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Abstract

Marcia Rioux, Director of the Roeher Institute, Canada, writes that in spite of the social and legal requirement under the Charter of Rights and Freedoms (Canada), people with disabilities are still waiting for equal rights with their differences being respected and taken into account. To understand why change is so slow, Rioux discusses the historical perspective of treatment of people with disabilities which cause people to want to "fix" the individual rather than recognising people's differences and using them as a basis for changing what exists to make it accessible. She argues "they" must become a part of "us" and we must move the agenda from charity to rights, service to support. This involves changing whole systems and needs legal entrenchment because it is one way the political system shapes social policy. **Keyword: Theory**

The Contradiction of Kindness; The Clarity of Justice

by Marcia H. Rioux
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I HAVE A PICTURE in my mind which troubles me. It is a picture of a child standing alone outside a school while other children are inside the school attending classes. I have another picture which troubles me. It is a picture of a woman standing outside an office building looking in at the people working. I also have a picture of a person beside a swimming pool watching others frolicking in the water. These mental pictures haunt me as I think about the lives of people with mental handicaps. The isolation and exclusion of some people — while others are given the opportunity to participate — suggest that something is fundamentally wrong.

The social well-being of a society requires that all people are included and accepted. It means finding ways of ensuring that everyone is a participating citizen without being penalized because of a difference in race, sex, ethnicity, religion, or physical or mental ability. This is not only a moral imperative but a social and legal requirement under the *Charter of Rights and Freedoms*, and under provincial/territorial and federal human rights legislation. It seems, however, to be taking considerable time for Canadians to alter their way of providing social, legal and economic benefits so that, in reality and not just in principle, all Canadians have equal rights and difference is respected and taken into account.

This unending wait for change frustrates those of us who work every day for obviously needed changes. For people with a mental handicap, the wait is debilitating. They continue to face exclusion from schools, from employment, from decision making, from ordinary life experiences. Members of Associations for Community Living and People First expend enormous energy telling Canadian citizens, politicians, policy makers and service providers of all kinds that people with mental handicaps are citizens too. Why do they have to keep doing that day after day, year after year?

The answer lies largely in the narrow and bigoted way people with mental handicaps have been seen. It also lies in the ignorance of people outside these organizations who cannot envision the contributions that people with mental handicaps make every day. While they have started to use words like self-determination, autonomy, rights, and citizenship, they continue to block the changes demanded. Jobs, control over money, homes are all still denied to people with mental handicaps because they are not like the rest of the population.

Recently, we have seen other groups reject attempts to make them conform in order to be accepted. Women, Native people and people of other ethno-cultural backgrounds do not want their differences ignored but recognised and respected. People with mental handicaps also reject government attempts to make them carbon copies of people without mental handicaps; they reject government's arguments that when they are the same as other people they will be entitled to have the same things other people have.

In the end, people *without* mental handicaps will have to change who they are and what they do. Recognising the contribution of people with mental handicaps is not a matter of making everyone the same. It is a matter of changing the way we do things to accommodate uniqueness and difference — and doing so in a way that ensures that, in every aspect of life, all people have the opportunity to participate. That is our job as advocates of change. We have to attack the very nature of the way things are done — not so people will all live the same way but so everyone can make real choices about how they want to live and can be recognised for who they are and the contribution they make.

To do this, it is important to understand how the restrictive laws, policies and programs we now are trying to change came into being. The history of the treatment of people with

disabilities reflects two distinct ways of thinking.

The first was that people with disabilities were dangerous and disruptive to society; therefore, society should protect itself from them. The result was that they were put in institutions and controlled. This meant creating laws and policy such as guardianship, institutional isolation and other forms of restraint. It also meant putting restrictions on people's right to vote, to immigrate, to marry, to have children and to own property. Arguments for such restrictions, and acceptance of them, were based on a perceived need to protect society from the assumed incompetencies and incapacities of persons with disabilities. In other words, people with disabilities were judged against incapacity, inability and difference from others. And the differences were viewed as negative, disruptive and dangerous.

The second wave of thinking, and its ensuing policy and programs for people with disabilities, viewed them as pitiable but deserving of charity and benevolence. The resulting policy was one of control, exercised through medical decision making and provision of services through local governments and charity. The decision to isolate people was no longer based on protecting society but on protecting the individual with the disability and providing "special" services for these "special" people.

Within this framework, institutionalisation and segregation were viewed as helping the individual. Therapy became the central reason for, and purpose of, treatment and services. The money available was given to the service provider rather than to the individual. This was based on the idea that a service provider was in the best position to determine the needs of the individual. Because it was thought that people with disabilities were being helped by special programs in institutions or other segregated settings, no one bothered to critically evaluate the programs. They were evaluated only in terms of other segregated programs for people with a mental handicap, and in terms of the attitudes of service providers — not for their value in making integration more likely.

Benefits considered fundamental to the well-being of other citizens were ignored in the criteria for the well-being of people with disabilities. The individuality and self-determination of people with disabilities were secondary within the paternalistic, protectionist

framework where habilitation and rehabilitation were the primary goals of care, treatment and programming. This again reflects a notion that difference is problematic and must be eliminated or ameliorated.

In both these ways of thinking about disability, the "problem" of disability has been presumed to reside in the individual. The individual is considered out of step with the world. Once labelled as different, the individual does not fit into the labour market, does not fit into the education system, does not fit into recreation and social programs, and does not fit into the community. The presumption then is that the individual must somehow be changed to conform with the social, political and economic programs already in place. The professional community and service providers in the field tend to focus on ways to "fix" the individual. The difference of disability is the problem and has to be corrected if people are to exercise their right to equality.

Alternately, a social and human rights approach is premised on the extent to which an individual can or will be supported to be able to function within society. It does not rely on differentiating people as a way of excusing governments and service providers from making generic resources available to them. In contrast, it recognises people's differences and uses them as a basis for changing what exists to make it accessible. It's a very different enterprise. "They" become part of "us". The implication is that we all have the benefits of citizenship, not as beggars but as persons entitled to it.

Human dignity, community, protection of rights and equality have to be substituted for classification (labelling), segregation, and the obligation of those with mental handicaps to prove themselves. In the process, the notion of *noblesse oblige* will have to be replaced. We must come to see the issue not in terms of what "we" ought to do for "them" but what we ought to do for ourselves. We must move the agenda from charity to rights; from best interests to choice; from disempowerment to empowerment; from professional control to self-advocate control; from cost-effectiveness to output-effectiveness; from fixing a weakness (rehabilitation) to developing a strength; from expedient categorisation to individual need; and from service to support.

There are examples of what this means in practice and what impact such an approach may have. In 1986 the Supreme Court of Canada

ruled in the *Eve* case that people who have a mental handicap cannot be required to undergo a non-therapeutic sterilisation authorised by any third party including parents or next-of-kin, the Public Trustee or the administrator of a facility. The Court went on to say that should any legislation be introduced in Canada to authorise this type of procedure, it would be subject to constitutional scrutiny under the *Charter of Rights and Freedom* which protects the right to equality of Canadian citizens. The *Charter* specifically includes those with a mental handicap. The *Eve* decision was based on the finding that such an intrusion on the rights of a person could never be shown to be in their best interests.

In 1987 the House of Lords of England rejected the findings of *Eve*. It applied the best interests test to a similar case and gave leave for the operation to be performed. Lord Hailsham stated that while the Canadian decision was helpful he found that:

"with great respect, [the] conclusion that the procedure of the sterilisation 'should never be authorised for non-therapeutic purposes' [is] totally unconvincing and in startling contradiction to the welfare principle which should be the first and paramount consideration in wardship cases. To talk of the 'basic right' to reproduce of an individual who is not capable of knowing the causal connection between intercourse and childbirth, the nature of pregnancy, what is involved in delivery, unable to form maternal instincts or to care for a child appears to me wholly to part company with reality."

In this way, the British Court reaffirmed the long-standing tradition of paternalism in dismissing the right to refuse treatment, the right to consent and the right to bear children for people with a mental handicap. It set a standard for exercising these rights that is different from any standard for those without mental handicaps.

The critique of the Canadian case by the House of Lords is important. The Canadian Court approached the issue from a rights and equality perspective, while the British Court conceptualised it as a welfare issue. In the Canadian case, the natural right of women to bear children took precedence over the right of the state to interfere with that right without the consent of the woman. The British Court, on the other hand, claimed the right to bear children as a limited right dependent on the ability to

exercise it. If, as they claim, the right is limited only to those who can make a legitimate case for being able to exercise it, then they can rightly argue that it can be removed by whatever authority is put in a position to determine who can fulfil the prerequisites on which the right is based. But to do that is to open the whole area of rights to paternalistic decision making granted by courts or legislatures. Starting from a rights perspective rather than a welfare perspective, the Canadian Court justifiably dismissed the ability to exercise the right as irrelevant to the decision in the case. The case for the Court then turned on whether the medical procedure was therapeutic or non-therapeutic.

This is a key difference between a rights and a charity perspective. If people with a mental handicap are to be accorded rights, then arguments around the best interests of the individual should not be sufficient to interfere with them. Although framed as a legal issue, the *Eve* case was really a forum for debating the status of people with a mental handicap in society generally and their claim to citizenship rights.

Other legal cases in Canada illustrate the supreme importance of the extent to which the law should empower anyone to exercise control over the life, liberty and security of another person because that person is regarded as "incompetent" due to a mental handicap. In 1983 the Supreme Court of British Columbia ruled that Steven Dawson, a seven-year-old boy, had the right to life-sustaining medical treatment to which his parents refused their consent. In 1982 an Ontario District Court judge denied an application by Justin Clark's parents to have him declared mentally incompetent so his father could be designated as his guardian and prevent Justin from exercising his choice to leave the institution where he had been for all his 18 years and live with friends in Ottawa. In 1987 a basic democratic right of citizenship was restored to those with a mental handicap when the Federal Court of Canada struck down the clause in the Canada Elections Act that disqualified every person "who [was] restrained of his liberty of movement or deprived of the management of his property by reason of mental disease". In the following federal election, for the first time in Canadian history, no one labelled mentally handicapped was legally disqualified from voting.

In 1986 the Trial Division of the Supreme Court of Nova Scotia granted an injunction prohibiting a school board from returning Luke

Elwood, an elementary school child with a mental handicap, to a segregated special education class in a non-neighbourhood school. He was permitted to remain in his neighbourhood school until his case was heard. His case was brought to establish that the *Canadian Charter of Rights and Freedoms* guarantees the right to an appropriate integrated education for persons with a mental handicap. During the year that he remained in his neighbourhood school, the case with the school board was settled in favour of Luke. The settlement was based on the testimony of teachers, fellow students and their parents that Luke belonged in that classroom.

In January 1991 the Quebec Human Rights Commission found the administration of Pavillon Saint-Theophile of Laval, an institution for people with a mental handicap, guilty of exploiting the institution's residents. The 88 people who lived in the centre were awarded \$1 million to be split between them: \$700,000 in compensation for moral damages for enduring humiliation and attacks on their dignity; and \$300,000 in compensation for the intentional exploitation to which they had been submitted. The administration of the centre was found to have misused government funds and to have treated residents in a manner described as "punishment, deprivation and infantilization". All of the residents are now living in the community. This case clearly established that the traditional way of treating people with a mental handicap is not good enough. Justice for people with a mental handicap includes treating them with respect and protecting their fundamental rights.

While I would hesitate to suggest that resorting to the courts is necessary in achieving rights for people, it has been an effective tool in Canada and in many other countries. Canadians, unlike our neighbours to the south, tend not to be a particularly litigious people. However, the shift from charity to rights for people with a mental handicap involves changing whole systems. And people with a mental handicap deserve an active and aggressive approach, not one that simply waits for discriminatory attitudes to change. The legal entrenchment of rights for people with a mental handicap is important because it is one way the political system shapes social policy. The exclusion of persons with a mental handicap from the protection of the law and the exemption of these persons from entitlement rights normally accorded to others is a reflection of the place they hold in society.

The entrenchment of the rights of people with a mental handicap within human rights legislation and the entrenchment of constitutional equality rights for people with a mental handicap within the *Charter of Rights and Freedoms* have had important consequences in Canada. Their rights are now legally entrenched on a basis equal with others: women; people of other races; cultures and religions; and the aged.

The impact of this legal entrenchment has been direct and indirect. Successful legal challenges are important; so too are the indirect ways in which the legal entrenchment of rights has influenced policy and attitude. There has been a shift away from the traditional ways of viewing people with mental handicaps. There is now a federal Commons committee that concerns itself with Human Rights and Disability, instead of health and disability. Serious questions are being raised about the fairness of keeping people in segregated workshops. Governments have developed policies that plans for the closure of large institutions. Governments are making money available to study "supported decision making" as an alternative to guardianship. Hospitals are changing their policies on refusing treatment of new-borns with severe mental handicaps. Some provincial Attorneys General have implemented protocols concerning people with mental handicaps giving evidence in court. Income programs have been established that provide direct funding to people with mental handicaps and their support networks to contract for their choice of services. Traditionally, funding was funnelled through the service agency. All these changes respect the rights and self-determination of people with mental handicaps. While the pace of change is too slow for some of us, these reforms would have been unthinkable even 10 years ago, when charity was still accepted as the basis for caring about people with mental handicaps, and before the legal entrenchment of their rights.

Rethinking what is needed to enable the real participation and involvement of people with a mental handicap in society involves much more than figuring out how to rehabilitate people so they are like others. It means recognising the contribution of people with a mental handicap — not despite but because of their differences. We have to recognise what we gain by the inclusion of people with mental handicaps. We have to acknowledge how changes in structures and services to include

those with differences improve the quality of life and well-being of everyone.

Difference is not a problem; it is a solution to the narrow-minded, bigoted attitudes that have hampered our ability to make real progress in achieving collective well-being. To be disabled does not mean to be unequal. The question we have to grapple with is how do we guarantee equality, citizenship and self-determination in both opportunity and outcome. Only then can rights, justice and power be claimed by those with mental handicaps.

This paper is based on Marcia H. Rioux's forthcoming book, *The Equality-Disability Nexus*.