

The Disability Rights Movement, The Canadian Experience

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At the heart of the disability rights movement is the fact that people with disabilities want to be seen as people first, to be treated as individuals, to have opportunities to participate in and contribute to society. They want to be seen as persons, not cases or categories of disablement, powerless to shape their own lives. .

Disabilities range from mild to severe and include physical handicaps, blindness, partial sight, deafness, hearing problems, developmental and cognitive disabilities. This is not a heterogeneous population. Not only do types of disabilities vary in the constraints they impose and alter experience of life, but also within each category are many differences. Among the disabled population are many gifted people, writers, poets, artists, professional and business people, but the majority are dependent on public and private services. Dependent on private and public services, they are vulnerable to governmental and community policies and society's prejudices.

The history of the Disability Rights movement in Canada charts a movement rooted in cultural and social biases and negative stereotypes. Throughout history, people with disabilities have been the forgotten victims of prejudice and abuse. During the first part of the 20th century, they were assumed to be a threat and a burden to the larger society. Devalued, segregated and isolated in institutions they were deprived of normal social environments and socially distanced from the larger society. It is the way people with disabilities are perceived that causes the social distancing and poses the gravest threats to their rights as human beings.

It is little known fact that among the first of Hitler's victims were more than a quarter of a million children and adults with disabilities. What is striking about this, is that in the Weimar Republic, progressive and pioneering schools and community treatment centers were developed. Under Hitler, every trace of progress was destroyed. Public health agencies, private physicians, schools and treatment centers were obliged to report every person with a disability. People with disabilities were portrayed as "useless eaters", a "burden" on society.

Parents were forced to institutionalize their children, even those with very mild handicaps. In overcrowded institutions, they were slave laborers, they were starved, poisoned and gassed in the gas chambers that were first developed in German psychiatric and mental retardation institutions (Rogow, 1999). In Nazi Germany biological disablement was also defined to include children and young people with emotional and behavioral difficulties, orphans, and young people who resisted joining Nazi youth groups. In Canada, the US and Britain, there were no mass killings, but people with developmental disabilities were isolated and dehumanized in crowded institutions and thousands were subjected to sterilization.

It was not until the 1960s that people with disabilities and their families began to compare their own situations with the civil rights movement and began to question and challenge the system. Out of their efforts, came new social models and the movement for inclusion and independent living. The beginnings of the movement were slow and tedious, they had no funding. In Canada, the movement gathered steam with the passage of the Charter of Human Rights in the 1970s. The International Year of Disabled Persons, 1981, was a catalyst in launching federal government cooperation with Canada's disability

community. Since then, there has been a declared commitment to achieve full access to social and economic opportunities for persons with disabilities.

The inclusion of physical and mental disability under Section 15 of the Canadian Charter of Rights and Freedoms in 1982 marked the first time in history that any national Constitution referred specifically to persons with disabilities (The Government of Canada's Record of Disability Issues: Backgrounder #98-21, p.1). This became an international model because it framed disability as a citizenship and human rights issue. Other highlights included the addition of disability in the Canadian Human Rights Act of 1985. In 1987, a parliamentary committee on Human Rights and the Status of Disabled Persons was made a permanent body that consults with people with disabilities and makes recommendations to Parliament.

Employment equity programs have been established to encourage federally regulated employers to break down barriers to employment. There have been efforts to improve accessibility in federally regulated transportation services such as airlines and railways. There has also been financial support for homeowners, landlords and others to make buildings accessible. The Office of Disability Issues in Human Resources Development Canada is now a focal point for federal disability action. Gains have been made in employment, health, taxation and social development. People with disabilities established their own human rights organizations and are active in promoting and protecting their rights.

Civil rights for people with disabilities are based on having opportunities to participate in community life. It is not about disability, it is about belonging and having the right to live independently.

The ultimate goal of the Disability Rights movement is being able to have control over one's life, to have acceptable options that minimize dependence on others. The extent to which these goals have been achieved provide the framework within which progress can be measured.

Implementing the rights of people with disabilities depends on the awareness of the larger community and its commitment to inclusion. Policy changes, financial cutbacks and lack of appropriate services interfere with the delivery of services that address individual needs and ability to participate in the life of the larger society. The ability to participate in the larger society requires the building of networks as well as accessible buildings and transportation and involvement in community cultural, religious and recreation events. Barriers to social participation are both physical and psychological. Architectural barriers affect the accessibility of housing and employment, and ability to participate in the religious and social life of the community. Social perceptions of disability create invisible barriers.

Education and social opportunities for children, accessibility of housing, employment, transportation, job training, culture and recreation for adults, and the availability of support services are inconsistent and vary from province to province and from community to community. Canadian social and educational services are organized on a provincial basis and communities within each province vary widely in the type and scope of resources provided.

Children's Rights

The Disability Rights movement has tended to focus on adults. Children with disabilities are subject to a service system that is fragmented and inconsistent. School

districts vary in philosophy as well as availability of appropriate educational services. Service systems vary in the quality of supports provided to parents and other caregivers.

Medical models of disability tend to focus on the disability, not the child. This model ignores the powerful environmental and social factors that are the main determinants of growth and development. Yet they often determine the treatment the child is believed to require. Research documents that the most powerful influences in the life of every child are the opportunities afforded for personal and social development. The more normal the environment, the more opportunities provided for social relationships and interaction with non-handicapped peers, the greater the expectations and opportunities for learning, the more progress children make. Opportunity, not disability is the most powerful determinant of children's progress, not disability. This is also true for adults.

A good example of this is in the field of language development. Medical, educational and psychological assessments need to consider the child's opportunities for social interaction and language acquisition. Language acquisition is a complex process and reveals the subtle ways disability interferes with speech and language development. Children who cannot speak are often assumed to be incapable; they are misunderstood and misjudged because of their inability to engage in conventional communicative interactions. Speech is a motor function. Inability to speak or write is not necessary indications of the ability to understand language.

No one knew that Christopher Nolan, the Irish author and poet, had language until he was given a computer at the age of 11. With his computer, he grew to become a gifted novelist and poet. His autobiographical novel "Under The Eye of the Clock" details his experiences. It should be noted that Nolan's parents supported him every step of the way;

they included him, kept his life as normal as possible and his mother taught him to read. My own experience as an educator have shown me that children with severe disabilities who love to listen to stories, who appreciate jokes and riddles comprehend language in the absence of speech. With the development of alternative systems of communication, we can give all children valuable language and communication experiences.

Inclusive education encourages normalcy and opportunities for social interaction and friendships. It also educates non-handicapped children and fosters attitudes of acceptance and appreciation of differences. Unfortunately inclusive education has not been a priority in every school in Canada. Financial constraints, lack of training of teachers and school aides, lack or insufficient family support services continue to pose barriers and prevent the development of inclusive educational policies.

Inclusive educational experiences, opportunities to interact with peers, support for learning, and explicit teaching in the use of alternative systems of communication are intrinsic to the rights of children. Special needs need to be balanced with social needs. Society and the child's community need to be made far more accountable than they are at present. Failures are often placed on the child and the severity of disability, rather than on lack of educational opportunity and consistency of social environments.

Children with disabilities are between two to ten times more likely to experience emotional abuse and neglect than non-disabled children. Abandonment, rejection, and neglect take place in public and private care facilities, group homes, schools and treatment centers. Children with disabilities are often excluded from services by child protective agencies. There is a need for a concerted effort on the part of the police or the courts to adequately protect children with disabilities. While physical and sexual abuse has received

attention, emotional abuse is not well recognized. Children with disabilities may also be subject to excessive medication and treatment that deprives them of normal life experiences (Armstrong, 1993).

Social Services for Adults

Accessible housing and employment rank as the most pressing issues facing adults. Adults with disabilities are still the poorest educated, housed and the most unemployed. Job preparation and placement programs that include skills training, guidance and advice, job find services and promotion of employment are still needed. Half of the people who live in private homes are unemployed and 60% of the disabled community live below the poverty line. Subsidized benefits such as attendant care are lost when people are employed. People who are employed often face loss of federally subsidized transportation and free medical equipment. This has meant that employed people often end up earning less than those on disability allowances. The inequities of the system work against seeking employment.

Independent Living

A variety of living programs are available in Canada. These range from living in a private apartment with the assistance of an aide to group homes. Group homes vary from hospitable group living where there is shared responsibility and choice to structured homes that are run like small institutions. Use of restraints, seclusion, neglect, violation of legal rights, degradation, lack of treatment and denial of education are common in some group home arrangements. In many places, compliance training, locks, and the use of physical force are still seen as normal and necessary (Sobsey, 1992). In the effort to prevent liability on the part of service organizations, decisions are often made without consulting or taking the people's preferences into account.

When Canada was given an award by the UN in 1999 for its accomplishments in the disability field, many Canadians with disabilities protested. Frustrated by a system that recognizes the kinds of supports that are needed, but does not show consistency in the way supports are offered. Over the years funds have been cut in federal transfer programs to the provinces and services such as home care and transportation. The Council of Canadians with disabilities complained that too much time is wasted just to fight to keep what they now have (Globe and Mail, March 1, 1998). In British Columbia, the Human Rights Commission reported more discrimination complaints from people with disabilities than from any other group.

Another area of concern for Canadians with disabilities has been the field of Bioethics and the way it is being applied and interpreted. People with disabilities are defending their right to determine their own quality of life. The Disabled People International recently declared that developments in biotechnology must not be used to control or manipulate people. They argue that no demarcation lines should be drawn regarding severity or type of impairment. The NOT DEAD YET society was organized to protest the misuse of biotechnical advances and the promotion of euthanasia.

From a world perspective, it must be said that Canadians with disabilities like citizens with disabilities in other democratic countries are living richer and more satisfying lives than in the past. In poorer countries, between 52 and 98% of children with disabilities get any education at all. In some of the richer countries, 41% receive only primary education. People with disabilities are 2 to 3 times more likely to be unemployed, and when they do find jobs, they are mostly poorly paid and unskilled. In some countries, blind people

are not permitted to vote or to stand for election. People with disabilities are still the poorest of the poor.

A great deal has been achieved in Canada, but there is still a long way to go. Financial cutbacks, policy changes, lack of employment and educational opportunities threaten the stability and the control people with disabilities have over their lives. People with disabilities must be permitted to take risks.

The Disability Rights movement is teaching us to focus on ability and the tremendous value for everyone to focus on ability. It is teaching us the perils of social distancing and the importance of building of relationships within the larger community. It is also showing us the importance of creating flexible and individualized services.

Life is a tight ecological web that links up and down the scale. Our abilities, personality and character are uniquely related to the wider world, family, friends, community and the larger society. Rehabilitation planning for the individual needs to be based on outcomes that is relevant to an individual's strengths and abilities and personal goals. The goals of rehabilitation need to consider the enhancement of strengths and the building of personal and social relationships.

Entire communities are enriched by integration and inclusion. Creating a feeling of belonging for everyone is the best way to prevent the kind of discrimination and exclusion that has been responsible for human tragedies and discriminatory practices. People with disabilities are our fellow citizens capable of contributing to their communities and shaping their own lives.

.References

Anderssen, Erin, (1998). “ Disability Groups Berate Ottawa For Unfulfilled Promises of Help,” *Globe and Mail*, March 1, 1998.

Armstrong, L. (1993). *And They Call It Help: The Psychiatric Policing of America's Children*. Addison Wesley Publishing Company, Reading, Mass,

Fleisher, D. and Zames, F. (2001). *The Disability Rights Movement: From Charity to Confrontation*. Temple U. Press,

Making Changes: A Place to Start. Report of the Community Panel;Family and Client Services, Oct. 1992

Noell, M. (1992). *Another Path to My Garden, My Life As a Quadruplegic*. Toronto, Dundurn Press.

Perske, R. (1988). *Circle of Friends: People with Disabilities and Their Friends Enrich The Lives of One another*, Abingdon Press, Nashville, Tenn.

Rogow, S.M. (2001). Child Victims in Nazi Germany. *The Journal of Holocaust Education* 8:3, (71-86).

Sobsey, D. (1992). *Violence and Abuse in the Lives of People with Disabilities*. . Baltimore MD. Paul H. Brookes.

Westcott, H. (1994). Abuse of children and adults who are disabled. In French, S. (ed.). *On Equal Terms: Working with Disabled People*. Butterworth Heinemann, Oxford, pp. 190-206.