Critical Disability Theory

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Critical Disability Theory:
Essays in Philosophy, Politics,
Policy, and Law

UBCPress · Vancouver · Toronto

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Canada

For our parents:

Ona and Charles
Geraldine and Tom

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Preface

This collection brings together twenty-three scholars from a variety of disciplines, scholars who are deeply concerned about conventional understandings of politics targeted at persons with disabilities and legal responses for them. As editors we want to thank the contributors for their willingness to share their ideas and insights in this collaborative enterprise. We also want to express our gratitude to Dalhousie Law School, the Canadian Law and Society Association, and the Canadian Association of Law Teachers for facilitating this project. Wes Pue and Randy Schmidt at UBC Press have offered generous guidance and the Aid to Scholarly Publications Programme has provided a much appreciated publication grant. We especially want to thank Dean Dawn Russell for her institutional support and the McIntosh Fund for its significant financial assistance in bringing this project to fruition. Last but not least, we wish to express our gratitude to David Dzidzornu for his superior editorial assistance and to Molly Ross for her wizardry with computers.

Critical Disability Theory

Introduction: Toward a Critical Theory of Dis-Citizenship

Richard Devlin and Dianne Pothier

North American societies take pride in promoting themselves as bastions of liberty, equality, and inclusion. In Canada, politicians never tire of proclaiming that it is the best country in the world to live in (Chrétien 2003), and judges and lawyers seldom miss the opportunity to celebrate the *Canadian Charter of Rights and Freedoms* and its commitment not only to liberty but also equality (L'Heureux-Dubé 2001). There is little doubt that, relatively speaking, the majority of North Americans do enjoy a high standard of living and that the quality of life, for most, when measured on a worldwide scale, is quite good.

However, not all share equally in the good life, or feel adequately included. Among those who face recurring coercion, marginalization, and social exclusion are persons with disabilities. Depending on how and what one counts, the disabled comprise from 6 percent to 15 percent of the Canadian population. Traditionally, responses to the needs of persons with disabilities have oscillated between charity on the one hand and welfarism on the other. As the following chapters will argue, both responses (despite their probably well-intentioned nature) have failed to adequately respond to the needs of persons with disabilities and, indeed, may have compounded the problems experienced by many of the disabled. The consequence, we suggest, is a system of deep structural economic, social, political, legal, and cultural inequality in which persons with disabilities experience unequal citizenship, a regime of dis-citizenship.

The issue of citizenship has garnered quite significant academic attention in the last decade or so (Hobson and Lister 2002). For some, citizenship has relatively formal significance, for example, the ability to hold a passport and to vote. For others, citizenship is more substantive: it is about the capacity to participate fully in all the institutions of society – not just those that fit the conventional definitions of the political, but also the social and cultural. This latter approach emphasizes that citizenship is not just an issue of individual *status;* it is also a *practice* that locates individuals in the

larger community. As such, the substantive approach raises questions of access and participation, exclusion and inclusion, rights and obligations, legitimate governance and democracy, liberty and equality, public and private, marginalization and belonging, social recognition and redistribution of resources, structure and agency, identity and personhood, and self and other (Kabeer 2002). Building on Hammar's (1990) concept of denizens to describe guest workers, who have some social rights but no political rights, in countries such as Germany, we want to suggest that because many persons with disabilities are denied formal and/or substantive citizenship, they are assigned to the status of "dis-citizens," a form of citizenship minus, a disabling citizenship.

In response to this dis-citizenship regime, this book posits that we need new ways to conceptualize the nature of disability, a new understanding of citizenship that encompasses the disabled, new policies to respond to the needs of the disabled, and a new legal vision of the entitlements of the disabled. More precisely, we hope to develop an anti-necessitarian understanding of disability that focuses on genuine inclusiveness, not just abstract rights. Such an agenda we will characterize as critical disability theory.

This introduction is, therefore, an inquiry into the possibilities and parameters of a critical disability theory. Our central arguments are that disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion; rather, it is a question of politics and power(lessness), power over, and power to. While liberalism has been subjected to a number of prescient and persuasive critiques in the last few decades (from feminists, communitarians, critical race theorists, and gay/lesbian/queer theorists, among others) we will suggest that, because of the particular needs of the disabled, critical disability theory gives rise to its own particular set of challenges to the core assumptions of liberalism. Indeed, we think that in some respects critical disability theory poses more fundamental challenges than do other critical theories. Liberalism, as a dominant ideology and principle of social organization, has a particularly hard time dealing with disability. As we will elaborate below, liberalism's approach to disability incorporates embedded assumptions that conceptualize disability as misfortune, and privilege normalcy over the abnormal. The corollaries are presumptions that the structures for societal organization based on able-bodied norms are inevitable, and that productivity is essential to personhood. The goal of critical disability theory is to challenge these assumptions and presumptions so that persons with disabilities can more fully participate in contemporary society.

To frame our overview, we organize our argument around four central themes: (1) language, definitions, and voice; (2) contextual politics and the politics of responsibility and accountability; (3) philosophical challenges; and (4) citizenship/dis-citizenship.

Language, Definitions, and Voice

A primary concern of critical disability theory is an interrogation of the language used in the context of disability. There are several layers.

First, what is the most appropriate descriptor to employ? The reader will have noticed that thus far we have referred to "the disabled" and "persons with disabilities" interchangeably. Contributors to this book invoke a number of other possibilities: "disabled persons," "people with impairments," people who experience "activity limitations," and "people who live with impairments." We believe that the range of descriptors is a reflection of a significant level of discomfort with what the English language seems to be able to offer as the available options.

In early discussions, the terms "handicapped" and "disabled persons" were common, but they generated criticism on the basis that it is inappropriate to convey the idea that the entire person is disabled because of a specific impairment. This led to the adoption by the Canadian federal and provincial governments of an explicit policy to use the term "persons with disabilities" instead, while strongly discouraging the use of "disabled persons" (Titchkosky 2001, 126). Yet, "persons with disabilities" or other "person first" language has its detractors. Without particularly defending the use of the term "disabled persons," Titchkosky offers a sociological critique of person-first language as an apolitical, individualized, and inappropriate means by which to "dismember disability from the self" (129, 134). Titchkosky is not seeking to ban the use of person-first language but, rather, to challenge its ubiquitous status and normalizing potential. While we think Titchkosky's critique, as a sociologist, is an important one, we, as lawyers, think an alternative perspective on the significance of person-first language should also be taken into account.

In legal terms, the concept of personhood is significant to equality rights: for example, in the contexts of race, gender, and sexual orientation. Before the Civil War in the United States, this was starkly illustrated by provisions in the 1787 American Constitution that officially counted enslaved persons as only three-fifths of a free person in determining each state's representation in the House of Representatives (e.g., article I, section 2, cause 3). In Canada, the recognition by the Judicial Committee of the Privy Council of women as legal persons under the *British North America Act* (1867), persons capable of being named as senators, was a crucial landmark on the road to women's equality (*Edwards v. A.G. Canada* 1930). Kathleen Lahey's book, *Are We "Persons" Yet? Law and Sexuality in Canada,* uses full legal personhood as the test of whether gays, lesbians, bisexuals, and the transgendered have obtained full equality (Lahey 1999). Viewed in this historical and legal context, it can be argued that "persons with disabilities" or other person-first language is not so apolitical after all. To be a person is to have the capacity to appear on the political radar screen. Yet, the first-person, or "with," language does still

have the potential to disconnect the disability or to make it appear that the disability is of a second order nature; we do not speak of "persons with a gender" or "persons with a race."

Part of the difference in language is that while the words "race" and "gender" do not themselves designate a specific subset of the population (and in that sense they are facially neutral), "disability" does explicitly engage in targeting (and in that sense is ideologically loaded). Moreover, in its origins, the term "disability" is clearly pejorative. The 1989 edition of the *Oxford English Dictionary* defines "disability" as "want of ability ... inability, incapacity, impotence" and "disable" as, among other things, "to pronounce incapable; hence to disparage, depreciate, detract from, belittle." The disability movement has had some success in reclaiming the word "disability" to remove its negative connotations, which may explain in part the re-emergence of the terms "the disabled" and "disabled persons." This is parallel to the transformation of "queer" from a derogatory slang word into a badge of pride for gays, lesbians, and bisexuals. Yet, on the disability front, the transformation has been far from complete. As an example, when someone is on the "disabled list" of a sports team, not only are they ineligible to play the game, they don't even count among the allowable number of players – a rather stark example of exclusion. This book is part of the project of trying to rid the term "disability" of its pejorative and exclusionary origins. For our purposes, we have chosen to use the descriptor "persons with disabilities," as we believe that currently it is the least worst option.[1]

Second, if we are prepared to use the word "disability," what qualifies as a disability? This is crucial because, as Mary Ann McColl, Alison James, William Boyce, and Sam Shortt demonstrate in Chapter 1, depending on how the definition is constructed, it can have a determinative impact on how people identify themselves and on how they are perceived by others. Equally importantly, it has a huge impact on the numbers question. As Dana Lee Baker points out in Chapter 8, in the context of autism, the numbers question can generate huge political and policy shifts. Another aspect of the what-qualifies-as-a-disability issue is equally political: while there is consensus, for example, that being blind or an amputee qualifies as a disability, other conditions are more contentious. What about anorexia, smoking, alcoholism, and gambling? In Chapter 13, Daphne Gilbert and Diana Majury tackle the question of whether infertility is a disability and, in a heterosexual context, whose disability it might be – the man's, the woman's, the couple's? They argue that male infertility cannot be collapsed into a couple's infertility, and also that infertility does not qualify as a disability.

Moreover, even if we could find agreement on what might qualify as a disability, what types of disability exist? A number of authors have suggested different categorizations for various types of disability. Karpin (1999, 284) suggests the triad of psychiatric, physical, and intellectual. Lepofsky (2004)

invokes a slightly different triad: physical, sensory, and/or mental disability. McColl and colleagues, on the other hand, suggest in Chapter 1 that it is useful to factor in age, and to distinguish between adult disability and old age disability.

These diverse ways of differentiating among types of disability invoke the challenges of consolidating the subject matter of, as well as the methods and arguments advanced by, critical disability theory. Here we would note the particular challenge of integrating analyses of mental disorder and mental disability as legal and medical categories within the critical disability literature and within the disability rights movement as social phenomena (Herr, Gostin, and Koh, 2003). This literature and social movement have historically been more oriented to challenging dominant conceptions of physical disability than of mental disorder and disability. However, particularly in light of contemporary scientific efforts directed at "unlocking the mysteries of the brain" to produce evidence of biochemical or genetic components of psychiatric disorders (so that they are finally on par with physical disorders) and to identify genetic components of specific forms of mental disability, critical disability theory is increasingly concerned with targeting the problematic assumptions of the biological model in the distinct historical and institutional realms of mental disorder and mental disability. This requires further fundamental challenges to dominant constructions of rationality and reasonableness, of agency and personhood, and of the hierarchical binary of mind and body that critical disability theory has arguably only begun to confront.[2]

The struggle over definitions and categories is important because, historically, we have tended to adopt a binary conception of disability: there are the disabled (them-us) and the able-bodied (us-them). McColl and colleagues (Chapter 1) are skeptical of such a dualistic approach to disability. Carolyn Tyjewski (Chapter 5) is also critical of a binary analysis of disability (as well as of other identity categories), objecting to the failure of American courts to recognize the existence of hybrids. What Tyjewski says about American court decisions is not directly transferable to Canada,[3] but her general point about the fluidity of categories does still resonate.[4] In other words, the binaristic approach to disability engenders a process of "othering" and categorization, when the more nuanced reality is that disability might be better understood as a dynamic and contextualized range. Disability, we argue, has no essential nature. Rather, depending on what is valued (perhaps overvalued) at certain socio-political conjunctures, specific personal characteristics are understood as defects and, as a result, persons are *manufactured* as disabled.

If this is accurate, the vital question is not whether the disability inheres in a particular person, but what is society's response to a particular person's circumstances? This is why we emphasize the importance of context. Whether a person is "disabled" is highly dependent on the social organization of

society – not only in the way we construct our buildings and our transport systems, but also in the performance benchmarks we utilize to assess people (see Chapter 4 by Theresa Man Ling Lee and Chapter 9 by Teri Hibbs and Dianne Pothier), and in the ways in which people are expected to engage in the daily activities of work, leisure, and living. As we change our patterns of social organization, so too might we have to change our understanding of what and who qualifies as disabled. Phrased slightly differently, when it comes to disability, there is a duality at play – the particular circumstance of a specific individual, and the larger social context within which that person operates – and the two are mutually constitutive (discussed in Chapter 7 by Kari Krogh and Jon Johnson, and in Chapter 10 by Catherine Frazee, Joan Gilmour, and Roxanne Mykitiuk). A revealing example of this is Darcy MacPherson's anecdote in Chapter 11 of "walking" in his wheelchair into a room full of students. MacPherson's incorporation of wheeling within "walking" can be seen as simply an effort to downplay the difference between moving by legs and moving by wheels. Such use of language, however, could also be a profound political challenge to the privilege society gives to walking in the "normal" way.

MacPherson's anecdote might also lead some readers to believe that the trajectory of the duality is that gradually we are getting better at responding to the needs of persons with disabilities, primarily through accommodation. This we will characterize as the narrative of progress. However, as several of this book's contributors point out, because of changing structural dynamics, things may be getting worse rather than better for some persons with disabilities. Neo-liberal policies of downsizing and retrenchment, for example, have resulted in increased marginalization and impoverishment of many persons with disabilities. Another example is that of computer programs increasingly tied to fancy graphics or to the use of a mouse, creating major barriers for users with visual impairments. The result, by fluke rather than design, is that older computer programs are often more adaptable to the needs of those with visual impairments. Even when new technologies enable the removal of barriers, the actual deployment in practice of such technologies may generate perverse effects. For example, the same technology that now makes it easy to produce large-print versions of a document (enabling a visually impaired person to read otherwise inaccessible text) equally facilitates the production of extremely small-print versions (increasing inaccessibility for the visually impaired).

However, even this contextualist approach to disability may not go far enough. Tremain (2002) suggests an even deeper level of concern. She argues that while the social constructionist understanding of disability is an improvement over traditional essentialist conceptions, it too draws on a problematic dichotomy between impairment, which is understood as a natural defect, and disability, which is understood as society's oppressive char-

acterization of an impairment. Her critique is that "impairment" is itself ideologically loaded, a medicalized discourse that assumes a perfect norm and the impaired (read defective) other. Similarly, in Chapter 10, Frazee, Gilmour, and Mykitiuk examine "impairment as a relational inquiry." In short, there is no apolitical way to think or talk about either impairment or disability, because language itself is an unavoidably political phenomenon. By way of illustration, Bickenbach (1993) has argued that there are at least four distinct ways of thinking about disability – the biological, economic, socio-political, and equality models – and that each approach generates not just different understandings but distinct policy/political responses, ranging from charity, empathy, and pity to surgery, to rights and entitlements. To speak of disability, then, is to already have engaged. As Ravi Malhotra points out in Chapter 3, there is no Rawlsian original position from which to pursue an impartial assessment of the situation of persons with disabilities or the basic institutions of society. One of the reasons we suggest that critical disability theory poses a fundamental problem for liberalism is that most liberal theory assumes that language is a relatively transparent neutral medium through which we communicate. Critical disability theory, however, posits that language itself is deeply partial.

So how do we understand disability? We take our cue from Gilbert and Majury, who suggest in Chapter 13 that stigmatization is pivotal (and on this basis argue that a man's infertility is not a disability). Frazee, Gilmour, and Mykitiuk document in Chapter 10 a particular form of stigmatization in circumstances in which the medical gaze on women with disabilities often transforms patients from human beings into "interesting conditions." While we think the emphasis on stigmatization is important in identifying disability, we want to suggest that the political dimensions of coming to terms with disability are even more entrenched than stigmatization. That is to say, stigmatization is still connected to an intentionalist understanding of disability. A more political/structural analysis would emphasize the existence of exclusionary social practices that are not dependent on intentions. From this perspective, social organization according to able-bodied norms is just taken as natural, normal, inevitable, necessary, even progress. It's just the way things have to be done. The resulting exclusion of those who do not fit able-bodied norms may not be noticeable or even intelligible. For example, most daily practices (e.g., work, leisure, and access to the necessaries of basic survival) are organized on the assumption that people have 20/20 vision, perhaps with the assistance of glasses or contact lenses. If this assumption is inaccurate, persons whose vision does not accord with this measurement run the serious risk of marginalization. Expanding cities are increasingly designed on the basis that people can drive, but if one cannot drive because of his or her eyesight, society is creating barriers for that person to get to work, to buy food, or to play. There may be no stigma involved

here, but the consequences are manifestly exclusionary. It is this focus on the combination of assumed inevitability plus social exclusion that leads us to suggest that what is required is an "anti-necessitarian" (Unger 1987) disability theory.

In light of the significance of language and definitions, it is also vital to emphasize the importance of voice. The editors and contributors to this book form a diverse group. Although we all share a commitment to advancing the social status and equality rights of persons with disabilities, there is a range of opinions as to how to accomplish such goals, both theoretically and practically. We also come from a diversity of academic backgrounds: law, politics, disability studies, geography, health policy, public affairs, and cultural studies. Moreover, however one defines the term, we are a mixture of disabled and non-disabled persons. Several of the contributors are persons with disabilities, although most do not self-identify as such in their chapters. However, four of the contributors, Lee (Chapter 4), Tyjewski (Chapter 5), Hibbs (Chapter 9), and MacPherson (Chapter 11), expressly invoke their personal experiences of disability as central features of their analyses. For those who do not do so expressly, we have little doubt that their personal experiences of disability inform their arguments and perspectives.

As editors, the two of us have developed an interest in critical disability theory by different routes. Devlin comes to this through an academic interest in critical theory and a political commitment to radical participatory democracy. Pothier comes to this through an academic interest in constitutional and public law, but with a more personal stake. Pothier's understanding of equality and human rights law has developed alongside her conceptualization of her own disability – visual impairment (on the borderline of legal blindness) since birth, because of albinism. The personal and academic experiences intertwine in challenging ways. Pothier engages in an ongoing process of using theory and legal analysis to reassess her own experiences of how she is treated as someone with a disability, and of using her experiences of how she is treated as someone with a disability to question the adequacy of theory and legal analysis.

Contextual Politics and the Politics of Responsibility and Accountability

The foregoing discussions of language, definitions, experiences of disability, and voice lead directly to a second general theme of critical disability theory: that it is a self-consciously politicized theory. Its goal is not theory for the joy of theorization, or even improved understanding and explanation; it is theorization in the pursuit of empowerment and substantive, not just formal, equality.

The origins of critical disability theory can be traced to a larger movement in politics and law that has become disenchanted with the promises

of liberalism (Minda 1995). Liberalism, in its most positive manifestations, was able to promote a welfare state, that is, a web of social and economic relations that went beyond formal equality to facilitate equal opportunity for some. However, liberalism has been unwilling and unable to pursue substantive equality. In response, a number of post-liberal voices – including critical theory, some forms of feminism, queer theory, critical race theory, and critical disability theory – have emerged, identifying both the weaknesses of liberalism and the requirements of a more inclusive democracy (Devlin 2001). This new critical realism, as it might be called, has taken on an increased urgency in the light of both neo-liberalism and globalization, the joint effect of which has been to further marginalize the historically excluded, including persons with disabilities.

Two key political insights undergird critical disability theory: power(lessness) and context. As suggested previously, issues of disability are not just questions of impairment, functional limitations, or enfeeblement; they are issues of social values, institutional priorities, and political will. They are questions of power: of who and what gets valued, and who and what gets marginalized. Critical disability theory interrogates a system of justice that is based on a politics of "just us." This is why context is so important to critical disability theory, because it is theory that emerges from the bottom up, from the lived experiences of persons with disabilities, rather than from the top down, from the disembodying ivory tower. As such, it is a form of embodied theory. But this does not mean critical disability theory does not engage with some of the big questions of philosophy and political theory; it simply means that it comes at them with a sharp awareness of the contexts of inequality based on disability. So, for example, critical disability theory is skeptical of liberalism, not just because it has potential ontological weaknesses (for example, its insufficiently relational understanding of a self) but because of its deep structural assumptions such as its narrative of progress, which many persons with disabilities find hard to imagine given the current context of state downsizing, budget cutting, and retrenchment.

The emphasis on power and context also provides a clue to the philosophical origins of critical disability theory. While some authors, for example Malhotra in Chapter 3, argue that liberalism can be given a radical turn, many critical disability theorists build on the insights of critical theory and feminism. Lee argues in Chapter 4 that even Will Kymlicka's egalitarian liberalism is inadequate to the task.

Liberalism's approach to disability is constrained by limiting normative assumptions. The starting point for liberalism is that disability is about misfortune or bad luck. As MacPherson describes in Chapter 11, tort law conceives of a pre-existing condition of disability as a subtraction from the norm. Conceptualizing disability as a misfortune has very specific implications, and forms the basis of the approaches referred to earlier, ranging from

charity to welfarism. If the starting point is misfortune, the first level of engagement must be prevention. As Tremain (2006) points out, the notion of prevention is taken so far as to normalize the selective abortion of impaired foetuses. We, as a society, develop and utilize prenatal testing techniques because we have determined that certain kinds of lives are not worth living. Such an appreciation of disability sends a very powerful message to persons with disabilities who are already born. Second, if disability cannot be prevented, the next level of engagement is treatment and cure. This is where the biomedical model of disability is paramount. The disability is located in the individual, and efforts, often extraordinary efforts, are pursued to eliminate the defect and get rid of the disability. Third, if neither prevention nor cure is possible, the last resort is rehabilitation, where assistive devices, prosthetics, medication and/or training the body to function in non-standard ways are used as means of coping with the disability. In this framework, disability is at best tolerated.

We do not mean to suggest that prevention, cure, or rehabilitation are, in themselves, bad things. But they are not the full picture. To start from the perspective that disability is misfortune is to buy into a framework of charity and pity rather than equality and inclusion. To contextualize and conceptualize disability as misfortune is to create a hierarchy of difference – fortune must be better than misfortune. Although liberalism is perhaps naive and simplistic in terms of what is necessary to achieve equality, in other contexts liberalism can, at a fundamental level, readily reject a hierarchy of difference. Relatively early in its development, liberalism was able to reject as both irrational and wrong the notion of privileging one race over another; in liberal thought, racial origins are obviously irrelevant to the entitlement to equality. Gender equality has been more of a challenge to liberalism, because of biological differences between men and women. While liberalism is still struggling to come to terms with gender difference, and while liberalism is still fixed on the binary conception of gender (Tyjewski, in Chapter 5, discusses the exclusion of intersexuals), the basic premise of gender equality is well established in liberalism. Unpacking and dismantling the social construction of gender is still a challenge, but, at the level of theoretical premise, liberalism can now easily accept that gender is irrelevant to the entitlement to equality. As regards sexual orientation, liberalism is still struggling with whether there is a hierarchy of difference. The current controversy over same-sex marriage is really a debate on whether non-heterosexuals are worthy of the institution of marriage. Opponents of same-sex marriage who claim to be pro-marriage but not anti-gay are preaching tolerance of homosexuals but not full equality; they are invoking a hierarchy of difference. The Supreme Court of Canada, in *Reference Re Same-Sex Marriage* (2004, 46), in ruling that the proposed federal statute to extend the

right to civil marriage to same-sex couples is consistent with the *Canadian Charter of Rights and Freedoms,* accepted that the federal initiative represented a furtherance of rights: "The mere recognition of the equality rights of one group cannot, in itself, constitute a violation of the rights of another. The promotion of *Charter* rights and values enriches our society as a whole and the furtherance of those rights cannot undermine the very principles the Charter was meant to foster." In other words, the Charter is meant to foster the elimination of hierarchies of rights and hierarchies of difference.

It is our contention that it is in the context of disability that liberalism has the greatest difficulty in rejecting a hierarchy of difference. In a utopian society, liberalism would not seek to abolish race or gender or sexual orientation. But it would seek to abolish disability, on the basis that human beings are not meant to "suffer" disability. In the practical life of our non-utopian society, not only is the abortion of impaired foetuses routine (Tremain 2006), but the murder of a child with a disability, Tracy Latimer, generates a great deal of public sympathy for the father who killed her. Ridding society of disability, that is, ridding society of the defective and inferior other, is widely seen as understandable and perhaps socially acceptable behaviour. On the theoretical plane, Malhotra's analysis in Chapter 3 points out that Rawls is quite blatant in expressly excluding the disabled from his social contract model, on the premise that their "fate arouses pity and anxiety" (Rawls 1999, 83-84). Similarly, Sampson, in Chapter 12, identifies pity as the core of the Supreme Court of Canada's approach to gender disability in *R. v. Parrott* (2001).

Equality is not about evoking pity or charity. As Krogh and Johnson highlight in Chapter 7, a charitable approach tends to focus on bare survival rather than on genuine participation in society, and is highly susceptible to claims of budgetary restraint. Rioux and Valentine discuss in detail in Chapter 2 the theoretical significance of moving from a charity-based approach to a human rights-based approach. To genuinely adopt a human rights approach means rejecting a hierarchy of disability difference, rejecting a privileging of the "normal" over the "abnormal," to use Frazee, Gilmour, and Mykitiuk's terminology. But it also entails an engagement with what Martha Minow (1990) has described as the "dilemma of difference," that is, when to factor in difference and when to ignore it. Given the diverse nature of different disabilities and the particular impacts a disability may have on different people, as well as the different spheres of life within which a person may operate in any one day, a disability may not have any essential significance. Its significance is contingent on the context. In some situations it will be necessary for both the person with the disability and the larger society to specifically factor in the disability; in other situations, the disability may be safely ignored.

Yet, as a general proposition, disability demands a coming to terms with difference. Critical theory generally challenges the assumption that difference can be ignored. Critical race theorists, for example, challenge the notion (originally in Justice Harlan's dissent in *Plessy v. Ferguson*) that the American constitution should be colour-blind. They argue that to ignore race is to perpetuate racism. Similarly, radical feminists understand that ignoring gender perpetuates patriarchy (MacKinnon 1989). Substantive equality necessitates taking difference into account in order to both identify the systemic nature of inequality and pursue solutions tailored to the goals of full inclusion and participation. This is even more crucial in the context of disability than elsewhere because to ignore the difference of disability is to engender exclusion. If the sign says that all are welcome, then gender or race is not an absolute barrier to getting in the door, but a set of stairs is an absolute barrier for a wheelchair user. Getting in the door may be a long way from full equality, but it is the necessary first step. Formal equality is inadequate for all equality seekers, but it is most inadequate for persons with disabilities where ableist norms that ignore difference, as well as rigid norms of rationality or reasonableness, can make participation simply impossible. Whereas liberalism says that difference should be ignored, critical theory demands that difference be confronted. The challenge is to pay attention to difference without creating a hierarchy of difference – either between disability and non-disability or within disability.

Finally, critical disability theory goes beyond political analysis to pursue a politics of transformation. In this regard it asks not only the traditional question of what is to be done, but also, who is to do it?

Critical disability theory argues that if we adopt an individualist and essentializing conception of disability, the primary responsibility lies with(in) the person with the disability. Hence, the emphases on prevention, cure, and rehabilitation that we identified earlier. If, however, we understand disability as a socially created barrier, then, as Rioux and Valentine (Chapter 2) and Baker (Chapter 8) note, responsibility and accountability shifts to the larger community. As one commentator has noted, "a person is a person through other persons" (Shutte in Kabeer 2002, 37). But this shift in the location of responsibility is only a first step. As we have already emphasized in this Introduction, a variety of options might be available to the larger community, including pity, charity, surgical intervention, accommodation, and transformation. Furthermore, even if the latter two approaches were to be adopted, that would only be the beginning of policy considerations. As Malhotra points out in Chapter 3, a number of possibilities present themselves: "tax subsidies for individual employees to pay for accommodations, greater flexibility in workplace rules mandated through state regulation, tax credits, or possibly even quotas for workers with disabilities." Moreover, the critical analysis continues, the problem is not just the disadvantaging

of persons with disabilities but the privileging of those who are perceived to be non-disabled. Again, our previous discussions of computer technology may be illustrative of this concern, as may be the conventional merit-based performance criteria, for example in the university context (discussed by Lee in Chapter 4, and Hibbs and Pothier in Chapter 9).

At the same time, however, critical disability theory does not want to portray persons with disabilities as passive victims. While there are undoubtedly pervasive structures of inequality, as Krogh and Johnson emphasize in Chapter 7, there are also many and diverse agentic practices developed by the disabled to resist the exclusion and oppression (Lepofsky 2004). For every moment and instance of "power over," there are moments and instances of "power to." As the various contributors have demonstrated, at every level, persons with disabilities have engaged with empowering strategies – at the level of the self; in the family; at school; at work; in local, national, and international politics; in the social realm; and in the cultural realm. Even in law. Viewed in this light, questions of responsibility and accountability can be resolved only through the joint efforts of both those who are disabled and those who are non-disabled.

Philosophical Challenges

As we have noted, perhaps the most important critical claim with regard to disability is that it is a social construct. Persons with disabilities may experience functional limitations (*Granovsky* 2000, 703, 721) that non-disabled persons do not experience, but the biggest challenge comes from mainstream society's unwillingness to adapt, transform, and even abandon its "normal" way of doing things. As the Supreme Court of Canada has acknowledged in *Granovsky v. Canada (Attorney General)*, we live "in a world relentlessly oriented to the able-bodied" (*Granovsky* 2000, 703, 723).[5]

Whether the social construct incorporates just disability or disability and impairment, the point is that the problem is not the person with the disability. Rather, it is the pervasive impact of ableist assumptions, institutions, and structures that disadvantage persons with disabilities. As Justice Gérald La Forest has pointed out, "This historical disadvantage 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 conditional upon their emulation of able-bodied norms" (*Eldridge* 1997, 668). These comments were made in the context of a claim for state funding of sign language interpretation for deaf patients being treated by doctors or at hospitals, ultimately a fairly modest challenge to the mainstream way of functioning. Where the claim was a more fundamental challenge, a

claim on behalf of a child with profound disabilities, a child very different from student peers, the court rejected a presumption of integration of students with disabilities in *Eaton v. Brant County Board of Education* (1997). Similarly, in *Auton v. British Columbia* (2004), arguments that fundamentally challenged the orientation of the health-care system were roundly dismissed.[6] A primary goal of critical disability theory is to force dominant society to break out of the "psychic prison" (McKenna 1997, 160) of ableism and move toward a barrier-free society (*Eldridge* 1997, 689) in which persons with disabilities (both the easy cases and the hard cases) genuinely belong (Michalko 2002). We will have more to say on this below.

The claim that disability is not just an individual impairment but a systematically enforced pattern of exclusion moves the analysis forward in important ways. However, it also raises a number of other questions. For example, as Malhotra points out in Chapter 3, there may be significant differences between a social model, a social constructionist model, and an oppressed minority model, each of which might characterize the problem, and potential solutions, differently.

Even more importantly, there is the question of whether the language of social construction is successful in its attempt to escape the dangers of essentialism. This, in part, is a consequence of a point we referred to previously: the complexity and diversity of disabilities. The range of potential disabilities is enormous, so how does one begin to talk about a group characteristic such as disability without slipping into commonalistic claims that reproduce categories of inclusion and exclusion? A number of authors in this book have struggled with this problem, aware that emphasis on particularism threatens to return us to a medicalized characterization of the circumstances of persons with disabilities.

This is compounded by the issue of intersectionality. As a number of authors argue, disability may run the danger of being too generic because it does not give significant emphasis to other aspects of disabled persons' identities, for example, their ethnicity (Lee, Chapter 4), gender (Sampson, Chapter 12), sexual orientation (Tyjewski, Chapter 5) or class (Hibbs and Pothier, Chapter 9; Frazee, Gilmour, and Mykitiuk, Chapter 10). Most authors agree that it is not helpful to adopt an additive conception in these situations, that is, race + disability + gender = discrimination (to the third degree). Rather, there is the sense of a concatenated experience that is more than the sum of its parts. Sampson, for example, in Chapter 12 offers a critique of the Supreme Court's decision in *Parrott,* claiming that, despite their differences, all the judges completely miss the gendered disability nature of the crime, that is, that an exclusive focus on disability is an inadequate analysis of a crime against a woman with a mental disability. Lee highlights in Chapter 4 the complexity of trying to disentangle interlocking patterns of discrimination based on race and disability. Similarly, Frazee, Gilmour, and Mykitiuk

in Chapter 10 question the possible significance of the differences in the composition of the focus groups participating in their study. Wilton in Chapter 6 underscores the significance of factors beyond disability that contribute to the reality of precarious work, providing a sharp insight into the specifics of exclusion depending on one's gender, age, or ethnic background.

On the one hand, these analyses appear to be promising because they help us break the stranglehold of essentialism. However, on the other hand, they may resurrect the fear that without some element of commonality, we cannot analyze the patterns of systemic exclusion, never mind mobilize to ensure greater inclusion and participation. These challenges are intensified by Tyjewski's invocation in Chapter 5 of the descriptor "hybrids" for those who do not fit nicely into preconceived conventional identity categories.

It is important to remember that disabilities range from the highly visible to the highly invisible. Moreover, whether the disability is visible may depend on the context. For example, although a wheelchair is generally a very visible sign of disability, if someone using a wheelchair is seated at a table with others who did not bring their own chairs, the disability may not be obvious to the casual observer (or to someone who cannot see the wheelchair because they cannot see at all). Many disabilities are not apparent unless specific activities impacted by the disability are being engaged in. For example, in a situation where no one is speaking, muteness or deafness may not be discernible. There are also many hidden disabilities that are not obvious unless the person chooses to disclose, or is required to disclose to qualify for benefits or accommodation, as discussed by Frazee, Gilmour, and Mykitiuk in Chapter 10 and Hibbs and Pothier in Chapter 9, respectively.

The reality of hidden disabilities leads to the possibility (and politics) of passing. If marginalization or discriminatory consequences are associated with being categorized as disabled, there may be an incentive to act as though one is not disabled, that is, to try to elude the social construction of disability. Given the negative connotation attributed to disability, the able-bodied majority generates an expectation that persons with disabilities should try to pass (Titchkosky 2003, 66-71). In its purest form, passing is a very deliberate attempt to pretend you are something you are not. People may put a great deal of effort into passing. Rod Michalko, who was diagnosed as legally blind (10 percent vision) at age eleven, describes how he went to great lengths to pass as fully sighted in his high school years. He preferred to attribute his inability to drive to a fictitious, impaired driving licence suspension than to admit he could not see well enough to drive (Michalko 2002, 74).

Even where someone is making no attempt to pass, that person may get caught up in a presumption of normalcy, especially if he or she is not visibly disabled. Most of the time, people are expected to act in an able-bodied

way unless there is very specific notice to the contrary. This can have important marginalizing or exclusionary effects. This goes well beyond the issue of intent or denial of access. Pothier witnessed an example of the exclusionary effects of the presumption of normalcy during her appearance at a court hearing with several other lawyers, one of whom was in a wheelchair. The chief justice was noticeably upset by the breach of protocol when this particular lawyer did not, like the other lawyers, stand up at the start of the hearing when her name was called. After a whispered comment from the judge sitting next to him, the chief justice seemed to understand why she had not stood up, but he gave no acknowledgment of his inappropriate reliance on a presumption of normalcy.

Even where the visibility or knowledge of a disability precludes passing in its pure sense, there can be another form of passing. A person with a disability may try to blend in as much as possible, trying to downplay the significance of the disability. This is a process of accommodating oneself to one's environment, while asking and expecting little or no effort of the environment to accommodate the disability. This is a form of passing that Pothier now recognizes as a practice of her younger self. The conceptual shift that Pothier has made in the last fifteen years is to not be satisfied with accommodating herself to her physical and human environment. Rather, she expects the physical and human environment to be welcoming to the presence of disability – hers and that of others.

The foregoing discussions indicate that critical disability theory is not just about the failure of liberalism as a political response to needs of persons with disabilities but also a philosophical challenge to conventional liberal assumptions. Liberalism tends to put great emphasis on the individual, assuming that the self is both sovereign and a foundational unit for analysis. However, critical disability theory forces us to reflect on a number of profound ontological questions. Who is a self? Is there such a thing as an authentic self? What is the significance of disability to the conception of self? Are the answers fundamentally different for those born with a disability than they are for those who acquire a disability after having a previous conception of self? How does the self relate to others? Lee in Chapter 4 considers, but ultimately rejects, the notion of the disabled as members of a cultural group. Krogh and Johnson in Chapter 7 and Frazee, Gilmour, and Mykitiuk in Chapter 10 interrogate how people reconstruct themselves and their sense of self to respond to the dominant norms and expectations of them. As the previous discussion of passing suggests, given the coercive demands of normalcy, are there not enormous barriers to being certain of whom a disabled person might be?

Liberalism also has put great store in the principles of liberty, autonomy, and choice. But once again, critical disability theory invites us to revisit the analytical and strategic utility of such discursive artifacts. Given the reality

that some persons with disabilities will necessarily be in situations of intense dependency and reliance, can liberty and autonomy – with their emphasis on freedom from – really be the lodestars liberalism has assumed? Despite liberalism's assumption that dependency is the opposite of autonomy, disability may force a reconciliation between autonomy and dependence. In other contexts, if a person with disabilities (for example, an autistic child, as Baker discusses in Chapter 8) has difficulty, even great difficulty, communicating her or his wishes to others, what work can liberty and autonomy really do? Is "choice" a useful, or realistic, way to discuss some issues of disability? Would a focus on sometimes mutually reinforcing, sometimes competing, coercions provide more insightful analyses and reflections? If it is true, as several authors have suggested, that the language of disability is always and already an exercise in categorization, regulation, and discipline, does this mean that the options are not between liberty and constraint, but between different forms of constraint? Could we not provide more grounded analyses by identifying the competing acts of violence that saturate the lives of persons with disabilities? However, we are also concerned that such a shift in focus and analysis might raise the spectre of paternalism and infantilization. Our goal in making such suggestions is not so much to abandon the discourses of autonomy, liberty, and choice as to decentre them to create space for more context-specific interrogations and analyses.

Citizenship/Dis-Citizenship

At the outset of this introduction, we introduced the concept of dis-citizenship, the idea that persons with disabilities are disabled citizens on both the formal and substantive levels. In immigration law, for example, disability is, under some conditions, explicitly considered a legitimate reason for denying an applicant admission to Canada (Voyvodic 2001). Krogh and Johnson point out in Chapter 7 that if some disabled people are unable to receive home care, they are disempowered from participating in the larger polis; they are privatized and closeted away. In the context of genetic testing, we are witnessing the denial of life, perhaps the most basic citizenship right.

While we obviously believe that the substantivist approach to citizenship is superior to the formalist analysis, we detect even in this literature a tendency to assume that genuine citizenship entails a capacity for productivity, and that if one cannot be productive, one is not worthy of full citizenship. Most of the literature on citizenship has focused on gender, sexual orientation, or race, to argue that the contributions (actual or potential) of women or minorities to the larger polis are being overlooked or undervalued (Kabeer 2002; Hobson and Lister 2002). This, however, raises a number of questions: is the lack of productivity the "fault" of the person with disabilities, or are the social barriers that make productivity impossible on his or her

part to blame? What is meant by productivity? What are the criteria? Who gets to make the assessment? And, most importantly, why should productivity (regardless of how we define it) be a legitimate criterion? Embedded in the discourse of productivity is an unavoidable cost-benefit analysis. In our opinion, no matter how well we move toward a barrier-free society, no matter how ameliorative medical interventions become, if one thinks in cost-benefit terms, there is always likely to be a significant segment of our community whose costs can be argued to outweigh the benefits they produce. But is this an appropriate way for us to value each other? Efficiency and productivity are irretrievably ableist discourses that can only condemn (some) persons with disabilities to a presumptive inferior status. An enabling citizenship needs to be unshackled from the ideology of productivity and efficiency.

Thus, we want to suggest that the landscape of citizenship discourse needs to be expanded to respond to the particular experiential circumstances of persons with disabilities. Our hopes in naming the hitherto unnamed are threefold: first, to highlight the unequal status to which persons with disabilities are confined; second, to destabilize necessitarian assumptions that reinforce the marginalization of persons with disabilities; and third, to help generate the individual and collective practical agency of persons with disabilities in the struggles for recognition and redistribution (Fraser 1989).

Structure of the Book

The book is organized into four sections and an Appendix. In Part 1: Setting the Context, McColl and colleagues identify the substantive and methodological significance of the numbers question and illustrate this significance by referring to three distinct policy initiatives: access to health services, income replacement, and human rights. Part 2: Conceptual Frameworks is designed to outline the various theoretical approaches that might underlie a critical disability theory. Rioux and Valentine argue that the reason we have confused and contradicting policy initiatives in Canada is that we have been unclear as to the most appropriate theoretical framework within which to understand disability. Malhotra suggests a solution to this dilemma by subjecting Rawls' theory of justice to a radical reconstruction based on the insights of critical theory. Lee, however, is more cautious and, through a critique of Kymlicka, raises concerns about whether treating persons with disabilities as a cultural group is sufficiently empowering for full citizenship. Tyjewski, through the introduction of the concept of hybrids, goes one step farther by problematizing the legal system's ability to deal with categories.

Part 3: Policy Analyses builds on the theoretical insights of the previous section through several case studies. Wilton analyzes the phenomenon of

precarious work, considering how the economic policies of neo-liberalism have had an impact on the employment situation of persons with disabilities. Krogh and Johnson discuss how cutbacks to home care programs can have negative impacts that go beyond the loss of physical support to include reconfigurations of disabled persons' sense of self and their capacities for civic participation. Both studies are careful, however, not to construct persons with disabilities as mere passive victims of the structural forces of globalization and neo-liberalism. Wilton discusses how different individuals find different strategies to respond to their circumstances, while Krogh and Johnson highlight the mobilization efforts of disability rights activist groups. Baker picks up on these insights to provide a comparative study of the impact of autism on public policy in both Canada and the United States to suggest that, given the right configuration of circumstances, there may be opportunities to move issues of disability onto the public policy agenda. Hibbs and Pothier conclude the section by demonstrating how reactive, as opposed to proactive, accommodation policies in the university reinscribe rather than challenge patterns of ableism and exclusion because they remain dependent on an individualizing, biomedical understanding of disability.

Part 4: Legal Interrogations provides four case studies of how the legal system has responded to disability. Frazee, Gilmour, and Mykitiuk analyze how medical and legal paradigms and discourses intersect to oppress and discipline women with disabilities in spite of privacy rights to which they are formally entitled. MacPherson discusses how the tort system's calculation of damages systemically devalues the lives of persons with disabilities. Sampson analyzes how the Supreme Court of Canada has a particularly difficult time in dealing with the equality aspects of gendered disability because it remains ensnared in an ideology of pity. Gilbert and Majury, rounding out the discussion, also pick up on the issue of the relationship between gender and disability to argue that it is a mistake to conceptualize infertility as a disability.

Finally, the Appendix, by Pothier, provides a brief but comprehensive overview of Supreme Court decisions on issues of disability from 1985 to 2004.

Conclusion

We began this introduction by suggesting that critical disability theory is part of a larger movement, the new critical realism, that challenges the promises and potential of liberalism. However, as the Introduction progresses, we suggest that in some respects the challenges posed by critical disability theory are greater than those of other critical realisms, such as feminism, critical race theory, or queer theory. We suggest that, despite

their constitutive identities, women, persons of colour, and gays, lesbians, and transsexuals pose a less radical challenge to the material, if not necessarily the normative, conditions of contemporary North American society. This is not true of many – but not all – persons with disabilities. In part, this is because critical disability theory emphasizes the inevitability of difference, it demands the material reorganization of our basic social institutions, and it challenges the assumptions of sameness and assimilation in a profound way. Furthermore, critical disability theory interrogates not only conceptions of productivity and efficiency – a strategy destabilizing enough on its own – but also taken-for-granted assumptions of adequacy and competency. In short, this collection argues that critical disability theory demands a reconceptualization of the nature of, and the lived relationships among, the citizen, the self, and the community, a reconceptualization that transforms the basic assumptions of contemporary philosophy, politics, policy, and law.

Acknowledgments

Notes
1 In an earlier draft of this introduction we experimented with the idea of "PERSONS with disABILITIES" (capitalizing the elements "PERSONS" and "ABILITIES" but leaving lowercase "with" and "dis"). Our aim was to avoid the twin dangers of, on the one hand, over-determining and essentializing the "dis" aspects of a person's identity and, on the other, underestimating how both the individual person and the larger society respond to disability. After further consideration we decided that, although this was potentially helpful, such a representation would not be easily translatable into the spoken word or alternative formats. Anyone using Braille or voice synthesis would need to be using very particularized settings to appreciate this format. We will, however, return to the identified twin dangers later in this introduction.

2 We would like to thank Sheila Wildeman for the insights articulated in this paragraph. More generally, we note that, with the exception of Sampson (Chapter 12), most of the contributions to this book tend to focus on physical rather than mental disability, a pattern that is common in much disability scholarship. In our forthcoming paper "Dis-citizenship," to be published by the Law Commission of Canada in 2006, we attempt to partially remedy this problem. For a recent collection specifically focusing on mental disability see Herr, Gostin, and Koh 2003.

3 The majority decision of the Supreme Court of the United States in *Sutton et al. v. United Air Lines, Inc.* (1999), a primary focus of Tyjewski's discussion, is antithetical to the unanimous decision of the Supreme Court of Canada in *Mercier* 2000. See further discussion in the Appendix.

4 In *Granovsky* 2000, the implications of binary thinking in the Supreme Court of Canada are stark for the plaintiff, who is ultimately not disabled enough to succeed in his claim.

5 In drawing this conclusion, the court assumed that impairment is not socially constructed.

6 See the Appendix for further discussion of these issues.

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