterosexual monogamous mating might very well come to be 'a fact of life,' and not a shortage or a problem" (p. 135).

in the above section. It seems counterintuitive, then, that we can effect reproductive justice by creating an additional barrier to reproduce that targets racialized women. Granted, Rogers, Ballantyne, and Draper (2007) demonstrate theoretical consistency with feminist relational theorists when they hold that choice needs to be understood within context, but the solution is to address context, to promote gender equality in education, employment, health, and so on, and to redress the racist overtones built into the mechanisms and strategies of reproductive control, so that women might be empowered when they mean to exercise autonomous choice, not to deny them the choice entirely.

While policy and practice seek to prohibit sex selection in the interest of gender equality, there is a failure to acknowledge, firstly, how racialized groups have been differentially impacted by policy and practice; and secondly, how identification of fetal sex operates in patriarchal contexts. Katz Rothman (1987) describes disclosure of fetal sex as an embedded social practice, not just in particular ethnic communities—one which affects pregnancy: “knowledge of fetal sex is something to reckon with, something which by its very existence changes the pregnancy experience. Knowledge of sex helps turn a fetus into a baby” (p. 123). In other words, the use of technologies to identify sex has had the effect of facilitating the personification and individuation of the fetus—a phenomenon that carries all the baggage discussed in previous chapters. More than this, though, disclosure of sex “implies gender” (p. 127), that is, assigns gender, marks the fetus, and changes the ways in which the fetus is perceived and treated. Due to technological intervention, gender is inscribed before birth, and social forces go to work early shaping identity and relationships. This interpretative work is based on the mere

“luck...that sex is such an obvious chromosomal difference” (p. 128) that can currently be identified. Of the myriad ways in which a fetus may be chromosomally differentiated, it is sex that is especially subject to rigorous interpretive work.

When examining the use of reproductive technologies capable of identifying chromosomal markers of sex and genetic conditions, Katz Rothman (1998) challenges the distinction made between prohibition of sex selection and promotion of disability de-selection. And yet, the SOGC (2007b) and the *Assistive Human Reproduction Act* (2004) both take the position that there is a clear distinction between determining sex and diagnosing health risks. While reproductive technologies may be used to select sex, they should be used to de-select disability. Sex selection comes to be morally excusable when links can be made between sex and genetic conditions. In the section that follows, I will consider how policy is turned on its head when families choose disability.

#### 4.4. Reproductive Justice and Disability De-Selection

In this final section, I will consider whether theories of reproductive justice can account for and appropriately respond to disability as difference, especially instances of deliberate selection of disability. At this point in the project, my purpose will be to determine whether it is possible to develop a framework for approaching reproductive decision-making; whether this framework requires autonomy, equality, and respect for difference; and if so, how each principle should then be characterized. With such a purpose in mind, I will review the work previously accomplished in this study to account for how autonomy and equality-based approaches have been applied to the use and

normalization of reproductive technologies. I will further explore how to incorporate respect for difference into a comprehensive feminist approach. When discussing legal praxis, I will return to policy on sex selection to note assumptions about the purpose of reproductive technologies being tied to disability de-selection. I will also investigate scholarly and public reactions to the use of pre-implantation genetic diagnosis to select disability, as these reactions reflect the socially and medically implicit purpose of reproductive technologies—a purpose, however, that could be transformed.

#### *4.4.1. Reproductive Justice and Disability De-Selection in Bioethics*

##### Woman as Autonomous Self, Woman as Responsible

Chapters past, I explored rationales for using reproductive technologies for the purpose of disability de-selection, beginning with the oft-invoked reproductive autonomy model. Recall that this model concentrates on liberating women by ensuring choices are better informed: “prenatal diagnosis is presented as a means of giving women information to expand their reproductive choices” (Lippman, 1993, p. 22). I considered at length the sort of autonomy employed—liberal in character, belonging to individual, consenting selves.

Reproductive autonomy so framed in effect decontextualizes reproductive issues, focusing on an early liberal feminist agenda to promote women’s right to terminate, when women encountering ableism, racism, and heteronormativity have had different experiences of oppression. According to Wagner: “in the absence of historical and socio-political context, abstract notions of choice and individual autonomy may have little

meaning, particularly for women from marginalized communities” (2008, p. 238). The women Wagner is identifying are marginalized from the concept of Self Beauvoir (1956) would have us become—the abstracted woman entitled to autonomy. Beauvoir’s autonomy entails liberation from reproductive function, and the Self of reproductive autonomy models studied here is thought to be liberated or abstracted from her body. What we find when we unearth the experiences of marginalized women, of these Others, is that choices are embodied and contextual, even when our models do not account for bodies or externalities.

Should the reproductive autonomy model fail to retain meaning when situated in context, I previously discussed the public health model as an alternative explanation socially employed to encourage women to make use of disability diagnostic technologies. This model operates in such a way that pressures women into preventing disability: “under the public health model, the routinized use of testing comes the potential to cast women as the genetic gatekeepers of society, not only responsible, but also accountable for the birth of disabled children” (Peters & Lawson, 2002, p. 3). Reproductive choice in such a context, where disability as difference conflicts with health standards, ceases to be authentic choice. This model might aid in explaining the pressures weighing on women’s decision-making in relation to disability diagnoses.

Recall that Foucault (1980) wrote on the continuous investment of power in bodies at minimal cost; the cost is minimal because under the panoptic medical gaze, people are expected to discipline themselves in order to approximate standards of normalcy: “an inspecting gaze, a gaze which each individual under its weight will end by

interiorising to the point that he is his own overseer” (p. 155). The energy required for managing and producing species typical bodies is minimized in a social order wherein people are responsible for their own management. Pregnant women are socially, medically, and legally expected to take responsibility for their bodies. Reproductive autonomy only functions in such a way that justifies social pressure to comply with a mandate to prevent the dys-appearance of bodies (Leder, 1990). Not only are women expected to manage their own dys-appeared bodies (to the extent that they are women, and pregnant—social and biological dys-appearances that call for management), but they are expected to prevent dys-appearance and disability in their offspring.

#### Equality between Certain Selves

Through a Foucauldian lens, then, we could claim that the public health model serves as a regulatory standard that reflects inequalities, and yet this standard is often hidden under the guise of autonomous choice, as though the autonomous self must as a rule accept certain responsibilities attached to autonomous decision-making. Previously discussed, equal distribution for Buchanan and colleagues (2000) was meant to ensure women have the freedom to make reproductive decisions, and children have the right to an open future. They thus frame the act of making use of reproductive technologies as simultaneously a means for enhancing autonomy and a moral obligation: “parents are regarded as having permission, and some would say an obligation, to produce the ‘best’ children they can” (p. 156). They can accomplish this contradiction because disability,

for them, is a difference unlike other differences—a difference of lesser worth. Karpin and Savell say of their seminal work:

[They] argue for a distinction between the disability rights movement and other civil rights movements on the grounds that, unlike the sexual or racial minorities, the able-bodied majority have a ‘morally legitimate interest’ in ‘avoiding the costs of changing society’ to better accommodate people with disabilities” (Buchanan et al., 2000; as cited in Karpin & Savell, 2012, p. 284).

Further, Anstey (2002) explains why the distinction was defended:

No matter what perspective one takes on the phenomenon of disability, it must be acknowledged that some conditions may inherently produce limitations at the level of bodily functioning, social activities or participation. Several bioethicists use this fact of inherent limitation to support the normative view that bodily impairments ought to be avoided where possible (p. 235).

We could call this normative viewing of disability geneticization, which arguably influences the purpose built into the use of reproductive technologies: “genetic knowledge incorporates and builds upon the concept of normalcy” (Taylor & Mykitiuk, 2001, p. 5). Through geneticization, these inherent limitations to persons Anstey (2002) identifies justify assignments of worth; species typical functioning comes to be reified, and all else that dys-appears is atypical. Rapp (2000) claims that with the rise of geneticization, “it comes easier to foreground the biological and background the social, as if they were separable” (p. 215)—a process which is reminiscent of Leder’s (1990) theory of dys-appearance.

It is my contention that geneticization, while clearly an example of a practice that perpetuates inequality, underscores formalized equality models. At least those models that are developed with the purpose of facilitating liberal autonomy, there are

assumptions being made about who is equal. Those selves who share similar properties, perhaps properties that are genetic, may enjoy equal rights. Fineman (1992) explains how gender-based difference once was (and might still be) compatible with concepts of equality:

Difference was the rationale and the justification for this exclusion which was based on the belief that women's unique biological role demanded their protection from the rigors of public life. It was no surprise, therefore, that...assimilation became the goal and equality the articulated standard (p. 1).

While women have sought to transcend the ways in which their biology determined their social roles (in problematic ways, granted, as noted in critiques of Beauvoir (1956) outlined in my last section), biology is still drawn from in order to build rationales for excluding disabled people.

#### Bringing Valued Difference to Bear on our Principles

We might ask at this juncture, are these principles necessary for building a just approach to reproductive decision-making? Or, do feminists err in trying to refashion concepts that just have too much baggage, that are unrecognizable after their re-haul? Does a politics of difference require these concepts, or is it better served engaging a radical conceptual approach that breaks from the language found in modernity?

Indeed, where reproductive autonomy and reproductive equality have fallen short, reproductive justice can explain how current uses of reproductive technologies constitute a failure to respect difference. One difference we might discuss is gender. Fineman (1992) considers the value of a gendered approach to reproductive health: "I suggest that

the concept of a 'gendered life' can be helpful in urging cooperation among women across our differences in areas where social and cultural definitions of 'Woman' operate to potentially oppress us all" (p. 4). She goes on:

Any contemporary consideration of differences must first address the question of what are the legally relevant differences between men and women. It is now generally, though not universally, conceded that narrowly defined reproductive roles represent a 'significant' difference worthy of some legal accommodation (pp. 13-14).

A gendered approach does not necessarily mean we would preclude different kinds of embodiments that affect reproductive decision-making, for an approach that takes female bodies as its starting point can account for bodily nuance. Indeed, feminists invested in intersectionality recognize that gendered approaches are not entirely limited to gendered difference, but are capable of and responsible for exploring other identity characteristics. Beginning with bodies means there is room for discussing disability, an identity which can certainly be read on the body and that readily marks bodies as different, dys-appeared, and disruptive. Unlike Buchanan and co-authors (2000), we need not make value-based distinctions between identities—we need not understand disability as being of lesser worth.

A gendered approach to reproductive health, one which takes for granted that women are necessarily embodied, and that their decisions do not happen in isolation, could use the feminist-framed concepts discussed throughout this study. Feminist relational autonomy better accounts for the decision-making transpiring in reproductive contexts, in contrast with liberal autonomy; for, relational autonomy is not conceptually closed off from notions of intercorporeality and interconnectivity. There can be no

relational autonomy without an acknowledgment of how power affects relations—women may interiorize and internalize the ways in which power is invested in their bodies and come to feel responsible for body management. Their lack of self-trust manifests in contexts where they lack power. Feminist equality models that account for power differentials can explain how self-trust is affected, and self-distrust in turn affects reproductive decision-making. Relational autonomy and substantive equality fit postmodern theory; they are just inadequate when not reoriented to serve the goal of promoting diversity.

In the writing that follows, I consider what bearing such a framework has on Canadian law and policy, and how it—better than predominant theoretical and legal frameworks—can better account for the transformative potential of reproductive technologies.

#### *4.4.2. Reproductive Justice and Disability De-Selection in Law*

##### Review of Cases Concerning Reproductive Rights and Disabled Persons

To review, in *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)* (1997), the Supreme Court of Canada considered the trial judge's ruling that G. was incompetent due to a mental disorder—a ruling which justified the invocation of *parens patriae*: “the trial judge had wrongly relied on the court's *parens patriae* jurisdiction of lunacy” (p. 13). We might speculate over why G.'s competence was questioned; even though the Supreme Court of Canada struck down the ruling on the grounds that it was not in compliance with the *Mental Health Act*, there is value in questioning how we

arrive at discourses around determinations of capacity, when we discuss whether and which pregnant women are capable of making decisions about their pregnancies for themselves. Perhaps G.'s substance use was tied to questions of competence; or perhaps a mother who does not comply with good pregnancy practice has questionable decisional capacity, as Lemke (2002) and Overboe (2007) warned against. Also of note, G. was of Aboriginal descent. Aboriginal persons in Canada have historically seen their decisional capacity questioned in the context of land disputes, religious choices, and their ability to raise, even bear, children (Orkin, 2003).

In *E. (Mrs.) v. Eve* (1986), Eve's mother sought to declare her daughter incompetent so that she could authorize a non-therapeutic sterilization procedure without Eve's consent. She pursued this course of action because Eve interacted with a male peer, and because Eve was "attractive and attracted to men" (p. 9). There was a concern that Eve would be incapable of raising a child because she was disabled. There was also concern on her mother's part that she (the mother) would have to raise Eve's child, because as a woman who produced a disabled child she would be radically responsible for all that followed. We might also consider that intellectually disabled people have been historically subjected to forced sterilization procedures due to a fear that disability is inheritable (Park & Radford, 1998).

If we were to compare these cases, we would find that both question a disabled woman's ability to mother. Both concern women whose identities have historically been associated with sterilization abuse, identities that would not readily benefit from the so-called liberation of women from reproductive roles, not when those roles had been so

often denied to members of marginalized identity categories. Although both cases have positive outcomes regarding the promise of non-intervention, there is no accounting for context inasmuch as there are no supports put into place that might make reproduction a viable choice. Further, there is no promise that they will be protected from institutionally embedded discrimination: G. might have seen this child too become a ward of the state, and Eve's school might have continued to have convinced boys not to talk to her so as to avoid her experiencing romance, intimacy, and possibly pregnancy. There is no acknowledgment in the rulings of the differences that define G. and Eve, differences which have been historically and socially devalued in reproductive contexts.

#### (Re)Producing Disability

American couple Sharon Duchesneau and Candy McCullough, who both identified as Deaf, wanted to have a second child together and chose as their sperm donor "a deaf friend with five generations of deafness in his family" (Savulescu, 2002, p. 771). Their purpose was to increase the likelihood of producing a Deaf child. In 2001, Gauvin McCullough was born Deaf, "like his mothers and sister" (Wagner, 2008, p. 231).

Wagner describes public reactions:

The child's birth and more importantly his conception were widely publicized and met with a spectrum of reactions, from the joy of his parents to pity and abhorrence in the international media. ...Since then, commentary in both the media and academia has grappled with the ethics of choosing to have a child with a disability (pp. 231-232).

The discourses borne out of examples like this pertain to the supposed limits and purposes of reproductive technologies. These technologies have the potential to be used

not only to facilitate the conditions that might ensure disability, but also for screening, testing, and thus deliberately selecting disability. When they are employed for the purpose of deliberate disability selection, media and scholarship raise the question: should they be? This particular "should" is of interest to my study because it builds greater nuance into expectations of maternal responsibility, or which reproductive decisions we are free to make within our given contexts.

Upon examination of context we see in this example, as we see in *G. (D.F.)* (1997), that the women involved identify as members of a marginalized minority, and though this point does not have direct bearing on the case, it is worth noting given how minority groups have experienced reproductive constraints. Like race, sexual orientation is an identity category that has been used to justify denial of the right to reproduce. Among other myths, non-heteronormative sexual orientation has historically been called unnatural, because that which does not equate with the social standard cannot be natural or right (Martin, 1988). Further, there have been fears that young persons can be influenced when exposed to people unlike themselves, which has led to efforts to bar members of the LGBT community from educational positions, and has kept them from adopting children or making use of reproductive technologies to produce children (Kallen, 1989). Although laws have relaxed and people from the LGBT community are no longer legally prevented from starting families (*R. v. K.(B.)*, 1995), this legal and social history continues to function as a distant echo, affecting and reflecting discriminatory attitudes.

What also complicates this case is that Duchesneau and McCullough sought to select a particular disability that is not always called a disability. According to Savulescu (2002), the couple regarded “being deaf as defining their cultural identity and...signing as a sophisticated, unique form of communication” (p. 771). Deafness is often seen within Deaf communities as a cultural and linguistic minority (Levy, 2002; Wagner, 2008). Perhaps it is worth noting that members of the Deaf community do not always identify with disability movements, the implicit assumption being that they still devalue disability as a limitation. Regardless of this tension between activisms, I would nevertheless hold that the Deaf cultural identity is an example of how disability can be valued differently rather than devalued, not as a lacking but as a minority—a difference that has been unnecessarily and unjustly accorded low worth.

At issue is the assumption underscoring the backlash to Duchesneau and McCullough’s decision—an assumption around the purpose of reproductive technologies. Savulescu (2002) asks in response to this case:

What is the goal of reproductive decision making? We offer genetic tests to couples to allow them to select the child—from the possible children they could have—with the best opportunity of having the best life. Indeed, I have argued that couples have a moral obligation to select the child with the best prospects” (p. 772).

Scholars have questioned whether deliberately selecting disability when conceiving violates what Buchanan and colleagues (2000) call a right to an open future (Davis, 1997; Feinberg, 1980). This right, for Davis (1997), involves autonomy: “[Deafness] violates the child’s own autonomy and narrows the scope of her choices when she grows up” (unpaginated). Anstey (2002) criticizes this characterization of autonomy in that it

“inappropriately essentializes disablement as a negative phenomenon”, and an “emphasis on a right not to have one’s range of opportunity narrowed too easily lends itself to the view that promoting autonomy is about securing more options” (p. 239).

As noted, this case occurred in the United States, so we have cause to ask: what might happen in a Canadian context should a woman select disability as an identity characteristic in her child? How would Canadian policy respond? When developing a legal approach might we draw from international instruments that recommend the principle of respect for difference?

#### Policy Beyond and Within Canada

In a previous section, I reviewed where the principle of respect for difference can be found in international covenants on specific minority populations. We might also explore instruments pertaining to bioethics. The United Nations Convention on Biological Diversity (CBD, 1992) and the UN Declaration on the Human Genome and Human Rights (DHGHR, 1997) both recognize humanity’s genetic diversity without “giv[ing] rise to any interpretation of a social or political nature which could call into question the ‘inherent dignity and...the equal and inalienable rights of all members of the human family’” (CBD; as cited in DHGHR, 1997, preamble). Although there is an appeal to sameness, we at least see acknowledgment that difference has in the past been politicized, and an attempt to avoid political assignations of worth to genetic difference.

The DHGHR highlights this attempt at reconciling sameness and difference in Article 1: “the human genome underlies the fundamental unity of all members of the

human family, as well as the recognition of their inherent dignity and diversity". The instrument understands the human genome to be central and essential to humanity, and yet it avoids allegations of geneticization and biological reductionism by claiming that the genetic material that binds humanity can be different and diverse. At the heart of that which human beings hold in common is biological—and I might argue, embodied—difference.

Article 3 elaborates on the potential of the human genome:

The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment, including the individual's state of health, living conditions, nutrition and education.

This Article explores the ways in which contextual factors invest in and shape the genetic body. With this recognition in mind, the DHGHR makes recommendations regarding genetic research such that member state parties are expected not to subject citizens to "discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity" (Article 6).

Do we see national laws incorporating the principle of respect for difference that manifests in these international instruments? Is the priority in genetic technologies and research on recognition of genetic diversity and protection from discrimination on the basis of genetic difference? The most definitive legislation advocating disability de-selection can be found in New Zealand. According to New Zealand's National Ethics Committee on Assisted Human Reproduction (NECAHR, 2005), pre-implantation genetic diagnosis cannot be used for the purpose of increasing the likelihood of disability: "PGD may not be carried out for the following: (1) social reasons, including sex selection

[and] (3) to select embryos with a genetic impairment seen in a parent” (s. 3). In order to avoid discrimination against disabled people, the NECAHR “supports the *New Zealand Disability Strategy* and considers that New Zealand should continue to recognise its obligations to support disabled people and continue to work towards the removal of barriers to full participation in society” (pp. 3-4). Nearby, Australia’s Infertility Authority of Victoria has also prohibited in s. 5(a) of their 1995 *Infertility Treatment Act* “the use of PGD to select in favour of genetic disease or abnormality” because “the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount”.

Although Canada’s policy on reproductive technologies—the *Assistive Human Reproduction Act (AHRA)*—is open-ended, with no outright prohibition of disability selection, there are similarities with policies from Oceania. According to s. 2 of the *AHRA*: “the health and well-being of children born through the application of assisted human reproductive technologies must be given priority in all decisions respecting their use”. In both Canada and New Zealand, women’s health and well-being are referenced, but there is thought to be little conflict or problem with prioritizing the right of the child to an open future (Wagner, 2008). Karpin and Savell (2012) argue:

The New Zealand law and guidelines are similar to the laws that we have described elsewhere [such as Canada’s, in that they] provide that PGD may only be used to prevent the transmission of ‘serious’ conditions but stop short of defining that limit legislatively, instead devolving that responsibility to the clinicians providing PGD (p. 230).

There is an understanding underscoring our policy that disability is importantly different, as Buchanan and colleagues (2000) claim, from other identity characteristics. Sex

selection is prohibited in the *AHRA* and related documents outside Canada, unless sex has bearing on genetic risk. The arguments raised in the last section against sex selection are not thought to apply to disability, because disability is simply not the same, not similar enough.

A Canadian report on biotechnology and human rights considers the selection of Deafness using pre-implantation genetic diagnosis: “is the right to reproductive autonomy broad enough to protect a woman’s choice of PGD to select in vitro embryos on the basis of certain favoured genetic traits?” (Hunter, 2005, p. 3). Should reproductive rights be entirely framed as a right to autonomy, we see policy considering the limits to autonomy, with the underlying assumption that autonomy is personal in character, accorded to separate, isolated rights-bearers. The limits to autonomy are thus imagined to be conflicts with other rights-bearers. One such limitation has been invoked: an unborn child’s right to an open future—a call to equality of opportunity, infringed upon when functional health standards are not met.

Even though Canadian policy is not definitively prohibitive, the framing of the rights conflict so described above is implicitly present. Health Canada defines the purpose of pre-implantation genetic diagnosis as identification of “genetic markers for inherited disease [so that] physicians caring for individuals at risk of passing on a genetic condition to their offspring are able to select and transfer only those embryos that do not carry markers for the conditions in question” (2005, p. 1). While sex selection is prohibited, because selecting against female births constitutes discrimination against

women, the *AHRA* claims the purpose of this reproductive technology is to select against disability.

The federal government of Canada established a Biotechnology Advisory Committee, the CBAC, which is “an expert, arm’s-length committee created under the renewed Canadian Biotechnology Strategy (CBS) to advise Ministers, raise public awareness and engage Canadians in an open and transparent dialogue on biotechnology matters” (CBAC, 1999, in Sherwin 2000 p. 6). This advisory panel aids the government in forming policy on reproductive technologies, such as the *AHRA*. According to Lippman (2000), the overarching strategy out of which the committee was borne co-opted “women’s demands for empowerment, for choice, and for gender-based care, research and policy...playing on our reasonable fears of paternalism, overmedicalization and exclusion” (p. 35). Only paternalism, overmedicalization, and exclusion have not been redressed—they are merely more deeply entrenched in institutional frameworks, called another name, and invested in women’s bodies. Recall that Foucault described how power is inculcated and embodied such that people are expected to self-manage, and are thought to be acting autonomously when they do: “within neo-liberalism, the best form of regulation is one which is self-governing” (Mykitiuk, 2000, p. 108). Mykitiuk goes on:

Will this information [derived from genetic diagnostics] be used in invidious ways to mark certain citizens or prospective citizens, or their characteristics, as deviant, abnormal, socially undesirable or risky? Is there a sense in which the new genetic technologies are being used, or are capable of being used, as a means of literally creating the responsible, autonomy, citizen of neo-liberalism—that citizen who makes no legitimate claims on the state but rather, who freely exercises their capacity for choice and manages their own self care? (p. 108).

### A Way Forward

Law informed by technology inscribes the body, both female and disabled. Gender and disability both are constructed and regulated by legal rules that shape interactions between them and medical practitioners (Frazee, Gilmour, & Mykitiuk, 1996; Karpin, 1992-1993, 2005). Karpin (1992-1993) claims: "in the process of regulating the female body, the law legislates its shape, its lineaments, and its boundaries. ...[The law] collaborates with other defining discourse such as science" (p. 325). Within medical contexts, these bodies are "usually all too fleshy, fluid, and uncontainable" (Shildrick, 2004, p. 150), and are in need of being shaped.

This does not have to be so, however. Rose (2007) says of the potential of reproductive technologies: "these new technologies, then, do not just seek to cure organize damage or disease, nor to enhance health. ... Their key feature is their forward vision" (p. 8). With the development of new technologies and their interpretation via a postmodern feminist lens, we could see "the emergence of a new form of person" (p. 152). Shildrick (2004) goes on:

The shifting relationship between genetics and identity deeply undermines any concept of the moral agent as an autonomous sovereign subject, not least to the extent that the conventional bioethical model understands the subject's interest in others to be contractual, and her interest in the body to be primarily that of property rights (p. 152).

This emergent, transgressive embodiment, though constantly being reshaped and controlled through medical and legal discourses, has the power to challenge those discourses, by confronting the abstract self, that impossible regulatory standard. Through this confrontation, we see that "the subject is always irreducibly embodied" (p. 155).

Reproductive technologies put to other uses might reshape body boundaries, eliciting a complex definition of self, even displacing the self. Says Karpin: “genetic discourses, indifferent to the surface of the body as a marker of identity, demand a more complex understanding of the self in law. What happens, for instance, when genetic discourses reveal that we are all ‘leaky,’ boundaryless, and transgressive?” (2005, p. 195). We could reorient our discourses, beginning with examples like Duchesneau and McCullough, “in order to open a space for subjects who are connected, vulnerable, and dependent on who cannot shed their dependencies in order to become the liberal subject” (p. 212). Does technology then have transformative potential? We have seen how it has been wielded in problematic ways, but technology itself, its meaning and purposes, are contingent on who wields it.

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## Chapter 5: Conclusion

We are at a point where final remarks are in order. The following concluding chapter will summarize the work accomplished, recounting previous chapters on the principles of autonomy, equality, and respect for difference. Throughout this recounting, I will evaluate whether I have adequately explored the study questions presented at the outset of this work. I will next consider the study's limitations in scope, including the focus on literature and conceptual discourses at the expense of primary research. Further, I will consider whether the development of my own personal reflections and positions constitutes a limitation; that is, whether the explicit focus on my own analysis has led to a problem in consistency and cogency given that I have changed throughout the course of this project. Finally, I will consider my project's applications to and implications for future research: what comes next in the theoretical pursuit, and whether and how policy might change to reflect the framework I would most readily endorse.

### 5.1. Summary

This summary traces through the arguments made in chapters past. I sought to answer three study questions that probed the potential conflicts between the principles studied. By addressing these potential conflicts, it has been my intention that I fine-tune discourses on reproductive decision-making. I meant to account for how loaded the terms we use are, that is, I sought to identify the sorts of histories and ideologies they carry with them whenever they are invoked. All along the way I critiqued the liberal

narratives within which these principles can be found embedded. Rather than merely offer up a critique, however, I also proposed the development of a theoretical and legal framework that employs autonomy, equality, and respect for difference as they are reimagined in feminist theory.

#### *5.1.1. Autonomy*

This chapter addressed whether use of the concept of reproductive autonomy results in an offloading of responsibilities onto pregnant women, especially when disabilities can or have been diagnosed.

#### Autonomy Theory

In order to answer the question so stated above, the chapter began with a review of autonomy theories. Kantian moral autonomy entails commitment to moral duties, that is, acting in accordance with a universal law that is accessible only through a person's reasoning faculties. There is only one universal law, entirely formal in character—a categorical imperative against which all particular maxims for action can be measured. Ascertaining the categorical imperative requires that the moral agent be detached and abstracted from external, heteronomous factors that weigh on the will. Moral autonomy is defined in Kantian theory as compliance with universal law, acting in accordance with reason (Kant, 1993, 1999). Those who fail to comply—that is, those driven by externalities and deviating from unequivocal, categorical duty—may not be persons at all, may merely be things undeserving of moral respect and recognition (Kant, 1996).

Here we see the autonomous self is only autonomous insofar as he complies with abstracted good. Autonomy consists in moral obligation.

The personal autonomies of liberal theories move away from this explicit effort on Kant's part to tie autonomy to obligation, by opening up and individualizing reasons for acting (Dworkin, 1988; Mill, 1978; Rawls, 1999). However, personalization of autonomy requires individuation and decontextualization (Berlin, 1969; Kymlicka, 1996; Lukes, 1973). The autonomous self is not imagined in such a way that accounts for oppressions and privileges, even though power differentials affect whether a choice is authentic, that is, whether it is the product of economic, political, social, even interpersonal pressures—not quite coercion, yet influential in far subtler ways. The liberal self must convey self-sufficiency, independence, and isolation to such an extent that interrelations are framed as weaknesses (Basser, 2011; Pateman, 1989; Sherwin, 1998, 2011; Smart, 1989). This language of distance may well result in the offloading of responsibilities such that the autonomous self, in order to convey a liberal autonomy, is synonymous with the responsible self, the self who needs not depend on others.

Relational autonomy is a concept developed by feminists convinced it is possible to strip autonomy of its liberal baggage, of its roots in rugged individualism (Christman, 2004; Code, 1991; Downie & Llewellyn, 2001; Keller, 1985; Nedelsky, 1989; 1993; Sherwin, 1998, 2011). The autonomous subject is reimagined, such that her boundaries are not limited to and bound by her skin. Rather, she embodies a corporeality that is grounded in other corporealities, and she is situated within networks of interdependencies and interrelations. Such a concept redresses the implications to personalizing and

abstracting the autonomous self. Such a concept may be what is needed to ensure that women are not rendered radically responsible for their reproductive choices.

#### Autonomy in Bioethics and Law

The theories presented in the previous section were applied to bioethical and legal discourses, beginning with consent and capacity literature. In medical contexts, autonomy is expressed through free and informed consent, where the consenting subject must be decisionally capable (Engelhardt, 1986; Faden, Beauchamp, & King, 1986). Capacity models consist of elements largely related to the mechanism for decision-making, namely understanding of the situation and appreciation for the stakes, as well as rational manipulation of raw data and the physical capability to execute or communicate a decision. Some capacity models include an additional, substantive criterion—a person is capable if his decisions coincide with a conception of the good (Beauchamp & Childress, 2001; Buchanan & Brock, 1989; Grisso & Appelbaum, 1998).

Feminist critiques of capacity shed light on what is required to be declared decisionally capable in liberal cultures, and here we see the same baggage that the autonomy of liberal theories carries (Kerzner, 2006; Shildrick, 1997; Stefan, 1993). Conditions must be met in order for one to claim to be acting autonomously, and these conditions are meant to distance the subject. The subject may be re-contextualized by accounting for the ruling relations within medical and legal settings that affect consent and determine capacity (Brody, 1980; Elander & Hermoren, 1993; Leino-Kipli et al., 2000; Seedhouse, 1992).

*Starson v. Swayze* (2003) unpacks current Canadian legal standards for capacity—standards which invoke the same language and concepts used in the theoretical discourses outlined in this study. *Starson* confirmed that Canadians need only satisfy the minimal conditions for capacity: namely, understanding of the situation and appreciation for the stakes. It was ruled that neither physicians nor Consent and Capacity Boards could declare a person decisionally incapable on the basis of the substance of that person's decision. *Starson* was within his rights to refuse treatment no matter how misguided his reasons were, so the logic went. While this case marked a victory for disability law in that it stripped capacity standards down to the minimum threshold, it reaffirmed the Canadian commitment to a concept of personal autonomy.

Ashley Smith's struggles in Canada's mental health system demonstrate the failings of personal autonomy. Smith was incarcerated for an indefinite amount of time, ended only when she took her own life, because she was declared to be decisionally capable (Office of the Ombudsman and Child Youth Advocate, 2008; Sapers, 2008). She was institutionalized for her own good, and perhaps even in the interest of public safety, because her actions were analyzed in isolation from the power relations that constituted her contexts. She was held responsible for her outbursts, and thus deserving of and accountable for the punishments meted out.

### Reproductive Autonomy

This section entailed an overview of varied positions on reproductive autonomy. Liberal positions (including liberal feminists) have sought to address or invalidate a rights

conflict between woman and fetus: claiming the fetus may have the right to life, for instance, but not the right to make use of the body of an unwilling woman (Jarvis Thomson, 1971; Overall, 1987); or arguing that the fetus has no moral status, and thus has no stake in the rights conflict (Singer, 1979; Tooley, 1972; Warren, 1973). The underlying assumptions that, firstly, reproductive autonomy is entirely constituted by the grand abortion debate, and secondly, that the debate can be framed according to who has rights and which rights take priority, have had the effect of individuating the problem, and of rooting reproductive rights to personal, liberal notions of autonomy. Such a conception has required that the fetus and woman be individuated, that we draw boundary lines within pregnant bodies (Gavigan, 1992).

This individuation has been reified through reproductive technologies such as ultrasound, where fetal imagery has been used to personify the fetus (Gavigan, 2009; Katz Rothman, 1987; Kukla, 2005; Mitchell, 2001; Stabile, 1992). Liberal positions on abortion err in having the terms of the debate set for them, because the conceptual bifurcation of woman and fetus does not accurately reflect the experience of pregnancy, nor does it serve the interests of women, who through bifurcation see their bodies reduced to nothing more than vessels, even cast as hostile. Put another way, bifurcation frames the responsibilities women do or do not have to their own bodies, and organize the question of reproductive autonomy around their entitlements from the state and obligations to another.

Some feminist positions on reproductive autonomy, at least regarding the question of abortion (if that is to be our starting point), reject discourses on competing rights and

interests on the grounds that a theory is needed to account for the connection between woman and fetus, the way in which a pregnant body is simultaneously one-and-two, or one-becoming-two (Karpin, 1992-1993; Katz Rothman, 1990; Mackenzie, 1995; Warren, 1989). The pregnant body may even serve as an entry point to a theory of intercorporeality, where we erase the boundary lines we have built between persons and instead allow for the possibility that bodies are interconnected and interdependent, that they might have mutual rather than competing interests.

This discussion was applied to the legal case *R. v. Morgentaler* (1988), in which the limits to reproductive autonomy were simultaneously extended and defined according to body boundaries. In Canada, since *Morgentaler*, the right to reproductive autonomy has been grounded in the *Charter* s. 7 right to security of the person. Feminist analysts, though they applaud the strides made in this case, critique the individuating effect of reducing reproductive rights to corporeal control (Dunsmuir, 1998; Gavigan, 1992).

Since the case, reproductive rights have proven insufficient in the face of administrative efforts to curtail abortion. Women may be entitled to abortion in a negative sense, to the extent that they are entitled to protection from state interference in decisions pertaining to their bodies. However, they are not entitled to having the services made available to them, nor are they protected from the creeping privatization of healthcare, wherein financial constraints may pose as obstacles to reproductive autonomy (Downie, 2011; Gilmour, 2002). The effect of personalizing reproductive autonomy is that women are responsible for their bodies—responsible for their children should they

choose pregnancy, and responsible for finding safe and financially viable services should they choose to terminate in a context that does not regulate abortion provisions.

### Reproductive Autonomy and Disability De-Selection

Reproductive autonomy has been used to justify the use of disability diagnostic technologies, the argument being that women can make better informed decisions when equipped with disability diagnoses. The more a woman knows, the greater her autonomy is enhanced (Buchanan et al., 2000; Ruddick, 1988, 2000). Despite how promising this argument seems, the provision of technologies and the delivery of diagnoses are not neutral, but ambivalent, forcing women into decisions and decision-making processes (Hubbard, 1982; Katz Rothman, 1987; McCoyd, 2007; Rapp, 2000; Sherwin, 2004). Not only is information ambivalent, but it is sometimes misconstrued in light of ableist assumptions around disability diagnoses (Goodling et al., 2002; Kerr & Shakespeare, 2002; Parens & Asch, 2000; Shakespeare, 2005). Further, reproductive technologies (ultrasound, for instance) have come to be integrated into the rituals of pregnancy management, such that they, much like abstention from various foods, alcohol, smoking, and so forth, have become—at least in terms of social pressure—maternal obligations. Some scholars have gone so far as to claim it is morally wrong not to make use of disability diagnostic technologies, or not to terminate when diagnoses are rendered (McMahan, 2002; Purdy, 1996; Rhodes, 1999, 2006).

Reproductive autonomy, then, is not enough to explain the prevalent use of reproductive technologies, especially given how their introduction to reproductive

decision-making expands and complicates the responsibilities of pregnancy maintenance. Underlying or accompanying the banner of autonomous decision-making is the mandate to maintain or uphold public health standards (Buchanan et al., 2000; Lippman, 1993). Women may be free from overt interference to make decisions, but with this freedom comes the responsibility of acting as genetic gatekeepers, where their vigilance, discipline, and choices are expected to maximize and protect the health of the citizenry to which their pregnancy would be contributing (Peters & Lawson, 2002; Mykitiuk, 2002).

This work around the responsibility to promote public health (read, to de-select disability) was applied to case law. In *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)* (1997), the Supreme Court of Canada ruled that the state has no right to detain a woman against her will for the purpose of protecting the fetus she is carrying to term. G. was entitled to bodily control, though she was not entitled to support in addressing her substance use when she first sought it out. Nor did it appear that G. was entitled to support raising the disabled children born to her, for she was declared unfit and they became permanent wards of the state. The rhetoric around autonomy that was foundational to this ruling rendered G. radically responsible for her decisions.

Similarly, in *Arndt v. Smith* (1997), a woman's decision (or in this case, what the Court supposed her decision would be) to commit to a pregnancy despite a diagnosable disability resulted in rendering that woman responsible for the child born. The Supreme Court of Canada ruled that Arndt could not seek financial compensation through tort law. Smith might not have disclosed the serious risks to maternal chicken pox but the Court determined that disclosure would not have impacted Arndt's decision to terminate or to

let the pregnancy run its course. Because Arndt allegedly would have chosen to bear a disabled child, no legal wrong was committed against her, nothing worth reparations. Her choice, what she would have chosen, rendered her responsible.

Throughout the course of this chapter, I sought to trace the instances and effects of personal autonomy in bioethical and legal discourses. In so doing I noted how the personal autonomy of liberal theory requires that the self be individuated, in isolation, distanced from social conditions; that the self admits of no dependencies but is sufficient; that the self bears the responsibility for his decisions. Situating reproductive rights squarely in liberal theory has the effect of reducing women's agency in medical contexts, of curtailing women's recourses pertaining to abortion provisions, and of glossing over the ways in which disability diagnostic technologies compound maternal responsibilities.

### *5.1.2. Equality*

In this chapter, I considered whether there are tensions—or, as it turned out, whether there is a relationship—between reproductive autonomy and reproductive equality. Specifically, I focused on the potential conflict between reproductive autonomy on the one hand, and disability equality on the other.

#### Equality Theory

I began with an exploration of equality theory, highlighting the centrality of autonomy to these theories. My purpose throughout this chapter was to demonstrate that theories of equality have historically shared an organizing principle or purpose: to

enhance or ensure liberty. Formal equality, a concept found in Aristotle's *Nicomachean Ethics* and *Politics*, is an empty, regulatory concept that demands similar treatment of those persons belonging to like categories. Equal treatment is proportionately distributed according to merit, a standard which is in turn measured according to excellence (Frank, 1998). Excellence is constituted by choice and skill. This ancient ethical system paved the way for later systems that employ equality as a regulatory principle, and importantly, that justify inequalities according to standards of desert—a standard tied to notions of choice.

There are modern egalitarian models that advocate equalized opportunity over formalized characterizations of the equality (Arneson, 1989; Dworkin, 1981a, 1981b; Rawls, 1999). Equal opportunity serves to maximize liberty and level the playing field for those who are differently advantaged by virtue of a birth lottery. Theories of this sort, most notably Rawlsian egalitarianism (1999), have the effect of explaining inequalities as either naturally endowed before opportunities are offered, or chosen and thus deserved once opportunities are provided within competitive contexts. These theories are not in tension with liberty interests; rather, the centrality of liberty to these theories means that egalitarianism too is mired in the baggage that accompanies personal autonomy. Equality serves merely a regulatory function, ordering the distribution of goods and rights to persons divided by their body boundaries.

Feminist theories of equality critique this interplay between liberty and equality by noting power relations underpin the distribution patterns that equality principles regulate (Harvey, 1999; Kogge, 2011; Llewellyn, 2011; Young, 1990, 2000). Feminists

have advocated—in the stead of equalized opportunity and distributive justice—relational equality and restorative justice, established between persons rather than parceled out to each person. These theories also incorporate and account for, rather than stand in conflict with, autonomy, for relational autonomy is impossible to make sense of without first accounting for the power imbalances which facilitate or prevent autonomy, those power imbalances which are internalized, embodied, and enacted.

#### Equality in Bioethics and Law

The equality theories covered were applied to bioethics, beginning with Nozick's (1974) work on formal equality and entitlement theory in healthcare settings. Just healthcare for Nozick hinges on the autonomy of healthcare providers. A compelling critique has been that such a healthcare model does not account for patients' needs (Beauchamp & Childress, 2009; Daniels, 1995; Williams, 2005); the autonomy of the physician is maximized at the expense of the equality interests of the patient.

Daniels (1995, 2008) incorporates need into his Rawlsian healthcare model. As explained, Rawls (1999) understands there to be two kinds of inequality: natural inequalities and deserved, or chosen, inequalities. Daniels's two-tiered model maps onto this theory by supposing that everyone should have access to basic healthcare to deal with natural inequalities, and privatized options are made available to those who have earned the wealth to afford them. His system also supposes that healthcare heals or manages those hindrances to social opportunity. A just healthcare system, then, is just only insofar

as patient autonomy is maximized, that is, insofar as natural hindrances to autonomy are addressed.

By way of contrast, feminist bioethics is reoriented and re-concretized by drawing attention to the interrelations of power that produce poor health (Colker, 2009; MacKinnon, 1989; Purdy, 2001). The focus is thus shifted to conditions that function to disempower people, to limit agency, and to affect decisions (Shildrick, 2004; Wendell, 1996). Further, more emphasis is placed on notions of care, which has the effect of disrupting bioethical discourses that stress privacy, individuality, and patients operating in isolation (Hillyer, 1993; Wendell, 1996). Feminist refashionings of just bioethics might contrast with the autonomy of liberal theory, but they are designed to cultivate relational autonomy, decision-making within contexts that account for power differentials.

The insufficiency of formal equality can be seen in early equality jurisprudence: in *Bliss v. Canada (Attorney General)* (1979), the Supreme Court of Canada ruled that a pregnant woman should be subject to the same treatment as men. The ruling in *Bliss* was criticized in *Andrews v. Law Society of British Columbia* (1989), and the Aristotelian “similarly situated” test used in *Bliss* was rejected. It was established that differential treatment can result in equality. But equality analysis was still not ironed out, and after *Andrews* subsequent cases struggled. The *Law v. Canada (Minister of Employment and Immigration)* (1999) ruling (since overturned in *R. v. Kapp*, 2008) sought to tie equality to human dignity in cases where no comparator is easily discernible. The implication was that equality was de-substantiated, abstracted, and re-assigned the baggage of liberal

theory (Fredman, 2011; Lawrence, 2003, 2006). So far we see that far from tension lines running between the principles of equality and liberty, equality law has been limited by its ties to liberty.

### Reproductive Equality

The section that followed investigated equality as a reproductive right. Whether or not that right could be framed formally was explored in an analysis of Rawls's consideration of abortion. Rawls (2005) seeks to balance competing interests in the context of a just, liberal society. The abortion dilemma cannot be resolved by appealing to comprehensive doctrines and background conditions, or so he claims. Daniels (2008) seeks to apply the more substantiated concept of equality found in Rawls—equality of opportunity—to healthcare, and discusses the example of pregnancy as a medical matter in need of management. Women are free to pursue more options only insofar as they depend on healthcare providers to manage their health. Liberty is facilitated by placing women in what feminists would deem disempowering relations (Wendell, 1996).

Feminist approaches prioritize the background conditions Rawls would reject, looking to the reasons driving women's reproductive decisions (Sherwin, 1997). These reasons are embedded in relations of power, conditions which influence decisions. Autonomy and equality remain indivisible even in this theory work, although their connection is construed differently (Colker, 1992, 2009). Relational autonomy requires an analysis of relations that entail power differentials and social inequalities. These

inequalities shape and limit choice, are internalized and enacted, and render choices inauthentic (McLeod, 2002).

In *Doe et al. v. The Government of Manitoba* (2004), an attempt was made to tie reproductive rights to s. 15 equality rights. Although such a connection would be promising, this case unfolded when equality jurisprudence was defined by *Law* (1999). That meant that equality was constituted by the tenets of liberal theory (Erdman, 2007). If equality is nothing more than a regulatory concept meant to promote reproductive autonomy, equality jurisprudence lacks the force to redress an inadequate delivery system in the context of reproductive health. Empty equality and negative autonomy can do little to mandate differential treatment in the form of abortion provisions (Cook & Howard, 2007; Metzger, 2007; Rodgers, 2006).

#### Reproductive Equality and Disability De-Selection

This section consisted in an extensive analysis of the seminal work *From Chance to Choice*. The authors of this book (Buchanan et al., 2000) use Rawlsian theory to argue that disability diagnostic technologies simultaneously enhance women's freedom and constitute an obligation, in the interest of preserving a child's right to an open future—a future where opportunities are not closed off by disability. A liberal society must balance the liberty of women and the potential liberty of fetuses. Equality thus regulates the distribution of rights, and manages the competing interests of woman and fetus.

The ideology underpinning this distributive model entails geneticization—the reduction and ranking of persons according to their genetic codes (Lippman, 1991, 1993;

Rapp, 2000; Taylor & Mykitiuk, 2001). The equality model advocated in *From Chance to Choice* assumes that persons are of differing worth based on their genes.

Geneticization may be reinforced and reified due to the use of reproductive technologies like prenatal testing procedures, which offer genetic profiles and in so doing mark fetal bodies with difference (Martin, 2002).

Here we see an exploration of the more specific study question posed, for with the introduction of disability diagnostic technologies and the disability studies-derived critiques of these technologies (Amundson, 2005; Kerr & Shakespeare, 2002; Melo-Martin, 2006; Parens & Asch, 2000; Saxton, 2000), we see tension between autonomy and equality: the autonomy of the pregnant woman, and the equality of persons whose disabilities are targeted by reproductive technologies. I sought to demonstrate that the conflict only exists as long as we understand the principles of autonomy and equality within the contexts of liberal theories. When realigned with theories that account for power relations, the conflict seems to be resolved (Generations Ahead, 2009).

Should we advocate an equality-based approach to reproductive rights, we need a substantiated concept of equality, one which can contend with difference. When discussing the 1986 case *E. (Mrs.) v. Eve*, I argued that although the case marked a victory for disabled persons, it did not account for Eve's context, nor was it grounded in the history of Canadian sterilization policy, which dramatically disadvantaged disabled persons. That is, the case declared the state could not interfere with the reproductive capacities of disabled people, and yet, no further effort was made to make connections

between attempts to control Eve's reproductive capacities and the history of social and political inequalities responsible for denying disabled people reproductive control.

There appears to exist a tension between reproductive autonomy and reproductive equality only if the principles derive from differing theories. When sharing conceptual baggage in common, the principles are in actuality indivisible. Should they share overlap in liberal language, for instance, equality lacks the force to mandate differential treatment, for it functions only to fulfill liberty interests—a negative liberty at that. Should the two principles both be framed as feminist, they stand a better chance of operating in such a way that effects justice, for the redress and restoration of context facilitates agency. Even when we move into specific applications, scholars engaged in the Generations Ahead project (2009) claim that feminists advocating reproductive rights and disability activists seeking disability equality should not be at odds, for they have mutual—not competing—interests.

### *5.1.3. Respect for Difference*

My final substantive chapter considered whether the assumption that reproductive technologies be used for the purpose of disability de-selection reflects tensions between reproductive autonomy and equality on the one hand, and the principle of respect for difference on the other.

### Respect for Difference in Theory

The work done in this chapter sought to pull together the dissertation's threads. Each section consisted of reviews and critiques of the work done in chapters past, all through a postmodern lens. I began with a recounting of the metanarratives of modernity, and traced Kantian autonomy (Kant, 1993) through liberal traditions (Locke, 1980; Rawls, 1999). The personal autonomy of liberal theories bespeaks a certain sort of self—one conceived in isolation, one capable of self-sufficiency. The autonomous self can be found at the heart of distributive models regulated by liberal egalitarian principles. The Aristotelian interpretation of equality as sameness (found in the *Nicomachean Ethics* and the *Politics*) presupposed that people earn equal treatment; and this presupposition underscores liberal theories that promote opportunity maximization. For, opportunity is thought to facilitate autonomous choice, but also has the effect of justifying inequalities; those who fail to enact the autonomous self are undeserving of equal treatment (Dworkin, 1981b; Rawls, 1999).

I developed a postmodern critique for the purpose of establishing difference as the condition for the possibility of these oppressive ideological systems. I considered Lyotard's (1984) position that the philosophies explored above constituted metanarratives—myths that justify the classificatory thinking of modernity. Derrida (1972) does work in this vein, developing difference as that which makes presence possible, that which through juxtaposition imbues the self with meaning. But difference, all that stands other to the self, is also a disruptive force that has the power to break down meaning, and to redefine. In the face of such a threat to order, current systems of power

have strategies in place to manage difference so as to mitigate its disruptive force. These strategies are embedded in regulatory mechanisms and practices that subtly work to produce and shape docile bodies (Derrida, 1992; Foucault, 1977).

Postmodern feminisms have taken up these themes to consider how the gendered body is produced (Bartky, 1990; Gimlin, 2001). Patriarchal rules are inscribed on women's bodies, and work to objectify women, to reduce women to bodies in need of maintenance, discipline, and control. That women's bodies may be intercorporeal is taken to be a weakness in contrast with the privileged autonomous subject (Bebube, 2002; Shildrick, 2009). That women's experiences overlap and intersect complicates the classificatory thinking that imagines the ideal self behind veils (Kittay, 1999).

There are indeed tensions running between egalitarian theories that prioritize the autonomous self on the one hand, and politics of difference on the other. Modernity's metanarratives are only meaningful through a process of othering, and through the management of those others.

#### Respect for Difference in Bioethics and Law

This section looked back on specific applications of the metanarratives of personal autonomy and formal equality. I identified the familiar autonomous self in consent and capacity standards; the criteria for decisional capacity are the markers of selfhood (Buchanan & Brock, 1989; Faden, Beauchamp, & King, 1986; Grisso & Appelbaum, 1998). These criteria function as regulatory mechanisms by, firstly, denying some kinds of people the right to decision-making (Shildrick, 1997); and secondly, by

justifying disproportionate resource allocation when the capable self is undeserving (Beauchamp & Childress, 2009).

The consenting, capable subject is separated out from the body, which is assumed to be a fixed, stable given (Shildrick, 1997). Health paradigms are in place to manage the dys-appearance—the disruption—of bodies that manifest disability, disease, injury, even pregnancy (Gimlin, 2006; Leder, 1990). Medical management classifies and treats bodily difference so the body might once again be relegated to the background, for the autonomous, deserving subject cannot be associated with body (Foucault, 2003). Liberal theories are maintained through the decontextualization and disembodiment of identity.

I went on to consider the framing of respect for difference in international policy, specifically the Convention for the Rights of People with Disabilities (2006). I also investigated the UN Declaration on Race and Racial Prejudice (1982), which recognizes lifestyle diversity and the right to be different; and the UN Declaration on the Rights of Indigenous Peoples (2007), which affirms that the right to be different contributes to the diversity of civilization, culture, and humanity. The Convention on the Elimination of All Forms of Discrimination against Women (1979) implicitly recognizes that women are differentially affected in reproductive contexts. I considered the trouble with recognizing difference on the one hand, and appealing to common humanity on the other—it may be that our policies exhibit limited imaginations for difference and diversity.

I looked to case law at home, specifically *Eldridge v. British Columbia (Attorney General)* (1997). This case expanded equality analysis by considering adverse effects discrimination—the result of the general application of rules, or same treatment.

Disabled people especially need protection from adverse effects discrimination because of the ways in which disability has been socially and historically devalued and disadvantaged.

The ruling in *Auton (Guardian ad litem of) v. British Columbia (Attorney General)* (2004) has been contrasted with that in *Eldridge* (Cousins, 2009; Finley, 2005). The ruling has been accused of employing a narrow equality analysis by justifying the delisting of ABA/IBI treatment from core medically necessary treatments, though the treatment itself raises questions around treatment of autistic children in healthcare contexts (Baker, 2008). Further, the use of comparators in *Auton's* equality analysis did not honour the work done in *Eldridge* to move away from equality as sameness (Gilbert & Majury, 2006).

*Withler v. Canada (Attorney General)* (2011) may mark the next evolution of equality jurisprudence, one where context overrides these past strategies of making comparisons and leveling playing fields. The contextualization of equality may move the principle away from liberal interpretations that have proven problematic, and in so doing re-situate that once isolated autonomous self. A politics of difference, in other words, may make use of the tensions previously identified between our principles, for the purpose of reorienting and reconstituting those principles.

### Reproductive Justice

I began with an analysis of Beauvoir (1956), according to whom women are othered due to reproductive difference. The process of othering involves interpretive

work that reduces women to their reproductive functions (Rich, 2007). The solutions posed by liberal feminists include liberation from reproductive roles and the rendering of the concept of gender neutral, even useless (Butler, 1999; Wittig, 1992). Instead of distancing women from their bodies, however, the answer may instead be to challenge the assumptions that bodies signify weakness, that the displacement of self during pregnancy is problematic (Chandler, 2007; O'Brien, 2007).

Jhappan (1998) frames gender neutrality as an equality pit, where equality is only distributed to those who can approximate privileged standards. The equality pit may be challenged by noting that women are differentially impacted during pregnancy by virtue of their biological, reproductive differences from men (Mahowald, 2000). Further, there is no essential, catch-all category for women, for reproductive contexts affect women differently based on race, class, sexual orientation, disability, and so forth (Hill Collins, 2007; hooks, 2007).

To avoid essentialism, then, and to revolutionize discourses around reproductive decision-making, we might employ theories of reproductive justice, which can account for contextualized, differential, and intersectional oppressions (Smith, 2005a, 2005b; West, 2009). We might locate respect for difference in such theories given the heed paid to concrete particulars and power relations.

I next considered whether reproductive justice would have any currency in Canadian law. In a LEAF publication, Majury (2006) and Sampson (2006) critique formal equality and advocate taking a contextualized approach to substantiating equality. Applied to reproductive health, Cook and Howard (2007) promote accommodation of and

respect for biological and social difference. Nevertheless, some feminists would frame reproductive justice as an alternative to, rather than an extension of, equality analysis (Jhappan, 1998; Smith, 2005a; West, 2009).

In addition to jurisprudence, I also investigated policy, specifically policy on sex selective abortion. Perhaps to prevent the practice, several hospitals in the Greater Toronto Area that service racialized communities are not forthcoming when it comes to disclosure of fetal sex (Yang, 2012). This variation in hospital practice is not regulated because, although SOGC guidelines (2007a, 2007b) do not prohibit sex selective abortion outright, they do recommend that disclosure of fetal sex should be left to the discretion of physicians, and can be withheld in the best interest of the patient. While scholars opposed to sex selective abortion speak of sexism and reproductive choice (Rogers, Ballantyne, & Draper, 2007; Thiele & Leier, 2010), they overlook how racialized women have been discriminated against in reproductive contexts.

#### Reproductive Justice and Disability De-Selection

I began by reviewing the reproductive model used to justify the employment of disability diagnostic technologies, and I suggested that reproductive autonomy arguments decontextualize reproductive issues (Wagner, 2008). The public health model, too, is problematic for its pressure on women to prevent disability, for disability is framed as a deviation from health standards. The concept of reproductive autonomy works through these models as a mechanism that maintains power relations; it gives the impression that women are distanced from social pressures and radically responsible for their decisions.

I returned to Buchanan and colleagues (2000), who tie reproductive technologies and disability de-selection to equality rights. They claim that disability is an importantly different characteristic than other identity markers—a claim which devalues disability (Anstey, 2002; Karpin & Savell, 2012). Such a position reflects geneticization, where genetic identity is normatively framed (Taylor & Mykitiuk, 2001).

Whereas reproductive autonomy and reproductive equality have been used to justify reproductive technologies, we might employ reproductive justice to explain how the routinization of the technologies marks a failure to respect difference. This approach is not necessarily antithetical to the principles of autonomy and equality, as long as these principles are conceptualized with feminist rhetoric. Reproductive justice models call attention to the contexts that women internalize when making choices, and acknowledge the differential impact of power relations on different identity characteristics.

This section went on to explain the example of a lesbian Deaf couple who used pre-implantation genetic diagnosis to increase the likelihood of having a Deaf child (Savulescu, 2002; Wagner, 2008). My analysis acknowledged gender and sexual orientation as compounding factors in reproductive decision-making (Kallen, 1989), and considered claims that Deafness is the defining characteristic of a politically active linguistic minority (Anstey, 2002). While the *Assisted Human Reproduction Act* (2004) does not prohibit couples from deliberately selecting disability, it does make the assumption that technologies would be used to de-select disability, and only sanctions sex selection in cases where sex affects genetic risk.

Once again I looked to international law to determine whether the principle of respect for difference can be or has been applied to regulation of reproductive technologies. The UN Convention on Biological Diversity (1992) and Declaration on the Human Genome and Human Rights (1997) both recognize genetic diversity and resist imposing social or political interpretations of this diversity. Specifically, the DHGHR simultaneously recognizes humanity's fundamental unity and inherent diversity. Although the rhetoric of sameness is here employed, we also see an effort to respect difference. The UN instrument also takes a contextual approach by acknowledging that social conditions shape the human genome, and seeks to safeguard persons from geneticized discrimination.

These instruments show promise, yet are they incorporated into national or federal legislation? I considered New Zealand's Ethics Committee on Assisted Human Reproduction (2005), which prohibits the use of pre-implantation genetic diagnosis for the purpose of increasing the likelihood of disability. In comparison, although Canada's *Assistive Human Reproduction Act* (2004) does not prohibit use of reproductive technologies for anything other than sex selection, the policy shares in common assumptions around the use of the technologies, and the prioritization of children's well-being.

How might we move forward from here? Perhaps, if we reframed our discourses, we could dispel our assumptions around the purpose of reproductive technologies. These technologies have transformative potential, for people who make use of them for the purpose of deliberately selecting an identity characteristic that has been devalued

challenge our politics, practices, and power structures (Karpin, 2005; Rose, 2007; Shildrick, 2004). And this is not to say that we need to abandon historically relied upon principles in our reframing, although our tools require recalibration. Autonomy should be understood in the context of relations of power that work on and through persons, so as to avoid use of the concept to decontextualize the subject. Equality should be substantiated by the acknowledgment of intersecting oppressions and should take an interest in correcting injustices rather than elevating persons to privileged, neutralized standards. The principles need not be in conflict as long as they are incorporated into a politics of difference.

## 5.2. Future Research

The following section will account for the limitations in this study's scope, noting the lack of primary research. Further, I will consider the troubles around my growing as a scholar alongside the development of the project. I will make recommendations for future research in an effort to point to how one might reach beyond my scope, and I will weigh the academic and political implications of my study.

### *5.2.1. Limitation in Scope*

With all the dogged persistence of an ivory tower academic, I developed theory-based work. My intention was to clarify the conversations we have on and around reproductive rights. I poured over the literature and analyzed legal transcripts and policy documents, making use of what needed to be a thoroughly established and defended

theoretical lens. While I ardently defend this line of work, I do acknowledge that it is difficult to produce something new; in lieu of primary research I might merely be reassembling and reordering the knowledges I have gathered. I can advocate a contextualization of theoretical and legal concepts, though I myself still tend toward a sort of abstraction. I can promote interdependence, interconnectivity, interrelatedness, and the like, all the while producing research in isolation.

I further acknowledge that this research embodies my transformation as a scholar over the years. I changed as I wrote. Perhaps that is the mark of an effective dissertation, in that I was able to grow. Perhaps the dissertation is meant to be a living document that itself grows, shifts focus, and changes into something unexpected. My work came to be heavier, my analysis more complicated, as I read, and learned, and wrote; as I spoke with committee members, reassembled supervisory committees, and navigated political waters. I would like to think that as I became a more competent, confident scholar, my work's direction came to be clearer, and veered down worthwhile paths. And yet, I acknowledge that this dissertation was for a long while a work in progress, an exploration, rather than a cogent argument imagined at the outset.

### *5.2.2. Implications and Recommendations*

I have already begun the process of breaking down portions of my work and submitting to scholarly journals. It is my hope that sharing my research will further the analysis of the current theory and law framing reproductive rights. Of whether it is possible for law to move in a postmodern direction I remain uncertain. But I have sought

to point out the possibility of a politics of difference, as well as the transformative power of reproductive technologies should they be reoriented, and should the systems and ideologies surrounding their use be reorganized.

Disability law and policy has surely come a long way, but its open-endedness has been a detriment, for oppressions have a habit of lingering, taking root in ideology, and sneaking in through policies' rhetorical back doors. I would like to think I have pointed to theoretical and legal gaps, those hazy gray areas in need of clearer delineation. I would like to think that I have substantiated those gaps with theories that continue to lack—though they deserve—political recognition. As long as feminism remains on the political periphery, and postmodern theory continues to function merely as critique, we might continue to struggle with facilitating authentic agency, of accounting for power, and of acknowledging diversity in concrete ways.

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