

Reaching One's Potential: A Discussion of Individual Human Rights and People with Developmental Disabilities in Canada

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Editor's note: The ideas presented in this paper primarily represent a useful, and user-friendly, summary of information contained in a report entitled "Enhancing the rights and personal freedoms of people with disabilities," published in 2000 by Accreditation Ontario and restated with permission.

Abstract

In recent years, understanding disability as part of the range of human characteristics for which society has an obligation to respond positively is replacing models that focus on individual deficits. Positive social response includes protection of human rights for people with disabilities. Yet, the history of services for people with developmental disabilities in Canada is fraught with human rights violations, and many continue in a variety of forms today. This paper summarizes basic rights protection for people with developmental disabilities in Canada, and points out numerous examples, both past and present, of how easy it is to violate those rights.

In recent decades, there has been a growing concern about protecting and enhancing the rights of people with developmental disabilities. In particular, there has been a gradual shift away from the concept of disability as pathology, and a shift toward disability being understood from the perspective of social and human rights-based models (Bach, 2003; Rioux & Carbert, this issue). However, we have been slow to change, and "the discourse of human rights has not yet influenced thinking in the area of developmental disability as much as it has in other areas, such as gender, race and religion" (Bach, 2003, p. 38). The discussion in this paper is an exploration of rights as they pertain to people with developmental disabilities in Canada in support of the trend toward a rights-based understanding of disability.

Defining "Rights"

The Oxford English dictionary defines a right as a "fair claim, and as a legal or moral entitlement." A person who is a right-holder, then, has a fair claim or entitlement to something. Further, the right-holder is entitled to claim or demand her/his right. An individual may also choose to waive or forfeit her/his rights, or have them overridden by someone else's higher rights. Some rights pertain to all humans (usually called human rights, but also universal or natural rights), while others apply strictly to persons living in a certain jurisdiction or belonging to a particular group (e.g., constitutional or legal rights, contractual rights). It is the area of human rights that is of greatest relevance in the following discussion.

The basis for claiming that all humans have rights is the belief in a universal human nature. A constructivist view of rights posits that there is an ideal or "moral" human nature, and as such, every human has the potential to become a "rational, autonomous moral agent, capable of making, developing, self-realizing herself through her interests, choices and projects" (Accreditation Ontario, 2000, p.7). This is the ideal potential for all humans, and that potential is realized through the social practices and institutions of the society in which a person lives.

From a constructivist perspective, rights are based on morality, and not on the empirical or physical attributes of an individual. In this view, the presence of a disability may prevent a person from achieving in some physical or intellectual ways, but disability does not limit achieving individual potential in the area of human rights. Each of us has, above all, the right to be treated as a human being:

People do not have dignity if they are treated as though their lives have less value than the lives of other people, or if they can be expected to put up with behaviour directed towards them that other people would not tolerate. Having rights means being treated fairly and humanely. (Accreditation Ontario, 2000, p.13)

Yet historically, and at the present time in many cases, people with disabilities are often not treated fairly or humanely.

The Social Model of Disability: Incorporating a Rights Perspective

There are many ways to understand and define disability. Traditionally, definitions based on legal or bio-medical perspectives have been used to

classify a person as having a disability. These perspectives tend to focus on individual abnormality and on lack of ability compared to the norm (Bach, 2003). Today, many people in the disability field are advancing a "social model" of disability, a model rooted in ideas of rights and entitlements. Bach explained that "[i]n a social and human rights model, disability arises from the discrimination and disadvantage individuals experience in relation to others because of their particular differences and characteristics" (p.34). This model recognizes that people with disabilities are first and foremost rights-bearing citizens.

In a supreme court of Canada case involving the equal rights of people with disabilities, Mr. Justice LaForest stated that the assurance of equal rights for those with disabilities, as outlined in the Charter, is a commitment ingrained in the social, political, and legal culture of Canada, to the equal worth and human dignity of all persons. Expressly stating that persons with disabilities have rights equal to all other citizens "instantiates a desire to rectify and prevent discrimination against particular disadvantage in our society" (Accreditation Ontario, 2000, p.34). The Charter of Rights and Freedoms, in expressly identifying certain groups in society as having equal rights, including persons with disabilities, acknowledges and attempts to remedy the historical injustices experienced by these groups in society.

Why is a rights perspective important?

Although people with disabilities have the same human rights as all citizens, the need for assistance to exercise those rights can sometimes lead others to assume that a person with a developmental disability is unable or unwilling to exercise her/his rights, or that it is not important to do so. Such an assumption may - and often has in the past - lead to lack of effort to provide the very supports needed to determine whether or not people with disabilities wish to exercise the rights they are supposed to have. This unfortunate thinking may be the prime contributor to rights violations. In fact, there are many examples of human rights violations in past and present service practice - even the most basic right, the right to life.

The history of services for people with disabilities reveals many examples of less than equal treatment in relation to rights. In many instances, rights violations were a matter of standard practice. Decisions about what people did and did not do were made routinely by others, without ever consulting the individual. (Accreditation Ontario, 2000, p.1)

Addressing the issue of individual rights requires a broad range of actions at many levels on the parts of service users and providers. These actions range from simply asking for an individual's opinion to pursuing legal processes that ensure that an individual's status as a citizen is not diminished. Individual abilities need to be assessed, assistance and training need to be provided where appropriate, opportunities for experience need to be expanded as much as possible for individuals, and, often, modification of environments needs to be made. Ensuring services that respect human rights also requires advocacy for change in the community and within the service system.

In carrying out these actions, it is important to remember that having equal rights is not synonymous with treating every person the same way. A person with a disability often has needs that are particular to the individual and that must be accommodated. The desired outcome of such an accommodation is that the "result of an intervention is as close as possible to being the equivalent to the result other [non-disabled] persons would expect from the same or comparable intervention" (Accreditation Ontario, 2000, p.30). In order for this outcome to occur, the guarantee of equal rights, as persons with disabilities have in Canada through the Charter of Rights and Freedoms (discussed below) and other documents, needs to be accompanied by supports that allow a person to exercise rights as her/his need requires. Thus, there are many occasions when treating a person with a disability the same as any other person may constitute an equal rights violation.

Rights Specific to Persons with Disabilities in Canada

The Universal Declaration of Human Rights, proclaimed by the General Assembly of the United Nations in 1948, sets out the basic rights of all humans (Rioux & Frazee, 2003). Canada, as a member of the United Nations, has accepted these principles. In order to meet its commitment to these principles, Canada has developed three levels of policy regarding human rights. They are: the Charter of Rights and Freedoms (part of the Canadian constitution); the Canadian Human Rights Act; and provincial and territorial human rights legislation.

The Charter of Rights and Freedoms

The Charter of Rights and Freedoms is an important document pertaining to rights in Canada. The obligation to respect people's constitutional rights and freedoms is on governments at all levels; thus, laws and policies developed

by any government must obey the rights and freedoms of citizens as set out in the Charter. The Charter guarantees equal rights to all citizens. There are several sections of the Charter that are particularly applicable to persons with developmental disabilities, either because the section addresses this group in particular, or because it represents an area in which the rights of persons with disabilities are often violated.

Section 2 of the Charter states that people have the freedom to assemble and to associate with other people as they choose. This right ensures that people with disabilities are free to choose those people or groups with whom they wish to associate and form relationships. Freedom of association is often a right that is violated for individuals with developmental disabilities living in institutional settings, or any residential placement where a person has no opportunity to express a preference as to where or with whom s/he wishes to live. In Ontario, there are still almost one thousand adults with developmental disabilities living in institutions. Moving people from these institutional to community settings has been logistically challenging, especially in trying to provide choice and opportunity for self-expression (Brown & Percy, 2003).

Section 7 of the Charter states that everyone has the right to life, liberty, and security of the person. In Canada, however, "[n]o group in our society, with the possible exception of Aboriginal people, has faced such determined and far-reaching violations of their rights to life, liberty and security of the person" as persons with disabilities (Accreditation Ontario, 2000, p.23). In Canada, the courts have upheld the right of people with severe disabilities "to receive necessary and life-sustaining medical or surgical treatment, even in the face of attempts by legal guardians to refuse such treatment on their behalf" (Accreditation Ontario, 2000, p.20). This has, unfortunately, been necessary, because the right of a person with a significant disability to life itself has, and continues to be, threatened in many quarters. Therapeutic abortions, decisions not to provide life-saving medical treatments, assisted suicide, and other practices involving persons with significant disabilities - as well as lenient sentences of those found guilty by our courts of committing crimes against people with severe disabilities - are violations of the right to life.

The right to security of the person "has a bearing on the preservation of personal autonomy when one's decision-making capacity is limited" (Accreditation Ontario, 2000, p.23). Both liberty and security interests, guaranteed by the Charter, are rights involved in the making of personal decisions for persons with disabilities, especially regarding residential

placement. It is sometimes argued that these rights are violated for people who continue to live in institutions or other residential placements where choice is not offered. The Supreme Court of Canada has ruled that security of the person "includes the psychological integrity inherent in being in control of what happens in one's life" (Accreditation Ontario, 2000, p.23). Often, people with disabilities are given very little opportunity for control in their lives, and as such, their rights to liberty and security are violated.

Security of the person has historically been violated for those with disabilities through the eugenics movement. This movement was characterized by attitudes that regard people with disabilities as having negative worth, and as being a detriment to societal well-being. The sterilization policies of the 1930s and 1940s that were accepted in some parts of Canada are disturbing evidence of the systemic violation of the right to security of person experienced by people with disabilities.

Section 15 forms a major component of the Charter of Rights and Freedoms as it applies to persons with disabilities. This is the only section of the Charter in which the rights of persons with disabilities are expressly guaranteed. The section states that an individual "has the right to equality under the law, and the right to the equal protection and equal benefit of the law without discrimination based, among other things, on mental or physical disability" (Accreditation Ontario, 2000, p.29). Of note is that Canada was the first, and remains one of only three countries (the others being Germany and South Africa), to adopt a constitutional guarantee of equal rights for people with disabilities. This is recognition of a person's status as an equal with all other members of society. Expressly stating persons with disabilities as having equal rights also recognizes the discrimination faced by this group in our society. Supreme Court Justice LaForest stated:

It is an unfortunate truth that the history of people with disabilities in Canada is largely one of exclusion and marginalization. People with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions... 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, people with disabilities have not generally been afforded the "equal concern, respect and consideration" that section 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... One consequence of these attitudes is the persistent social and economic disadvantage faced by people with disabilities. Statistics indicate that people with disabilities, in comparison to non-disabled people, have less education, are more likely to be outside the labour force, face much higher unemployment rates, and are concentrated at the lower end of the pay scale when employed. (Accreditation Ontario, 2000, p33)

This statement illustrates the rationale for expressly guaranteeing equal rights for persons with disabilities. It also illustrates the need, as discussed above, to make accommodation for persons with disabilities such that they might be able to enjoy these rights.

Other human rights legislation

The Charter of Rights and Freedoms is not the only policy that deals with human rights in Canada. Every Canadian province and territory has human rights legislation that includes the prohibition of discrimination against anyone on the grounds of disability, as does the federal Canadian Human Rights Act. These policies state that persons with disabilities have the right to be respected and given equal opportunity. Generally, human rights legislation is designed to benefit those citizens who have historically been denied respect and equal opportunity, whether or not it is intended:

It should be borne in mind that a violation of a person's human rights as set out in human rights legislation does not have to be an intentional denial of equal treatment. The test of discrimination is whether a distinction was made in how the person was treated on the basis of that person being a member of a protected class of persons, such as those having a disability, and that the distinction resulted in an adverse impact on the individual. (Accreditation Ontario, 2000, p.38, emphasis original)

Human rights legislation is generally developed to give "an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have" (Accreditation Ontario, 2000, p.40). Human rights legislation requires that accommodations be made that will enable a person with a disability to participate in such areas as employment, except in cases where doing so would result in undue hardship to the employer. Guidelines have been set out in Ontario by the Ontario Human Rights Commission to determine when this is the case. Equal employment opportunity is a major

component of human rights legislation, and one of particular significance to people with a developmental disability. Human rights legislation makes it illegal to refuse to hire a person for a position for which s/he is qualified simply because of the presence of a disability (Rioux & Frazee, 2003).

When the presence of a disability prevents a person from being able to earn her/his own livelihood, s/he has the right, under the human rights statutes of all Canadian provinces and territories, to receive social assistance. In some jurisdictions, a person with a disability may be entitled to benefits beyond those received by people without a disability who are in need. Unfortunately, in Ontario, access to social assistance has been greatly restricted since 1995, with fewer people being deemed eligible for support under the Ontario Disability Support Program (ODSP) (Brown & Percy, 2003), and fiscal restructuring elsewhere has resulted in similar restrictions. Another source of financial assistance available to people with developmental disabilities in Ontario is direct funding through programs such as Special Services At Home (SSAH). Although approximately one quarter of all people with developmental disabilities receive funding through SSAH, families often receive only a portion of what they require (Brown & Percy, 2003).

Looking back over time, the experience of people with disabilities has been one of being required to yield to the preferences of others, even in the area of rights:

Denied an autonomous, empowered position from which to enter into this natural process of social negotiation, people with disabilities have frequently been misled as to the degree to which their rights are limited by the rights of others. (Accreditation Ontario, 2000, p.133)

An important human right is the right to make one's own decisions about matters in every day life (Peppin, Beatty & Baker, 2003). Two pieces of legislation in the province of Ontario dealing with decision-making are the Health Care Consent Act and the Substitute Decisions Act. Both of these acts stipulate that decision making rights should only be removed when necessary, because of a person's incapacity to make a decision. Even when a substitute decision maker or guardian is responsible for making a decision for a person with a developmental disability, this other person must foster the independence and participation of the individual with the disability, and choose "the least restrictive and intrusive appropriate course of action available" (Peppin et al., p.74).

Toward the Future

The human rights of people with developmental disabilities in Canada have often been violated on both an individual and a systemic level. A discussion of human rights is beginning, however, in the field of developmental disabilities. Service providers are beginning to address the issue of how to assist people with developmental disabilities to exercise their rights. Fundamental to ensuring that rights are respected is a belief that given the appropriate support and intervention, it is possible for every person, regardless of ability, to experience the rights important to them.

There are many challenges to ensuring that the rights of people with developmental disabilities are respected. There are broad social forces that threaten to undermine the human rights of people with disabilities. For example, developments in genetic science now allow the detection of developmental disability prior to birth, and, in many cases, the decision is made to prevent such births, suggesting that people with developmental disabilities are unwanted in the human family (Rioux & Frazee, 2003). These complex issues point to the importance not only of human rights legislation and court rulings, but also of education. Rioux and Frazee pointed out:

Human rights education and approaches to policy decisions made in government, industry and community organizations are critical in our efforts to achieve dignity, respect and equality for persons with intellectual disabilities in Ontario, in Canada and throughout the world. (p.63)

We need to further the discussion of human rights as they apply to people with developmental disabilities in order that individuals may enjoy all that life in Canada has to offer them.

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