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Does Theory Matter? Exploring the Nexus between Disability, Human Rights, and Public Policy

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Legal cases, social policies, and programs point to a divergence in the way the legal and social parameters of human rights and equality for people with disabilities are framed. While the concept of human rights is widely accepted as an organizing principle for law, policy, and advocacy, its meaning in practice is widely divergent and actively debated, resulting in a lack of conceptual clarity. This lack of consensus is evident beyond the judicial branch, extending to legislative and administrative developments and to the disability movement. The goal of this chapter is to illustrate theoretical frameworks found in current practice. In particular, we are interested in exploring the tension between promoting rights and enabling citizenship on the one hand, and paternalistic protection, which underlies legal cases, policies, and practices, on the other hand.

The chapter concludes that theory *does* matter because the development of theory associated with disablement and equality has an impact on, first, an understanding of the meaning of disablement and, second, the development of consistent laws, policies, and practices. The shift in meaning of disablement, grounded in current constitutional protection of disability equality rights and in government policy statements, is uneven. The result is a lack of consensus across the various arenas of policy making concerning the relationship between disability and equality.

This debate is complicated because it requires that we unravel the confusion about the meaning of disablement itself, about which there is no general social or legal consensus. This uncertainty about the meaning of disablement both causes and contributes to the ongoing conflict around policies, programs, laws, and advocacy that are purported to be based on equality and human rights.

A critical disability theory approach offers an important lens in unravelling the inherent complexities associated with disablement and equality. It begins with the assumption that theories of human rights and equality provide the necessary foundation for understanding the linkages between the

existing legal, economic, political, and social rationales for the full inclusion of people with disabilities, and the systemic barriers and oppression that continue to construct people with disabilities as inherently unequal and disempowered to citizenship rights. Critical disability theory offers a politicized view of the meaning and experience of disablement in contemporary Canadian society.

Theoretical Overview

Since the late 1970s, there has been a consistent trend in both international and domestic developments linking disability and human rights. Indeed, throughout the 1980s and early 1990s, a series of federal initiatives were pursued to advance the political, civil, and social rights of Canadians with disabilities. As part of the constitution, the passage of the *Canadian Charter of Rights and Freedoms* (1982) is perhaps the most significant domestic development affecting Canadians with disabilities. There is, however, an important and noteworthy paradox.

While governments have enshrined formal equality rights in the Charter and in other human rights codes, substantive citizenship rights – especially at the provincial and municipal level – have not been attained in programs and services. Therefore, most people with disabilities continue to be inhibited from achieving full citizenship. Examining policy frameworks in place at the provincial level reveals a profound contradiction in disability politics. Indeed, the fundamental – but unstated – divergence between governments and the disability community resides in two unreconciled views of the meaning of “inclusion” and “citizenship.” Since the passage of the Charter, there has been broad agreement on guaranteeing equality of Canadians with disabilities. Federal and provincial human rights legislation extends anti-discrimination measures to the private and public spheres. People with disabilities have taken this to mean that they should have certain entitlements in all government programs. Governments, on the other hand, see equality as limited by their need to contain spending, and so tend not to talk about entitlements but, rather, “discretionary benefits.”¹ Because both governments and the community use the terms “citizenship” and “inclusion” but interpret the meanings differently, the language around disability itself creates a circle of tension and confusion.

The pattern of discrimination and inequality remains entrenched even when individuals and the advocacy community have adopted a rights-based approach and have gone to court to confirm their rights and consequent entitlements to certain services. Arguments grounded in economic rationalism or in biomedical views of disablement have led governments to justify their discretion over policy and spending at the expense of the exercise of rights for people with disabilities. This has occurred even in the face of

Figure 2.1

The social and scientific formulations of disability

INDIVIDUAL PATHOLOGY	
Biomedical approach (consequence of biological characteristics)	Functional approach (consequence of functional abilities and capacities)
<ul style="list-style-type: none"> • Treatment: through medicine and biotechnology • Prevention: through biological or genetic intervention or screening • Social responsibility: to eliminate or cure 	<ul style="list-style-type: none"> • Treatment: through rehabilitation services • Prevention: through early diagnosis and treatment • Social responsibility: to ameliorate and provide comfort
SOCIAL PATHOLOGY	
Environmental approach (consequence of environmental factors and service arrangements)	Human rights approach (consequence of social organization and relationship of individual to society)
<ul style="list-style-type: none"> • Treatment: through increased individual control of services and supports • Prevention: through elimination of social, economic, and physical barriers • Social responsibility: to eliminate systemic barriers 	<ul style="list-style-type: none"> • Treatment: through reformulation of economic, social, and political policy • Prevention: through recognition of conditions of disability as inherent in society • Social responsibility: to provide political and social entitlements

the courts, including the Supreme Court of Canada, having confirmed those rights in cases based on the *Canadian Charter of Rights and Freedoms*, human rights legislation, or other statute law. The inherent tension in contemporary debates about disability in Parliament, in the courts, and among disability activists is grounded in the theories that underlie the collective understanding of disablement. The leading formulations of disablement – the social scientific view of disability, which includes the biomedical and functional approaches, and the social pathology view of disability, which includes the environmental and human rights approaches – shed light on why there is such a discrepancy in implementation of rights and equality in the area of disability. Figure 2.1 summarizes these competing views of disability and disablement and the social responsibilities that attach to each formulation (Rioux and Zubrow 2001).

Social and Scientific Views of Disability

How disability is perceived, diagnosed, and treated, scientifically and socially, is reflected in assumptions about the social responsibility toward people with disabilities as a group.² The assumptions or postulates about disability are neither mutually exclusive nor temporally chronological. Some disciplines have characterized disability as solely a biomedical condition, a genetic condition, a disease category, or a personal deficit, while others have adopted the framework of disability as a consequence of social, environmental, and political conditions. There are also hybrids of these two major schools of thought. Consequently, there are tensions in the areas of policy and programming, within both the professional sphere and government, that reflect attempts to accommodate these diverse understandings of disability as a status and of how it should be addressed.

There are four identifiable social and scientific formulations of disability reflected in the treatment of people with disabilities in law, policy, programs, and rights instruments. They can be traced to the concept of disability as a consequence of an individual pathology and the concept of disability as a consequence of a social pathology.

Formulations of Disability Based on Individual Pathology

Of the two identifiable formulations of disability that arise from the assumption that disability is an individual pathology, one is grounded in a biomedical approach and the other is grounded in a functional approach, that is, that disability is a consequence of individual functional abilities and capabilities.³ The two have a number of common characteristics, including:

- approaching disability as a field of professional expertise
- primarily using a positivist paradigm⁴
- emphasizing primary prevention, including manipulation of biological and environmental conditions
- characterizing disability as incapacity in relation to non-disabled persons (a comparative incapacity)
- distinguishing disability and its attached costs as an anomaly and social burden
- portraying the inclusion of people with disabilities as a private responsibility
- using the individual as the unit of analysis for research and policy purposes
- depicting the individual condition as the primary point of intervention.

Generally, the social responsibility, both professional and political, that has attached and continues to attach to this perspective on disablement is directed to the elimination and cure of disability, and where that is not possible, to ameliorate the condition and provide comfort to the individual,

identifying as inevitable the disadvantage suffered by the individual. While the role of the state in regulating and correcting disadvantage and inequality may be either expansive or restrictive, in this case, the privatization of the disadvantage justifies and perhaps even mandates a restrictive or passive engagement in its resolution (Rioux and Zubrow 2001; Mishra 2002). From this perspective the disadvantage is privatized, in the sense that it is presented as an individual condition, and thus the scientific rationalism that underlies this characterization of disability justifies the limitation of state intervention to prevention and comfort. A distinction is then made between what falls within the public domain and what falls within the private domain. Limiting economic expenditure to ensuring the relief of private disadvantage is then arguably reasonable. In this way, a cost-benefit analysis is factored into how far one has to go to ensure the rights and citizenship of people with disabilities.

The rise of neo-liberal ideas has led to an increase in policies and programs that view disablement as primarily an individual pathology. In Ontario, for instance, after years of moving policies and programs away from medically oriented, disease-related criteria, in 1995, the provincial government began reintroducing program eligibility criteria primarily based on formulations that characterize disability as a condition of individual pathology. These changes affected almost every area of public life, including social assistance, transportation, housing, health care, and education.

Formulations Grounded in Social Pathology

In contrast to the two approaches to disability based on individual pathology, two identifiable approaches recognize disability as a consequence of social pathology. They both start from a perspective that assumes that disability is not inherent to the individual. Rather, they assume that the disability is a consequence of the social structure and that the social determinants of disability can be identified and addressed. The pathology is that there is something wrong with the society that needs to be fixed, rather than that there is something wrong with the individual that needs fixing (World Health Organization 1980).

These two approaches have a number of shared identifiable characteristics, including:

- assuming that disability is not inherent to the individual, independent of the social structure
- giving priority to political, social, and built environment
- emphasizing secondary prevention rather than primary treatment
- recognizing disability as difference rather than as an anomaly
- portraying the inclusion of people with disabilities as a public responsibility

- using the social structure as the unit of analysis for research and policy purposes
- depicting the social, environmental, and economic structures as the primary points of intervention.

According to the environmental approach, advances in knowledge based on an understanding of disability as a social pathology demonstrate that personal abilities and limitations are the result, not only of factors residing in the individual but also of the interaction between individuals and their environments. Increasingly, researchers find that the impact of disability is compounded by the failure of ordinary environments to accommodate people's differences. Increasingly, there is evidence in policy research showing that the impact of disability can be lessened as environments are adapted to enable participation.⁵

From this perspective, disability is identified as a consequence of the barriers in society that restrict the participation of people with impairments or disabilities in economic and social life. This includes criteria or program parameters that restrict individual determination of needs and individual control of services and supports. Structural barriers to independent living or community living become the site of "therapy" or modification.⁶ Prevention, then, is through the elimination of social, economic, and political barriers. Elimination of physical barriers – for example, by building ramps or adopting employment equity or affirmative action policies – is a method of prevention from the perspective of this approach to disability.

The human rights approach to disability is that disability is a consequence of how society is organized and the relationship of the individual to society at large.⁷ Research, policy, and law from a human rights approach looks beyond particular environments to focus on broad systemic factors that keep some groups of people from participating as equals in society. The emphasis is on the social determinants of disability. This approach identifies wide variations in cognitive, sensory, and motor ability as inherent to the human condition and, consequently, recognizes the variations as expected events and not as rationales for limiting the potential of persons with disabilities to contribute to society.

Policy from this perspective constructs an analysis of how society marginalizes people and how society can be adjusted to respond more effectively to the presence and needs of those who have been systemically marginalized. Treating the disadvantage is postulated as being the reformulation of social and political policy. Prevention is effected through recognizing the condition of disability as inherent to society. It is presumed that people with disabilities are an inherent part of society, not some kind of anomaly to normalcy.

From this perspective, the measure of whether rights are being advanced is the degree to which civic inequalities have been reduced. In other words, the fewer the social and economic disadvantages, the greater the likelihood that discrimination against people with disabilities will not be experienced. This approach to rights makes clear that the disadvantage that attaches to disablement falls within the public domain. As a consequence, therefore, society is obliged to provide supports and aids and devices enabling social and economic integration, self-determination, and legal and social rights for the disabled. The focus is on the disabling aspects of society and on supporting human diversity and on empowering disadvantaged individuals.

The Ontario Direct Funding Program (ODFP), a relatively recent Ontario policy and program development advocated by the disability rights movement, illustrates a policy framework based on notions of social pathology. The ODFP provides funding for six hundred adults with physical disabilities who can direct their own personal support services (i.e., hire, fire, or manage attendant workers), enabling the individual to become an employer of his or her own attendants. Attendants assist persons with physical disabilities with routine activities of living, such as dressing, grooming, and bathing. The program respects the independence of persons with disabilities, recognizing that they have the skills and knowledge to control the resources affecting their daily lives.

In sum, the complexity found in these various formulations of disability, and the social responsibility inherent in them, have meaning and find expression in law, policy, administrative arrangements, and even in the advocacy demands of the disability movement itself. The lack of consensus in framing the legal and social parameters of what human rights and equality mean for people with disabilities demonstrates that elements found in each of these conceptualizations of disablement exist in tension among governments and the disability movement.

Views of Equality

As a theoretical construct, equality, like disablement, is subject to interpretation.⁸ Equal treatment, equality of opportunity, and equal well-being make different claims for the meaning of equality and suggest different burdens of responsibility for governments in regard to equality generally, and arguably even more so in the area of disability. Assumptions about the meaning of equality can be found in the way in which distributive justice is applied to disablement.

If equality depends on sameness (the equal treatment model) and being *similarly situate* (in the same circumstances), the concept of equality requires that "likes" be treated alike and presumes the impartial enforcement of legal and social rights. This standard of equality can be fairly easily met. If, for

example, disability is characterized as an individual pathology, the equal treatment standard can be met even in the face of significantly different social and economic entitlements and outcomes, because the difference between a person with and a person without a disability can be demonstrated. This standard of equality justifies many existing policies and services that disadvantage people with disabilities because the policies and services are not designed to recognize their being accessed by a diverse population. Obvious examples are the public education system, which may exclude children with intellectual or learning difficulties; forced therapeutic treatment of people with psychiatric disabilities; and the institutionalization of people with disabilities.

Using an equality of opportunity model for ensuring equality for people with disabilities creates a dilemma in that the model presumes that the natural characteristics of people with disabilities can somehow be overcome, when in fact this is neither possible in an objective sense nor in many cases desirable from a personal perspective.⁹ The concept of substantive equality is often based on an assumption that the objective is to provide access to the competitive, individualist market, not to such non-comparable goods as minimal nutrition and medical support. The basis for a claim to equality has to provide the potential for it to be based on citizenship, humanness, or a general egalitarian value assumption so that the claim to resources enables participation, even though in some cases individuals are not likely to be competitive – within the existing social and economic climate – without some sort of ongoing support. The claim is not for support to redress past discrimination or to overcome particular barriers to participation (equality of opportunity). Instead, the claim of people with disabilities is for redistribution of state resources and ongoing systemic support to enable them to exercise the same rights as do all other people.

A model of equality based on well-being as an outcome incorporates the premise that all humans – in spite of their differences – are entitled to consideration and respect as equals, and have the right to participate in the social and economic life of society. It takes into account the conditions and means of participation that may vary for each individual, entailing particular accommodation to enable that participation. Equality, characterized as inclusion and participation, shifts the basis for distributive justice away from economic contribution as the primary factor of entitlement to other forms of participation (Young 1990). The rationale for social institutions, law, and policy is, within this context, to support the outcome of equality of well-being for all citizens.

Views of Citizenship

Citizenship is a strategically important and contentious idea that is central to an understanding of disablement. At the same time, citizenship is a messy

concept, and therefore its boundaries are often contested. It constructs a system of inclusion and exclusion, defining boundaries between who belongs and who does not, who enjoys the privileges (and duties) associated with membership and who is denied such privileges. Kymlicka and Norman (1995, 283) observe in their survey of contemporary literature on the subject that the concept of citizenship evokes an understanding of individual entitlement, as well as attachment to a particular community. Across modern liberal democracies, it brings into focus normative and empirical debates on justice, fairness, rights, identity, and equality. These debates are especially central to the lives of persons with disabilities (among other marginalized groups) who, throughout the twentieth century, have been effectively denied legal and substantive citizenship rights.¹⁰ In Canada, for instance, people with psychiatric disabilities did not get the political right to the federal vote until 1991. Much of the literature on citizenship, however, does not examine how and why people with disabilities are constructed as non-citizens, and are thereby denied their presence as political actors.

Understanding citizenship is important for our purposes because it defines a set of principles for the relationship between individuals and the state, as well as for relationships among individuals; in this respect, it is “the concrete expression of the fundamental principle of equality among members of the political community” (Jenson and Papillon 2000, 5). This conception allows for an assessment of who belongs to and who is excluded from the community, and under what conditions. Citizenship is a dynamic relationship among three complementary dimensions: rights and responsibilities, access, and belonging. Citizenship grants rights and demands the exercise of responsibilities. But citizenship also provides access to public goods and services – to work, to education, to technology, and to social protection. These are the elements, therefore, that take citizenship beyond a passport to a sense of belonging in a community, in a country (Maxwell 2001).

For people with disabilities, citizenship requires the creation of an inclusive generic base of supports, such as child care, education, recreational programs, and accessible architectural environments for *all* citizens – not only those with disabilities. It also requires that portable and flexible supports targeting the particular needs of individuals with disabilities are in place. These include in/out home supports, respite care, education supports, and assistive devices. Citizenship principles allow us to follow the ways that patterns of access are being altered under the pressure of new economic and social realities and public choices (Valentine 2001).

Developments in international and domestic law and policy are indicative of the importance that is being placed on equality and citizenship rights as organizing principles for disability rights. These recent developments have put pressure on governments to clarify the theoretical constructs of disablement and the theoretical constructs of equality, as well as their interaction.

For people with disabilities, however, there is a substantial (and widening) gap between the rhetoric of equality found in both international and domestic policy instruments and the actual policies and programs put in place to enable people to live, work, and play in our communities:

A Need for Consensus: The Intersection of Approaches to Disability, Equality, and Citizenship

The concepts of disability, equality, and citizenship are central to advancing disability rights because the norms, standards, values, and biases on which these theoretical concepts are built lead to particular standards and constructs of policy, programs, and legal status. These in turn have an effect on whether the human rights of people with disabilities are respected or abridged.

For example, if there is a general acceptance that disability is an individual pathology, it is likely that the courts and governments will presume a model of equality that makes equal treatment of people the standard. They will argue that a person's inability to meet the standards or norms that are set for participating in society (in schools, in the workplace, in the recreational arena), justifies policies of exclusion based on individual pathology, that is, on the biological condition or functional anomaly. Consequently, despite equality advancements, a person with a disability is likely to be differentiated on the basis of his or her objective deviation from the presumed norm. This in turn leads to dissimilar social responsibility, legal treatment, and ethical standards. Not being able to participate in the same manner as others is central to the determination of how much equality, equity, and justice is determined to be the responsibility of the state.

Figure 2.2 provides a way to characterize policies, programs, and laws in relation to the underlying premises of the concepts of disability and to various constructs of equality. The intersection of these two important trends shows the types of law and policy that evolve from the ways in which the constructs intersect. Using this framework, it is possible to show the significant tension underlying current policy and law. It illustrates the need for consensus in framing the legal and social parameters of what disability, equality, and citizenship mean for people with disabilities. This lack of consensus on how to address disability has led to confusion about the meaning of equality for people with disabilities and, subsequently, about how to correct inequities in social entitlement and well-being.¹¹ Figure 2.2 shows three constructs resulting from the intersection of the formulations of disability and equality, and the types of legislation, jurisprudence, political and administrative developments, and policy that result.

Theories of equality are also based on some shared premises and can be loosely classified according to three general ideas.¹² Civil disability, charitable privilege, and citizenship status are theoretical constructs premised

Figure 2.2

Theoretical constructs of entitlement arising from the intersection of disability and equality

Concepts of equality	Formulation of concept of disability			
	Individual pathology		Social pathology	
	Biomedical approach	Functional approach	Environmental approach	Rights outcome approach
Equal treatment	Civil disability			
Equal opportunity		Charitable privilege		
Equal outcome			Citizenship status	

on the ways in which the norms and standards of equality and disability are constructed in policy instruments, as well as in the manner in which a government chooses to meet its commitments to the agreed upon equality standards.

Civil disability is a theoretical construct of entitlement in which a social responsibility to protect individuals with disabilities, both legally and socially, flows from the presumption that disablement is the consequence of an individual's largely unchanging pathology, coupled with an understanding of equality premised only on equal treatment. People with disabilities are given a status that entitles them to protection by the state (both positive and negative measures) to which others, who do not hold that status, are not entitled. The state, therefore, assumes responsibility to protect such individuals from the ill effects and limitations of disability and to provide them with minimal assistance. In practice, this translates into paternalistic decision making, politics, programs, and services, including, for instance, institutional living, segregated education, and sheltered workshops.

Charitable privilege has a long and continuing history in the provision of care and treatment to people with disabilities. It is based on benevolence and compassion and on forms of paternalism. The social responsibility arises from the acknowledgment that while there is a functional incapacity inherent to the individual, the physical and social environment may exacerbate it. If people with disabilities are seen as biomedically and functionally incapable of participating in the social life of their communities, the obligation of the state is likely to be circumscribed and limited only to humanitarian relief. Discrimination is rationalized as being good for an individual in these

circumstances – as a mechanism to protect the individual from harm to self and to others. Goods and services, such as medical care, housing, welfare, and therapeutic services, are provided to the individual not as a matter of right but as a matter of charity and compassion. Whether an individual has rights is premised on the ability of service providers to distinguish difference, which is characterized as incapacity. Without clear guidelines to evaluate the individual's capacity to function in a less hostile and restrictive environment, that is, in an adapted environment, the individual will predictably be viewed as different and unequal. Hence, equality of opportunity should be provided to the extent that the disability is a consequence of external factors. When this standard is used, people with disabilities trade rights for charity.

Finally, citizenship status is an emerging standard in which treatment, care, and allocation of resources are based on citizenship rights and equal outcome for people with disabilities. Society's responsibility is to provide for the disabled political and social entitlements that are equal in outcome to those of other citizens. It is built on the acknowledgment that disability is a consequence of social, economic, and political factors, not simply of individual pathology or incapacity. Further, it acknowledges both the historical disadvantages that people with disabilities have faced as well as the role and function of the current structure of society in contributing to their ongoing marginalization.

The legal and social policy consequences of these theoretical constructs show why theory matters. Indeed, there is significant tension and confusion among these three theoretical positions. This is evident in both judicial developments and political and administrative developments affecting disability in Canada. Moreover, the intersection of these constructs – civil disability, charitable privilege, and citizenship status – also provides a means for explaining the incongruous decisions in case law and political and administrative developments involving disability, as well as the discrepancies in international instruments affecting the rights of persons with disabilities.

The Recognition of Disability Rights in International Agreements

International developments have played a key role in advancing the recognition of disability as a human rights issue. A number of events in the past thirty years have led to this recognition (see Figure 2.3). The instruments arising from these developments could put social and economic rights on a par with the earlier entrenched civil and political liberties and rights, and could set a normative standard requiring that nations honour their commitments to these substantive rights without distinction based on category, including disability.¹³ These international norms and standards, which are not restricted by the economic and biomedical considerations that often drive policy and programs in nation-states, have both enabled and encour-

aged a broader perspective of disability rights. Through these norms and standards it has been possible to draw attention to disability within the broader context of human rights. The release of intellectual and practical imagination that has been generated by this international attention to disability rights has spurred domestic developments. Further, they subject the social policy of nation-states, at least nominally, to international norms and monitoring. In the case of disability, this has particular consequence, because the conventional assumptions about disability as a restrictive condition attributable singularly to the inherent biological or medical condition of the person individualize the discrimination. Thus, the restrictions on rights and citizenship are characterized as a cross-national phenomenon.

This internationalization of disability rights has been important in moving toward a greater theoretical and conceptual clarity of the understanding of disability as an issue of rights as distinguished from charity, medicine, or rehabilitation. The *UN Standard Rules on the Equalization of Opportunities*

Figure 2.3

Initiatives undertaken by the United Nations and human rights agencies concerning persons with disabilities

Date	Initiative
1948	Universal Declaration of Human Rights
1971	UN Declaration of the Rights of Mentally Retarded Persons ^a
1975	UN Declaration on the Rights of Disabled Persons
1981	UN International Year of Disabled Persons
1982	Adoption of the World Program of Action on disabled persons
1983-92	UN Declaration of the Decade of Disabled Persons
1984	Appointment of the first UN Special Rapporteur on Disability
1993	Sub-Commission on Prevention of Discrimination and Protection of Minorities releases special report, <i>Human Rights and Disabled Persons</i>
1994	Committee on Economic, Social and Cultural Rights issues General Comment No. 5, in which disability is treated as a human rights issue
1998	UN Commission on Human Rights passes a series of resolutions linking human rights and disability (citizenship status)
2002	First meeting of the UN Ad Hoc Committee to discuss a UN convention on the rights and dignity of people with disabilities
2003	Second meeting of the UN Ad Hoc Committee and the establishment of a Working Group to consider the content of a UN convention on the rights and dignity of people with disabilities

^a Both this and the 1948 declaration fall within the rubric of charitable privilege because they explicitly limit the rights advanced, to the extent that an individual can exercise them and as far as the state can accommodate them. Thus, they are rights circumscribed by disability. They do not make any claim on the state to facilitate the exercise of the rights by distinguishing people with disabilities as regards the way in which the state protects their rights.

for *People with Disabilities* is important in bridging the domains of rights and service delivery (United Nations 1993). The Rules provide a roadmap for ensuring the development and implementation of services and social development policies and programs that support and contribute to advancing the rights of people with disabilities – not simply providing them with charity and protection. The United Nations, in a series of resolutions in the last half of the 1990s, made clear that rehabilitation, equalization of opportunities, and service delivery related to disability had to have as their end goal the full exercise of human rights by people with disabilities. The resolutions formalized the need for equality provisions to ensure disability rights. In other words, the resolutions recognize that service provision, rehabilitation, and remedial barrier removal would not necessarily be adequate to ensure the enjoyment of rights by disabled people. This is an important underpinning in the context of the current commitment to the development of a UN convention on the rights and dignity of people with disabilities.

There are, however, limitations to the internationalization of disability rights. Perhaps most important to note is that it does not make factual equality the measure of legal and political action in enhancing rights for people with disabilities. In many countries, the way in which inequality for people with disabilities is addressed is through a series of measures contained in a program of action with an attached timetable for the removal of architectural barriers, return-to-work obstacles, and discriminatory practices. While important, this approach does not begin to address issues related to the restructuring of the imbalance found between persons with, and those without, disabilities among the social, political, and economic realms of life.

These international developments have also affected domestic developments in Canada. It has been argued that the pronouncements, declarations, and conventions of the UN's expanded notions of individual and collective citizens' rights have been influential in the pace of development and direction of domestic public policy (Quinn and Degener 2002).

The Recognition of Disability Rights in Canada

The pressure mounted from the disability rights movement and other rights movements, coupled with international developments, succeeded in getting the Government of Canada to embrace the equality rights of Canadians with disabilities (Rioux and Prince 2002). In the 1980s, the most important legislative advances at the national level included the passage of the *Canadian Charter of Rights and Freedoms* (1982), which extended protection against discrimination because of physical and mental disability; the passage of the *Canadian Human Rights Act* (1977), which prohibits employers and service providers from discriminating on the basis of a number of personal characteristics, including physical or mental disability; and the *Canadian Employment Equity Act* (1986) (repealed and replaced 1996), which

requires that all federally regulated employers, Crown corporations, and grant recipients move toward a representative workforce by removing employment barriers faced by four designated groups, including people with disabilities.

The extension of anti-discrimination protections for people with disabilities in each of these legislative frameworks represented a significant advance on the road to full equality. This momentum, however, has not been sustained. After the 1990s, there have only been sporadic advances for disability rights, and most of these were increasingly overshadowed by losses associated with the ascendancy of neo-liberal ideas and policies, which led to correspondingly reconstituted notions of disability, equality, and citizenship. Evidence of shifts away from full citizenship status toward notions of charitable privilege and civil disability status are evident in judicial, political, and administrative developments affecting disability in Canada.

Judicial Developments Affecting Disability in Canada

While the executive and legislative branches of government are central, the passage of the Charter has meant that the judicial branch now plays an important role in building a picture of what human rights and equality mean in practice, and in determining how pervasively the notion of charity and disenfranchisement continue to attach to disability. A number of recent Supreme Court of Canada cases illuminate the inherent and ongoing tension between various views of disability and conceptions of equality in Canadian society. These decisions draw a line in the sand as to where rights can be exercised by people with disabilities, and where the usual rules, norms, standards, and customs do not require that people with disabilities be treated to equality of citizenship.

In 1986, the Supreme Court in *E. (Mrs.) v. Eve* ruled that no individual could be lawfully sterilized without personally consenting, unless it is a matter of medical necessity. This case represented a significant breakthrough for disability politics and the rights of people with disability in Canada. The court reasoned that the right to procreate or the privilege to give birth is fundamental, and circumscribes the power of the state to restrict fundamental rights based on disability or on the duty of the state to protect vulnerable people. Although framed as a legal issue, in a number of countries, decisions about sterilization have become a forum for debating the status of people with disabilities generally and, in particular, for debating their claim to citizenship and equality.¹⁴ In a similar case in England, the court ruled in *Re B (a minor)* 1987 that it was in the best interests, and clearly within the jurisdiction of the *parens patriae* power of the state, to sterilize a young woman. In other words, the Canadian court used a citizenship status model of law to decide the case, while the English court used a charitable privilege model, basing its decision on the welfare principle.

Ten years later, however, the Supreme Court of Canada decided *Eaton v. Brant County Board of Education*, which contributed to pushing the equality of people with disabilities back toward the margins of mainstream society.¹⁵ This case involved the educational placement of Emily Eaton, a twelve year old with multiple disabilities, in a regular classroom setting with her non-disabled counterparts. Overturning the Ontario Court of Appeal's decision, the Supreme Court of Canada ruled that Emily's interests were best served in a segregated school setting, excluding her from her non-disabled peers. The case is an example of the tension between conceptions of equality and disablement in a model of law based on civil disability and the conceptions of equality and disablement in a model of law based on citizenship. On one hand, the court found that unlike other types of differences (e.g., race and gender), disability involves individual variations and, therefore, may require variable degrees of inclusion and exclusion. The court based its decision on the individual functional characteristics of the child and drew a distinction of those characteristics based on disability and difference (Frazee 2003). At the same time, the court did say clearly that integrated education is preferable for students with disabilities because of the benefits it provides. Thus, while the court made a particular decision in Emily's case, it ruled that wherever possible, regular schools should accommodate students with different learning needs because of section 15 of the Charter. In other words, the court recognized that inclusive education is an important ingredient in citizenship status, based on a social pathology model of disability and an equal outcome approach to equality. Yet, in this case, the court placed more weight on Emily Eaton's functional limitations and her capacity to learn within the conventional non-inclusive pedagogical environment than on the societal benefits to her inclusion based on notions of equality and rights.

In another case in which three people who were deaf were not provided with an interpreter for health-care services in British Columbia, there was another shift in the court's presumption.¹⁶ The decision in *Eldridge v. British Columbia (Attorney General)* reflects a much clearer shift from a charitable privilege model of law and policy to a model of law reflecting citizenship status based on human rights for Canadians with disabilities. It prompts a paradigmatic shift away from both the view that disability is a condition that requires a cure and the consequent policies of exclusion and institutionalization that follow from that view. Indeed, there is both symbolic significance and practical importance to this strengthening by the Supreme Court of Canada of the contention that disability is a human rights issue and an issue of equality in an expansive sense. At a number of particular points, the court made determinations that support a human rights perspective, and that suggest a wider application of the findings of the case. The court's holding that "once the state does provide a benefit, it is obliged to do so in a non-discriminatory manner" (*Eldridge* 1997, para. 73) is im-

portant because it gives recognition to the entitlement of people with disabilities to government benefits, an entitlement that is not discretionary or charitable. It recognizes the right of people with disabilities to receive what others receive, as a legitimate claim and not as government largesse. They are not in the role of supplicants, nor are the benefits they receive entitlements based on charitable privilege.

The court also made clear the interpretation of equality that the Charter protects. The denial of equality in *Eldridge* arose from the failure of the government to take action (rather than the imposition of a burden). The discrimination arose from the adverse effects of a public benefit scheme that failed to provide the same level of service to the disabled as to other citizens. In Justice La Forest's opinion, to argue that "governments should be entitled to provide benefits to the general population without ensuring that disadvantaged members of society have the resources to take full advantage of those benefits ... bespeaks a thin and impoverished vision of s. 15(1)" (*Eldridge* 1997, paras. 72-73). The important principle here is that there is a positive obligation on the government to remedy inequality notwithstanding that the benefit scheme appeared neutral and the remedy meant that the government had to spend money. And in this case, the positive obligation deemed communication to be fundamental to the service (medical treatment) that was to be provided. In other words, equal treatment and equality of opportunity would not have met the standards of equality the court was trying to set in this instance.

These cases make clear the divergence in opinions that arise in framing the legal and social parameters of what human rights and equality mean for people with disabilities. While the *Eve* and *Eldridge* cases brought us closer to the goal of full inclusion for people with disabilities in Canada in the context of a citizenship status, the *Eaton* decision moved us back toward a charitable privilege model of law and policy. For our purposes, these cases do not concern the substantive issues of sterilization, education, and health services; rather, they are case studies of the interplay between law, social theory, and disability. They illuminate the tension between promoting equality rights and enabling citizenship, and paternalistic protection, a tension that pervades legal cases and other policy developments (Rioux 1990). More recent Supreme Court cases, as discussed by Pothier in the Appendix, follow from these precedents.

Political and Administrative Developments Affecting Disability in Canada

Throughout the 1990s, the advances in linking disability, equality, and citizenship were largely undercut by the forces of neo-liberalism and instrumentalism, as well as jurisdictional complexities that dominated the disability policy sphere. For instance, the three areas identified for advancement by

federal, provincial, and territorial governments in the *In Unison: A Canadian Approach to Disability Issues* (Canada 1998) agreement – namely, disability-related supports, income, and employment programs – have been, at best, limited.¹⁷ In addition, because of the arbitrary nature of the agreement on the three areas, important disability issues have been largely overlooked because they do not fit neatly into those three policy areas. The voices of those in the disability movement who advocated for other areas of importance were not heard. Examples of areas in which there was a good deal of lobbying but little success because of the neo-liberal hegemony of the government's platform are issues related to children with disabilities within the family setting and First Nations people with disabilities. Compounding the continued exclusion of these societal groups is the fact that there has been no major restructuring of the system to remove existing policy and program barriers and to put in place those elements that would enable participation. The result has been that, despite agreement on a policy framework for disability, each level of government has policies and programs in each of those three areas but without any coherent, authoritative clarification of the concept of disability or an understanding of the impact of the overlap and competitive nature of the programs put in place.

This situation is a result of the tension among the three theoretical constructs of entitlement associated with the norms and standards of equality and disability. Some examples illustrate this tension. First, the disability community frames the issues of disablement by equating inclusion with equality, and full citizenship status with the underlying (and largely unstated) assumption that citizenship is essentially based on human rights (i.e., section 15 of the *Canadian Charter of Rights and Freedoms*). Neo-liberal ideas have ushered in a new wave of policies in which the criteria for government disability entitlements still applies some version of the civil disability model of entitlement, that is, a biomedical formulation of disability that does not incorporate the notion that it is the social and legal construction of disability that leads to the individual disadvantage. In practice, this translates into paternalistic decision making policies, programs, and services, including, for instance, institutional living for children and adults with disabilities (especially developmental disabilities), sheltered workshops, services based on professional classification schemes, and rehabilitation protocols, as well as precarious forms of employment such as part-time work and short-term contracts (see Wilton, Chapter 6).

Second, as neo-liberal ideas permeated most aspects of policy making in Canada, driven primarily by the goals of fiscal restraint, deficit reduction, and smaller government, the relationship between the Canadian welfare state and citizens began to shift (Rice and Prince 2000). These shifts led to an increased role for voluntary and charitable organizations in providing to

Canadians, including Canadians with disabilities, supports and services that the state had no interest in offering or capacity to provide to its citizenry. Tension among the three theoretical constructs of entitlement is exhibited in part because the voluntary sector has no clear model for understanding disability, and in part because some people still hang on to the vestiges of charitable privilege of entitlement – a view of people with disabilities as the deserving poor requiring social protection. This falls far short of full citizenship status for persons with disabilities and represents a step backwards. In practical terms, the neo-liberal period has meant that rights and benefits providing income supports and employment for people with disabilities are largely determined according to individual potential for self-reliance.¹⁸ A marked preference and concern for those seen to have the greatest potential for independent functioning is inherent to the goals of prevention and amelioration. However, for the residue – the “deserving poor” – who need some form of long-term care and financial support, benefits are provided as a humanitarian and charitable gesture, rather than as an entitlement based on equality and citizenship.

Third, while using language based on equality, the neo-liberal period has resulted in federal and provincial governments' assuming that achieving inclusion is determined largely by financial capacity; thus, they try to hang on to discretion over spending on disability programs, which has created an uneven mix of policies based on both civil disability and charitable privilege. In short, most policies and programs aimed at promoting the full citizenship status of people with disabilities are underfunded. Perhaps the best example is found in our public schools. Despite the fact that at the international level, Canada – along with the United States – has been a leader in advancing the notion of inclusive education, recent studies on special education indicate that special education policy, practice, and funding are inconsistent across the country. This creates a situation that imposes significant hardships on many Canadian children and their families. A recent study of the well-being of children and youth concluded that “families with children with disabilities are facing cutbacks in teaching assistant and teacher-training for inclusion – and shorter school days for children with disabilities.” Moreover, “cutbacks in related services funded under Health and Social Services have further reduced access to education for children with disabilities” (Canadian Institute of Child Health 2000, 248). Children may, in fact, be included in regular classroom settings, but often they are not provided with the supports and services that are responsive to the students' individual needs. That is, the child has no individual supports, nor is there any support for the systemic change that would be needed to enable the child to function without individual support. In other words, a child with low vision may be in a regular classroom but not have adequate access to Braille

instruction because of a shortage of funding for itinerant teachers of Braille, and because non-specialist teachers are not required to have the capacity to provide Braille instruction.

For Canadians with disabilities, the tension among these three theoretical constructs of entitlement is more than an academic curiosity. It represents a very real barrier to their full participation in mainstream Canadian society, and goes some distance in explaining the underlying reasons for the ongoing patterns of exclusion and oppression among people with disabilities (including children and their families) from our communities, workplaces, and schools (Valentine 2001).

Conclusion: The Still Unfinished Project of Disability, Human Rights, and Public Policy

In this chapter we sought to illustrate why theory does in fact matter in advancing the rights of Canadians with disabilities. Using an approach to critical disability theory that offers a politicized view of the meaning and experience of disablement, this chapter began by considering the assumptions or postulates about disability evident in the most salient theoretical social and scientific views of disability, and by considering the theoretical constructs of equality and citizenship in contemporary Canadian society. Using a review of the most significant initiatives (at the international and domestic levels) affecting persons with disabilities, we conclude that a lack of consensus exists at the intersection of approaches to disability, equality, and citizenship with respect to persons with disabilities. Despite significant advances in political, administrative, and judicial documents in recognizing disability as a matter of human rights, there continues to be significant tension among three competing theoretical constructs of entitlement – civil disability, charitable privilege, and citizenship status. A review of key developments in the contemporary period reveals a divergence of opinions in regard to advancing the equality right of Canadians with disabilities, and the onset of neo-liberalism has led to increased confusion and tension in framing the legal and social parameters of what human rights and equality mean for people with disabilities. In short, we have confused law and confused policy concerning the meaning of disablement and its intersection with equality.

This confusion is perhaps to be expected in an area of equality rights as complicated as disability. Achieving equality for persons with disabilities, however, requires that all political, administrative, and judicial actors understand the meaning and experience of disablement as nothing short of full citizenship status. Getting to this point, however, will require significant and ongoing debate in our legislatures, in our courtrooms, and in civil society.

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Notes

- 1 A recent example would be reforms to the Canada Pension Plan that changed the eligibility criteria for people with disabilities.
- 2 This section has been adapted from an earlier published article. See Marcia H. Rioux, "Disability: The Place of Judgement in a World of Fact," *Journal of Intellectual Disability Research* 41, 2 (April 1997): 102-11.
- 3 This distinction was originally developed from an empirical analysis of the ideas, concepts, and programs related to disability. See Rioux 2003; Rioux and Zubrow 2001.
- 4 In general, the positivist paradigm emphasizes the supremacy of human reason, arguing also that there is a single objective truth that can be discovered through scientific techniques. This paradigm regards the world as a rational and ordered place, with a clearly defined past, present, and future. The positivist paradigm encompasses a variety of perspectives, including the economic, behavioural, cognitive, motivational/trait/attitudinal, and situational.
- 5 See, for instance, Peggy Hutchinson, Peter Dunn, John Lord, and Andrea Pedlar, *The Impact of Independent Living Resource Centres in Canada* (St. Catharines, ON: Brock University, 1996); Roeher Institute, *Final Evaluation Report on the Direct Funding Initiative* (North York, ON: Roeher Institute, 1997). Finally, on the relationship between disablement and the workplace environment, see National Institute of Disability Management and Research, *Strategies for Success: Disability Management in the Workplace* (Vancouver: NIDMR, 1997).
- 6 For examples of this approach, see, for instance, the Canadian Association of Independent Living Centres, *A Time for Change/The Time for Choices: A Proposal for Improving Social Security Arrangements for Canadians with Disabilities* (Ottawa: Canadian Association of Independent Living Centres, 1994); Sherri Torjman, *Income Insecurity: The Disability Income System in Canada* (Downsview, ON: Roeher Institute, 1988).
- 7 A significant body of research is available on this approach. See, for instance, W. Roth, "Disability as a Social Construct," *Society* 20 (1983): 56-61; P. Beresford and J. Campbell, "Disabled People, Service Users, User Involvement and Representation," *Disability and Society* 9 (1994): 315-25; M.H. Rioux and M. Bach, eds., *Disability Is Not Measles: New Research Paradigms in Disability* (North York, ON: Roeher Institute, 1994); Roeher Institute, *Social Well-Being: A Paradigm for Reform* (North York, ON: Roeher Institute, 1993); Canadian Society for ICIDH, "The Handicap Creation Process," *ICIDH International Network* 4 (1991); M. Oliver, *The Politics of Disablement: A Sociological Approach* (London: Macmillan, 1990).
- 8 This section is taken substantially from M.H. Rioux, "On Second Thought: Knowledge, Law, Disability and Inequality," in *The Human Rights of Persons with Intellectual Disabilities*, ed. S. Herr, L.O. Gostin, and H.H. Koh, 287-317 (Oxford: Oxford University Press, 2003).
- 9 For a critique of the social model from a post-materialist/post-structuralist perspective, see M. Corker and T. Shakespeare, *Disability/Postmodernity: Embodying Disability Theory* (London: Continuum, 2002).
- 10 These debates also apply to other oppressed and marginalized citizens, including women, gays and lesbians, and First Nations peoples.
- 11 As Frazee, Gilmour, and Mykitiuk in Chapter 10 of this book, as well as Sampson in Chapter 12, explore in their discussions on the gendered body, the construction of disability for women is an important example of regulation by systems of law and policy.
- 12 We are not here trying to cover the entire expanse of equality theory, something which is beyond the parameters of this chapter. Rather, we are looking at the general trends of

- equality theory as a way to understand that some formulations of disability, in conjunction with particular constructs of equality, will lead to very distinct legal, policy, and program directions and justifications of actions, even when they result in disadvantage. For an analysis of equality, see Malhotra's discussion in Chapter 3.
- 13 For an extensive review of international human rights instruments in the context of disability, see Quinn and Degener 2002.
 - 14 See further, Marcia H. Rioux, "Sterilization and Mental Handicap," *Leisurability* 17, 3 (1990): 3-11.
 - 15 For three years, Emily Eaton regularly attended elementary school in Brant County, Ontario, with a full-time educational assistant – until an Identification, Placement and Review Committee found that her needs were not being met in the regular classroom. Accordingly, a special educational tribunal decided that Emily should be placed in a special class for students with disabilities. The tribunal reasoned that because of her intellectual and physical disabilities, Emily would not learn in a regular classroom. Wanting her to stay in her neighbourhood school, Emily's parents argued that Emily had the right to inclusive education under section 15 of the *Canadian Charter of Rights and Freedoms*.
 - 16 On 9 October 1997, in a unanimous decision, the Supreme Court of Canada ordered the Government of British Columbia to pay for sign language interpreters when deaf people access health-care services. The failure to provide sign language interpretation, where it is needed for effective communication in the delivery of health-care services, violates the rights of deaf people.
 - 17 The *In Unison* agreement was reached by the federal, provincial, and territorial governments. In it, the governments adopted a common pan-Canadian vision and long-term policy direction in the area of disability. It is a vision based on the values of equality, inclusion, and independence, and which seeks to translate the vision of full citizenship into objectives and policy directions in three interrelated building areas: disability-related supports, employment, and income. This is a commitment the Government of Canada, and some provincial governments, continue to reaffirm in broad-based policy frameworks on disability. See, for instance, Canada, *Advancing the Inclusion of Persons with Disabilities: A Government of Canada Report, December 2002* (Hull: Human Resources Development Canada, 2002); Manitoba, *Full Citizenship: A Manitoba Strategy on Disability* (Winnipeg: Ministry of Family Services and Housing, 2001).
 - 18 An interesting example of post-secondary education and students with disabilities is explored by Hibbs and Pothier in Chapter 9.

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