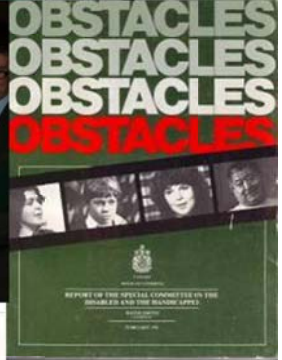


# Celebrating Our Accomplishments



**Council of Canadians  
with Disabilities**  
A VOICE OF OUR OWN

**Conseil des Canadiens  
avec déficiences**  
CETTE VOIX QUI EST LA NOTRE

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# ***Celebrating Our Accomplishments***

**November 2011**



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# Foreword

By  
Minister Diane Finley, HRSDC



On behalf of the Government of Canada, I am proud to offer my congratulations to the Council of Canadians with Disabilities (CCD) as you mark 30 years of achievement.

Significant progress has been made in Canada over the past thirty years for those with disabilities. And it has been a collective effort by individuals, business, government and organizations like CCD.

Our legislative framework has been strengthened to ensure equality for those with disabilities, improved access to employment services and facilities – and protection against discrimination. Important pieces of legislation such as the Canadian Charter of Rights and Freedoms (1982), the Canadian Human Rights Act (1985), and the Employment Equity Act (1995) now reflect fundamental components for those with disabilities.

CCD has been an active and influential organization over the years. That includes having played a key role in the development of the United Nations' Convention on the Rights of Persons with Disabilities, which our government ratified last year. Ratification marks an important step in removing obstacles, creating opportunities and making Canada, as a whole, more inclusive.

The Government of Canada contributes to the participation of people with disabilities in society through a broad range of programs and services. In 2008, with the help of CCD, we developed the historic Registered Disability Savings Plan as a way to help people with disabilities and their families save for the future. That same year, we created the Enabling Accessibility Fund to make facilities more accessible and to date, I am proud to say that over 600 community based projects across Canada have received funding.

As demonstrated here, important work is being done at the local level. That is why we continue to work closely with the Provinces and Territories to respond to the employment needs of people with disabilities through Labour Market Agreements for Persons with Disabilities. Through programs like the Opportunities Fund, people with disabilities have the opportunity to hone their skills, prepare for the job market and contribute to their communities.

Together, we are all continuing to work towards our goal of ensuring equality for all Canadians. Evident by this publication, CCD has indeed made significant achievements on behalf of those with disabilities, along with elevating the dialogue and helping create change.

Your tireless hard work and advocacy efforts have made a marked difference and helped all Canadians to be recognized for their abilities.

Congratulations, thank you – and I wish you much continued success in the future as we work together to build a stronger Canada, for everyone.

A handwritten signature in black ink, appearing to read "Diane Finley". The signature is written in a cursive, flowing style.

The Honourable Diane Finley, P.C., M.P.  
Minister of Human Resources and Skills Development Canada

# Foreword

By

Tony Dolan, National Chairperson of CCD

## People With Disabilities Have Transformed Canadian Society



As Canadians with disabilities we should be very proud. Our collective action over the last 30 years has transformed Canadian society and made it more inclusive and accessible. Too frequently we do not stop to reflect on what we have achieved. I know that the pace of change has been, at times, glacially slow, but when we pause to look back our record of achievements is astounding.

That is why we are producing this booklet; both to celebrate our success and to help others understand the contribution of the disability rights movement in Canada. “A Voice of Our Own” is our mantra, and that voice has been heard, respected and acted upon. We have a vision of a different kind of world. Joel Barker, an author has said “Vision without action is merely a dream. Action without vision just passes the time. Vision with action can change the world.” This is what people with disabilities have done, we have changed the way in which our world sees us. Read this booklet and you see highlights of some of the fundamental changes that have come about here in Canada.

Our vision put into action has resulted in inclusion in the *Charter*, legislative reforms, victories in several Supreme Court decisions (Eldridge, Latimer, VIA Rail etc.), visible changes to the environment such as Closed Captioning, Braille on elevators, access to print, power doors, wheelchair ramps, low floor buses and much, much more. These changes have come about only with significant determination and effort by persons with disabilities willing to stand up for what they correctly believed they were entitled to as citizens of this country.

Changes that have come about in Canadian society have made the lives of many people with disabilities better. It is fitting and appropriate that CCD and others

take time to celebrate our achievements and recognize our allies. People with disabilities and their organizations have transformed Canadian society and will continue to do so. This transformation is not simply external but also can be seen everywhere in our everyday activities. People with disabilities are present and active in our communities. There are visible symbols of our participation: ramps, curb cuts, closed captioning, accessible elevators, folks with disabilities going about their daily routine of going to school, work, shopping, theatres, day cares, parks, restaurants, etc. Yes we have much to do but those of you who are not presently disabled seem not to understand that someday you too will need similar services.

Let us celebrate our achievement whenever we can but let us also remember that after our celebration we have to get back to the work of building a more inclusive and accessible Canada.

# Foreword

By

Laurie Beachell, National Coordinator of CCD

## The Disability Rights Movement: The Agent of Change for Creating a More Inclusive Canada



I have been National Coordinator of CCD since 1984 and while I regret missing some of the exciting founding years of CCD and of the disability rights movement, I have been privileged to be a part of what has truly been a transformative journey. Throughout this journey the one thing that is clear and cannot be disputed is that the voice of Canadians with disabilities has fundamentally changed our society. People with disabilities are now seen as citizens of the diverse fabric of Canadian society, with equal rights and equal responsibilities. This societal transformation has not occurred with the speed many had hoped for but there is no denying that things are better for Canadians with disabilities today than they were 30 years ago. The central agent of these changes has been the voice of persons with disabilities and their organizations.

It is instructive and maybe important, for young people and others to remember some of what was common in the early days of the movement. There were few integrated schools; public barriers such as curbs/stairs existed everywhere; there was no public accessible transportation; access to print materials was a huge issue; housing options were few; and in many instances, people were institutionalized. People were sterilized without their consent; some were denied the right to vote; others could not marry; and many were wards of the state. Post-secondary education was rare; employment options were few; access to support services was limited; and families were expected to be the primary caregivers. There was no such thing as self-managed systems; mental health issues were stigmatized to the point of not being spoken about; human rights protections did not exist; and people with disabilities were frequently dependent upon family and the “charity” of others.

Today the expectations of Canadians with disabilities and their families are decidedly different. Canada has become more inclusive and accessible because people with disabilities have spoken out and ensured that their voices were heard in public policy debates. The voices were heard at every level of Canadian society, local, provincial, national and beyond our borders. Canadians with disabilities today seek equality not charity. They expect to attend their local school, get a job, have relationships, raise their families, and contribute to Canadian society in the same ways as non-disabled Canadians. They expect barriers to be removed and no new ones created. The changes that have come about have been made a reality because of the disability rights movement. Equally true is the fact that this could not have happened without governments' support of that movement. That support must never erode for new challenges emerge every day as our society and world find new ways of functioning and governing.

Yes, huge challenges remain; but we have come a long way. I thank CCD, its leaders, members and allies for allowing me to be part of this exciting and transformative journey. Together, all Canadians must support the disability rights movement in our country, recognizing that it is the agent of change that has created a more inclusive and accessible Canada, and it is the body that will continue to do so.

# *Inclusion*





# Women with Disabilities - Thirty Years

By

Emily A. Ternette<sup>1</sup>

Thirty years ago, the disability rights movement had not identified women with disabilities as having any issues specific to that population. However, in June of 1985, a Networking meeting was held in Montreal resulting in a **Report: Women with Disabilities** written by Jacqueline Pelletier. In this report, Pelletier indicated that violence against women with disabilities exists everywhere - in cities, rural areas, in hospitals, at home and on the streets. Women with disabilities are at greater risk of violence than other women. It was at that Networking meeting, with a handful of women listening to that Report, that DisAbled Women's Network (DAWN) Canada emerged.

Of course, prior to 1985, women with disabilities had been organizing, talking and writing about their lives. *Resources for Feminist Research* published an entire issue specifically on women with disabilities. In 1983, *Voices From the Shadows: Women with Disabilities Speak Out* by Gwyneth Matthews was published. What was and still is missing, though, is that women with disabilities are not being embraced by the mainstream women's movement - that is, there is a form of "ableism" occurring that excludes women with disabilities who want to create change for all women - both on a social and political level.

In the late 1980s and early 1990s, DAWN Canada did groundbreaking work on shelters for women with disabilities with a project called "*Bridging the Gaps - Violence, Poverty and Housing: An Update on Non/Resources for Women with Disabilities*". This project developed a tool called the **National Accommodation Accessibility Survey (NAAS)** which has provided important information for government to use in order to improve accessibility to women's shelters.

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<sup>1</sup> I have done work in the area of disability in Winnipeg for the past thirty years. My associations include employment with the Manitoba League of Persons with Disabilities (MLPD) and contract work with the Independent Living Resource Centre (ILRC). I am currently the Co-chair of DisAbled Women's Network (DAWN) Manitoba.

Also in those early years, DAWN Canada's President, Carmela Hutchison went to Ottawa to present a Brief on Economic Security to the Parliamentary Committee on the Status of Women.

In 2006, DAWN Canada, along with other community partners, held a conference that would focus on an effective strategic development that would work towards ending the isolation and exclusion of women with disabilities and help these women develop their strengths and leadership potential. The goal was to allow women with disabilities to participate in policy and social program developments aimed at improving their social conditions.

In February of 2011, DAWN Manitoba held a Healthcare Forum to determine the gaps in the healthcare system for women with disabilities in the province. They found many, and took their findings to Women's Worlds 2011.

There have been some changes for women with disabilities over the past 30 years. Employment opportunities are somewhat better and access to healthcare is improving. What is most important is that women with disabilities are more visible in the wider women's community, and they are benefiting from us being there. However, we have a long way to go.

# Women with DisAbilities: Towards Full Inclusion

By

Bonnie L. Brayton<sup>1</sup>

In the last 30 years, Canadian women with disAbilities have gone from being virtually absent in public discourse and decision-making to being recognized as experts in both the theory and practice of full inclusion. Some of the highlights of our achievements are described below.

Establishing a national organization:

In 1985 the first funded national meeting of women with disabilities was held, which led to the formation of the DisAbled Women's Network Canada in 1987. The creation of a national body controlled by, and comprised of, women with disabilities is in itself a major achievement, and DAWN Canada continues to serve as the cornerstone for the movement, leading the way in policy development, legislative change, research, and activism. In 2007, the organization rebranded itself as a bilingual organization called DAWN-RAFH Canada, strategically moved its head office to Montreal, and created a leadership position of National Executive Director.

Challenging Violence Against Women with Disabilities

Since 1989 DAWN-RAFH Canada has conducted research, developed assessment tools and training manuals and provided recommendations to government and women's groups aimed at understanding and preventing violence against disAbled women. Building on work begun in the 1990s, we conducted a follow-up survey on the accessibility of women's shelters in 2007-08. In 2008, DAWN-RAFH Canada presented at the First World Conference of Women's Shelters, where we highlighted the need for accessible women's shelters to an international audience. In January 2011, we were contracted by the Canadian Women's Foundation (CWF) to conduct a series of pan-Canadian focus groups

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<sup>1</sup> Bonnie Brayton is the National Executive Director of DAWN-RAFH Canada (DisAbled Women's Network Canada) ([www.dawncanada.net](http://www.dawncanada.net)). For twenty-five years, DAWN Canada has been focused on advancing the rights of women with disabilities in Canada and Internationally. Ms. Brayton is also the President of Coup de balai - Clean Sweepers, a social economy organization ([www.coupdebalai.com](http://www.coupdebalai.com)). Bonnie also serves on the Boards of the FEMINIST ALLIANCE FOR INTERNATIONAL ACTION (<http://www.fafia-afai.org/>) and **La Maison Parent-Roback**, a Quebec feminist collective in Montreal (<http://www.la-mpr.qc.ca/>).

as part of their Violence Prevention Review. We also served as key informants in this process.

### Court Challenges

A number of successes for women with disAbilities have come through court challenges. Along with the Women's Legal and Education Action Fund (LEAF) and other disability organizations, including the Council of Canadians with Disabilities, DAWN-RAFH Canada has served as intervener in several such cases. Some of these include: *Eldridge v. Attorney General* (1997) in which deaf women were denied access to sign language interpretation while in hospital; and *Barney v. Canada* (2005) in which compensation was sought for Aboriginal residential school survivors subjected to multiple forms of abuse. DAWN-RAFH Canada currently has intervener status on two pending cases: *L.M.P. v. L.S.* (2011) in which spousal support paid to a woman with a permanent disability was rescinded based on the husband's testimony that she was capable of working outside the home; and *R v. DIA* (2011), in which the testimony of a woman with an intellectual disability who claimed to have been sexually assaulted was excluded because her competence to testify was successfully challenged.

### A Model of Inclusion

DAWN-RAFH Canada was selected as the disability consultant to Women's Worlds 2011, an international gathering of nearly 2000 women. As a result, women with disAbilities were able to participate in all aspects of the event, and set a new standard for inclusionary practice in feminist gatherings.

# A Revolution of the Mind – The Independent Living Philosophy

By

Traci Walters<sup>1</sup> for Independent Living Canada

In the early 1980's a new perspective on disability was beginning to sweep across the country. Traditional charity and medical models of service delivery were becoming intolerable to many Canadians with disabilities. Having someone else control your life, make decisions for you, classify whether you are employable or not and decide your future was being challenged. People with disabilities, inspired by the Civil Rights Movement in the United States, were demanding a power shift and were breaking away from negative stereotyping and oppression.

The Independent Living philosophy and movement were developed as a response to traditional models of service delivery. In general, society viewed disability as a deficit and that people with disabilities were considered "sick" and in need of care. Unlike traditional paradigms, the IL model encourages people with disabilities to take control over their own lives, examine options, make their own decisions, take risks, and even to make mistakes in the learning process. The IL philosophy encourages self-determination and self-actualization and promotes disability pride.

The premise of the IL philosophy has not changed over the past thirty years, only new ways in which to implement and apply it. At the heart of the IL philosophy is a change in how individuals view themselves and the society in which they live. Through the IL lens, viewing the disability as the problem is an old and outdated perspective. The barriers are not the disability - they are attitudinal and environmental. The solutions to these barriers are advocacy, peer support, self-help and barrier removal. Disability is natural and simply part of the human experience.

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<sup>1</sup> Traci Walters, the retired National Director of Independent Living Canada, is an award winning disability educator/Independent Living leader, Alumni - Governor General's Leadership Conference, Recipient - International Meritorious Service Award for Endless Effort and Passionate Heart by the Global IL Network. Traci continues to passionately promote the Independent Living Movement as a volunteer IL Ambassador.

Allan Simpson (one of the founders of Independent Living Canada) once said, “Independent Living is not only an outcome, it is a process. When applying the IL approach, the means of addressing goals and issues were just as important as the goals themselves.”

It has been demonstrated through research “that as the individual becomes empowered, participation in community life increases and in turn, the community becomes educated and significant changes occur, both within the life experiences of the individual and the community as a whole. By helping people with disabilities view themselves as valuable and contributing members of society; we have created a revolution - a revolution of the mind. There is nothing in this world more powerful than that and the many positive changes that have resulted from this.”<sup>2</sup>



Henry Enns, Hon. Jake Epp, Allan Simpson at Funding Announced for IL Movement

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<sup>2</sup> *The Impact of Independent Living Resource Centres in Canada on Persons with Disabilities*, Hutchison, Pedlar, Lord, Dunn, McGeown, Taylor, Vandetelli, Canadian Journal of Rehabilitation, 1997, 10:2, p. 99-112.

## CACL's Deinstitutionalization Initiative: A Long Struggle

By  
Diane Richler<sup>1</sup>

CACL's efforts to close institutions began in 1971 when Dr. Wolf Wolfensberger came to Canada as a Visiting Scholar. His task was to promote the concept of normalization – the idea that people who had an intellectual disability should be able to live lives similar to others in their communities -- and didn't need institutions. Although schools and some workshops for people with intellectual disabilities existed then, the concept of providing residential services in the community was still very new and the first group homes – many of them huge by today's standard – had just begun to pop up across the country.

Many families responded very positively to the concept of community living, but others were fearful that if institutions disappeared there would not be adequate care for their family members. Most professionals were extremely critical of suggestions to dismantle the existing system. However, gradually, as more community services developed during the 70's, the tide began to turn. More families and professionals realized that people could be supported in the community. However, although the number of people entering institutions slowed down there was no major effort to close existing institutions and in the mid 80's there were at least 30,000 people with intellectual disabilities in large institutions and estimates of equal numbers in nursing homes.

In 1985, the participation of self-advocates led CACL to adopt its current name and create a Task Force to explore the implications of the name change. The result was a plan called Community Living 2000, adopted in 1986. The plan spelled out a vision for the future, which among other things, called for institutions to close.

In 1988, the federal government (which then cost-shared institutions with provincial governments under the Canada Assistance Plan) agreed in principle

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<sup>1</sup> Diane Richler worked at CACL in various capacities from 1971 to 2001. She is Past President of Inclusion International and chairs the International Disability Alliance, the global network of organizations of persons with disabilities which works for the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

on the need to close institutions and made \$1 million available to CACL to develop a feasible plan. Many provincial governments also agreed in principle that institutions should close, but argued that while people started to move out there would be a need for additional funds which they did not have. CACL then began working with its provincial counterparts in provinces where the numbers of people living in institutions was modest and the costs to close would not be exorbitant, and with federal officials to lobby for a transition fund to demonstrate that closing all institutions would be possible. In 1993, the federal Minister of Health and Welfare approved a budget of \$15 million for a province-wide demonstration of deinstitutionalization. Initially New Brunswick was to be the demonstration province, but when they backed out, Newfoundland was ready. An agreement between the two governments and national and provincial Associations for Community Living was signed. The initiative, “The Right Future: A Future with Rights” successfully supported over 200 people to move from the Waterford Hospital to their own homes around the province. The project demonstrated that even people who had spent decades incarcerated could develop rich lives in the community. It also helped to develop a series of community services that served many people who never lived in an institution and provided valuable lessons for other jurisdictions. But while “The Right Future” was an important step on the road to complete deinstitutionalization, the journey for too many people is not over.



# Multicultural Communities Making Progress on Disability Issues

By  
Meenu Sikand<sup>1</sup>



In the past thirty years, the Canadian disability rights movement has increased access to disability services, asserted legal rights through the courts and has gained some visibility on the public policy agenda. These gains have also led to positive experiences within the multicultural communities of Canada. The progress within these communities may be perceived as less significant by those who measure advancement according to traditional western values. Within ethnic communities most individuals don't have rights. Hierarchy and interdependent relationships are considered a norm and achieving individual rights has a lesser importance. So the disability movement and the advancement of disability rights looks much different in ethnic communities than in its western counterpart.

Thirty years ago, people with disabilities were largely invisible in multicultural communities. They were hidden because of shame associated with having a disability, as well as the public policies and disability support system which restricted families to keep children with disabilities at home. Earlier, disability support services were only available in institutions or to adults who lived alone in apartments. Thirty years ago in Canada, disability supports were most often denied to those who preferred to stay within a family unit. Public policies were mainly designed to support individuals living in institutions or, alternatively, living alone. Such trends discriminated against ethnic communities where living with one's family was desired yet disability support services were needed due to one's disability. Disabled people wishing to live with their families were forced to live in inaccessible residences and depend on their family members for personal care and other support. Government programs were not available in family settings. Sending a loved one to an institution carried a taboo within these groups and even when they tried to access institutions, most institutions didn't accommodate the cultural needs of these families. So children and adults

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<sup>1</sup> Meenu Sikand holds a graduate degree in Critical Disability Studies from York University. Currently, she is working as an Accessibility Planning Specialist. She specialized in developing and implementing strategic accessibility plans developed using an accessibility and inclusivity lens. She has been actively involved with the Canadian and International disability movements for the past 25 years and has received numerous awards for her humanitarian and social justice initiatives. Currently Meenu resides in Woodbridge with her son, husband and mother.

with disabilities in these communities were mostly hidden and supported by their family members. As a South-Asian disability rights advocate, I experienced that the disability rights movement within my community was making sure to tackle discriminatory policies that denied access to services such as attendant care and home modification grants which other Canadians with disabilities were slowly beginning to enjoy in the community.

Through the application of a “diversity and inclusivity lens” some of these barriers have now been slowly removed and individuals living with their families can apply and access a variety of disability support programs within their homes in extended family units. As a result, when watching multicultural events, movies or cultural celebrations one cannot help noticing increasingly large numbers of people with disabilities participating in the life of their communities and cultural events. Many of my experiences are within the South-Asian community and I am extremely pleased to see a positive shift of attitudes towards disability. As living in large family units and relying on family members to support each other is normal, gaining autonomy and independence is desired and achieved by members of minority cultures differently than their Canadian peers.

Most South-Asians have personal relationships in dealing with disability because extended family units include children, parents, siblings, grandparents, uncles, aunts, cousins. So everyone is affected by disability personally. These cultural norms created allies and champions who helped to move forward a disability agenda to tackle accessibility barriers.

During this time, I have also worked with the mainstream disability groups where a lack of minority representation continues to exist and therefore cultural issues have been largely misunderstood and ignored by Canadian disability leaders. Perhaps the recognition and inclusion of diversity in the disability movement has overlooked the cultural diversity that also exists among Canadians with disabilities.

An intersection or crossover is very much needed in the future to benefit from the strengths that each group possesses. Offering and accepting help from others is not considered offensive, or as an attack on someone’s human rights,

therefore the rights movement within the multicultural groups remains focused on gaining access to services. Striving for individual empowerment, autonomy and peer supports have received less attention, which were the key areas that the Canadian disability movement mainly focused on for the past thirty years.

As a Canadian immigrant, I have been very fortunate to support and lead the disability agenda for both groups. I remain optimistic that in the future diversity within the disability agenda will be acknowledged and will put an end to exclusion of people with disabilities from multicultural communities.

# The Impact of the Social Development Partnerships Program on the Ethnocultural Disability Communities

By

Dr. Zephania Matanga<sup>1</sup>

As you are undoubtedly aware, the disabled ethnocultural community is one of the most marginalized segments of our population. As a consequence, the empowerment of such communities requires a coordinated national intervention. It was through the Social Development Partnerships Program that opportunities for community participation for persons with disabilities from the ethnocultural disability were being created. Such creations of opportunities for these marginalized communities were enabled through the funding of projects specifically targeted to persons with disabilities from ethnocultural communities by the Social Development Partnerships Program. Case in point, in 2004 CMDCI had an opportunity to undertake the project: *National Policies and Legal Rights: From the Disability and Multicultural Perspectives*

Through this project, experts and persons with disabilities from ethnocultural disability communities were invited from all over Canada to discuss barriers and opportunities which prevented and enabled this marginalized community to participate fully in Canadian life. One of the major outcomes of this project was putting in place initiatives that set out a strong Canadian disability strategy based on a vision of people with disabilities from ethnocultural communities as full citizens. However, CMDCI believes that these initiatives will be further strengthened by allowing the Social Development Partnerships Program to continue. This is particularly important considering that Canada is home to some 5 million visible minorities (Statistics Canada, 2009), which translates to about 600,000 of them with disabilities assuming the 12% rate used for the general population by Statistics Canada. It is important to note that this number is likely higher because most visible minorities are engaged in employment activities that increase their likelihood of acquiring disabling conditions and that this segment of the Canadian population can only be expected to grow as Canada continues to welcome new immigrants.

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<sup>1</sup> Dr. Zephania Matanga is the Executive Director of The Canadian Multicultural Disability Centre Inc. (CMDCI). Currently, he teaches at the University of Manitoba as an instructor in the Faculty of Education; Department of Psychology and administration. He came from Zimbabwe in 1992 with a wealth of experience and first-hand knowledge about the debilitating effects of disability on professionals in his homeland and throughout Africa.

I would like to conclude by introducing our organization: The Canadian Multicultural Disability Centre (Inc), formerly known as The African Canadian Disability Community Association (Inc), is a national community based organization founded in 1996. It was first incorporated in Ontario in 1996 and later incorporated in Manitoba in 2002 where it is headquartered. As it relates to services, The Canadian Multicultural Disability Centre (Inc) is a community based organization whose purpose is: (1) To identify solutions and opportunities that enable persons with disabilities to participate fully in Canadian life; (2) To provide education on the role of cultural diversity in developing opportunities for persons with disabilities, particularly persons with disabilities from ethno-racial backgrounds; and (3) To enhance the skills of persons with disabilities through training programs such as health education, computer literacy and job networking.

# Building An Inclusive Quebec

By  
Richard Lavigne<sup>1</sup>

Since the end of the 1970s, our country has resolutely steered towards the formal and theoretical recognition of persons with disabilities as citizens deserving the same rights as those enjoyed by the rest of the population. Since then, the Confédération des organismes des personnes handicapées du Québec (COPHAN) and its 52 regional and Quebec members have mobilized to ensure that the political, economic, community and social actors at play bring about a major and historic shift that will enable the persons we represent to take their rightful place in society.

Armed with the strong conviction that persons with disabilities can and must participate in the evolution of human activities as they have much to offer to society, COPHAN has contributed to the adoption of numerous laws and policies advocating for increased societal participation by the persons it represents. This is why, in 1978, Quebec enacted, for the first time in North America, an *Act to Secure the Handicapped in the Exercise of their Rights*.

Since then, COPHAN has tirelessly taken on a watchdog role and has been able to influence many governmental decisions at the Quebec, Canadian and International levels. Here are some examples:

- The implementation of a public network for rehabilitation and workforce support services;
- The implementation of an employment integration and retention program for disabilities in the workforce;
- The adoption of school integration policies;
- The complete revision, in 2004, of *An Act to Secure the Handicapped in the Exercise of their Rights*, aimed at ensuring their professional, social and school integration;
- The adoption of a global Quebec policy entitled *À part entière, pour un véritable exercice du droit à l'égalité des personnes handicapées*, aimed at ensuring greater involvement in society by persons with disabilities and their loved ones;

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<sup>1</sup> Richard Lavigne is Executive Director of COPHAN.

- The adoption in Quebec of an employment integration and retention strategy for persons with disabilities that aims to cut in half the gap in employment rate between persons with disabilities and those in the population at large without disabilities;
- The adoption of a print material and government services access policy for persons with disabilities;
- The adoption and ratification by Canada of the U.N. international Convention on the Rights of Persons with Disabilities (which Quebec adheres to).

For over ten years, a growing number of Quebec stakeholders have developed an approach based on the full and equal participation of people with disabilities in society. Quebec decision-makers increasingly adhere to the concept that, for us, the right to equality represents the application of the following principles: universal design, the duty to accommodate, access to programs and measures enjoyed by the population at large, maintenance and development of specific programs and services where necessary, and the off-setting of additional costs related to disability or handicap situations.

In short, COPHAN and its members are very proud to note that, even if much remains to be done, we can collectively build an inclusive Quebec if we all strive for it.

# The Disability Community and the Academic Community in Canada: We've Come a Long Way!

By  
Michael J. Prince<sup>1</sup>



In Canada today, at the national and provincial levels, is a blend of general think tanks and specialized disability-oriented think tanks. As well, within the federal government and provincial and territorial governments, plus the university sector, are departments, agencies, advisory councils, academic programs, and research groups involved in policy-related disability research. This was not the case 30 years ago.

Production of disability knowledge is a crucial though under-resourced activity. In part, this knowledge production is an input to the other facets of the community; knowledge that supports service provision and administration, litigation or tribunal hearings, government lobbying, and cultural politics. A considerable part of disability research is in clinical and pharmaceutical trials, biomedical studies, engineering research and development, and rehabilitation treatments and protocols. As well, a growing segment of the research community is involved in the area of disability management – with links across business, government, organized labour, medicine, and the insurance industry – addressing issues of recruitment, retention, return to work, injury prevention, and workplace accommodations. Frequently, the view of disability here is in terms of health problems and impairments of the individual.

Disability studies programs in Canadian colleges and universities are of recent and growing significance. Disability studies scholars and students are producing, critiquing, and disseminating artistic, comparative, historical, and theoretical forms of knowledge on disability and normalcy. Academe evaluates policies and practices as well as assists in bringing to wider audiences the narratives of people and communities. When done in an emancipatory manner, such research not only enlightens but empowers. When done imaginatively, such work shifts the boundaries between private and public domains, making personal troubles into policy issues, drawing attention to the absolute importance of 'the family' in understanding inclusion/exclusion and citizenship.

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<sup>1</sup> Michael J. Prince is Lansdowne Professor of Social Policy at the University of Victoria.



Disability studies also have an important role to play in ensuring the effective design and implementation of disability mainstreaming techniques, and their evaluation, in state institutions.

Divergent perspectives on disability circulate within Canada's policy research community. One perspective, a social model of disability (and variations on that model) emphasizes the values of equality rights and full citizenship, and usually employs a critical analysis for studying social structures and public policies. Another perspective prominent in disability research deals with functional impairments, rehabilitation, and integration. Disability management and rehabilitation therapy programs at certain universities reflect this perspective. So, too, do particular research centres on children and health services. In this orientation, people with disabilities commonly appear as individuals with special needs, facing possible risks, with official identities as program clients and care recipients.

Policy-related disability research considers public policy development and program delivery; examines the effects of policies and programs, the social environments, life transitions, and opportunity structures of persons with disabilities; and critically assesses conceptions of disability contained in laws and social practices. Intended to be usable by policy makers and practitioners, such research may serve any number of purposes: the definition and understanding of an issue; the more effective response to and management of a need or problem; the resolution or alleviation of a problem or need; the expression of voice by a group and the recognition of their experiences; the empowerment of a group through the research process; and the identification of additional lines of inquiry.

Thinking of the disability community as a knowledge production network raises implications that ought to figure in decisions about future research directions and funded projects. One such consideration centres on attracting organizations into this research community that previously have not been involved, thereby adding new players to the network, such as groups that represent employers, professionals, seniors, or unions. A second is the possibility of using the research agenda for fostering partnerships among organizations in the community and/or with actors in a related policy realm. Another is leveraging resources from the foundation sector, which, in Canada, is not a major source of funding for policy institutes and think tanks. A fourth consideration is to ensure that

disability organizations of people with disabilities are adequately included in research agenda setting, resources, processes, and products of policy-related disability research. The ways of actually doing a disability knowledge strategy must involve empowering and inclusive social relations. This is absolutely crucial – otherwise, other efforts at expanding capacity could inadvertently result in crowding out and further marginalizing disability organizations within the research community.

# Finding My Voice

By  
Paul Young<sup>1</sup>



I think the greatest accomplishment for persons with disabilities is finding a voice of our own and using our voice to make real change for people with disabilities. In the past, others including agencies, service providers, and the medical community spoke for us. People didn't think we had anything to say. We have been speaking out about the issues like VIA Rail, the Latimer Case, and working to close institutions for people labelled "intellectually disabled". Having our own voice has given us the vehicle to end exclusion. To be included is to be part of the whole. Life should connect you to other people. My story shows how I moved from exclusion to inclusion and how it can happen for other people.

I was labelled "mentally retarded". I attended a segregated class and a sheltered workshop. These experiences prevented me from being included. When you are excluded, you learn that you will never be able to grow. I was told I would never be able to: own a home; drive a car; get a job; love someone; be loved.

My skills and interests have given me the way to valued social roles which have led me from being excluded in a sheltered segregated environment for the "mentally retarded" to an inclusive life. I had an interest in music and radio that helped me to meet other people who were interested in music and radio. Because of this interest I met a radio announcer at a station in my hometown and he advised because I had such a keen interest in radio and music to look for a job in radio. I took his advice. I got a job at CBC Sydney as a full-time Audio Technician. I worked there for 18 years. Radio helped me grow. There were high expectations for me to do the work needed for my job. The skills I developed because of my job gave me the self-confidence to learn how to make other responsible decisions.

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<sup>1</sup> Paul Young is a consultant on Disability Issues. He is the Past President of People First of Canada, founding President of People First of Nova Scotia, and the first person with a label to be the chair of the Council of Canadians with Disabilities.

I have become a homeowner, a husband, learned to drive a car, got my driver's licence, and learned to play golf. I am a student, lecturer and teacher. My valued experiences have given me the opportunity to meet many people and to develop relationships with them. In June 2006, I was awarded an Honorary Degree from the Nova Scotia Community College. I was nominated and awarded my degree because of my participation in the Community College and the last thirty years of my work for fighting for equality for people. All of these life experiences and roles have led me to be a valued citizen, having personal social integration and valued social participation. I am involved with my community and I am a contributing citizen. For me, this is inclusion.

I decide to get involved with the Disability Rights movement and it helped me to find my own voice. I heard leaders talking about the issues and I got involved with a local chapter of the cross-disability group in Sydney. Ron Canary invited me to a conference in Ottawa, where I heard Ron, Allan Simpson and Jim Derksen speaking about the lack of accessibility and inequity for persons with disabilities. Before I heard them, I was taught to feel sorry for people with disabilities. There I saw very strong men talking about the issues. I was inspired by them and decided I wanted to get involved.

It was the disability rights movement that helped me to find my voice. Because of my involvement with People First, I learned that institutions were wrong, should be closed and people should live in their community. For people who are labelled with intellectual disabilities, the closing of institutions and people being included in their communities is a major accomplishment.

My greatest advocacy accomplishment has been to get my brother, Tony, out of the institution. For 43 years, Tony lived in an institution 6 hours away from the rest of our family. After two years of advocacy, Tony came back home to Cape Breton in 2001. He now lives in a small group home and is experiencing things he never would have if he was still living in the institution.

The most important part of being included is having relationships with different people. Archbishop Desmond Tutu defines Ubuntu which best explains why relationships are important for all people: "In our African language we say, 'A person is a person through other persons.' I would not have known how to be

human at all except I learned this from other human beings. We are made for a delicate network of relationships of interdependence. We are meant to complement each other. All kinds of things go horribly wrong when we break that fundamental law of our being.”



Hon. Jane Stewart, Laurie Beachell, Paul Young and Jim Derksen



# Building an Inclusive and Accessible Canada: Inclusive Education

By  
Bendina Miller<sup>1</sup>

I retired on July 31, 2011 following a 42 year career in education. As I reflect on the impact of inclusive education over those 42 years and specifically over the past 30 years I can speak from my experience in Western Canada, however, since education is the jurisdiction of individual Provinces and Territories there isn't a common impact across the country and Federal data doesn't give a clear picture.

My personal reflection, based on experience as a teacher and administrator at the school district and provincial levels in the four Western provinces, is that in 2011 the majority of students are receiving their education in inclusive classrooms in their neighborhood schools for their elementary years and receive their education through a combination of inclusive classrooms and specialized subjects in secondary schools. Thirty years ago it was more common for students to be registered in special classes away from their neighborhood schools and their neighborhood peers. Thirty years ago it was also more common that students in secondary schools were registered in 'Resource Rooms' where they had very little interaction, even on a social basis, with their nondisabled peers. Thirty years ago segregated schools were accepted by many jurisdictions as appropriate settings for students with disabilities, however, that would be a rare circumstance in 2011.

Children who are educated in an inclusive setting have a social advantage and a positive impact on their health. Students who become friends in their elementary schools and neighborhoods are more likely to be friends, advocate for and support each other through secondary school and into adulthood. The impact that inclusive education has on building safe and supportive communities means that all citizens are able to live in a manner which is more conducive to success. In a recent document *'Inclusive Education Knowledge Exchange Initiative: An Analysis of the Statistics Canada Participation and Activity Limitation Survey'* Dr. Vianne Timmons and Maryan Wagner report that

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<sup>1</sup> Bendina Miller is the Past President of the Canadian Association for Community Living (CACL).

parents whose children are educated in inclusive settings say that their children are healthier, enjoy going to school, make good progress in school and interact well with their peers.

Inclusive employment and inclusive postsecondary options have been developed over the past 30 years with students who have graduated from inclusive secondary schools being successful in these settings rather than being placed in segregated day programs. The skills and confidence developed through inclusive education contributes to the success of inclusive adult environments which are enabled by both employers and post-secondary staff who have grown up in inclusive schools and by students with disabilities who graduate with an expectation of continued inclusion. This powerful reality has developed in a limited way over the past 30 years with the expectation that inclusive employment and post-secondary education will become more commonplace for students as they graduate from inclusive secondary schools.

As I anticipate the future I am optimistic that CACL's vision, 'diversity includes', will be a reality for all. *The United Nations Convention on the Rights of Persons with Disabilities*, ratified by Canada in March 2010, sets out an agreement that all Provinces, Territories and the Federal government support articles which provide for an inclusive society, including Article 24 Education. Thirty years later we are able to learn in a collaborative manner which engages us in thinking and considering practice to become more honouring of the learning needs of all students. I urge you to access '[Inclusiveeducation.ca](http://Inclusiveeducation.ca)' as a way of staying connected through powerful input of parents and practitioners who share a commitment to inclusion.

# Reflecting on Progress Since 1981 for Post-Secondary Students With Disabilities

By  
Frank Smith<sup>1</sup>

I'm honoured to have been asked to contribute to this book that the CCD is putting together. I'll be offering some reflections on advances and changes that have taken place for post-secondary students with disabilities since 1981. I've been working as the National Coordinator of the National Educational Association of Disabled students (NEADS) for 25 years, so there's a lot to reflect upon over the period that I've been working actively on the issues. But let's start with an observation based on my own university experience. Way back in 1981, I was a first year student in the Journalism program at Carleton University in Ottawa and I had a friend who was blind, a year ahead of me, in the same program. I don't know how he completed what was a very demanding journalism course load and media assignments, given almost insurmountable obstacles in his path. This was long before the Internet, of course, email and adaptive technologies that students take for granted now. And this friend didn't even have a computer through much of his studies. He relied on Braille and 4-track tape recordings of his class materials. And I know that his books on tape were almost always weeks late.

Fast forward 30 years and this same student would have a computer, access to a range of adaptive technologies, books available in accessible electronic formats, and a wealth of materials online. Things aren't perfect now by any means, but great strides have been made for college and university students with all types of disabilities. NEADS now has some 220 post-secondary institutions that have designated disability services offices in a fully accessible, searchable database on our website. These centres are staffed with experienced personnel that can assist with individualized accommodations to students with disabilities so they can be successful in their studies. And the disability service providers have organized themselves in a national group —along with some like-minded provincial groups -- that attempts to ensure a standard level of professional service delivery and support across the country.

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<sup>1</sup> Frank Smith is Coordinator of the National Educational Association of Disabled Students (NEADS), a position he has held for 25 years. The NEADS office is in Ottawa at Carleton University. Frank holds a Bachelor of Journalism degree from Carleton.



Universities and colleges across Canada – -aided with provincial and federal funding -- are allocating significant resources in their budgets to support disability services and to provide adaptive equipment in libraries and other places on campuses. In many parts of the country-- Ontario with the AODA is a prime example —schools are having to report to their provincial governments on progress they are making to improve physical access, provide services, accommodations and badly needed adaptive hardware and software. With greater awareness comes greater acceptance as well. For example, professors and teachers are much more willing to provide accommodations like extra time for exams and assignments and private areas to do exams than they were years ago. The student population generally considers classmates with disabilities as peers, part of the fabric of the campus community and there is less discrimination in universities and colleges than there used to be.

Another big change that I've seen is in the level of involvement of students with disabilities on their campuses, in working with key players to ensure that all aspects of accessibility and services to students with disabilities are being met. Many schools are asking students with disabilities to sit on influential committees that are making decisions on key campus issues including: new construction, methods of delivery of course materials in the classroom, the purchase of new technologies, and the development or modification of disability policy statements. A growing number of students' unions/associations are supporting the establishment of organizations of students with disabilities, with office space for their activities. These centres are being set up and supported along with the centres of other equity seeking groups: women, international students, first nations students and GLBTQ students. Students with disabilities are now more likely to compete for positions on their student governments, which is hugely important.

I've also seen great advances in the level and type of financial assistance available to students with disabilities. Most students in college or university study are familiar with the Canada Student Loans Program offered through the federal government. Now, in addition to regular student loans that most students can access, there are Canada Student Grants for students with permanent disabilities that cover a range of equipment and accommodations costs. This can amount to thousands of dollars in grant funding over a student's years of study. And now there is an upfront grant of up \$2,000 per year that

disabled students can access to cover costs like tuition and books. If you factor in provincial grant and loan funding programs, students with disabilities and their families are in a much better position to support the costs of their education and any additional disability-related expenses, than they were 25 years ago. But of course tuition fees and the cost of living continue to increase at an alarming rate, so access to adequate funding will continue to be a concern for many disabled students. And there will always be added concerns for students who have higher costs, such as deaf students who need sign language interpreters.

Also on the subject of funding, I have noticed that an increasing number of colleges, universities, private sector funders and non-governmental organizations are offering scholarships, awards and bursaries designated for students with disabilities. NEADS has catalogued hundreds of these funding sources in a fully accessible, infinitely searchable financial aid portal that we launched about a year ago: [www.disabilityawards.ca](http://www.disabilityawards.ca) There was little of this kind of support years ago and there certainly wasn't one place where you could access the details on disability scholarship programs.

The other significant change that I'm seeing, which is critical, is an increased interest in academic programming that addresses disability and human rights with a disability lens. Disability Studies programs are emerging all over North America on university campuses. There are many such programs in Canada now, most notably at York University, Ryerson and the University of Manitoba. As the area of disability studies has become a serious area of academic research, the graduates of these programs move into society to make substantive changes at all levels for persons with disabilities.

While improvements have been made and great strides have been taken since 1981, there are still areas that cause us considerable concern. In our office we are hearing from an increasing number of students who have considerable challenges because of chronic health conditions — often autoimmune related disabilities -- that can cause interruptions in studies for periods of time and difficulties addressing changing accommodations requirements in the classroom. Sometimes these students have to drop out of school altogether because they can't cope with the stresses of school and illness. Students with mental health conditions face great barriers because of the invisible nature of

their disabilities. And it seems that the proportion of students battling mental health problems is rising dramatically.

So, in summary, big things have happened in the last 25 years and many advances have taken place. But we can't be complacent because there are always obstacles to learning to overcome and technology, which can be the great equalizer in the classroom, does not solve every access problem. I encourage students with disabilities to visit our website or contact our office directly for information, advise or assistance.

# Disability Studies

By  
Olga Krassioukova-Enns<sup>1</sup>

Disability Studies (DS) has emerged as a discipline within the contexts of the disability rights and independent living movements, which have advocated for civil rights and self-determination since the 1970s. These movements have achieved significant policy change on behalf of the persons with disabilities in Canada and the United States. By bringing together academics and disability community advocates who shared common concerns the movements have also assisted with the continued development of DS. DS has moved disability from medical and rehabilitation domains into the political and social realms. It has resulted in the development of a 'disability framework' which examines the social, political and economic forces that have marginalized and oppressed persons with disabilities for centuries, just as feminist and other frameworks have been developed to address the historic and systemic disadvantages of women, children, poor and other marginalized (or minority) groups. While DS recognizes physical, mental and other differences amongst individuals, this perspective stresses the importance of proper interpretation of such differences.

In Canada, part of the DS history began in Winnipeg, when in the 1990's the late Henry Enns (Co-founder and first Executive Director of the Canadian Centre on Disability Studies) and other disability community activists began to lobby the University of Manitoba to develop a Disability Studies program. In May 1998, CCDS hosted the first Symposium on Disability Studies to continue these discussions. Contributors from Manitoba, Alberta, Quebec, Ontario and Chicago, addressed the symposium participants who represented disability organizations and universities across Canada. That working meeting enabled CCDS to consult with members of other academic institutions who were in a position to advise on, and assist with, the implementation of the interdisciplinary Master's degree program. The nature of CCDS's vision was the development of a Master's program that would be meaningful to people with disabilities, have high

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<sup>1</sup> Olga Krassioukova-Enns, executive director of the Canadian Centre on Disability Studies, has more than 25 years of international experience in disability policy, programs/project design, implementation and evaluation, as well as research, curriculum development, teaching and administration. Educated as a medical doctor, trained in policy development and participatory research, she has been involved in numerous national and international projects with the focus on disability studies development and teaching, aging and disability, visitability, livable and inclusive communities, inclusive education, universal design, poverty reduction, as well as international and social development.

academic standards and integrity, provide disability knowledge and critical thinking to future professionals, and serve to facilitate the full inclusion and participation of persons with disabilities. Many consumer organizations have agreed on the need for a Disability Studies program that emphasized cultural and social definitions of disability, while adopting an interdisciplinary approach.

Growth of Disability Studies in Canada:

1999 – 1<sup>st</sup> undergraduate disability studies program at the Ryerson University's School of Disability Studies

2002 – 1<sup>st</sup> Interdisciplinary Graduate Program in Disability Studies at the University of Manitoba

2004 – Canadian Disability Studies Association

2007 – 1<sup>st</sup> PhD program in Critical Disability Studies at the York University

2011 - 10 Disability Studies Program at postsecondary institutions

Dream (by 2015) – every postsecondary institution in Canada will have an interdisciplinary disability studies program at the graduate level.

Disability Studies helps to change the way society perceives and responds to disability. It can deepen our understanding of the disability rights movement and generate and/or disseminate knowledge that can enhance the process of social change. However, Disability Studies also has implications that reach beyond people with disabilities.

Disability Studies helps to shed light on broad societal issues, challenge societal thinking regarding the ways it meets the needs of all its citizens, the processes of adequate resource distribution, etc. By encouraging the value of diversity, it can help create a more just and responsive society.

# From Committed to Commission

By  
Jean Beckett<sup>1</sup>

This is a story about a journey of many years taken together by many people. I was not present for the entire journey so I will give you a little history as I have been told and then speak of my personal journey.

When I was young, the women in my family did home care. I loved helping the women care for everybody so I dreamed of becoming a doctor. When I was nine, my dad died and mom started drinking. Seven years later she died and I became a homeless orphan. The trauma of my childhood had left me struggling with Post-Traumatic Stress Disorder (PTSD) and Agoraphobia with Depression to add to my asthma and severe allergies.

Meanwhile, a group of Viet Nam veterans decided being placed in wheelchairs and confined to VA hospitals was not acceptable. They wanted to pick up their lives where they left off and live active lives in an inclusive society. The Independent Living Philosophy was born. It became a movement founded on empowerment, inclusivity, and a barrier-free society. They fought for and won the Americans with Disabilities Act which compels public places, goods and services to be fully accessible.

In the early seventies, people with disabilities (PWDs) in Canada began a movement of their own and Independent Living Canada was born. Resource centres that practiced the independent living philosophy and use a peer support model began to open up across Canada. They are non-profit grassroots organizations with Boards of Directors, staff and membership who are primarily PWD's. They advocate for inclusion and an end to discrimination and stigma.

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<sup>1</sup> Jean Beckett has been involved in community work for twenty years. She is a founding member of RISE Resource Centre for Independent Living and is also very involved within the mental health system. She sits on four boards and numerous committees. She sits on the Council of Canadians with Disabilities in her role as President of the National Network for Mental Health. [www.nnmh.ca](http://www.nnmh.ca). Married 38 years, she enjoys spending time at home in Parry Sound with her husband, seven grandkids, and her dog, Bob.

In the early 1990's I attended a training course for upgrading from my Personal Service Worker (PSW) and met the instructor Kathie Horne. The minute she entered the room I was fascinated by this woman who obviously had a fairly severe form of Cerebral Palsy. Her body was twisted, her speech quite stilted and her eyes crossed. I saw through all of this and was completely gob smacked by her intelligence, humor, and courage. Her beautiful brown eyes sparkled and danced with passion when she spoke. She was positively fearless! She spoke of the Independent Living movement and her desire to start an IL centre in our small Ontario town.

We became immediate friends and partners in the work. We organized a group of PWDs and began lobbying for access. For five years we worked with the community, governments, and funding bodies to further our cause. We established an Access Awareness Committee and did public information presentations and events. Finally, we opened the doors to RISE Resource Centre for Independent Living and stepped up our advocacy work. We joined hundreds of PWDs across Ontario to become the Ontarians with Disabilities Act Committee. This lobbying group focussed on writing the Ontarians with Disabilities Act (ODA). The government wrote an ODA of their own that was soon struck down and replaced by the Accessibility for Ontarians with Disabilities Act (AODA).

Meanwhile, back at the Independent Living centre, we were developing the Direct Funding Program for Self-managed Attendant Care. Next, we trained our staff and volunteers in Universal Design and went out doing accessibility audits for builders, architects, and organizations and promoting the newly revised accessibility standards in the Ontario Building Code. We continued to lobby for inclusion and for improvements in goods and services. As changes were achieved and implemented, we quickly developed activities to educate people and promote the changes, as we recently did by providing workshops about the new Registered Disability Savings Plan. This exciting program has been implemented by the Federal government to proactively empower PWDs to save for their later years without jeopardizing any income security program they may be currently receiving.

Then, in 1999, I joined a group of individuals who were persons living with mental health issues. Identifying themselves as Consumer Survivors, they had been mirroring our work within the mental health system. They were also

creating a movement and fighting for power and control over their own lives. They use the catchphrase “Nothing about us without us.” Since I identified as being a person with lived experience, I joined them to partner in their work.

Our biggest success so far is a network of consumer survivor initiatives that are peer support organizations similar to the IL centres. With research showing that peer support is Best Practices in the mental health field, we continue to lobby the Ontario government to strengthen these groups and enhance their programming.

Meanwhile, the federal government has responded by creating the Mental Health Commission of Canada whose mission is “to promote mental health in Canada, and work with stakeholders to change the attitudes of Canadians toward mental health problems, and to improve services and support”. To achieve that end, they have been involved in activities ranging from the development of a Knowledge Exchange Centre, a housing project, a peer project, and programming designed to foster partnerships and reduce stigma through education and understanding. They are developing a national mental health strategy and spearheading collaborations involving persons with lived experience, family members, professionals, the corporate world and multi-levels of government.

It has been a long road travelled by many thousands of people united for a cause and we have come a long way.

It is just the beginning.



# Your Vote Please

By  
Ross Eadie<sup>1</sup>



Four days in April, 1992 sent me on a path leading to a successful election to Winnipeg City Council in October, 2010. During an Independence '92 plenary session that included Henry Enns and Allan Simpson, people from around the world heard about great success in Independent Living advocacy efforts in the industrial world, but the following words rang out to me: We have yet to elect persons with disabilities into governments at all levels where we can influence decisions from within. Imagine if people with disabilities had been sitting in cabinet while a new *Charter of Rights and Freedoms* was discussed in the context of what it should cover. Including the rights of persons with disabilities in the *Charter* would have started at the beginning, instead of requiring a huge effort to include them near the end of the process.

Advocacy efforts drove me to become a politician at the municipal level. The city comes into one's life more often than the other levels. But, I have campaigned at the federal, provincial and school board levels, which involve education, health, housing and income. All four of these issues are at the top of the list to improve life for persons with disabilities and those without disabilities.

We have had some success in electing persons with disabilities in Canada. At least two persons who are blind have been school board trustees in the prairies. A woman with a disability has been the mayor of a small city, and a man using a wheelchair became the mayor of Vancouver. A person who is deaf became a member of the Ontario government, and a woman with a disability has become the Minister of Labour in Manitoba. A man who experiences quadriplegia and a woman who experiences paraplegia have become Members of Parliament. I am sure there are more examples, but there needs to be many more to be representative of our society.

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<sup>1</sup> At 51 years old, Ross Eadie lives in Winnipeg with his wife and two teenage boys. Currently Ross works as the elected city councillor for the Mynarski Ward (North End and West Kildonan). With a strong sense of citizenship, Ross Eadie has advocated for many improvements that have added to the well-being of many people. Ross's activity and experience can be found at [www.rosseadie.ca](http://www.rosseadie.ca).

One interesting point must be made in terms of electoral progress in Canada. None of these people ran on the issues of people with disabilities. We were part of campaigns about issues everyone in society is concerned about. Each of us has political ideals from our political parties. We are women and men; fathers and mothers; single and married; gay and lesbian; and of many ethnic backgrounds. It can be difficult to hear from voters who want to make your disability an issue, but I truly believe the huge effort in educating the public over the past 30 years has made this a very small number of voters.

It is my belief that much more success will come in electing persons with disabilities in the next decade. I am not sure about where my political career will culminate before retirement, but I do know nobody will be asking me to wait at the door while they get money to donate to “the blind guy”. They know it is “your vote please.”

# *Transport*



# Moving Forward - Looking Backwards

By  
Pat Danforth<sup>1</sup>

In 1981 a wheelchair user could not take the train or bus from the West Coast to the East Coast. In 2011 a wheelchair user cannot take the train or bus from the East Coast to the West Coast. Individuals with sensory disabilities still cannot travel with confidence that they will be able to see or hear what is going on. Has anything changed? Have we progressed? Yes things have changed and yes we have progressed but in a piecemeal, scattered way that often frustrates the traveller with a disability but our goal of full participation and equality is slowly taking shape.

Looking back it is hard to believe that 30 years ago many of us living with disabilities were being denied basic transportation. Canadians with disabilities were denied the right to participate in our communities and country because of manmade barriers. The majority of fixed route transportation systems - road, rail, or air - were inaccessible! Change came because locally we, people with disabilities, participated in and advocated for the development of parallel transit services and then conventional transportation to meet the needs of folks who do not climb stairs and now we champion better access for people with sensory disabilities. Nationally we have won great victories by voicing our concerns and championing for change. In the late 1980's we helped put in place the Canadian Transportation Act. It governs air, rail and interprovincial ferries. The Act entrenched the concept of equal access by recognising obstacles to our mobility, and includes investigating complaints, developing regulations plus codes of practise and conducting compliance reviews.

Despite the provinces and municipalities being responsible for urban transportation and the federal government responsible for interprovincial and international transportation, we struggled and eventually established two significant precedents. VIA Rail's purchase of inaccessible rail cars in 2000 was confirmed as discrimination and those cars were ordered to be retrofitted. The process took 7 years but the Supreme Court clearly said "no new barriers" when it comes to transportation and travelers with disabilities. One person - one fare

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<sup>1</sup> Pat Danforth has been involved in disability rights issues for over 40 years including advocacy, legislation and policy development plus public education.

recognised individuals will not be charged more than one fare if they need help in flight for personal care or safety and/or because of their size needs more than one seat. It only applies in Canada and to the major airlines but it is making a huge difference to individuals who need this. These wins help us move towards a transportation system that is consistent, seamless and useable by all including people living with a disability.

We have made tremendous progress over the last 30 years but we still have a ways to go to assure our systems of transportation will be inclusive. Our challenges include travel information being accessible for people with sensory disabilities, real time information available visually and audibly, tactile and audible signage systems, new technology that is useable, and most important - no new barriers!

We intend to meet the challenges head on.



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Pat Danforth at Supreme Court of Canada

# The Development of an Accessible Urban Transportation System

By  
Dave Martin<sup>1</sup>

I will never forget the day about seven years ago when I rolled up to my father's house on the west side of Winnipeg for an unexpected visit. He was outside cutting the grass as I came up the driveway in my electric wheelchair.

He didn't notice I was there until I said, "Hey, you missed a spot."

He spun around with a puzzled look, as if he was seeing a mirage. Looking around for a van or Handi-Transit vehicle that might have dropped me off, he was confused because there were none to be seen.

"How in the world did you get here?" he asked.

"I took the regular bus for the first time." I answered with a grin.

In many ways, my bus ride that day and surprise visit to my dad's was the perfect tribute to years of work by countless people from Winnipeg's disability community. Just a few short decades ago, many people with mobility disabilities were often stuck in their homes, because they had no accessible transportation available to them. Other times they had no option but to pay expensive fares to specialized wheelchair transportation companies, just so they could get somewhere they wanted to go.

Then, in the 1970s, people with disabilities started to learn from groups representing the rights of women and visible minorities. Many of their concerns

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<sup>1</sup> At one time, David Martin was the Provincial Coordinator of the Manitoba League of Persons with Disabilities. He is currently working in the Disability Issues Office of the Manitoba Government.

were similar to those of people with disabilities who were just starting to fight for access to a society that had ignored their needs.

Access to public transportation was one of the first priorities of the new disability rights movement. People with mobility disabilities in particular were tired of not being able to use a transit system they were paying for with their tax dollars. Organizations like the Manitoba League of the Physically Handicapped (now Manitoba League of Persons with Disabilities) led the fight at Winnipeg's City Hall to convince civic leaders that people with disabilities had a right to use public transit.

This advocacy eventually saw the introduction of Handi-Transit as a parallel public transportation service operated by the City with fares equal to those paid by regular transit riders. It was a significant liberator for many people with mobility disabilities as it allowed them to get out and start participating in society to a much greater extent.

Since then, Winnipeg's transportation system has changed dramatically. In the late 1980s, the Manitoba Taxicab Board required the taxi industry to offer wheelchair accessible service for the same price charged to other customers. Although not typically viewed as public transportation, taxis are an important service for many people who do not have their own car or who cannot drive. Making taxi service accessible to people who use wheelchairs was a huge improvement for their mobility.

In the 1990s with the emergence of new bus designs, the City adopted a plan to purchase only accessible buses for use in its regular transit fleet. Over time, this would mean that people using wheelchairs who could get to a bus stop would be able to travel anywhere in Winnipeg served by regular transit. For those who could not get to a bus stop, the Handi-Transit service would still be available.

Similar stories were unfolding in other cities across Canada. Some, like Vancouver, had accessible taxis earlier than Winnipeg while, even today, other cities are just starting to make their transit system fully accessible. Everywhere



though, policy makers were accepting that people with disabilities have the right to move about their communities using public transportation.

Looking back at my first trip on a regular transit bus, I recall glancing around at the other passengers and noticing the diversity of people who were riding with me. There was a young woman with a baby in a stroller. I remember smiling about that because, to make it easier for her to push the stroller on the bus, she used the same ramp I had used. There were also many elderly people who probably all appreciated the bus's easy access features. Then, there was a young man with a Mohawk haircut and some large earrings hanging from his ears.

I definitely experienced a sense of equality riding the bus with such an interesting group of characters. Of course, they were probably looking at me and thinking I was a little interesting as well.



# *Access*



# Awareness Campaigns: National Access Awareness Week

By  
Francine Arsenault<sup>1</sup>



While Chairing the Council of Canadians with Disabilities (CCD), and because I also sat on the executives of boards of directors of persons with disabilities at the provincial, regional and district levels, I was asked to participate on the National Access Awareness Week (NAAW) Committee. After Rick Hansen's World Tour, he started this group to encourage all Canadians: persons with disabilities, business, labour, and government to make meaningful changes in the daily living of persons with disabilities. The objectives were: 1) assess the accessibility of services and facilities, 2) set measurable goals, 3) make practical improvements, and 4) celebrate achievements.

One of our catch-phrases was that if Transportation, Housing, Education, Recreation and Employment became accessible, persons with disabilities would be **THERE**.

The National Access Awareness Week Committee was composed of organizations of and for persons with disabilities, whereas CCD was, and still is, an organization of persons with disabilities, representing themselves. To reach a broader scope across the country, it was felt NAAW should include organizations for disabled persons too.

Citizens from the Atlantic Ocean to the Pacific Ocean, from the South to the far North planned how to make access a priority in their towns. When the United Nations declared December 3, the International Day of Persons with Disabilities, it became a focus for municipalities to improve access for persons with disabilities.

In 1989, the Government of Australia asked the Canadian Department of Secretary of State to send someone there to discuss how we were proceeding in

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<sup>1</sup> In addition to being a Chairperson of CCD, Francine Arsenault was also active in the Kingston Independent Living Centre and she received an honorary doctorate from Queen's University for her work on disability issues.

our struggle for inclusion. NAAW sent me to Sydney, Australia. A Social Services Department representative met me at the airport and we traveled to a nearby hotel where I met the Community Partnership Board that had planned my visit. In the next 14 days, I visited 17 cities and did 21 presentations. Australia was an institutional country at that time so I can only hope that the Canadian examples I shared contributed to that country's move to full inclusion.

As I assist my Mom into a fully accessible apartment, or see someone in a wheelchair catch a regular bus, or notice tactile letters on an elevator, or see a sign language interpreter being used for the deaf, I think perhaps all our efforts were not in vain.

In Ontario, our ground breaking Accessibility for Ontarians with Disability Act of 2005 began a process to make all public facilities accessible. The Act was revised by Charles Beer in May, 2010 to set standards in place to make all businesses accessible before 2012.



Francine Arsenault, Gerry MacDonald and Laurie Beachell  
at CCD's Diary Read-a-thon.

# “Just A Deaf Thing”? Reflections on the Achievements of the Canadian Association of the Deaf (CAD)

By

Jim Roots and Henry Vlug<sup>1</sup>

Thirty years ago, the first captioned television program was broadcast in Canada. It was a triumph of the campaign that the Canadian Association of the Deaf (CAD) had begun in 1967, when the earliest experiments in captioning were reported at the CAD’s Annual General Meeting. Today, nearly 45 years after the CAD started this crusade, we can boast that Canada has the most captioned programming of any country. Captioning has not only benefited the 3 million Deaf and hard of hearing Canadians; it has also benefited functionally illiterate people, seniors, immigrants learning a new language, children learning to read, and anyone who has ever tried to watch TV in noisy bars or food courts or other public places. This is not “just a Deaf thing”.

Thirty years ago, no communication supports were available to Deaf or hard of hearing people in hospitals and medical centres. Deaf people who signed had no access to interpreters; hard of hearing people who could speak had no access to devices that could help them hear. Imagine how frightening such communication barriers can be in a medical emergency, a hospital operating room, a referral to specialists in cancer or other serious diseases! Thanks to the Supreme Court decision in the Eldridge case, supported by the Canadian Association of the Deaf, now we all have the legal right to full and equal communication access in medical services and centres. This is not “just a Deaf thing”.

Thirty years ago, the Canadian Deaf Education Fund closed its Deaf scholarship program because its grants were too small to be of any real assistance to Deaf Canadians who wanted to attend university or college. The Canadian Association of the Deaf began the tough fight to force Canadian post-secondary institutions to provide Deaf and hard of hearing students with interpreters, notetakers, live captioning, listening devices, and all other means of accessing

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<sup>1</sup> Jim Roots and Henry Vlug have been working for Deaf rights and accessibility since the 1970s. Jim is Executive Director of the Canadian Association of the Deaf (CAD) in Ottawa. Henry is a retired lawyer in Vancouver who has held many positions in the CAD and in other organizations.

education. Today, anyone with any kind of disability who wants to attend Canadian universities and colleges can be confident of being provided with appropriate supports. This is not “just a Deaf thing”.

There are countless other achievements that the Canadian Association of the Deaf can boast about in its 71-year history. We’ve helped to make this country a great, shining beacon of hope and accomplishment in accessibility. And everything we have done for Deaf and hard of hearing Canadians has ended up benefiting all Canadians. We may be the Canadian Association of the Deaf, but we are not “just a Deaf thing”!



# Access to Websites: The Golden Key to Communicating

By  
Donna Jodhan<sup>1</sup>

It can easily be said that access to websites has been, and continues to be, one of the most important keys to communications on the Internet and as the technological landscape continues to evolve, it is only reasonable to expect that blind and partially sighted persons would want to be and remain a part of this world.

We are living in an information society and a knowledge based economy and the importance of accessible websites is becoming more vital because of the need to be able to access and respond to information on a timely basis. Websites give us the opportunity to do such things as: request and respond to information; complete online forms and applications; go online shopping, do our online banking; plus much more.

It is one thing to have websites where we can do all of this but it is quite another if these websites are not accessible. Accessible websites benefit everyone; from the mainstream person to the one who has a disability that would range from being blind or partially sighted, to the one who is print disabled, and to the one who has either a physical or learning disability.

What makes a website accessible? In a nutshell, an accessible website is one that gives the visitor the opportunity to find whatever they seek in relatively quick time and they can do this easily and without having to ask for assistance.

What can we do as a community to ensure that more websites are made accessible to all persons? We can lobby our Federal Government to take the lead by mandating all companies that provide services to make their websites fully accessible. The Federal Government needs to lead by example. We can

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<sup>1</sup> Donna Jodhan is the President of the Alliance for Equality of Blind Canadians (AEBEC). Ms. Jodhan is undertaking test case litigation in an effort to compel the Federal government to make its websites accessible to persons with disabilities.

work to create awareness among IT professionals re the benefits of designing and developing accessible websites and we can help the mainstream person to understand how accessible websites can help to improve communication and why inaccessible websites can be a definite drawback to everyone's ability to communicate effectively.

Accessible websites are the bridges to our online world and without them we are lost. We need them if we have any hope of being able to keep up with technology and information on a daily basis. They are our lifeline to a world in which the Internet dominates and will continue to do so for way past our time. We need to keep all of this in mind as we continue our efforts to lobby for greater access to more websites.

We have come a long way with regard to raising awareness but there is much more for us to do. We need to keep up and increase the pressure for more websites to be made accessible. Electronic communication has made it possible for us to play a more significant role; much more than say a decade ago. Let us not waste our efforts.

# Stand Up (Sometimes Metaphorically) to Be Counted

By  
Peter Hughes<sup>1</sup>

Once upon a time it was thought that people with disabilities should be kept at home, where they could live out their lives in private, cared for by their loved ones, out of the sight of the general public. When the future American president Franklin Roosevelt was crippled by polio, members of his family and most advisors counseled him to forget his political aspirations and to refocus himself on his private affairs, hiding away on his rural estate in Hyde Park, New York. He refused to do this. But such was the temper of his times that in order to participate in public life he had to engage in a great deception. Using his financial resources, he contrived always to appear in public in such a way as to disguise his infirmity. He was never photographed in a wheelchair. Heavily braced, and unobtrusively supported by his son, he approached the speaker's podium on foot. Had the true extent of his disability become known, he could not have won the presidency.

Even today, democracy is threatened by negative or negligent attitudes towards the disabled. Electors must often overcome hurdles to vote. Some polling places have been located or set up so as to discourage or even prevent people with disabilities from casting their ballots. I encountered obstacles in voting in some recent federal elections. In my case, these were resolved by the decision of a human rights tribunal. I am proud that I stood up for the rights of mobility-impaired citizens and am hopeful that the settlement made with the people at Elections Canada will result in improvements, not only at my polling place but across Canada.

Physical obstacles at electoral sites are not, as some might think, just part of the structure of the universe. They are created, or allowed to persist, because of the attitudes of human beings. In my negative experiences at the polls, what upset me the most was my feeling that I was not expected to be there. In Roosevelt's day the thought was that the disabled must be kept housebound and out of

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<sup>1</sup> Mr. Hughes made a complaint to the Canadian Human Rights Commission against Elections Canada about the barriers he encountered. In the Hughes Case, the Canadian Human Rights Tribunal ordered Elections Canada to "cease from situating polling stations in locations that do not provide barrier-free access". CCD regards this decision as a victory, because the Tribunal's order compels Elections Canada to keep access considerations front and centre as it conducts elections.

sight. Now, while we would never publicly endorse that old prejudice, we still think that it is enough if provisions can be made so that the disabled might vote in special places, on different days, or privately. While these special provisions might, in themselves, be a good thing, permitting many who could not otherwise vote to do so, by themselves they are insufficient to allow all those who wish to be fully engaged in the political process to do so.

I feel that there is much to be gained, for a disabled person, by being present at the official polling place on election day. Advanced polls, write-in ballots, and computer voting are all great things, and useful to those whose schedules do not permit them to attend on the day of decision. But there is more to our electoral franchise than just the bare right to cast a vote. We should be permitted, if we so desire, to witness the entire electoral campaign before voting. Advanced polls allow us to vote, but do not allow us to make the most informed choice in an election. Even more important, I believe, is our presence in the polling place. We are there to vote and also to be seen voting. We are not to be hidden away, but must be allowed to stand up (sometimes metaphorically) to be counted, and by our presence effectively to say, "I am handicapped, I am here, this is my territory, in a place that is for me as well as for others. You should expect to see me here often in the future."

# The Changing Faces of Museums, Art Galleries, and Historic Properties

By  
John Rae<sup>1</sup>



For many persons with a disability - even a lifelong history and museum lover like me - the prospect of a visit to a museum, art gallery or heritage property can be a rather intimidating prospect. To date, many of us assume such facilities will have little to offer us. However, times are changing and this need not be the case.

Many museums and art galleries began as institutions that were little more than storage spaces for works of art and archaeological artefacts, aimed at satisfying the curiosity of upper-class dilettantes. Today, museums, art galleries, and heritage properties are the treasure houses of our civilization, repositories of our historical, artistic, scientific, and cultural heritage. They are also much, much more.

Over time, the roles of these institutions have evolved and these days they are involved in the more encompassing activities of: acquiring, conserving, researching, communicating and presenting exhibits and information, for purposes of research, education and entertainment for all members of the community. The key word here, perhaps, is "all".

But too often access to these incredible heritage collections is still limited for individuals with a disability. Thus, to make these facilities welcoming to all members of our communities, museums, art galleries, and heritage properties need to adopt a more inclusive concept of accessibility which encompasses much more than just providing physical access to their facility. And we consumers must do more to accelerate the pace of change.

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<sup>1</sup> John Rae is 1st Vice President of the Alliance for Equality of Blind Canadians (AEBBC) and 1st Vice Chair of CCD. He is also an avid museum visitor, who writes and speaks on ways of making museums and art galleries more accessible to persons with various disabilities.

To many blind patrons, being able to touch objects on display is paramount! In heritage facilities, like pioneer villages or historic forts, implements that helped to build this country are often out in the open, easily available to touch. In larger museums and art galleries, however, our desire to touch objects too often brings us into conflict with conservation staff, who are afraid that tactile access will result in irreparable damage to these irreplaceable objects.

As a history and museum lover, I am equally concerned about preserving the remains of the past, and believe firmly that conservationists' fears can be mitigated. Most tactile tours cover less than 10 objects in a 60-90 minute tour, and the more objects that are available to be touched, the less frequently each object will be handled. The use of gloves will also go a long way to preventing damage to these collections.

Today, a range of approaches are being employed to expand our appreciation of collections, including the use of replicas, raised line drawings, audio guides, audio described tours, accessible materials on websites, and providing information through the use of new technological innovations. These approaches, however, do not replace our desire for tactile access to objects in regular collections.

A number of museums and art galleries have begun offering "multisensory" tours. A typical multisensory tour at the Art Gallery of Ontario (AGO) lasts 60-90 minutes with two Gallery Guides and involves up to 10 visitors. The first such tour that I took included the smells of dried lavender or cloves contained in snuff bottles from the Thomson collection; verbal discussion of several pieces of art augmented by a musical component, and the opportunity to touch a number of items like Henry Moore's "Reclining Woman."

An additional component of these tours is usually a discussion of how the artist created the work being described, e.g. "perspective" which shows how an artist constructs a painting on a canvass. Through the use of cut out sections of board, a landscape was divided into sections to show the different layers of a painting.

Valentina Gal, of AEBC's Toronto chapter commented: "I didn't realize how complicated the idea of depth and perspective is as it is experienced by seeing people. The overlays they made that show how the artist starts by painting the horizon and then putting in background and then moving forward and so on, were fabulous. It is the best example of a teaching tool that I've seen in a long while."

Multisensory Tours also expand the horizons of Gallery Guides. Jessica Duarte, who leads many of these tours at the AGO, says, "It's the simple exercise of looking at art by means of all my senses, and engaging in thorough discussions with visitors about this experience, that opens my mind to its various levels of meaning."

Duarte adds, "The fulfilling part of multisensory tours comes from the emotional and intellectual reward of making a small difference in people's lives through art, and discovering deeper ways of appreciating art and human understanding."

The Canadian Museum for Human Rights in Winnipeg has some different challenges. Its emphasis is on presenting information, not artefacts, and it has been consulting widely with Canadians, including members from the disability community.

Increasing access to museums, art galleries and heritage properties, like most other facets of life, requires more from us. We must continue to push for more involvement and opportunities. Some of these facilities welcome our involvement, and more need to learn the benefits of including us as they reach out further and further into their communities.

# The Evolution of Access

By  
Marie White<sup>1</sup>



As I reflect on the world today versus the world I entered 24 years ago when I acquired a disability – the differences are clear. In 1987, as I began my “new life” as a person with a mobility impairment and using a wheelchair, the physical and attitudinal barriers were many and varied. Living in St. John’s NL, the geographical challenges in terms of the topography were readily apparent; the challenges I would face in terms of overall access and inclusion, even more so.

Initially I struggled against systems that determined my care was too expensive and deemed an institution to be appropriate. My house was inaccessible; I could no longer drive; accessible transportation was limited and inflexible; and although I am a university graduate and had been working as teacher, inaccessible schools and closed minds meant this was no longer a career option. There were few programs available at that time to support my interest in returning to work or indeed to participate fully in my community. Leisure facilities were relatively inaccessible as were many of the restaurants, bars, theatres, shops and other similar pursuits in St. John’s, across the island and in many other parts of Canada. My abilities were questioned and my place in society was somehow lessened by my physical status.

Of note is the fact that while “access” was a stated word, true understanding of the concept for persons with disabilities was lacking. Even if a facility, program or service was made “accessible”, it did not always facilitate inclusion. We were still not part of the everyday citizenry.

Fast forward 20+ years and I see quite a difference. If I were to acquire the same mobility disability today, I would be less confounded by government systems and more supported. A better understanding of the linked concepts of access and inclusion has resulted in increasing numbers of children with disabilities experiencing success in school and more going on to postsecondary

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<sup>1</sup> Marie White is the Past Chairperson of CCD and Chairperson of CCD’s Social Policy Committee.



opportunities. Employment is becoming an increasing reality for persons with disabilities. Recreational and leisure facilities are incorporating the universal design features which really do demonstrate they are available to all citizens.

We see progress in housing and homelessness initiatives, poverty reduction strategies, sports and leisure strategies, home care systems and transportation networks. Our country is moving along a continuum and evolving to be a truly welcoming place which not only encourages but also demands access and inclusion.



Marie White at Poverty Rally, Ottawa

# Information and Communication Technologies (ICTs): Then and Now

By

Catherine Fichten<sup>1</sup>, Adaptech Research Network, Dawson College, Montreal

*For people without disabilities, technology makes things easier. For people with disabilities, technology makes things possible.*<sup>2</sup>

Take, for example, the 1980's precursor to the Adaptech Research Network... I and a student with a visual impairment are working on a research paper. Our main technology is the typewriter. But... we heard of exciting innovations! Alas, a day and hundreds of windings and dollar signs (control characters) later we realize that word processing software for people who are blind is not yet ready for prime time. Back to the typewriter! But not for long.

By the 1990s, a major challenge is price. But American legislation resulted in more and more general use ICTs incorporating access features. Primitive, yes, but definitely the beginning of universal design in this realm as people with different disabilities used mainstream ICTs as adaptive aids. For example, most people use spell checkers. For people with some learning disabilities this is adaptive technology that helps compensate for the disability. Dictation software, developed for professionals, was now used as adaptive technology by people with neuromuscular impairments. Screen reading and word prediction technologies, intended for individuals with disabilities, crossed over into the mainstream and were increasingly available on mobile devices. People with disabilities also used ICTs in idiosyncratic, creative ways, further clouding distinctions between general use and adaptive computer technologies.

It's the 2000s, and prices have started falling. The main problem now is "interoperability." Adaptive ICTs often did not work with general use software; or with each other. But this phase, too, is now more or less behind us and, with the

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<sup>1</sup> Catherine S. Fichten (Ph.D. in Psychology, McGill University) is a Co-Director of the Adaptech Research Network, a Professor in the Psychology Department at Dawson College, an Associate Professor in the Department of Psychiatry at McGill University, and a clinical psychologist in the Behavioral Psychotherapy and Research Unit of the Jewish General Hospital.

<sup>2</sup> Adapted from Mary Pat Radabaugh, IBM Disability Support, Center for Persons with Disabilities

development of tablet computers and smart phones, distinctions between general use and adaptive ICTs continues to blur. We all surf the web and listen to mp3 audiobooks. Retailers' shelves are stocked with exotic trackballs, mice and touchpads, many under \$25. The premier dictation software now costs around \$100. Schedulers and alarms on iPhones keep people with cognitive impairments on time. Ditto for the rest of us.

Look in the Adaptech Research Network office in 2011. You see everyone sitting in front of a computer. "So what," you say, no? No. For what you would quickly realize is that one team member's screen is black. She does not turn it on since she uses screen reading software. Another person types away with one hand on a tiny keyboard. Under her workstation resides a foot mouse. A third team member listens to music on her computer as she works. But the audio cable is attached to her digital hearing aid. Someone tries to use dictation software but gives up as a team member screams, "Oh, it's so cool! It's so cool!" as she evaluates accessibility of iPhone and iPad apps. Another team member is testing a "free or inexpensive" (under \$200) wand scanner to see if it can read to people with learning disabilities in a library (see Downloads at <http://www.adaptech.org>). Not a typewriter in sight!

Are things perfect in the land of adaptive and adaptable ICTs? By no means. Has the disability community benefited from changes in the past 30 years? Absolutely!



Adaptech Research Network student with refreshable braille keyboard.

# Hard of Hearing, The Invisible Disability

By

Doreen Gyorkos<sup>1</sup>

Hearing Aids for the hard of hearing have come a long way from the big cumbersome body aids with wires running from your ears to the box tucked somewhere under your clothes to hide it. Or the big trumpet held to the ear by the hard of hearing person in order to have the sound magnified.

Fortunately time has provided some improvements in technology producing computerized hearing aids, cochlear implants and assistive devices making coping with a hearing loss improved, but certainly not better. The costs of these aids and devices are so high that many are unable to afford them and therefore become withdrawn from society. Government assistance is provided for one hearing aid replacement every five years. Most people require two hearing aids to provide the proper balance of sounds, so it is a matter of ten years before an aid can be replaced with assistance. Children under the age of eighteen and seniors over the age of sixty-five qualify for minimum financial assistance and the in-between years pay for their own. Today students with a hearing loss in schools receive help in the form of devices and special need aids – also, in advanced education, greater help is available for as long as they are attending classes at that particular institution.

Depending on a person's hearing loss the new technology in cell phones, BlackBerries, i-Pods, etc., through the ability to text, makes communicating easier for some by reading a form of captioning. Telephones have improved with volume and tone control adjustments. TTY phones are in some airports, and other public buildings. However, cell phones are still not compatible with a hearing aid.

Captioning of some television shows has aided the hard of hearing along with the deaf, but it is far from perfect as often the spelling errors are impossible to decipher. Some area movie theaters have rear captioning but not in my area.

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<sup>1</sup> Doreen Gyorkos represents the Alberta Committee of Citizens with Disabilities on the CCD National Council of Representatives.

Accessibility for the hard of hearing has really not improved in the past years. The hard of hearing still do not have Churches, theaters, meeting rooms, funeral homes, senior complexes/assistive living facilities, etc., with appropriate sound systems installed even though the building code states that new buildings must have them installed. Senior complexes are being built without strobe fire alarms; with dining areas with high ceilings, and glass walls of windows with no coverings to baffle sound so that the clanging of dishes/cutlery make it impossible for conversation; and with gathering rooms that have no sound system installed so they can enjoy conversation.

Hospital and nursing home/assisted living facilities staff do not understand the needs of the hard of hearing patient, as it is not part of the training process. This results in needless stress on the part of the hard of hearing patient. Even though workshops are continually being offered and presented, some easy to correct suggested changes are not being made.

Some Hospitals are providing newborn hearing tests to catch the problem early.

Attending Speech Reading classes benefit the hard of hearing in not only following conversation but also in providing coping skills to make every day living easier.

Once hearing is damaged it cannot be restored, so one has to learn to live with whatever degree of hearing they have left.

It is up to the hard of hearing person to educate the public as to our needs, for the communities do not understand! *Hard of Hearing is the invisible disability!*

# The National Building Code over the Decades

By  
Barry McMahon<sup>1</sup>

Canada's National Building Code (NBC) is the de facto code that includes a barrier-free design section. Several provinces use the NBC in its entirety, others adapt it to their local needs. In general, when attempting to fulfill obligations for making buildings accessible, Division B Section 3.8 is the part referred to by designers, developers and building authorities. It stands apart, segregated from the rest of the code, perpetuating the special accommodation mentality. It sets out what they refer to as "acceptable solutions" to various design situations and is written in an objective based format. So basically, the object is allow people with disabilities to use the building - it's up to the designer to decide how. Canadians also have Canadian Standards Association Standards regarding design for people with disabilities, which are more inclusive and go further than the NBC in several topics.

Thirty years ago, Canada was still adjusting to the concept of integrating persons with disabilities into mainstream society. Many brave advocates filed complaints with the Human Rights Commissions when access was denied. The vast majority of cases were decided in favour of the person with the disability. As a result, building code authors throughout the country started to respond. Vancouver even went so far as to adopt its own building code (The first Canadian municipality to do so.).

The private sector in Canada has been highly influenced by standards applied in the USA. American companies operating in Canada, brought with them barrier-free design practices far surpassing ours. Hotels, large chain stores, convention centers, fast-food outlets all had building designs complying with the Americans with Disabilities Act. Canadian companies were forced to imitate.

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<sup>1</sup> For decades, Barry McMahon, from Ottawa, has been advocating for full inclusion of persons with disabilities by advising City of Ottawa staff and council, Ontario Government leaders, federal government departments and private sector organizations. His ideas on implementing a universal approach to design all places, products, and services are now reflected in many policies, practices, and provincial legislation.

The National Building Code is limited in application, applying only to new construction and “major renovations”. That is why we see little action regarding the removal of existing barriers in the built environment. Furthermore, barrier-free sections of the codes don’t apply to houses. It is extremely rare to find new homes with zero step entrances, adequate door widths, and bathrooms with a 5 foot turning radius. Can anyone explain why accessible, adaptable housing design has escaped the attention of our government leaders when the benefits to society are so numerous.

Across the country, groups of concerned citizens have called for greater action on removing barriers and preventing new ones from being created. Much of this action has been prompted by inadequate building codes.

The Province of Ontario, responding to strong grassroots pressure, created 2 pieces of legislation with a goal of creating an accessible Ontario by the year 2025. The first, the Ontarians with Disabilities Act 2001, (a.k.a. the ODA) was applied to provincially regulated entities. The second is the Accessibility for Ontarians with Disabilities Act 2005, (the AODA) which was supposed to be applied to all sectors, public and private.

Application of the ODA has had some success over the last 11 years because it compelled the government to create and maintain “Annual Accessibility Plans” on an annual basis. It was compulsory thinking. It also required a consultative process with people with disabilities. Barrier-free access was now on the agenda. Unfortunately, It didn’t apply to the private sector.

The AODA on the other hand has been a very large disappointment. After over 6 years, the only regulations that have been issued are weak, unobtrusive hints so people can be nice to those with disabilities. As of this date, nothing has been done with regards to the built environment. The long promised regulations will intentionally do nothing to eliminate existing barriers, but instead will apply only to new construction. And by the time these regulations are fully integrated into the Ontario Building Code, we are looking at from 5 to 10 years before we witness any change resulting from the AODA.

A critical observer would think that the AODA was used to fully manage the “Accessibility Issue” (quell the masses) since nothing has really changed and not a single existing physical barrier has been eliminated because of this piece of legislation. Amazingly, the Ontario government has touted the merits of this unique ground-breaking AODA, proudly pointing out that by 2025 Ontario will be fully accessible. It remains to be seen if anything substantial will happen between now and then.

The codes need to evolve into a universal design approach ensuring that the greatest possible percentage of the population can use the built environment. An accessible pathway must be the principal pathway, not a segregated one. The main door would be the most accessible. And vertical circulation in buildings would be one usable by everyone.

Hopefully the National Building Code will get rid of the barrier-free Section 3.8 in Division B, and fully integrate all aspects into standard design procedures. Everyone benefits from a universal design approach. The built environment will end up being easier to use, uncomplicated, safer, intuitive, friendlier, and easier to adapt. Ultimately, the design professionals will be creating more successful buildings.



Jim Derksen at York Steps, Ottawa



# Pathways, Potholes, Paradoxes, and Possibilities

By  
John Rae<sup>1</sup>

Over the past twenty or thirty years, the world has undergone dramatic changes. This is also true in the lives of persons with disabilities, including those of us who are blind, deaf-blind or partially sighted.

We used to say that access to information was our greatest barrier, then the internet came along, and now we also must deal with information overload, yet Donna Jodhan was compelled to file a Charter challenge against the federal government over inaccessible federal government websites.

Technology has made it possible for some individuals with disabilities to live more independent lives, yet much of the world's new technology is not developed with us in mind, often requiring work around or expensive adaptations.

The range of jobs is probably wider, yet some jobs that employed numbers of blind persons, like darkroom technician, transcriptionist, and telephone operator have been rendered largely obsolete by this same technology.

Braille is easier to produce than ever before, yet less and less is being made available, as some incorrectly argue it is no longer needed.

More and more blind students are attending colleges and universities, yet, even in this more technological era, these students must still deal with obtaining essential texts and other course materials in a readable format and timely manner.

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<sup>1</sup> John Rae, Vice Chairperson of CCD, has 36 years of active involvement in Canada's disability rights movement.

The Charter of Rights and Freedoms protects the rights of persons with disabilities, but the federal government cancelled the Court Challenges Program, which makes it extremely difficult to go to court to test the reach of these rights.

Human rights codes now cover persons with various disabilities, yet enforcing our rights have too often become bogged down in legal procedural wrangling and growing case backlogs.

Descriptive narration is now being introduced to some movies and television shows, but some Canadian broadcasters will not, or cannot, "pass through" the described video (DV) track from some American programs that already include the DV track.

Intervenor services for deaf-blind persons have been developed, but governments have failed to adequately fund these critical programs and today they are also facing cutbacks.

Many museums are more physically accessible, but their displays often contain even more "hands off" restrictions than in years past.

More blind persons are out and about in their communities, yet few restaurants offer Braille or large print menus.

More and more audible pedestrian signals are appearing in our communities, but community pressure leads to some being turned off at 10:00 or 11:00 p.m., long before some of us are home and snug in our little beds.

Studies tell us public attitudes have improved, but our level of employment has not increased significantly.

And while there is now a growing network of consumer-led organizations of us rightsholders across Canada, governments and businesses too often still turn to service organizations when they are seeking advice on disability issues.

Disability is the only equity seeking group that everyone can, and many will, join during their lifetime, and with the aging of the baby boomer population, more and more individuals will experience disability, either permanently or temporarily, and so may their family members, friends or associates. Thus, it is in everyone's interest to help persons with disabilities join the mainstream of Canadian society.

The more persons with disabilities are employed in newsrooms, the more likely we will see stories that cover the reality of our lives, and that will tell the public about our aspirations and needs.

The more we work with developers and manufacturers of new technology, the more likely that universal design approaches will be built in from the start of the development phase.

The more Canadians with disabilities participate actively in the political process-- as staff members for the various parties, seek nomination as candidates, run for elected office, and succeed in getting elected-- the more we will be participating in the decision-making that will help bring us into the mainstream of Canadian society.

The research has been conducted. The recommendations are in. As our numbers continue to rise, how will we see increased government and business commitment and concrete action?

Engage with us. Involve us. Collaborate with us.

# Inclusion by Design

By

Jeffrey D. Stark<sup>1</sup>

Today, I can access my bank account wherever I am from the browser in my mobile phone. My credit card company provides me with up to the minute reports on transactions that occur by text messaging my mobile phone and sending me regular email updates. I can find out where I am by checking the GPS on my mobile phone. I can read documents, take notes, keep track of my day-to-day activities, communicate with colleagues and keep in touch with loved ones via text, audio, video or email, all from my mobile phone. I can point the camera of my phone at a piece of paper and have it read out verbally the content of that document. I can grab my phone and find out the weather outside even though I can't see it through the window in my room. Yes, I can also use it to call people.

The mobile phone has been the single most influential technology to shift people's lifestyle and the way they perform certain tasks. This little small pocket computer, that has been the enabler for myself as a blind person and leveled the playing field for many people with disabilities, did not get to where it is today without a number of significant events over the last 20 years.

Inclusion by design in the information and communication technology domain has been a long, uphill journey.

Many advocates pushed for information in an electronic and accessible format: from banks, such as the Royal Bank, being required to provide statements and banking information in an accessible format to governments being required to create information and communication systems that are accessible. This means that today, technology such as the screen reader on my mobile phone has information that I can consume in an independent, effective and efficient

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<sup>1</sup> For the last 20 years, technology has been Jeffrey's focus both professionally and personally. Professionally, Jeffrey is widely respected as an expert in his field of interest and has been a guiding voice in a number of accessibility initiatives in Canada. He has provided training for developers, publishers, technicians and a wide variety of other audiences across Canada on topics such as accessible application design, web accessibility & adaptive computer technology.

fashion. Without these challenges being overcome, my mobile device would just be a phone. Yet there is still work to be done in this space as new companies, services, technologies and media become available.

Many advocates pushed for mobile phones to be created with features that made them usable by people with disabilities. The National Federation for the Blind in the US convinced Apple to make their devices usable by people who are blind. The Alliance for Equality of Blind Canadians, Neil Squire Society and many other disability-related organizations helped to convince the Canadian Radio-television and Telecommunications Commission that carriers should provide phones that are operable by Canadians with disabilities.

Ideally we'd like change to happen on its own. However, sometimes change requires a catalyst; when that change happens, companies can fight it or embrace it. Accessibility and inclusion should be something sexy and something a company can be proud of. There is no better example of this than Apple who have gone on to market accessibility as something that makes them distinct and you know they have truly "got it" when that inclusion is a key note in their marketing to the mainstream.

# Visitability - is it too much to ask?

By  
Olga Krassioukova-Enns<sup>1</sup>

There is growing awareness and interest in visitability in Canada. Visitability lends itself to social interactions among friends, family, and neighbours in the community, but more importantly, in each of our homes. It guarantees that regardless of physical mobility everyone will be included and able to visit a friend's home, feel welcome to share meals and use the washroom. Visitability is a policy and technical strategy to change the way we think about social inclusion, interactions in our own homes, and participation in our communities. It begins to address the evolving needs of seniors, people with limited mobility, children and parents. In order to make visitability the norm we require inclusive and sustainable approaches to community planning and the design and construction of single and multifamily homes.

In order to make all homes more usable and safe for the people who inhabit them and more welcoming for those who visit them, three basic features are essential: a zero-step entrance, wide doorways (at least a 32" clear opening), and an accessible bathroom on the main floor.

In 1976, Sweden started using the term of visitability and practicing the design strategies that subsequently filtered into the rest of Europe, the United Kingdom, Japan, Australia, the United States, and finally into Canada in the beginning of this century. Eleanor Smith, the founder of "Concrete Change," pioneered visitability in North America in 1980s when as a young girl she was excluded from birthday parties and other social gatherings on the basis of "home design (steps, narrow entry, no accessible washrooms)." She began this social movement that is now changing the way we design, build, and live in our homes. Visitability is bridging gaps in the accessibility between public and private spaces, and is becoming known as an affordable and sustainable design strategy for increasing basic access of family homes and neighborhoods.

We have seen significant progress in accessibility of public buildings and spaces, driven by legislation support, but single-family homes have yet to have similar

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<sup>1</sup> *Olga Krassioukova-Enns*, executive director of the Canadian Centre on Disability Studies, has more than 25 years of international experience in disability policy, programs/project design, implementation and evaluation, as well as research, curriculum development, teaching and administration. Educated as a medical doctor, trained in policy development and participatory research, she has been involved in numerous national and international projects with the focus on disability studies development and teaching, aging and disability, visitability, livable and inclusive communities, inclusive education, universal design, poverty reduction, as well as international and social development.

requirements. The United Kingdom, the United States, Japan and Denmark are but some of the countries that have incorporated visitability into the codified requirements for housing. In Canada, CSA Standard B651 has recently introduced technical specifications for visitability and the province of Manitoba is taking a lead in both the research and practice of visitability. Furthermore, some municipalities in British Columbia, such as Saanich and North Vancouver have embraced the concept of visitability and have developed bylaws requiring their incorporation into new housing.

Visitability is a movement to change home construction practices so that virtually all new homes – not merely those custom-built for occupants who currently have disabilities – are equipped with a few specific features that make them easier to live in and visit for people who develop mobility disabilities.

Visitability is a major element of social inclusion; it is about our friends, family, neighbors, and it is about everybody's home. The concept of visitability offers a simple and affordable solution to the changing needs and desires of a population that seeks to stay active and connected with other people while remaining in their homes. It is a solution to make our communities more livable and inclusive.

# Accessible Currency: A Story of Canadian Innovation and Continuous Improvement

By  
Vangelis Nikias<sup>1</sup>

About ten years ago, shortly after the tactile mark (often referred to as Braille) had been added to the Canadian currency, I found myself being admonished by a friend in Newfoundland, who managed to combine his British humour with the Rock's legendary flare for linguistic expressiveness. "Nicholaus," he said-- that is how he addressed me, unable to master accurately neither my first nor my last name which sounded Greek to him. "Nicholaus, you now have to do something to get more of this accessible money into the hands of blind people. This will bring them even more enjoyment and satisfaction. " While this comment was offered in gest, it does reflect an existing challenge blind and other Canadians experiencing various disabilities continue to face; namely, weak labour market participation and, hence, poverty. In other words, CCD's work is not finished. Neither is the work finished for rendering paper bills fully accessible to all print-disabled persons. We have, however, made considerable progress.

Last June, the Bank of Canada announced that it was going to issue a new series of bank notes, starting in November 2011 with the \$100.

The Polymer Bank Note Series will contain enhanced security features. It will also retain the same suite of accessibility features which, however, will be improved based on recommendations resulting from a study conducted in 2007.

The first recommendation addresses improved durability of the tactile feature. "The polymer substrate is a much more durable material and will retain the tactile feature longer than the current paper notes do."

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<sup>1</sup> Vangelis Nikias codirected, with Bank of Canada officials, the accessibility features project in the Canadian Journey Series while Director of Government Relations of the CNIB.



The second improvement concerns access by people who prefer to use the bank note reader. “The bank note reader code will be placed at both short edges of the note so that the bank note reader can denominate the notes in any orientation.”

#### Matters of Tangible Progress

The above enhancements will render the Canadian bank notes even more accessible and usable for print-disabled Canadians.

I had become involved in the Canadian Journey (CJ) series of bank notes which included a number of accessibility features: an improved bank note reader, larger numerals, and higher colour contrast. These features were not new but built on previous initiatives. These improvements, as well as the innovation in the Canadian Journey series, of the tactile mark, were tested and validated by a number of focus groups of blind and vision-impaired people that we conducted across the country. In this sense, then, the effort involved in the CJ series, in addition to the technical improvements, brought into the process of design and development a broadly-based user-participation component; a voice, a view, a touch of our own.

The Canadian accessible currency represents a tangible example of changing our environment to make it more accessible and more inclusive for all, regardless of how they recognize and handle paper money. The effort itself, in its development and suite of accessibility features, anticipates the principle of universal design incorporated in 2006 in the Convention on the Rights of Persons with Disabilities (CRPD). It is also based on the legal requirement of equality enshrined in the *Canadian Charter of Rights and Freedoms* without which it may not have happened. It also reflects the principle of progressive realization, whereby we seek to remove barriers and move toward ever-increasing inclusion. We do not need to wait for perfect solutions and perfect circumstances as those rarely occur.

It is tangible proof that it makes sense to undertake progressive steps, learn from our experience, including our mistakes, take advantage of enhanced

technologies and move on. This is, in fact, what we have agreed as a community, internationally, in CRPD and have committed to through ratification as a country. Continuous improvement is the key to further success in our commitment to build an inclusive and accessible Canada. The Polymer series is, it is hoped, another “durable mark” toward achieving this goal.

# Service Animal Teams: Now and In the Future

By

Terrance J.Green<sup>1</sup> and Helen Smith<sup>2</sup>



Although people who are blind have used dogs as guides for centuries, and guide dogs have been generally accepted by the public for over 85 years, recognizing the many other ways in which assistance animals can help persons with disabilities is a relatively recent phenomenon. Assistance animal organizations are scrambling to keep up with the need for training standards, which are the basis for the legislation that allows the animals to accompany persons with disabilities into public places. Those same standards are necessary to assure the person with a disability that the animal has been selected and trained appropriately to form the bond necessary for an effective service animal team.



Terry Green was certified with his first guide dog in 1982 as the human member of a service animal team. Over the past 30 years, he has been denied access to hotels, taxis, restaurants, drug stores and other public spaces simply because of his guide dog. The same denial of access to public space for service animal teams other than guide dogs and their handlers, much of which originates from a lack of understanding of the roles animals play in a service animal team, is now prevalent across Canada. All 14 jurisdictions in Canada now have statutory protection for service dogs, and some even for service animals, which extends protection to animals other than dogs. But these laws have to be publicised and enforced.

Although guide dogs have, for the most part, been accepted in Canadian society, other service animals such as hearing ear dogs, mobility/special skills animals,

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<sup>1</sup> Terrance J. Green, B.A., L.L.B., M.P.A., was born in Halifax, N.S. May 1951.

He has been an advocate of rights of persons with disabilities since he was a teenager, first, for persons who are blind, then rapidly moving into cross-disability issues as the publisher of the tabloid, "Touchstone – A Voice Of Our Own." He is a recipient of awards of excellence and the Governor General's 125 Commemorative Medal for his work in social equity.

Now he takes his knowledge of disability issues into the courtroom as a lawyer in Ottawa, litigating for rights. As the chairperson of ASIST/Assister ([www.assist.ca](http://www.assist.ca)) he is working towards the adoption of standards for the training and certification of all types of service animal teams.

<sup>2</sup> Helen Smith is author of *Ottawa's Farm: a History of the Central Experimental Farm*. She is secretary to the board of ASIST/Assister.

psychiatric support animals, anxiety or panic service animals, medical alert animals, autism support dogs, and many others have yet to be accepted. "Ignorance is bliss" may be true for the general population, but the lack of public education about various service animals can lead to "pure hell" for the service animal team.

Teamwork is crucial. The person with the disability relies on a support team of family, friends, medical personnel and trainers, but, in becoming part of a service animal team, it is equally important for that person to build and maintain a strong bond with the animal they select as their animal team partner. The human-animal bond forms the basis for the human-animal team. Each partner in a team – human or animal – has needs that deserve equal consideration. Taking care of all needs makes the team stronger and the partners work better together. Integrating all the elements necessary to produce a strong, successful team is how persons with disabilities will educate, by example, Canadian society.

Over the past 30 years, Canadian society has taken steps to protect the rights of guide dog users. Now, it is time for it to expand its understanding of how animals can help with other types of disabilities and include the same protection for all service animal teams.



Churchill Green, guide dog

# Communication: The Themes Remain the Same

By  
Jeffrey D. Stark<sup>1</sup>

Communication is a very common theme that comes up time and time again in the disability community; whether that's access to information such as printed material or the ability to be included in a conversation. The barriers change as our world changes but the themes and common elements have remained the same over the last 30 years.

In a professional setting being able to communicate and having access to the information being communicated in many cases is the difference between being able to do the job and not being able to do it. If you can't hear the verbal information being provided, or you can't see the information being referenced, you are essentially excluded from an important component of the activity.

I, as a person who is blind, have found myself in this situation many times. If I go to a meeting and all the information is put up on a front projector, then I am essentially excluded from that material. One commonly proposed solution to this is to have the presenter or leader for a given activity read out whatever material they have on the flip chart or front projector. As you can imagine, this is awkward and time consuming at the best of times and doesn't really let me review the material. As computers, laptops and electronic notetakers became commonplace, the proposed solution that used to be common was to distribute the material electronically in advance and hope I could figure out which document, page, slide and information was currently being referenced. If a group wanted to collaborate on the same document or material, then this becomes even less effective because my copy of the material gets more and more stale as the updates to the document occur.

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<sup>1</sup> For the last 20 years, technology has been Jeffrey's focus both professionally and personally. Professionally, Jeffrey is widely respected as an expert in his field of interest and has been a guiding voice in a number of accessibility initiatives in Canada. He has provided training for developers, publishers, technicians and a wide variety of other audiences across Canada on topics such as accessible application design, web accessibility & adaptive computer technology.

My requirements are not unique and meetings and collaborative sessions have often been a barrier. This area has evolved tremendously over the last 20 years. Unfortunately, until recently many of the solutions were only available as separate solutions that each required a different technology component and required a huge undertaking to provide. Captioning, sign language interpretation, accessible information, accessible flip charts, alternate communication systems were all separate components and all had to be handled separately.

At a recent meeting I attended, for the first time in my career, I was able to play on an equal footing. I had access to the same information as my sighted peers during the meeting and had access to any new information or changes that happened on the front projector. They had this nifty box called an "Accessible Event Hotspot" that acted like an "accessible projector". I connected my laptop to the AE Hotspot and the same information that was projected on the front screen was also pushed out to my laptop. This meant that I could review it in my medium of choice using my technology of choice (a screen reader). As soon as a change happened on the presenter's screen, the same information was provided to me in real time. This same device can also be used to capture and present other channels of information such as captioning and signing. This essentially makes it an all-in-one solution for people who have hearing impairments, visual impairments, or print-related disabilities so participants can take full advantage of all aspects of any on-site or online event or presentation. This technology allows participants with disabilities to access slides, spreadsheets, web pages, documents and real-time captioning.

This is essentially full inclusion, where the various channels of information from the spoken information to the presented information can be supplemented in real time with equivalents that ensure that everyone can participate on a level playing field.

# ***Abilities* Magazine**

## **Reflecting and Inspiring Change**

By

Raymond D. Cohen<sup>1</sup>

It's hard to fathom that barely a generation ago many people with disabilities were locked up, warehoused and denied access to the community. When I created *Abilities* magazine 26 years ago, the medical model was in full swing. People with disabilities were considered “patients” to be dealt with, rather than people who were capable of—and deserving of—the ability to make choices for themselves and work towards self-actualization. Over the years, we have watched as institutions closed down one by one in favour of community inclusion. We have been proud to bear witness to—and share with our readers—the paradigm shift to a social rights model of disability.

As a lifestyle magazine, we cover topics from relationships and parenting, to work and travel, to social policy and rights issues. And, over the many issues of *Abilities*, we have seen progress in every one of these areas. Certainly in terms of accessibility, but perhaps more importantly, we have also observed a transformation in how the general population—and significantly those with disabilities themselves—think about disability.

It has not always been easy. There are unique challenges that accompany disability. We believe that if government continues to put structures into place to level the playing field and promote independence and accessibility, and if the mindset within corporations and communities continues to further embrace diversity, anything is possible.

Over the last 26 years, *Abilities* has both reflected—and, hopefully, inspired—change. Back when issue number one was at the printer, there were few

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<sup>1</sup> Raymond D. Cohen has occupied human service positions at major centres across Canada, including Montreal, Vancouver, Calgary and Toronto. His positions have ranged from front-line to senior management, and working with, and consulting to, the corporate, non-profit, and government sectors. Today he is the Chief Executive Officer of the Canadian Abilities Foundation and editor-in-chief of *Abilities* – Canada's Lifestyle Magazine for People with Disabilities.

opportunities for people with disabilities in terms of housing, transportation, accessibility and human rights. Now, the bar is continuously being raised in all of these areas. I like to think that *Abilities* has provided a positive voice leading towards a more positive sense of disability both within and beyond the disability community.

It has, after all, been a meeting place of sorts—a place where corporations, governments, service organizations and consumer rights groups have all found common ground—and we all know that this is rare in a world filled with far too many “silos.”

There have been significant milestone events over the years and *Abilities* has stood in testimony to all of them: Canada’s ratification of the UN Convention of the Rights of Persons with Disabilities; new accessibility legislation in Ontario; the proliferation of enabling technology and so much more. We have seen it and we have shared it with our readers.

In our Forum section, we have also carried the word of the major disability organizations across Canada so that they, too, could reach out to our audience. We’ve all come a long way over the last 30 years—people with disabilities and their families are becoming socially and economically empowered. There is much to celebrate. But we can’t stop the revolution now. There is a long (and exciting) journey ahead to create the kind of world that we want for ourselves and for generations to come. And *Abilities* magazine will be there to report on it as it happens.



# *Social Policy*



# Special Parliamentary Committee on the Disabled and the Handicapped

By  
Sherri Torjman<sup>1</sup>

A significant turning point in Canada's awareness of disability issues came in 1981, the International Year of Disabled Persons. In respect of that designation, Canada appointed an all-party House of Commons Committee to identify the challenges related to disability and to propose recommendations for change.

It was the first time in Canada that such an exhaustive inventory had been undertaken on disability. The Committee produced the *Obstacles* report, which made recommendations on all major policy issues including human rights, income security, employment, technical aids and devices, transportation and communications.

One of the most important aspects of 1981 was that it preceded the year in which Canada repatriated the Constitution. The *British North America Act* of 1867 became the *Constitution Act* of 1982. The *Act* was going to embed a *Canadian Charter of Rights and Freedoms*, which was being drafted. Several Committee advisors saw the introduction of the *Charter* as a once-in-a-lifetime opportunity to protect and promote the rights of persons with disabilities.

Not surprisingly, the Government of Canada was not keen to include disability protection in the *Charter of Rights and Freedoms*. There was no precedent for this Constitutional inclusion anywhere in the world. The federal government was worried about being swamped by lawsuits and associated costs – ironically, a fear that demonstrates how much this legislative protection actually was required.

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<sup>1</sup> Sherri Torjman is currently Vice-President of the Caledon Institute of Social Policy. Sherri worked as a researcher for the House of Commons Committee on the Disabled and the Handicapped in 1981.

After extensive deliberations, the federal government made an offer to the Committee. The *Charter of Rights and Freedoms* would include prohibition of discrimination on the basis of physical disability. Mental disability would not be incorporated in the *Charter* because the implications were unknown and potentially too great.

Members of the House of Commons Committee faced a serious *crise de conscience*. They knew that this was a unique opportunity to ensure inclusion of disability in the *Charter*. How many times in the course of history does a country renew its Constitution? But they also knew that excluding mental disability from the *Charter of Rights and Freedoms* would make the Committee guilty of the very discrimination that its members were fighting to overcome. The acceptance of physical disability alone would have been a hollow victory at best.

The Committee decided to refuse the offer. The Government was surprised by the response and agreed to back down. Canada became the first country in the world to include in its Constitution the protection of the rights of persons with physical and mental disabilities.



Pat Derrick, Sherri Torjman, Senator Smith, Mercedes Benegbi and Jim Derksen

# Reflections on Parliament and Disability

By  
William R. Young<sup>1</sup>

For the past three decades, the Canadian Parliament and its Parliamentary Committees have had an enormous influence not only on the disability policy debate, but also on disability policy development and the lives of Canadians with disabilities.

It began with the International Year of Disabled Persons – 1981, when Parliament set up an all-party House of Commons Special Committee on the Disabled and Handicapped and mandated it to undertake a comprehensive review of disability issues. In its report, *Obstacles*, the Committee made 130 recommendations that touched the universe of the social, economic and legal situation of people with disabilities. These dealt with human rights, leadership and coordination of disability issues, employment, income, disability supports, access to information and communications, transportation, Aboriginal peoples with disabilities, among many. *Obstacles* set a benchmark that lasted for well over a decade and served as the impetus for significant reforms that promoted the inclusion of persons with disabilities in Canadian society. At the top of the list of major reforms that followed the release of *Obstacles* is the recognition of disability as a ground for discrimination in Section 15, the equality guarantee clause of the *Canadian Charter of Rights and Freedoms* contained in Canada's *Constitution Act (1982)*.

Nothing since has equalled the range and scope of *Obstacles*, but the Parliamentary offspring of the *Obstacles* committee, successor committees with mandates to study disability issues, kept up their work studying ways to level the playing field for people with disabilities and the means of furthering inclusion. They issued reports with recommendations and government after government – no matter which political stripe – was held accountable for its actions and responded sympathetically to the committees' concerns. Committees produced reports outlining the need to include people with disabilities in the implementation of the Charter (*Equality for All*, 1985), for ways of dealing with media stereotyping, (*No News is Bad News*, 1988), for a comprehensive disability strategy (*Challenge*, 1987; and *A Consensus for Action*,

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<sup>1</sup> Dr. William (Bill) Young, Parliamentary Librarian.

1990), for appropriate treatment of the additional costs of disability (*As True as Taxes*, 1993), for recognition of the situation of Aboriginal People with disabilities (*Completing the Circle*, 1993), for transportation systems that accommodated people with disabilities (*Getting Back on the Road*, 1993) and for overall economic and social inclusion (*Profitable Choices for Everyone*, 1993; *The Grand Design*, 1995 and *Reflecting Interdependence*, 1999).

Parliamentary committees developed such expertise that in 1996 the government called upon several MPs to participate in a Federal Taskforce on Disability Issues. In its October 1996 major report, *Equal Citizenship for Canadians with Disabilities: The Will to Act*, the Task Force recognized a federal role with regard to disability issues and a need for a disability policy framework. The Task Force believed that the government should use the levers available to it – the tax system, federal legislation, and federal fiscal transfers to the provinces – and that it should develop an overarching approach that would include all relevant federal departments and agencies. Among many other recommendations, it called for the appointment of a minister responsible for disability issues and for the publication of an annual report on disability issues. It also recommended that the *Canadian Human Rights Act* (CHRA) should be amended to include an obligation to accommodate people with disabilities (see sections 2 and 15 of the CHRA).

Following this, in March 2002, the Subcommittee on the Status of Persons with Disabilities tabled a report concerning the administration of the Disability Tax Credit (DTC) by the Canada Customs and Revenue Agency (CCRA). The report, *Getting It Right for Canadians*, acknowledged the necessity to make the DTC work more fairly for people with a mental illness and those with learning disabilities. It also addressed the need for the tax system to recognize cyclical, progressive and degenerative diseases like multiple sclerosis. In its 16 recommendations, the Subcommittee called for immediate action to reform the DTC. The report was one of the forces behind reforms to the tax system in the years that followed.

From *Obstacles* onward, parliamentary committees distinguished themselves by the way that they provided access to, listened to, heard and understood, citizens with disabilities. In particular, the Subcommittee on the Status of Persons with Disabilities made Canadian history in 2002 by conducting the first online consultation by any parliamentary committee in Canada -- among the

first carried out by any legislature in the world. The topic -- the Canada Pension Plan Disability Program [CPP(D)]. The Sub-committee determined that Canadians widely supported a public disability insurance program based on the principles of universality, portability, user contributions, and partial wage replacement. In its 2003 report, *Listening to Canadians*, the Subcommittee made 53 recommendations focused on near-term improvements that should be made to the CPP(D) program, including a host of administrative and program modifications aimed at making the program more flexible and responsive to the needs of people with disabilities.

This story of Committees during the last thirty years has been, in many ways, a unique contribution in disability – and parliamentary – history. To a large extent, this record of achievement boils down to the fact that when disability issues were not on anyone else’s radar screen, Senators and Members of Parliament recognized that people with disabilities had the same rights as other citizens and that economic and social inclusion benefitted all Canadians. They put aside their partisan differences to make common cause in searching out ways to improve the lives of their fellow citizens. In doing this, parliamentary committees demonstrated the possibilities, not just for Parliament but for the lives of people with disabilities.

# Taking Policy (or lack thereof) To Task

By  
Traci Walters<sup>1</sup>

The writing was on the wall with the introduction of the new Canada Health and Social Transfer (CHST). Federal disability programs and funding were being clawed back, eliminated or downloaded to the provinces. Disability leaders became publically vocal about what they saw as the federal government abandoning people with disabilities.

On June 5, 1996, Human Resources Minister Doug Young, Finance Minister Paul Martin and National Revenue Minister Jane Stewart announced the creation of a Task Force. Dissent from within the Liberal Party over the way in which Mr. Young was handling disability programs led to the creation of the Task Force. On June 6, 1996, *The Globe and Mail* reported on its front page: "Mr. Young unleashed a firestorm of protest... with his unequivocal comments about the government's plans to get out of disability programming." In addition, *The Globe* reported that "the task force emerged after other ministers, back-benchers and advisers in the Prime Minister's office complained about his [Mr. Young's] approach."

Shortly after the announcement of the Task Force, representatives from 22 national disability organizations met with Andy Scott, MP and newly appointed Chairperson of the Task Force to discuss its mandate. The disability community urged Mr. Scott to appoint observers to the Task Force which would lend credibility to the process.

Andy Scott agreed and Lucie Lemieux-Brassard (Council of Canadians with Disabilities (CCD)), Fred Clark (Canadian Hard of Hearing Association (CHHA)) and myself (Canadian Association of Independent Living Centres (CAILC), now Independent Living Canada (IL Canada)) were elected by the national groups to be the official observers. Other Liberal Members of Parliament appointed were Andy Mitchell, Anna Terrana and Clifford Lincoln.

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<sup>1</sup> Traci Walters, the retired National Director of Independent Living Canada, is an award winning disability educator/Independent Living leader, Alumni - Governor General's Leadership Conference, Recipient - International Meritorious Service Award for Endless Effort and Passionate Heart by the Global IL Network. Traci continues to passionately promote the Independent Living Movement as a volunteer IL Ambassador.



We set out across Canada to consult with the disability community and answer some fundamental questions about the role of the federal government in the lives of people with disabilities.

In the beginning we anticipated that as observers we would probably be at odds with the Members of Parliament. As a group we travelled to every province and territory to consult with the disability community and stakeholders. We spent a great deal of time together on buses, planes, in airports, hotels and over meals. With shared experiences like this we naturally bonded.

Over the consultation period, the MPs began to understand the issues from a disability perspective and as observers we were able to see what was possible and what wasn't from a political and jurisdictional perspective. We ended up becoming a team and were "on the same page" so to speak. If I remember correctly, there was even some criticism that we were becoming too close.

Behind the scenes, the expert researchers/writers gathered comments from consultations, sifted through written submissions and sat through numerous presentations by various academics. I do remember many positive ideas that were being floated about but I will never forget one presentation where the presenter suggested that individuals who receive the Disability Tax Credit should submit receipts for their expenditures. That was one day that my jaw dropped to the floor. I guess the presenter believed that some people with disabilities were scamming and this needed to be controlled.

To that end, after deliberations the Task Force members (including the observers) gave their stamp of approval on the report entitled "Equal Citizenship for Persons with Disabilities – The Will to Act" which covered issues such as citizenship, employment, income support, funding and taxation. The federal government responded by immediately addressing 8 of the recommendations.

Mel Graham, then a CCD Communications Officer, wrote, “Without their credibility and the skills they [the Observers] brought to the process, the Liberal Task Force on Disability Issues might have been little more than another valiant attempt at inclusion that, in the end, faded into a public relations exercise.”

Following the federal government’s re-election in 1997, the Parliamentary Committee on Human Rights and the Status of Persons with Disabilities was dissolved. Responsibility for disability issues was shifted to the Committee on Human Resources Development. The focus became one of employment, not citizenship, and I don’t have to tell the disability community what has happened since then.

Looking back, 15 years later there are a few things I know for sure. Firstly, the process was absolutely the most inclusive government/community exercise that I was ever involved with during my career. Secondly, I know for sure that none of it would have happened if it wasn’t for key disability leaders becoming publicly vocal and refusing to watch the government further erode what was left in disability programming. And lastly, I know for sure.....the report is still relevant in 2011.

# Legislative Reforms

By  
Michael J. Prince<sup>1</sup>

I wish to talk about the *Employment Equity Act*, about legislation in several provinces on poverty reduction, and about accessibility laws. [Fundamentally important developments in the Canadian Human Rights Act, the introduction of the *Canadian Charter of Rights and Freedoms*, in 1982, and the UN Convention on the Rights of Persons with Disabilities, each with equality guarantees to persons with physical and mental disabilities, are discussed elsewhere in this booklet.]

Employment equity means more than treating persons in the same way; it requires the accommodation of differences through special measures *and* universal designs. First passed in 1986 and updated in 1995, the purpose of the federal *Employment Equity Act* is to achieve equality in the workplace so that no person shall be denied employment opportunities or benefits for reasons unrelated to ability and, in the fulfillment of that goal, to correct the conditions of disadvantage in employment experienced by persons with disabilities, among other groups identified in the legislation.

A recent annual report on the law states: “many employers have successfully implemented education programs for managers on accommodating persons with disabilities in the workplace and have brought in specialized equipment to assist members of this designated group in their work. These measures allow persons with disabilities to contribute more fully to their organization and allow employees who are injured or become disabled to return to work more quickly.” While there has been measurable progress, there is a need for continued and enhanced employer efforts on employment equity. We need to note as well that this law applies only to the 10 per cent of the Canadian labour force under federal jurisdiction.

Another significant policy development is that between 2002 and 2011, six provinces have formally adopted comprehensive poverty reduction plans, one part of which addresses the needs and circumstances of persons with disabilities. These provinces are Newfoundland and Labrador, Nova Scotia, New

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<sup>1</sup> Michael J. Prince is Lansdowne Professor of Social Policy at the University of Victoria.

Brunswick, Québec, Ontario, and Manitoba. Most have based their poverty reduction plans in legislation.

Year	Province	Title
2002	Québec	<i>The Act to Combat Poverty and Social Exclusion</i>
2006	Newfoundland and Labrador	No specific legislation
2007	Nova Scotia	<i>An Act to Establish a Poverty Reduction Working Group</i>
2009	Ontario	<i>Poverty Reduction Act</i>
2010	New Brunswick	<i>Economic and Social Inclusion Act</i>
2011	Manitoba	<i>Poverty Reduction Strategy Act</i>

Ontario has the *Accessibility for Ontarians with Disabilities Act, 2005*, which, among other goals, aims to develop and enforce accessibility standards with respect to goods and services, facilities accommodation, buildings and employment. Manitoba has new legislation, the *Accessibility Advisory Council Act, 2011*, the purpose of which is “to enhance accessibility by identifying barriers that disable people and the ways in which those barriers can be prevented and removed.” Examples of barriers listed in the legislation are physical, architectural, information or communications, attitudinal, technological, or a barrier established or perpetuated by an enactment, a policy or a practice. These reforms will likely take several years, if not a decade or more, to bring in transformative changes in these provinces; and, other provinces and territories should follow suit with similar legislation.

These legislative developments offer potential benefits and opportunities; present possible challenges; and, they raise questions for the disability community: How will the recent actions on accessibility and on poverty reduction influence disability policy development, horizontal coordination, specific program reviews and possible reforms? How does the document *In Unison: A Canadian Approach to Disability Issues*, agreed to in 1998 by Federal/Provincial/Territorial Ministers responsible for Social Services, relate to poverty reduction plans and to accessibility laws and standards? And, whatever happened to the idea of a national disability act in Canada, which federal political parties have endorsed?

# Technical Advisory Committee on Tax Measures for Persons with Disabilities

By  
Sherri Torjman<sup>1</sup>

The 2003 federal Budget announced the creation of a Technical Advisory Committee (TAC) on Tax Measures for Persons with Disabilities. Its mandate was to advise the Ministers of Finance and the Minister of National Revenue on ways to improve disability tax measures, with a special focus on the disability tax credit. Persons with impairment in mental function, in particular, had been disadvantaged in qualifying for this credit.

The Committee consisted of 12 members – consumers and individuals from various backgrounds including human rights, accounting and mental health. Their diverse areas of expertise made for lively debate. Finance and Canada Revenue Agency officials provided invaluable advice and support throughout the process.

The Committee’s exhaustive (and often exhausting) deliberations ultimately proved fruitful. Virtually all its recommendations were announced in the 2005 Budget. In fact, the government had set aside \$85 million upfront to implement the Committee proposals.

The TAC recommendations fell into three major categories.

The first theme proposed changes to the disability tax credit, which provides tax relief to individuals with severe impairments in function that restrict them in the activities of daily living. It is also available to those who require extensive therapy to sustain a vital function. The credit is based on the assumption that persons with severe and prolonged disabilities likely incur additional disability-related costs they are not able to claim under the medical expense tax credit.

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<sup>1</sup> Sherri Torjman is currently Vice-President of the Caledon Institute of Social Policy. Sherri Torjman and Bob Brown cochaired the Technical Advisory Committee.

The Committee called for legislative, interpretive and administrative changes that embody the principles of fairness and equity.

The second group of recommendations focused on the itemizable costs of disability and, more specifically, on tax measures that enable persons with disabilities to pursue education and employment. The Committee proposed a new deduction that recognizes the cost of disability supports purchased for education and employment. The new measure, announced as an 'early action' in Budget 2004, also helped broaden eligibility and increase benefits calculated on the basis of net income – e.g., the Canada Child Tax Benefit and the GST credit.

The third cluster of proposals focused on tax measures that recognize the additional costs of caregiving. The Committee also recommended assistance for private savings to help families ensure a better quality of life for their children with severe disabilities. The Registered Disability Savings Plan (RDSP) was announced in 2007.

While these improvements are vital, the Committee concluded its deliberations by recommending that any new funding to promote inclusion for persons with disabilities not be allocated to tax reform. TAC members preferred investments that would enhance the availability and quality of disability supports.

# The Emergence of Individualized Funding in Manitoba--“In The Company of Friends”

By  
Clare Simpson <sup>1</sup>

Thirty years ago I had recently ended employment with the Manitoba Association for Community Living (30 years ago the organization was called the Canadian Association for the Mentally Retarded, Manitoba!) – the name change alone is a significant accomplishment!!

At the Board of Director’s level in the organization there was considerable discussion about moving people out of the institutions in Manitoba; small community residences were springing up in urban and rural areas. The idea was that people living in small groups within a community would be a step closer to community inclusion, and that each would enjoy more private space and could better participate in and contribute to community life. This was true, however there was still one major hurdle – individualized funding!! People living in community residences or small group settings are still confined to the common good of the “group”, confined to the budget of the residence, confined to staff whom they may or may not get along with, to eating as a group, to recreating as a group, to sharing space with others. Individual aspirations, dreams, and goals often were not realized due to the limited time, energy, skill and motivation of residential staff.

In the late summer of 1993, my husband Allan and I were invited to meet a young adult man who had lived most of his life in an institution in Winnipeg. Ron had lived at St. Amant Centre since the age of 2. He was non-verbal, disabled due to spastic cerebral palsy and also an intellectual disability. He required the use of a wheelchair for mobility and needed assistance with most aspects of his personal care – AND he wanted to move out of the institution. On meeting this personable, handsome and determined man, I was amazed to witness his forward thinking and determination to make a change in his life. So began a new

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<sup>1</sup> Clare Simpson is currently an employee of the Council of Canadians with Disabilities. She has been active in the disability rights community since the mid-seventies and involved with the program “In The Company of Friends” for 18 years.

adventure for my family as Ron invited us to join his Support Network and help him plan for his move into the community.

At the same time I was aware that the Manitoba Government, together with a group of determined individuals from the community, had come together as a Steering Committee and were about to launch a demonstration project to promote deinstitutionalization – IN THE COMPANY OF FRIENDS (ICOF). This project was to demonstrate that an individual with an intellectual disability could live in the community with the guidance and advice of a Support Network (a group of friends, family and associates) who would voluntarily support a person to make life decisions. Participants in the ICOF project would receive dollars directly to live their life – hire staff, rent an apartment, purchase goods and services, make decisions on how to spend their time.

In 2011, Manitoba now funds the program, In The Company of Friends, to over 60 individuals. ICOF is one option of supported living within the Department of Family Services. It is a program which has moved well past the demonstration phase. It is an example of Individualized Funding, independent of the provincial Income Assistance program. The one criteria is that a Support Network of friends and family must be in place and active with each participant.

An organization called Living in Friendship Every Day (LIFE) was formed in 2000 to provide a resource to the participants of ICOF, to monitor and assist with the maintenance of Support Networks and to ensure the integrity of the ICOF model is upheld.

Other provinces in Canada now have programs similar to ICOF. Manitoba is unique in that participants budget and receive funds for all aspects of their life (housing, food, transportation, staffing, leisure, etc.).

For Ron, having access to his own funds to determine his own lifestyle, has been life changing. He lives where he chooses, he hires staff of his choosing, he plans volunteer/leisure time of his choosing, he is making the same difficult decisions about money management that most people face. His life has been challenging, full of decisions and new experiences. I have been involved on Ron's support



network for 18 years. At times it is very hard work, but having watched Ron develop and grow in character, convinces me with no doubts that Individualized Funding gives to an individual personal freedom, personal determination and allows a person to develop a lifestyle of their choosing. While traditional caregiving services still exist in all provinces across Canada for individuals with an intellectual disability, the concept of Individualized Funding has been demonstrated as a positive step forward.

Life has changed dramatically for people who are a part of the ICOF supported living program over the past 30 years.

# Self-Managed Attendant Services Direct Funding Program – DF for short - in Ontario

By  
Sandra Carpenter<sup>1</sup>

When I was in my early 20's, there was a vocational rehabilitation guy working for the Province of Ontario, named David Pitt, who was going around saying (and here I paraphrase) that the concept of funding people who needed support, rather than the programs that provided those supports to them, might better enable individuals with disabilities to achieve independence in society.

This concept always intrigued me. I used to spend hours thinking about how the costs society already spent on me – the costs of being in an institution, the costs of income support, the costs received by specialization transportation services, and later the costs of various attendant service programs in the community – might have had far more leverage towards my independence if given directly to me, all in one huge lump sum, rather than given to me in dribs and drabs over many years through a host of government programs.

By the 80's when I was in my 30's, the Independent Living Movement and philosophy was beginning to really take hold. Canadian versions of Independent Living Resource Centres (ILRC's) emerged. These were largely in response to a growing anti-institutionalization sentiment among those of us who, thanks to advances in medical technologies, were living longer lives.

The DF model arose from Independent Living principles whose mandate is to allow individuals with disabilities to achieve self-determination, take risks, and achieve greater quality of life through;

- Consumer control
- Choice
- Individual responsibility
- Full participation in community life

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<sup>1</sup> Sandra Carpenter is a member of CCD's Social Policy Committee and is the Executive Director of the Centre for Independent Living in Toronto.

Very similar to basic human rights principles of autonomy, dignity, respect, inclusion, participation and non-discrimination.

After at least 10 years of negotiating, the Ontario Government agreed to launch DF as a pilot project in 1994. Following a highly successful evaluation report in 1997, DF became a Ministry of Health program in 1998. The DF project was steered by a committee of individuals and representatives from both the consumer (user) and Government sectors.

DF is unique in enabling adults with a physical disability to take full responsibility for managing their own attendants. The Centre for Independent Living in Toronto, working with other ILRCs in Ontario (10), negotiates monthly budgets with DF participants to meet their attendant service needs rather than provide direct service to them. This innovation has created a model which provides a high level of choice, control, responsibility and community participation for DF participants. It is individually flexible and portable within Ontario.

My dream is to see this model duplicated across Canada with automatic transferability rights, so that people will also have the portability and freedom to move from province to province. But seeing as how it has taken nearly 40 years to get to this point, I'm thinking that maybe other people will have to take up that cause.

I would like to acknowledge Ian Parker, Vic Willi, Hazel Self, Audrey King, Karen Yoshida, Marcia Rioux, Judi Fisher, Frank Wagner, Patrick Laverty, Warner Clark and many, many others who made DF a reality in Ontario today.

# The Disability Rights Movement in Quebec - 30 years of Accomplishments

By  
Lucie Dumais<sup>1</sup>

I've been interested in disability policy for ten years. While preparing this note, I reread historical texts from Quebec colleagues. I have witnessed remarkable progress in Quebec during the past thirty years, both in terms of action on policy and improvements in the situation of persons with disabilities. However, I surprise myself by making observations that invoke the difficult period experienced during the 1980s.

I often say it. Chatting with a young couple with disabilities at the grocery store only to have them leave towards their apartment, you would not have seen that before. During the past thirty years, our demands for social integration and standardization have become a reality. Quebecers have altered their views regarding disability and the potential of a great number of individuals. However, numerous spheres of activity are still closed to them. Substantive issues, such as inclusive education, divide public opinion, while other issues such as access to public transit remain unresolved. It must be noted that the workplace and programs enabling employment inclusion have evolved for the better.

I often hear that Quebec policies look nice on paper, but are infrequently applied. Have we lost the head start gained from the 1984 *À part... égale* policy, which proposed a global approach to the situation of persons with disabilities? Several associations had succeeded in imposing this forward thinking vision upon the Quebec state. They had united into a collective able to face a government that, albeit socio democratic in its tendencies, was still rather paternalistic. The late inclusion of discrimination on the basis of disability in the 1976 Quebec Charter of Human Rights also resulted from repeated pressure upon the government. During the 1990s however, the passage of time, the lack of handover and the public funding crisis weakened the associations and fractured the movement once again into regional or needs based particularities. This has diluted its cohesive force.

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<sup>1</sup> Lucie Dumais is a sociologist and political scientist who has worked in academia (Quebec and Ontario) for 20 years.

Have things improved during the 2000s? I am of mixed opinion on this. According to our research here at the LAREPPS, over 1,300 community groups and associations offer services to persons with disabilities in Quebec, of which 500 also include advocating for their rights in their mission. How can we then reunite into a common front? By comparison, the 1981 associative movement mini-summit encompassed 40 organizations. I think that needs based particularities have surfaced once again. This is in part tied to the offer of diagnostic services and ultra-specialized rehabilitation services for children, for example. The reconstruction of a common discourse, of a collective movement is therefore going through some difficult days. However, I cannot help myself from seeing a positive side to the current situation. Services to individuals are improving little by little and obstacles are vanishing. Some associations are finding, by themselves, the audacity and perseverance necessary to reinvent housing visitability with the assistance of bureaucrats and community organizations. As per thirty years ago, innovation in the types of services, or simply in construction, constitutes a true step forward in living conditions.

# Employment Equity and the Disability Rights Movement

By  
Michael Huck<sup>1</sup>



30 years ago, Canadians with disabilities came together and began to understand and resist the disability status quo. The US civil rights movement, women's liberation struggles, and anti-Vietnam War protests are the roots of our resistance. We witnessed and learned from the human rights struggles taking place south of the border.

Vietnam vets came home. Many came back with traumatic injuries and permanent disabilities. One of the most powerful images of the time was Vietnam vets in their wheelchairs, throwing their medals on war memorials. They were protesting the lack of programs and services for disabled returning vets.

Within this context of social and political upheaval of the 1960s and 70s, Canadians with disabilities began to organize themselves and to speak with a united voice. The Canadian disability movement identified employment as one of the most pressing social issues confronting Canadians with disabilities. Compared to the general population, Canadians with disabilities experienced higher rates of unemployment, lower labour force participation rates, lower educational attainment rates, occupational segregation.

The full and equal participation of persons with disabilities in the Canadian labour market required the recognition of our human rights under the law. In the 1980s, disability groups learned the tactics of advocacy and coalition building to change human rights law to include disability as a protected category. The advocacy work of the disabled community is reflected in the 1981 Obstacles Report prepared by the Special Parliamentary Committee on the Disabled and Handicapped. The disability rights movement focused on changes to the *Canadian Human Rights Act* and the inclusion of persons with disabilities under the *Charter of Rights and Freedoms*.

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<sup>1</sup> Michael Huck has been a CCD Chairperson as well as a Chairperson of its Employment Committee.

People with disabilities understood the need for a paradigm shift from a charity model focused on changing employer attitudes to a social model focused on changes to employer behaviour. Broad-based remedies were needed for a class of persons and not just for an individual. Advocacy efforts focused on making sure federal and provincial human rights legislation allowed for special programs like Affirmative Action. Affirmative Action programs recognize the importance of equality of results and understand that identical treatment does not necessarily mean equal treatment or lack of discrimination.

In 1984, Commissioner Rosalie Abella published *Equality in Employment: A Royal Commission Report*. Judge Abella introduced the term 'Employment Equity' to distinguish the Canadian approach to gaining equity results from the American affirmative action and claims of reverse discrimination backlash. Abella concluded persons with disabilities were systematically discriminated against in employment and that persons with disabilities should be included as an employment equity target group. The Abella Report called for federal government action, including the introduction of Employment Equity throughout Federal Public Service and Crowns, federally regulated industries, and federal contractors.

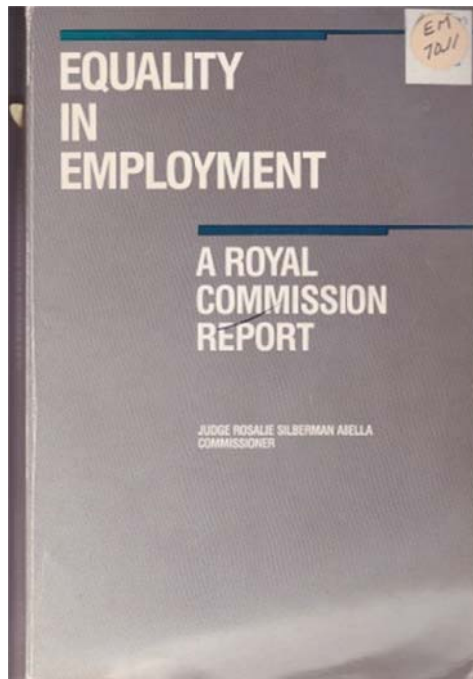
In 1986, the federal government passed the *Employment Equity (Amended 1995) Act* requiring federally regulated businesses (banks, airlines, interprovincial transportation) to achieve equality in the workplace. The Federal Contractors Program was also introduced requiring companies supplying goods and services to the federal government to implement employment equity.

The Government of Canada states it has achieved employment equity for persons with disabilities in the federal public service. The representation of persons with disabilities in the Federal Public Service has increased from 1.6% in 1987 to 5.9% according to the Annual Report on Employment Equity in the Federal Public Service 2008-09.

The disabled rights movement argues the workforce availability (WFA) is not representative of the population of persons with disabilities. It does not include potential and discouraged workforce participants with disabilities. The federal

government should set equity targets based on the percentage of people in the population with disabilities.

In a final analysis, persons with disabilities in Canada have made some gains with the introduction of employment equity programs. However, the facts remain. The vast majority of persons with disabilities are unemployed or underemployed and living in poverty. Persons with disabilities continue to experience direct and indirect employment discrimination. The work of the disabled rights movement to overcome these conditions continues.





# CPPD Reforms: An Example of Leadership Within the Civil Service

By  
Laurie Beachell<sup>1</sup>

The Canada Pension Plan Disability (CPPD) Benefit has been and remains a program of critical importance to Canadians with disabilities. It provides a partial income replacement benefit to those who have been in the workforce but are unable to continue working because of disability. This program's evolution over time has been a model of what is possible if government and community work together. There was a time when recipients of CPPD felt they could earn no additional income and some even questioned whether they should participate as a volunteer on boards and with nonprofit associations. Today, while challenges remain, the story is quite different.

Those on CPPD can and are, in fact, encouraged to earn additional income from employment. Beneficiaries can earn up to \$5000 per year with no loss of benefits and they may be able to earn more and still not have it considered "gainful employment." Other income support programs have a very low earnings exemption and claw back additional earned benefits quickly, or, in some instances, deny the benefit.

CPPD has also created a "rapid re-instatement" policy allowing those who are receiving CPPD to return to work. If within two years for reasons of disability, they are unable to continue working, they will automatically receive once again CPPD benefits. Also true is the fact that those returning to work can retain their benefits for three months while they explore whether they are able to participate in the workforce once again. Other income support programs seldom have such incentives.

CPPD has also improved its application process for those with a terminal diagnosis. Those making application who are terminal will have their application processed within 48 hours. This is a great improvement over the past situation

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<sup>1</sup> Laurie Beachell is the CCD National Coordinator.

where the benefit was often paid out to the estate of the applicant because he/she had already passed away.

CPPD continues to create incremental improvement to its process and continues to work with representatives of the disability community to remove barriers to both the receipt of the benefit as well as provide incentives to return to work. These changes have come about because of two factors, the input of people with disabilities and their organizations has been sought and supported, and senior civil servants running the program have demonstrated committed leadership to removing barriers and making the program more inclusive and accessible.

The CPPD improvements over time are one example of how senior civil servants, who share our vision, have been able to make a very concrete and positive difference in the lives of Canadians with disabilities. Many advances in policy reform over the years have come about because of champions of our issues within the civil service.

# The Registered Disability Savings Plan: A Building Block for Financial Security

By

Jack Styan<sup>1</sup>, RDSP Resource Centre



Poverty is one of the most intractable issues facing people with disabilities in Canada. Over a million Canadians with disabilities live on annual incomes of \$12,000 or less. The RDSP will one day provide greater financial security to as many as half a million people. Already, nearly 50,000 people have saved about \$450 million in RDSPs. In thirty years, an estimated half a million people will have accumulated \$4.5 billion in assets, which will provide them with more than \$200 million in income every year.

The idea of a “savings plan for people with disabilities” was not new, but it took Planned Lifetime Advocacy Network (PLAN) nearly five years to research the implications, refine the concept and catch the ear of the newly elected Minister of Finance, James Flaherty. Minister Flaherty immediately became the idea’s greatest champion. Recruiting a small team comprised of James Love, Remy Girard and CCD’s own Laurie Beachell to give the idea further shape, and enlisting teams from several federal government departments, he quickly turned the idea into legislation and encouraged the financial institutions to participate. The RDSP was launched in December 2008.

The Government of Canada provides generous incentives for saving in RDSPs. An RDSP can receive up to \$20,000 in Canada Disability Savings Bond without any personal contributions. Personal contributions of as little as \$125 per month from the individual, family or friends can trigger up to an additional \$70,000 in matching Canada Disability Savings Grant. Consequently, investing \$30,000 can result in savings of approximately \$400,000 (with average investment returns of 5% annually) over 30 years. More importantly, when it comes time to use the funds, an RDSP of \$400,000 can produce \$1,500 per month in income for 30 years or more.

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<sup>1</sup> Jack was a key player in PLAN’s work to implement an RDSP for Canadians with disabilities. He is currently Managing Director of the RDSP Resource Centre, which assists people to access and use the RDSP to increase their financial security.

Just as importantly, people with disabilities can now save in an RDSP without affecting their provincial social assistance. In the past, people who depended on provincial financial assistance would lose their benefits if they saved more than a few thousand dollars. In addition, receiving income from most sources would reduce their monthly social assistance payments. Now people can save in an RDSP in all provinces without affecting their benefits. Furthermore, to accommodate the RDSP, the federal Guaranteed Income Supplement program and social assistance programs in most provinces have completely exempted income from an RDSP. (Three provinces provide a partial exemption.) This means that people can use it for anything that they want and their social assistance will not be reduced. These are monumental changes.

Over time, the RDSP will be responsible for even more changes. As people with disabilities begin to have assets, they are going to be seen differently. They will be seen as investors and customers rather than as service recipients. People with disabilities are also going to change. In the future we will hear more and more people talking about “investment options” and “risk versus return”.

But most importantly, people with disabilities can start dreaming, like other Canadians, about how their savings will improve their lives.



Hon. Jim Flaherty and Laurie Beachell

# Supporting the Voice: The Money Trail

By

Laurie Beachell<sup>1</sup>

The story of the creation of the consumer disability rights movement of people with disabilities has and will be told by many; and it truly is a story of creating a transformation of our society. However, for myself and other administrators of NGO's like the Council of Canadians with Disabilities (CCD), formerly known as Coalition of Provincial Organizations of the Handicapped (COPOH), a more mundane but critical part of creating change requires finding the money to sustain the work of the associations. A significant achievement is the fact that the voice of people with disabilities and their organizations has been supported by the Government of Canada since 1979.

The first funding for COPOH and its provincial member groups was approved through a Memorandum to Cabinet in 1979. That Cabinet decision, championed by Hon. Monique Bégin, Hon. Serge Joyal and Hon. Lloyd Axworthy, specifically named COPOH and all its provincial member groups as recipients of funding. This funding was delivered through what was then the Secretary of State Department. The fund grew in the mid 80's with the Mulroney Conservative government's creation of the National Strategy for the Integration of Persons with Disabilities. From 1986-1991 the funding program was expanded and was named the Disabled Persons Participation Program (DPPP) with a budget of approximately \$3.2 million. The primary objective of the program was "to enhance the capacity of disabled persons to effectively represent their rights and responsibilities as Canadian citizens." Not only was the voice being heard, it was being supported. In fact, the evaluation of DPPP in 1991 stated "there is a continuing need and rationale for the program. The program is consistent with the mandate and mission of the Citizenship Sector of the Secretary of State. The program has been effective, particularly in increasing public awareness and understanding, improving the information available and facilitating the formation of coalitions and alliances." At the same time, the Hon. Jake Epp announced five year demonstration funding for support of the Independent Living Movement in Canada.

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<sup>1</sup> Laurie Beachell is the National Coordinator of CCD.

In June 1990 Dr. Bruce Halliday, MP and Chair of the Standing Committee on Human Rights and the Status of Disabled Persons, tabled a report, *A Consensus for Action*, in the House of Commons. The report outlined barriers that prevent the full participation of persons with disabilities in daily life. In the Speech from the Throne on May 13 1991, the Government of Canada reiterated its commitment “to remove the barriers disabled Canadians still face to full participation in Canada’s political life and economic prosperity.” Thus the National Strategy for the Integration of Persons with Disabilities was born. Funding at that time was targeted to consumer-controlled advocacy groups that sought to improve the status of persons with disabilities. Under the National Strategy the government committed \$159 million, 71% of which was new funding to, “addressing issues of access, participation and economic integration through initiatives in various departments. “

The National Strategy ran until 1996 when a new challenge arrived. The Liberal Government informed the disability community that federal funding would be eliminated over a three-year period because disability was a provincial issue and there was a limited role for the federal government. The community was in shock, and its vocal response made the government rethink its position. That rethinking resulted in the creation of a Liberal Task force mandated to travel across the country to hear from Canadians with disabilities about their concerns. This Task Force, known as the Scott Task Force, was led by the Hon. Andy Scott, a Liberal MP from New Brunswick. Attached to the Task Force as observers and travelling with them were three strong, vocal consumer advocates – Traci Walters, Lucie Lemieux-Brassard, and Fred Clark. Diane Richler of CACL and I, as coordinator of CCD, were named as Special Advisors to the Task Force. The Task Force, which held 15 forums from coast to coast, heard from over 2000 people, most of them Canadians with disabilities. The Task Force report Recommendation 17 stated, “The Government of Canada should continue to support national organizations of people with disabilities in recognition of the extraordinary demands that participation and advocacy place on these organizations, which are least powerful and able to sustain this demand to begin with. This commitment should include, but not be restricted to, providing assured core funding, with a base amount of \$5 million, to sustain national organizations as a recognition of the additional disadvantage of people with disabilities in having their voice heard at the federal level.” Disability issues were back on the federal agenda and in an extraordinary meeting that included representatives of key national organizations and Ministers Paul Martin, Alan Rock and Jane Stewart, the Social Development Partnerships Fund (SDPP) was launched.

I will not try to highlight the various changes that SDPP has undergone, but important to remember is the fact that this program continues today to provide grants to 18 national organizations, plus project funding to an array of disability groups, academics and policy bodies. It was renewed in 2003 for five years by the Liberal government and the Hon. Diane Finley, in 2008, once again committed the Government of Canada to supporting the disability community with a renewed program for three years. Soon a decision must be made regarding the funding program's future. Clearly the voice of Canadians with disabilities has changed Canadian society's view of persons with disabilities. Equally true is the fact that without the support of the Government of Canada these changes would not have occurred. Canadians with disabilities and their organizations have been supported by the Government of Canada since 1979. The achievements of the past 30 years would not have been possible without that support.

# Jordan's Principle

By  
Anne Levesque<sup>1</sup>

It is often said that the experience of a person with a disability, and the types of barriers and stereotypes he or she will encounter, will largely depend on his or her other intersecting identities such as his or her race, gender, sexual orientation or social status. First Nations people with disabilities in Canada living on reserves are perfect examples of this. In addition to experiencing disproportionate levels of poverty, First Nations Peoples living on reserves and who have disabilities often encounter significant hurdles when trying to access government services that most Canadian take for granted. In some cases, these individuals are even completely denied government health, special education or home care services because it is unclear whether the provincial or federal government has the responsibility of paying for this. This was the experience of a 5-year-old boy named Jordan River Anderson, a First Nations child from Norway House First Nation in Manitoba who was born with a muscular disorder. After spending the first two years of his life in a hospital, Jordan's doctors determined that he was well enough to live in his home. However, neither the federal or provincial government wanted pay for the home care Jordan required to return to his family in his home community. After spending over two more years in hospital while the provincial and the federal government argued over who should pay for his home care, Jordan died in hospital in 2005.

Following Jordan's death, Parliament unanimously adopted a resolution aiming to prevent children from being harmed by jurisdictional disputes between governments. This resolution, called Jordan's Principle, directs the government that is first asked to fund a service to do so until the jurisdictional dispute is resolved. This prevents First Nations children, and particularly those with disabilities, from being denied services available to children living off reserve. The Government of Canada is currently taking steps to implement the resolution. Some provinces have also partially implemented Jordan's Principle in the area of children with complex medical needs.

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The implementation of Jordan's Principle is an important step towards the equality rights of First Nations people with disabilities living on reserves. If fully implemented, the resolution will allow some of Canada's most vulnerable people with disabilities to have equal access to all government services.

# Home Support and Persons with Disabilities

By  
Mary Ennis<sup>1</sup>

Only a few decades ago, many persons with disabilities were hidden away from the public eye, institutionalized, disempowered, pitied, and/or taken care of. Many were abused, and few were supported to enjoy full citizenship rights.

Today, persons with disabilities and policy makers envision a society in which persons with disabilities are active and participating citizens. They recognize too, that to make this so, many persons with disabilities require some sort of disability-related support to enable them to be part of that vision. One of the critical factors for facilitating that vision for many persons with disabilities has been and continues to be, home support services.

Today there are both formal (paid) and informal (unpaid) systems of home support. Depending on jurisdictional policies, home support services can be moved from the home to community, to work place, to school. For many, home support services are still restricted to the home environment. Some provinces or territories offer direct funding as an option; and in those cases, persons with disabilities can receive their home support services in other locations like the ones mentioned.

Home support enables citizens with disabilities to engage in social, economic, and political activities. It supports them to study, work, volunteer, have families and friends, travel, and most importantly, live in their homes instead of an institution. Home support enables many recipients to reassess their goals in life and have higher expectations of their potential. Home support helps ensure personal safety and protect emotional health. It is certainly a determinant of health and of quality of life.

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<sup>1</sup> Mary Ennis is the Past Chair of the Health Reform Committee of the Council of Canadians with Disabilities.

Another highlight of home support services is the role it plays in supporting persons with disabilities to engage in policy making decisions. Their lived experiences put persons with disabilities in a unique position to provide valuable perspectives on how policy can impact their lives. And over the years, government officials have come to recognize that expertise and to provide opportunities for persons with disabilities to engage in consultation and other policy processes. For many individuals, this would not be possible if home support services were unavailable.

The positive impact of home support services on the life of the individual are clear, but a lot remains to be done to ensure equitable and sufficient supports are in place for those who need them. While much has been accomplished, Government and community must be vigilant in pursuing effective monitoring of, and continuing enhancements to, home support services in Canada.

# In Unison: A Canadian Approach to Disability Issues

By  
Sherri Torjman<sup>1</sup>

A primary objective of the disability community is to promote the inclusion of persons with disabilities. Inclusion means that all citizens are able to participate to the best of their ability in all aspects of community life – whether they are children attending community programs or child care facilities, learning at school or playing in the park; young people attending school or seeking to join sports, cultural and social events; or adults pursuing training, postsecondary education, employment or volunteer opportunities.

Inclusion is promoted through barrier-free environments that remove obstacles to participation. Inclusion is also made possible through policies that ensure equal access to generic programs and services.

But even with barrier-free design and generic programs and services, there will always be individuals who require extra assistance. There will always be a need for specific measures to help offset the cost of disability, facilitate integration into the paid labour market and enable participation in all aspects of Canadian society.

These principles of citizenship and inclusion comprised the foundation of the federal-provincial/territorial vision paper, *In Unison: A Canadian Approach to Disability Issues*. *In Unison* was published in 1998 by the Federal-Provincial/Territorial Ministers Responsible for Social Services. The commitment to its principles was reinforced in a follow-up report, *In Unison 2000: Persons with Disabilities in Canada*.

*In Unison* described three core building blocks – disability supports, employment and income – in which changes must be made to promote inclusion. Each of the three building blocks identified a set of core objectives and associated policy directions for implementation by the federal and

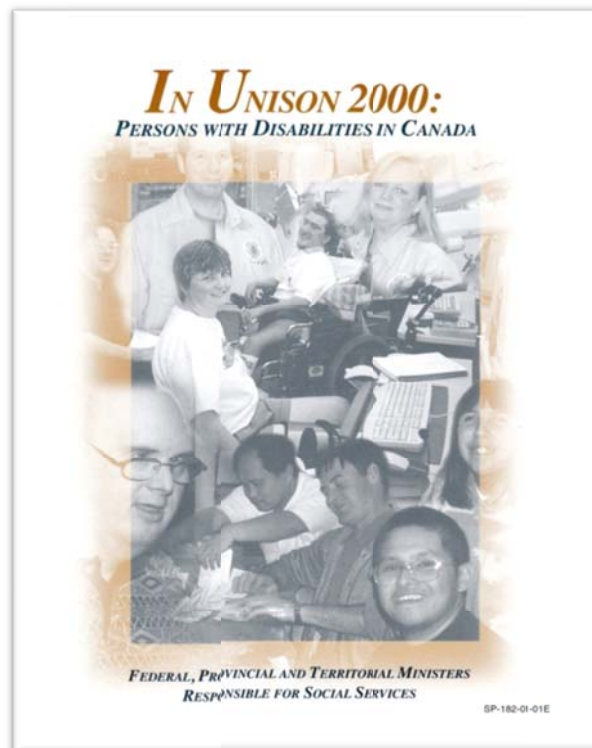
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<sup>1</sup> Sherri Torjman is Vice-President of the Caledon Institute of Social Policy and author of the “In Unison” report.

provincial/territorial governments. Proposals included ensuring greater access to disability supports and offsetting disability-related costs, enhancing employment opportunities for persons with disabilities and removing the work disincentives embedded in various income security programs.

The three core building blocks that comprise the essence of the *In Unison* vision are intrinsically linked. Availability of and access to disability supports are required to promote employability. These supports allow access to education and training programs and ensure that persons with disabilities can get to and function in their workplaces. Access to paid work clearly has a direct impact upon earnings and the need to rely upon programs of income support. The availability of adequate income affects individuals' ability to pay for the disability supports they require.

*In Unison* committed all governments in Canada to work toward these objectives. Equally important, it encouraged all governments to work *together* to achieve these goals.



# Towards the Democratic Codevelopment of Disability Policies

By  
Yves Vaillancourt,<sup>1</sup> LAREPPS-CRISES, UQAM

As a researcher and citizen, I have been interested in social policy for forty years. However, it is only during the past fifteen years that I have had the opportunity to study disability policy. This began when I had the privilege of conducting research in partnership with the FOHM (Fédération des OSBL d'habitation de Montréal) on innovative social housing practices involving community support aimed at socially and economically vulnerable persons.

When I study emerging social policies these days, I often ask myself if they were built solely by the state, or whether they were codeveloped democratically as a result of a true cooperation between the state (both elected officials and public administrators) and a diversity of actors involved in civil society, most notably the very citizens experiencing social difficulties that the social policy is targeting and who have lent their support to associations in order to be heard. This is what I call the participation of citizens in the democratic codevelopment of public policy and social programs.

When looking back at the body of policies over the past thirty years aimed at persons with disabilities in Quebec, I consider that this coconstruction was very present at certain times and less so at others. For example, it was there at the end of the 1970s during the advent of a series of socio democratic initiatives launched by the first Parti Québécois government headed by René Lévesque. Of note among these initiatives are the enactment, in 1978, of the Act to secure handicapped persons in the exercise of their rights and the creation in 1979 of the Office des personnes handicapées du Québec (OPHQ). In effect, the genesis of these initiatives was made possible by a democratic deliberation involving representatives of the Quebec government, as well as those from the associative movements that had voiced the demands of persons with disabilities in public.

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<sup>1</sup> Yves Vaillancourt holds a Ph.D. in political science. He is « associate professor », at the School of Social Work at the University of Quebec in Montreal (UQAM). On the Canadian scene, he is involved in a CURA (Community-University Research Alliance) on disability policy led by Yvonne Peters and Michael Prince.

This type of democratic codevelopment in the sphere of disability policy continued at the start of the 1980s with the development and emergence of the *À part... égale* policy of 1984, in a background of welfare state crisis. This was a visionary policy for persons with disabilities that was endorsed by the government after having been developed by the OPHQ in close collaboration with the associative movement of persons with disabilities.

During the years that followed, the *À part... égale* policy has remained a powerful source of inspiration. However, it seems to me that the practice of codevelopment has waned somewhat since the 1980s. Granted, on the discourse front, it must be noted that, over the past fifteen years, Quebec state policy regarding persons with disabilities has been deemed to be on the cutting edge internationally. These policies have also succeeded in incorporating the principles, values and terminology of associations of persons with disabilities. Nonetheless, in terms of concrete procedures, the expected benefits of unveiled reforms have yet to materialize.

It is possible to explain these policy gaps by identifying several responsibilities that pertain to governments and political parties. However, it would also be desirable to critically reflect on the responsibilities inherent in civil society and the associative movement of persons with disabilities. We speak of “movement” in the singular; however we all know very well that, concretely, the associative movement has, in fact, evolved to be a very fragmented plurality that reflects the distinctiveness of various disabilities.

Personally, I think that we have for too long been ensconced in a sterile debate regarding the distinction between community organizations involved in rights advocacy and those that provide services. However, in reality, out of the 1,300 surveyed community organizations (please see the Lucie Dumais article), a large number of these organizations are involved in both rights advocacy and the provision of alternative services. Fundamentally, I think that these two missions are necessary. A new social policy model that seeks to enlist the participation of citizen-users requires the involvement of the third cooperative and associative sector. Otherwise, disability social policy will remain encumbered by what we at the LAREPPS call neoprovidentialism and social-statism.

# Nearly 30 Years of Disability Statistics

By  
Cameron Crawford<sup>1</sup>

I've been working in the field of disability since the mid-1970s. For much of that time I have conducted or supervised a range of research projects on disability, human rights and social inclusion. Thinking back to when I first started working with major statistical data sets I was initially quite surprised – and pleasantly so. This was when I was first introduced to the Health and Activity Limitation Survey (HALS) of 1986. HALS was based on a recommendation of the landmark *Obstacles* report, which was produced in 1981 for the House of Commons by the Special Parliamentary Committee on the Disabled and the Handicapped. As the outcome of the Committee taking comprehensive stock of the challenges facing Canadians with disabilities, *Obstacles* noted that there was a lack of national data concerning people with disabilities. The Committee directed Statistics Canada, through Recommendation 113, “to give a high priority to the development and implementation of a long-term strategy which will generate comprehensive data on disabled persons in Canada”. That led to the creation of a national database on disability that began as the Canadian Health and Disability Survey of 1983 and 1984. HALS was launched after the Census of 1986 and gathered a tremendous wealth of information about the personal characteristics of people with disabilities including the nature and severity of their disabilities, their education and employment situation, the human and other disability supports needed in a variety of social and economic contexts, their income and the barriers they face to full social and economic participation. It was a fascinating privilege to be able to work with such a rich and diverse source of information. In 1991 HALS was conducted again and this time it gathered even more information.

Due to federal budget constraints, HALS was not conducted after the Census of 1996 so we had only fragmentary glimpses of how people with disabilities were doing following the recession of the early 1990s and following the major changes to the federal employment, health and welfare and other ‘systems’ around disability in the early- through mid-1990s. Following a consultation in 2000 by then Human Resources Development Canada, which prioritized the

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<sup>1</sup> Cameron Crawford is the Director of Research and Knowledge Management at the Canadian Association for Community Living, President of the Institute for Research and Development on Inclusion and Society (IRIS) and PhD candidate at York University’s Critical Disability Studies program.



data needs of the disability community, the successor to HALS – the Participation and Activity Limitation Survey (PALS) – was launched in 2001. It gathered much the same kinds of information as HALS. At about the same time, Statistics Canada began using a more consistent approach to flagging people with disabilities in other major surveys such as the Census, surveys on health, literacy, employment and income. PALS was rerun following the Census of 2006, which again yielded an enormous wealth of detailed information for ‘mining’ by policy analysts, government officials, think tanks, NGOs and academics.

Minister Diane Finley of Human Resources and Skills Development Canada recently took the decision to cancel PALS and to adopt a different data gathering strategy concerning people with disabilities. While what we had was not perfect, it was very good and was looked to internationally as an impressive approach to gathering and disseminating data and analysis on the social and economic situation of more than one in seven Canadians. People with disabilities had been actively involved in the design of HALS and PALS, which reflected the information needs and insights into disability of this community. It is early going so difficult to tell how the new approach will work out. It will involve tapping into a variety of surveys for the information they contain about people with and without disabilities. Testing of the new approach is currently underway and initial results look promising. It is to be hoped that the new approach will deliver on the Minister’s commitment to her department’s developing a new data collection strategy that will yield more “timely, responsive and flexible” data, and that is more “efficient and inclusive.” It is also to be hoped that the new approach will fulfill the information and analytical needs of governments, NGOs, academics and other researchers at the provincial/territorial level and will enable Canada to effectively deliver on its human rights monitoring and reporting obligations under the UN Convention on the Rights of Persons with Disabilities.

# Disability and Immigration: A Double Issue

By

Luciana Soave<sup>1</sup> and Teresa Peñafiel<sup>2</sup>

In 1978, the Quebec government founded the l'Office des personnes handicapées and enacted *An Act to Secure the Handicapped in the Exercise of their Rights*.

Thirty years ago, in 1981, the associative movement was viewed favourably by the Quebec government, which started to fund associations of persons with disabilities. Several such associations were created at the end of the 1970s and at the start of the 1980s.

Given that 1981 had been declared the International Year of Persons with Disabilities by the United Nations, the Quebec government planned a socioeconomic conference on the condition of persons with disabilities. Provincial and federal associations were invited to the summit, during which their leaders decided to create a coalition, now known as COPHAN, of which the new Multi-Ethnic Association for the Integration of Persons with Disability (AMEIPH) was a founding member.

In 1981, three couples of ethnocultural origins – all parents of a child with a disability – bonded for support and to consider how existing services could be adapted to provide support to both ethnocultural persons with a disability and their parents.

The creation of the AMEIPH provided visibility to this minority amongst minorities that was until then – and often still is – “inVISIBLE”. The AMEIPH has, during its thirty years of existence, worked tirelessly to inform and sensitize

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<sup>1</sup> Luciana Soave est un des membres fondateurs de l'AMEIPH et Directrice générale depuis 1981. Afin de sensibiliser sur la double problématique vécue par les personnes ayant des incapacités issues de l'immigration, elle siège et a siégé sur des nombreux conseils d'administration, comités, coalitions ([www.ameiph.com](http://www.ameiph.com)).

<sup>2</sup> Born in Chile, Teresa Peñafiel immigrated to Canada in 1979 along with her family. In 1987, she began working full-time as a social assistant at the Multi-Ethnic Association for the Integration of Persons with Disabilities until 1990, when she assumed the position of Promotion Coordinator, a position she maintains to this day.

public and community based service organizations on the specific needs of persons experiencing difficulties integrating in a new country as a result of their disability, a language barrier, or being unaware of specialized services.

The existence of persons with a disability linked to immigration no longer needs to be proven in Quebec, given that sensitization efforts continue to be a priority and the demand for training from the AMEIPH remains high. This serves as a reminder to the community of persons living with a disability that the gains made during the previous three decades are still fragile and warrant constant protection.

The recognition of the existence of the “Disability and Immigration” issue enabled the AMEIPH to be invited for preparatory work and to take part in the World Conference against Racism that was held in Durban, South Africa in 2001. It was the only NGO to present on the issue of discrimination against persons with a disability. At the closure of the Conference, the U.N. Secretary-General announced the creation of a Convention on the Rights of Persons with Disabilities, which is now a reality. This Convention is not only a major legal instrument for advocating for the rights of persons with disabilities, but must be recognized as such and fully utilised.

With this year marking its thirtieth anniversary, the Multi-Ethnic Association for the Integration of Persons with Disability can say that it has contributed to the recognition of a minority that was hitherto ignored and to an issue that deserved being recognized.

# Mental Health Commission of Canada

By  
Chris Summerville<sup>1</sup>

The World Health Organization indicates that depression is ‘common,’ with 121 million people affected worldwide, describing it as one of the leading causes of disability across the globe.

Mental health problems and illnesses are also the leading cause of short- and long-term disability in Canada, with the economic burden of mental disorders in Canada estimated at \$51-billion per year.

Recognizing the need to address the disturbing facts around mental health issues in Canada, the federal government announced the creation of the Mental Health Commission of Canada in March of 2007 as a vehicle to focus national attention on mental health issues.

The Commission was a key recommendation of *Out of the Shadows at Last – Transforming Mental Health, Mental Illness and Addiction Services in Canada*. Released in 2006 by then-Senator Michael Kirby and the Senate Committee on Social Affairs, Science and Technology, *Out of the Shadows* was Canada’s first-ever and largest-ever national report on mental health.

Canada is presently the only G8 country without a mental health strategy, a fact that is central to the Commission’s mandate.

The development of a Mental Health Strategy for Canada is now well underway, with a set of strategic directions for transforming the mental health systems in Canada identified.

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<sup>1</sup> Dr. Summerville is a board member of MHCC and CEO of Schizophrenia Society of Canada.

While the Mental Health Strategy for Canada progresses, the Mental Health Commission of Canada has also been tackling the issues of homelessness, mental health awareness and stigma associated with mental illness. The Commission identified these as important issues for improving the lives of people living with a mental illness and has developed projects focused on addressing them.

At Home / Chez Soi, the MHCC's national research project investigating mental health and homelessness, is currently housing 1,325 people at homes in five cities throughout the country. The project is pursuing research on the most effective strategies to help our most vulnerable citizens.

The Commission is also educating Canadians, with more than 40,000 people now trained in Mental Health First Aid across the country to help them detect signs and symptoms of mental illness in friends, family, colleagues at work and others.

Opening Minds, the Commission's anti-stigma initiative, is the largest stigma reduction effort in Canadian history. We are all aware that stigma is a major barrier preventing people from seeking help. We have already learned through Opening Minds that Canadians feel it is harder living with the stigma of mental illness than with the illness itself, leading to discrimination and loss of the support networks that are important to recovery.

Opening Minds is building a national network of consumers, stakeholders and professionals, evaluating current anti-stigma programs and building a research knowledge base that will be shared so that everyone contributes to decreasing stigma.

MHCC is supporting improved psychological health and safety in the Canadian workplace, with a voluntary *National Standard of Canada for Psychological Health and Safety in the Workplace* being developed to provide organizations

with the tools to achieve measurable improvement in employee mental well-being.

We are also seeing an increase in action and support for mental health, with Canadians becoming more and more aware of the fact that ignoring mental health is detrimental to individuals and families, as well as our society and economy as a whole.

Canadian companies such as Bell, RBC, Great-West Life and Canada Post, are investing millions of dollars to raise awareness. Governments across the country are also addressing mental health in more meaningful ways with new strategies and investments.

Progress is being made in changing attitudes about the disability of mental health, but there is still much work to be done.

# *Human Rights*





# A Missed Wedding, a Landmark Protest and a Legal Victory

By  
Yvonne Peters<sup>1</sup>



On October 31, 1980, I arrived in Ottawa ready to participate in a weekend meeting of the National Council of the Coalition of Provincial Organizations of the Handicapped (COPOH) (now known as the Council of Canadians with Disabilities). I attended this meeting under much protest from my family. My sister was getting married, and here I was, choosing to miss her wedding so I could discuss the Constitution and the inclusion of disability rights.

I was a relatively new member to the Council. But I was outraged by the lack of legal protection for the human rights of persons with disabilities and was therefore eager to work with my colleagues to correct this injustice.

Much of our Council discussion that weekend focused on the federal government and how to shake its refusal to consider the inclusion of persons with disabilities in the proposed Constitutional *Charter of Rights and Freedoms*. Earlier that fall, Prime Minister Trudeau convened Parliament to consider a resolution asking the British Parliament to patriate the *British North American Act*. He proposed that part 1 of the Act contain a Charter that would provide Constitutional protection of the Rights and Freedoms of persons living in Canada. Of particular interest to persons with disabilities was the Charter's "non-discrimination" clause.

This clause guaranteed equality and prohibited discrimination on a number of grounds. However, there was no mention of disability. Our drive to have this clause expanded was supported by a resolution passed at COPOH's first national conference. The resolution called for Members of Parliament to support the entrenchment of the human rights of persons with physical disabilities in any new constitution. We amended our position to include mental disability when we partnered with the Canadian Association of the Mentally Retarded, now the

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<sup>1</sup> Yvonne Peters has practiced law as a sole practitioner since 1993, specializing in human rights and equality rights. Yvonne's current work includes: legal advisor to the Council of Canadians with Disabilities, Vice-Chair of the Manitoba Human Rights Commission, a co-investigator in a Community-University Research Alliance project entitled Disabling Poverty/Enabling Citizenship.

Canadian Association for Community Living (CACL). We started with physical disability, but we recognized the need to include mental disability.

Prior to the Council meeting, COPOH flooded Members of Parliament with telegrams and letters urging them to include disability in the nondiscrimination clause. Unfortunately, just days before the Council meeting, a special advisor to Jean Chrétien, the then Minister of Justice, advised COPOH, that only grounds "that have been long recognized" and which do not require "substantial qualification" would be included in a nondiscrimination clause. Disability, he said, did not fit this criteria.

Council members were alarmed and dismayed by this response, and thus we spent much of our time discussing and debating how to get our message of inclusion taken much more seriously.. We finally settled on the need to publicly demonstrate our concern and frustration at being left out of the Constitution-making process. Consequently, instead of returning home to our families and jobs that Sunday evening, we gathered in an Ottawa hotel room to organize the details of a public demonstration, prepare protest signs, and devise a media strategy.

On Monday, November 3<sup>rd</sup>, 1980, 14 members of COPOH demonstrated on Parliament Hill, chanting slogans and waving signs in an effort to get our message across to government. We attracted significant media because the sight of people with a variety of disabilities shouting for their rights was quite a new concept in Canadian society. Allan Simpson, the then Chair of COPOH, told an Ottawa newspaper that "coalition members were prepared to take their case to the United Nations or to ask the British Parliament to delay patriation of the constitution until their demands were met."

Prior to the protest, I phoned my employer to advise her of my activities. As a strong human rights activist, she supported my participation. She suggested that I not be the "first to throw the blood on the steps" so to speak. However, unknown to me, my protest-loving guide dog pushed her way to the front and the next day our picture was splashed across Canada in a number of newspapers. Fortunately, my employer was very supportive of our cause and I retained my job.

Following the demonstration Ron Kanary (COPOH's Vice Chair) and I were asked to extend our stay in Ottawa to engage in the direct lobbying of key politicians. Many of the politicians we met with were genuinely interested and receptive to our issue and were obviously trying to make sense themselves as to how a *Charter* would function in the Canadian context. At a minimum, our goal was to obtain an invitation to appear before the Joint Parliamentary Committee, mandated to convene hearings on the proposed Constitution. To this end, our efforts can be deemed a success as shortly after our tour of Parliament, COPOH received the much sought after invitation to appear before the Committee to argue our case.

Our appearance before the Joint Committee marked a turning point for COPOH's Constitutional lobby. The public protest and the appearance before the Committee gave our issue profile and credibility. While we may never know

what prompted the eleventh hour change of mind by the government, it is likely that factors such as supportive government representatives and members of Parliament, the proclamation of the 1981 International Year of Persons with Disabilities and further threats of protests by persons with disabilities on Parliament Hill, all played an influential role in shifting the ground in favour of persons with disabilities. Thus, on January 28, 1981, the Joint Parliamentary Committee on the Constitution unanimously accepted an amendment to the *Charter* which, at long last, included the ground of both "physical or mental disability" in Section 15, now known as the guarantee of equality in the *Canadian Charter of Rights and Freedoms*.

Looking back over the past 30 years, I am now truly sorry I missed my sister's wedding. But I still feel I made the right decision to attend that infamous National Council meeting back in 1980. Clearly, our efforts helped to achieve a significant legal victory, which marked a new social consciousness of disability rights. I am deeply honoured to have had the opportunity to play a small role in this important victory.



*Stuart Wilson*  
**Handicapped protest** — CP photo  
 Apr 1/80  
 Yvonne Peters, president of the Saskatchewan Voice of the Handicapped, leads a demonstration on Parliament Hill Monday planned by the Coalition of Provincial Organizations of the Handicapped. The demonstrators, who included 12 people in wheelchairs, say their human rights are denied under the proposed constitution.

# Inclusion of Disability Rights in the Equality Rights Section of the Canadian Charter of Rights and Freedoms

By  
Jim Derksen<sup>1</sup>



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The Council of Canadians with Disabilities (CCD) and its allies have achieved constitutional protection of the right of persons with disabilities to equal benefit and protection under and before the law in Canada.

Thirty years ago, Canadians with disabilities were without specific constitutional protection of their rights to equality in the operation of Canadian governments and the laws they enacted. Prime Minister John Diefenbaker's Bill of Rights provided some general protections for Canadians but this proved quite ineffective in protecting equality rights of Canadians in general and offered no specific equality rights protection to persons with disabilities. Canadian and several provincial human rights statutes offered some protection from discrimination on specific grounds but these did not have the constitutional power to overcome the federal and provincial governments. As regards protection from discrimination on the basis of disability, more often than not, this was limited to the prohibition of such discrimination only in the area of employment and not in the provision of goods and services.

With the repatriation of the Canadian constitution from England the door was open to the idea of embedding a charter or a bill of rights in the constitution, itself. Prime Minister Pierre Trudeau had opened discussion about the possibility of a constitutionally established set of rights in Canada earlier in the 1980's. Canadians with disabilities had watched the American Rehabilitation Acts of the early 1970's improve the status of disabled persons in America through being interpreted as having quasi-constitutional power. Disabled Canadians began to plan strategies to be included in any constitutional rights legislation in Canada.

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<sup>1</sup> Jim Derksen is a past Chairperson of CCD and he currently sits on CCD's Human Rights, Ending of Life Ethics and International Development Committees.

\* Jim Derksen picture by *Boris Minkevich/Winnipeg Free Press, Jan. 11, 2008, reproduced with permission.*

When the Joint Committee of the House of Commons and the Senate on the Constitution of Canada, chaired by the Honourable Jean Chrétien, then Canadian Minister of Justice, met to hear the views of Canadians, CCD and its allies presented arguments for the inclusion of physical and mental disabilities in the equality rights section of the Charter. CCD also coordinated a night telegram campaign urging all parties to support the inclusion of disability in the Charter. Fortuitously, CCD's national coordinator had been seconded to the House of Commons Committees Branch as special advisor to the all party Special Committee on the Handicapped and Disabled. This committee was persuaded to make a preliminary report to the House of Commons recommending, "Should it be the will of Parliament to entrench Human Rights in a patriated Constitution, your Committee believes that full and equal protection should be provided for persons with physical or mental handicaps." The members of this Special Committee on the Handicapped and Disabled then undertook a consistent and committed lobby in each of their respective party caucuses for party support of this recommendation. The opposition New Democratic and Progressive Conservative parties were quick to support the recommendation but the governing Liberal party was more difficult to convince.

The deliberations of the Joint House of Commons and Senate Committee on the Constitution were live broadcast by satellite across Canada and CCD representatives (in particular those with visible disabilities) were ever present as audience members behind the elected members of the committee to remind the committee and indeed all of Canada of the importance of disability rights in the Charter. Eventually, a federal government constitutional lawyer met with CCD's national coordinator to understand how constitutional equality rights for disabled Canadians could be implemented. Chief Commissioner Gordon Fairweather of the Canadian Human Rights Commission also intervened at the eleventh hour by private discussion with government officials to ensure that Canadians with mental disabilities would also be included in the equality rights section of the Charter. Early in 1981, the Honourable Jean Chrétien announced that the governing liberal party would also support the inclusion of disability rights in the charter.

# CCD's Role in Shaping Charter Equality

By  
David Baker<sup>1</sup>

The disabled community, led by CCD, had worked hard to ensure that disability was included amongst the groups enumerated in the equality rights clause in the Charter of Rights and Freedoms. And so a great experiment was begun. Believe it or not, even as the Charter became the supreme law of Canada, there was not yet a consensus about what Charter equality meant and how it would be applied in actual cases. Almost anything was possible.

In the United States equality rights under the Bill of Rights had been limited to formal discrimination involving hatred and animosity between groups. Many, including most legal academics, assumed that this was all that was contemplated by the Canadian equality clause. If this assumption proved correct the Charter would have had the same negligible impact on the day to day reality of Canadians with disabilities as the Bill of Rights has had for Americans.

CCD had begun its work of intervening in human rights cases before the Supreme Court of Canada a few years before the first Charter equality case was argued there. Planning far ahead, its leadership had already recognized and accepted that real equality could transform how people with disabilities were perceived and treated. Meaning was attached to the words "equal benefit of the law" as it invited the Court apply a meaning of discrimination that took direct aim at the barriers that served to isolate and disadvantage persons with disabilities. Why shouldn't persons with disabilities gain equal benefit from education, transportation and social programs? Why shouldn't employers be compelled to find inclusive ways of performing work that opens doors for persons with disabilities. The Court accepted CCD's invitation and interpreted human rights law as redressing discriminatory effects, regardless of the motivation of those responsible. It made sure that when the first disability cases came along the law was ready.

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<sup>1</sup> David Baker was CCD's counsel in the Andrews case and many other important cases, such as VIA Rail. CCD made David an Honourary Member of the organization.

By so doing the Court created a kind of substantive equality that was distinctively Canadian and had the potential to challenge the formal kind of equality applied by courts south of the border.

CCD formed a working group composed of some of its most forward thinking members to discuss the kind of Charter equality that would work best for persons with disabilities. It quickly became apparent that the best possible option was to convince the Court that substantive equality, as reflected in its recent human rights jurisprudence was the way to go. But how to convince it to go there?

The Committee's members recognized that it would take some time before Charter disability cases started to come before the Court. As with the human rights cases, it decided to waste no time in finding a way to share their dream of persons with disabilities entitled by the Charter to enjoy equal opportunity and equal benefit from all branches of government at every level. It decided to intervene in the first Charter equality case to come before the Court: *Andrews v The Law Society of British Columbia*. Improbably the case concerned whether non-citizens could become lawyers. Undaunted CCD's leaders said the perspective of persons with disabilities must be amongst those heard when that first case gets argued.

CCD understood that other equality seeking groups were also interested in how the Court decided this first case. Emissaries were dispatched to share CCD's dream and to see if ways could be found to present a united front. Remarkably these groups were respectful of the work CCD had done and its willingness to work collaboratively. The results were very positive. Groups came around to recognizing that the substantive equality aimed at overcoming unintended as well as intended barriers worked well for all. As a consequence, there ended up being great commonalities in the positions interveners, including CCD, presented to the Court.

The Court listened respectfully to the arguments made on behalf of the communities who had worked so hard to ensure that there was a Charter in the first place. It was pleased to learn that the model of equality it had recently applied in human rights cases found favour with CCD and other equality seeking

groups. It carefully examined the American alternative and found it inadequate to the task Canadians had set for their Charter.

Hopefully the disabled community will never forget how influential CCD was throughout this process. Something transformative was accomplished by a dedicated group of people who ably served their community.

While the Court's approach to equality has wavered over the years, and there have been disappointments, it is heartening to watch as the Court has recently returned to *Andrews* as the source of what is meant by equality. It got it right the first time, and disabled people have gained ever since.

The rest of the world has an interesting perspective on what CCD accomplished. There is great respect for Canadian Charter cases amongst persons in all corners of the world who follow the impact the law has had on the lives of persons with disabilities. We should pay heed to what they have to tell us and take some satisfaction from what was accomplished back then, without for a moment forgetting how much remains to be done.



VIA RAIL Case  
Supreme Court of Canada

**Seated:** Paul Claude Bérubé, Mary Louise Dickson, Mark Brose, Traci Walters,  
Pat Danforth, David Shannon

**Standing:** Joe Foster, Janice MacNamara, David Baker, John Rae.



# The UN Convention on the Rights of Persons with Disabilities: A New Era of Disability Rights

By  
Anna MacQuarrie<sup>1</sup>

Every movement, every generation, every struggle for justice has defining moments. For the disability community, the UN Convention on the Rights of Persons with Disabilities (CRPD) is one of those moments. Not just for the history it represents but for what it will mean for generations to come. Not just for what it is but for the potential impact it has to make real and meaningful difference – not just for persons with disabilities and families but also for governments and communities.

It's not everyday the United Nations crafts an international human rights treaty. The CRPD is the first human rights treaty of the 21<sup>st</sup> Century. It was also the fastest negotiation of a human rights treaty in UN history and the first time in UN history that the voices and lived experience of people and organizations directly affected by a Convention have been actively involved in its development and negotiation.

UN Conventions and international human rights laws, are often, and quite reasonably, seen as the domain of legal experts and legal minds. Yet, with the development of the CRPD we saw, both in theory and practice, that this Convention did not belong exclusively to the legal domain. The participatory nature of the development and negotiation of the CRPD put a name and a face to the exclusion persons with disabilities and their families face around the world. It was the voice and lived experience of persons with disabilities, families and disability organizations that was seen as the necessary expertise brought to bear on this Convention. From the outset, the CRPD belonged to all of us.

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<sup>1</sup> Anna MacQuarrie is the Director of Policy and Programs for the Canadian Association for Community Living. She has a Masters degree in Human Rights, from the University of Essex. She has worked with the Canadian Association for Community Living for the past 7 years with a domestic and international focus on the rights of persons with intellectual disabilities and their families. She worked actively on the development of the United Nations Convention on the Rights of Persons with Disabilities and calling for Canada's ratification. She works with other disability organizations and government partners on making the CRPD real and meaningful for people with disabilities and families.

In many ways, the negotiations brought the world together to talk about disability. It brought understanding and perspective on the lived experience of disability to government delegations and disability organizations alike. It provided space for the disability community to come together on issues that had previously been divisive and to develop common positions on critical articles. The unprecedented level of collaboration taught all of us that working together works better – for everyone. Collaboration wasn't always easy but we learned in the negotiations that working through tough issues together moved the CRPD forward.

As a result, the CRPD understands disability and disability rights differently. The CRPD is anchored in a social model of disability that sees disability as a set of barriers external to an individual. Further, it marks a shift in understanding human rights in isolation to seeing their realization within a context of development and cooperation. Rights are made real in our communities and this convention clearly lays out where and how rights based violations have occurred and what needs to be done to make rights real and meaningful. The CRPD is not simply a listing of entitlements but a road map for change.

Canada's imprint on the CRPD is substantial and substantive. Uniquely Canadian concepts – like inclusive education and supported decision-making – are now, for the first time, entrenched in international law. The leadership from Canada's delegation and the Canadian disability community on Article 12 will have – and already is having – resounding impact around the world. Sustained leadership from Canada is needed to ensure the CRPD is interpreted and implemented progressively.

Moving forward, I argue the CRPD gives us the next evolution of "*Nothing About Us Without Us*", the powerful slogan of the disability community that demanded the voice of people with disabilities be heard on disability issues. The CRPD gives us "*Nothing About Us Without Us*" version 2.0. The CRPD goes beyond a traditional approach to disability. It recognizes that it's not enough to say that people with disabilities and disability organizations should be involved in disability issues. The CRPD is about making sure the voice of people with disabilities is incorporated in all we do: Education policy; health care policy; employment policy; foreign policy.

Canada ratified the CRPD on March 11, 2010. On that day, Canada turned a corner on disability rights. The CRPD ushers in a new era of disability rights. It is up to all of us – disability organizations, governments, communities, partners and allies – to claim this defining moment and to breathe life and meaning into the CRPD. It is up to all of us to ensure that 30 years from now, when we reflect back on this moment, we can say that a human rights framework informed by the voices, perspectives and lived experience of persons with disabilities and families made all the difference.

# Up to the Basics: The Right to Decide

By  
Dulcie McCallum<sup>1</sup>



Thinking back, I am amazed by what the disability community in Canada has achieved during the last 30 years. While many inequities continue to plague the daily lives of people with disabilities, on the occasion of End Exclusion 2011, I would like to focus on a major achievement. Thirty years ago, I began work for a committee of self-advocates who intervened in the *Re Eve* case in the Supreme Court of Canada. This marked the first time a group of people labeled intellectually disabled intervened in their own right in Canada's highest Court. Twenty-five years ago the decision came down unanimously supporting the position advanced by the committee; non-therapeutic sterilization - never. It was a landmark case: the law recognizing that people who had been marginalized and disenfranchised could speak for themselves.

Fast forward three decades and I am a non-government delegate for Canada along with Steve Estey at the United Nations [UN] to draft the *UN Convention on the Rights of People with Disabilities* ["Convention"]. There I witnessed another major leap forward to ensure everyone's right to self-determination. There were many synchronistic moments at the UN. One was when Canada was given the lead by the Chair on discussions around Article 12 – Equal recognition before the law. This role reflected the collective stellar reputation for achievements made by persons with disabilities, advocacy organizations, parents, friends and some governments. These included the inclusion of constitutional protection for mental and physical disability in the equality section of the *Canadian Charter of Rights and Freedoms*, progress on instituting duty to accommodate, landmark cases such as *Re Eve*, major advances in inclusive education, ban on institutionalization, lead in supported employment, and the *Justin Clarke* case and the rejection of the guardianship model.

Early in the negotiations a critical issue arose about process. Some countries [State Parties] objected to the intense involvement non-government advocacy

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<sup>1</sup> Initially trained as a Registered Nurse [1970], Dulcie McCallum gained a Bachelor of Law from the University of Victoria. During her work as a barrister and as a consultant, Ms. McCallum's principal focus has been on the constitutional and human rights of people with disabilities. She sits as vice-president of the NS Association for Community Living.

organizations were insisting upon. The custom at the UN is for countries to draft international instruments largely on their own terms with minimal involvement of civil society. When some countries began to resist the idea of an inclusive process, Canada along with others took a firm stand on the involvement of civil society and supported their full participation: honouring their slogan *nothing about us without us*. This turned out to be the critical factor in the brilliant design of the *Convention's* text; it was conceived of and drafted largely by people who themselves have a disability.

This was history in the making – people with disabilities themselves being wholly included in the process of drafting an international instrument. Ironically the most excluded group of people in society became the most included in the history of the UN; a process which encouraged advocates to express ideas, proposals, solutions, hopes and dreams and have them woven into the text. It was just short of a miracle; an inclusive process to develop a *Convention* for persons with disabilities that had as its paramount goal to make our world a more inclusive one.

A cornerstone provision revolved around the capacity of people to be able to benefit from the guarantee rights and freedoms. At the end of the negotiations, Article 12 remained a bone of contention for many States Parties. It reads:

1. *States parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*
2. *States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
3. *States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*

In the final moments of the negotiations, it boiled down to whether Article 12 could be agreed upon and thus included in the *Convention*. The critical point was this: in order to exercise a right whether it be the right to vote, to have access to housing or employment, on an equal basis with others – do you have to be recognized as having the capacity to exercise that right? If Article 12 had been lost it would have meant many millions world-wide would have been considered persons before the law but would not be considered able to have the capacity to act. The result would be most of the other rights embedded in

the *Convention* would have been rendered meaningless because some people would be considered incompetent to make their own choices; for example where to live and with whom or where to work and what sports to play. In the end, Article 12 passed. The Article requires all countries to recognize that all persons have full legal capacity in all aspects of life and to fulfill their duty to provide the supports people require in exercising their legal capacity – frequently referred to as “supported decision making.” Hailed as a huge victory, Article 12 happened because a host of advocates, family and friends from Canada in concert with many others of the over 400 non-government groups registered at the UN made it happen. While it took thirty years, *Re Eve* began a process that culminated in the *Convention* sanctifying the fundamental guarantee of every person’s right to decide.



Dulcie McCallum, Steve Estey and Ambassador John McNee

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# Reflections on the Court Challenges Program of Canada

By  
Ken Norman<sup>1</sup>

Thirty three years ago a funding program for minority language litigation was established. In 1985, when the equality rights section of the *Charter* came into effect, the federal government was persuaded that equality seekers needed the same sort of program. This program was shelved in 1992 only to be reinstated in 1994. On September 25, 2006, it was again shut down though it had twice easily passed muster in independent evaluations. The most recent such report said:

Since its inception, the Program has supported many cases that have made an important contribution to constitutional law. Many important constitutional cases would not have proceeded without financial support from the Program. ... The importance of the Program's financial assistance on cases is undisputed. Many of the Program's applicants would have been unable to mount their challenges or conduct their consultations without the Program's support.

As the Canadian Bar Association's appointee to the board of directors of the Court Challenges Program, I am proud of the stance taken by the CBA on the eve of the shut down. A resolution passed at its annual meeting on August 13, 2006, notes that the CBA "...is a long-time supporter of the Court Challenges Program and has worked actively to ensure its continued viability, expansion and renewal..." The Resolution stands on the proposition that "...the Court Challenges Program provides a vital role in increasing access to justice for marginalized and vulnerable groups and makes a unique and important contribution to democratic values and citizenship..." The Resolution further asserts that "...the Court Challenges Program contributes to Canada's capacity to fulfill its obligations under international human rights instruments as recognized by the United Nations Committee on Economic, Social and Cultural Rights and others..."

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<sup>1</sup> Ken Norman is a Professor of Law and a Court Challenges Program Board Member appointed by the Canadian Bar Association.

On March 9, 2007, the UN Committee under the *Convention on the Elimination of Racial Discrimination* stated:

The Committee recommends that the State party [Canada] take the necessary measures to ensure access to justice for all persons within its jurisdiction without discrimination. In this connection, the Committee urges the State party to reinstate the Court Challenges Program, or devise a functional replacement mechanism with equivalent effect, as a matter of priority.

In June of 2008, the federal government restored the official languages portion of the program by establishing the Language Rights Support Program. As for vulnerable equality seekers, it is 'back to the future'. They are where they were thirty years ago – on their own.



# *International*



# Disability Rights: Coming of Age at the United Nations

By  
Steve Estey<sup>1</sup>

It takes a long time to clear security at the UN headquarters these days. But after waiting nearly eight years for the moment, I was in no rush on March 11, 2010. This was the day that, with UN Secretary-General Ban Ki-moon as witness, the Government of Canada took the final step towards ratifying the new UN Convention on the Rights of Persons with Disabilities (CRPD); and I had a ringside seat!

As I stood there proudly watching our Foreign Minister, the Hon. Lawrence Cannon, hand over the formal articles of ratification to the Secretary-General, I was filled with a sense of joy, a sense of history, and a feeling of optimism for the future of people with disabilities in Canada and all over the world.

This was a true moment of history for the disability movement. Ours has been described as the last civil rights movement. On Thursday, March 11, 2010, in the presence of the Secretary-General, we finally came of age.

Between 2002 and 2006 representatives from over 100 governments, and hundreds more civil society organizations, came together over many weeks to draft and negotiate this new treaty, which people with disabilities have been seeking for more than a quarter of a century. It guarantees us the same basic human rights as other people have, including for example, the right to life, the right to education, and the right to freedom from torture or unlawful confinement.

In December of 2006, the UN General Assembly adopted the Treaty and on March 30, 2007 it was opened for UN Member States to sign and ratify. Canada was among the first countries in the world to sign the treaty that day. Organizations of people with disabilities worked to ensure ratification by

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<sup>1</sup> Steve Estey is the Chairperson of CCD's International Development Committee and he was a member of the Canadian delegation which worked on the wording of the Convention at the UN.

Canada. Ratification is the final signal that governments at all levels are in compliance and prepared to be bound by the new treaty.

Why does this matter? Globally the World Health Organization estimates there are 650 million people with disabilities, while in Canada we know there are over four million of us or 14.3 % of our population.

The CRPD is built on the fundamental belief that disabled people have exactly the same rights as everyone else: no more and no less. The treaty is an attempt by UN members to breathe life into this idea.

It speaks, for example, about the right people with disabilities have to be treated equally and not to be discriminated against. Fine words, to be sure, but what do they mean in practice? The CRPD says that in order to be fully equal, disabled people have a right to expect a reasonable accommodation, to ensure, for example, that they can attend school or access medical services. This is a concept well-developed by Canadian law.

These concepts and the laws needed to bring them to life offer tremendous hope for disabled people the world over and Canada's ratification of the treaty sends a strong signal that we support the approach both domestically and internationally.



Traci Walters, Hon. Lawrence Cannon, Bendina Miller and Steve Estey

# A Voice Like No Other: Ours

By  
Diane Driedger<sup>1</sup>



In 1981, the United Nations International Year of Disabled Persons, there existed a voice of people with disabilities. It had been increasing its volume since the early 1970s. At that time, two organizations arose in Saskatchewan and Manitoba. People with all kinds of disabilities, mobility and sensory saw that they had a lot in common as a “people”. Society wasn’t set up for them. The problem wasn’t what the rehab providers said it was. It wasn’t in them, in their bodies, waiting to be fixed by professionals. No, society had been built without their participation and society did not seem interested in hearing how that had happened.

In 1981, the Coalition of Provincial Organizations of the Handicapped (COPOH) had been around for 6 years and it had spread its membership cross Canada. One reporter in Ottawa even called COPOH “KAPOW” on the Hill, as COPOH representatives talked to Government about access to Canadian society and insisted on participation in an International Year that was their namesake. Indeed, over the next Decade COPOH’s representatives were involved in government delegations to the United Nations, to draft a World Plan of Action for Disabled Persons, that included the very heart of the disabled people’s movement: we need to be involved in all levels of planning about our own lives as people with disabilities. This World Plan of Action evolved over the years with input from COPOH and its international counterpart, Disabled Peoples’ International (DPI) and eventually became the UN Convention on the Rights of Persons with Disabilities, adopted by Canada in March 2010. The Convention boldly states:

*Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including: . . .*

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<sup>1</sup> Diane Driedger is Provincial Coordinator of the Manitoba League of Persons with Disabilities (MLPD). Her latest book is *Living the Edges: A Disabled Women's Reader* (Inanna, 2010).

- ii. *Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels (Article 29).*

In 1981, COPOH was a catalyst in the founding of Disabled Peoples' International (DPI) a world voice of people with disabilities. In 1980, the idea for DPI was born in Winnipeg at the Rehabilitation International Congress. COPOH had planned ahead. It had a Secretariat at the Congress and rented space to enable people with disabilities to meet several times. There, RI denied people with disabilities the right to have a majority voice in the running of an international organization concerned with "fixing" their lives. Incensed, the two hundred and fifty disabled persons present from 40 countries and all regions of the world, decided to found its own voice with the motto, "A Voice of Our Own". Canadians were very involved in the founding of DPI as the Secretariat was in Winnipeg and Henry Enns of COPOH was the Chair of the international Steering Committee. Canadians have continued to be involved in the running of DPI through the Development Office and the World Secretariat in Winnipeg and then in St. John's Newfoundland.

Indeed, 30 years later, our voice endures. COPOH, now the Council of Canadians with Disabilities (CCD) has been fortified by strengthening the representation of people with all types of disabilities in its structure, and is a world leader in confronting the barriers that face persons with disabilities.



Henry Enns and Jim Derksen

# The Canadian Disability Rights Movement Goes International

By  
Yutta Fricke<sup>1</sup>

This is the way my former boss Henry Enns told the story:

It was Monday evening, June 23, 1980, Winnipeg, Canada. The atmosphere was pregnant with excitement... Never before in the history of humanity had disabled people from all over the world had an opportunity to come together to share their experiences... One after another they began to tell their stories of oppression, exclusion and rejection.

Henry was referring to the 1980 Rehabilitation International (RI) Congress held at the Winnipeg Convention Centre. Back then, RI was one of few international organizations speaking for persons with disabilities. Among the 4,000 healthcare professionals, government officials, rehabilitation counsellors and administrators were some 300 disabled people from over 40 different countries.

The overseas guests with disabilities were greeted by Canadians promoting a common purpose: equal representation of people with disabilities in RI. Because the United Nations had designated 1981 as the International Year of the Disabled, it was especially important to revolutionize RI's medical model focussing on individual diagnoses and lifelong rehabilitation. Instead, disability advocates wanted to eliminate social and environmental barriers; their vision was full participation and equality of persons with disabilities.

Despite intense lobbying and creative pressure tactics (like Dinosaur Awards for backward thinkers), the professionals concluded that individuals with disabilities did not have the required expertise. They rejected the resolution to have at least 50% of all members of RI governing bodies be people with disabilities.

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<sup>1</sup> Yutta Fricke was the Development Program Director at DPI from 1988 - 1999.

Enter Plan B:

In preparation for the RI Congress, the Coalition of Provincial Organizations of the Handicapped (now the Council of Canadians with Disabilities) had organized a number of meetings for the participants with disabilities, including a barbeque following the RI General Assembly. With the resolution defeated hours before, and with fire in their hungry bellies, the barbeque served up much more than burgers.

As individuals from all over the world told their stories of oppression, it became clear that people with disabilities needed more than a voice at the RI table. And so, when Henry Enns, with the support of allies like Allan Simpson and Jim Derksen, called out “Do I hear that you want to create an organization of your own?” the response was resounding. By the end of the evening, 14 people were elected to form the steering committee of the new international organization.

And so the idea of Disabled Peoples' International was born.

Winnipeg was the right place at the right time. People with disabilities around the world were gaining a sense of their own identity; together they caught sight of their liberation. By the 1980s, the United Nations and increasing numbers of governments were socially prepared for this “last civil rights movement.” Furthermore, the Mennonite Central Committee offered the fledgling organization financial support early on. Within a year, the Canadian disability advocates convinced their government to fund international organizing and training of people with disabilities. So, with additional support, particularly from Sweden, future meetings could be planned and in 1981 a National Assembly in Singapore elected the first Council of Disabled Peoples' International (DPI).

While this story, and the continued presence of DPI headquarters in Canada decades later, features prominent roles for Canadians, it is a story we share with our worldwide community of persons with disabilities. In 2008, the history of the international disability rights movement reached its most significant milestone: The United Nations Convention on the Rights of Persons with Disabilities became international law.



# The Guards Allowed Us in Together

By  
Vangelis Nikias<sup>1</sup>



There had been a fire alarm at the United Nations headquarters in New York and hundreds of participants in the negotiations on the Convention on the Rights of Persons with Disabilities (CRPD) were hurriedly evacuating the building. As it was cold and rainy that winter day, people were seeking shelter in whatever way possible. One of my colleagues and I in the Canadian delegation came across a blind observer, a member of a non-governmental organization, who was trying to figure out where he could find shelter from the inclement weather. We invited him to join us in the warmth of the lobby in the building housing the Canadian Mission to the UN.

Once safely inside, and with the welcoming permission of the security guards who had recognized and been reassured by the Canadian Mission security passes my colleague and I wore, I asked my blind guest why he had been surprised at our invitation. He confessed he had not anticipated the invitation to a posh New York high rise. He came from marginalized circumstances himself, being a member of a struggling Palestinian non-governmental organization of people with disabilities.

I have often thought about this event. I have asked myself if it is a sign of a slowly changing world. Does it point to positive change in which, for example, disability activists and official state delegates to the UN are all participants?

I like to think and hope so. I also like to think that this experience says something about Canada, the Canada we are all working (indeed, struggling) to build, a Canada that is accessible and inclusive.

As a member of the official Canadian delegation to the CRPD negotiations, I

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<sup>1</sup> Vangelis Nikias is currently working for the Council of Canadians with Disabilities (CCD) as manager of the Convention on the Rights of Persons with Disabilities (CRPD) Awareness project. Previously, while working for the Office for Disability Issues (ODI), he was a member of the Canadian delegation which negotiated CRPD. He participated in all relevant meetings. Vangelis has, in the past, chaired CCD's Human Rights Committee.

have many treasured memories of deliberations about content, word-smithing, legal principles and give-and-take sessions. For a naturalized Canadian citizen and a blind person, these memories are only possible in a broader context. The inclusive and accessible Canada I am hoping for is becoming a reality thanks, to a large extent, to the efforts and contributions of Canadians with disabilities. The Council of Canadians with Disabilities (CCD), as well as other disability organizations, are in the process of changing the lived experience of persons with disabilities and, as a result, redefining Canada and the world.

My participation in CCD led human rights activities equipped me with the knowledge and experience required to become a member of the Canadian delegation and advance positions consistent with Canadian human rights and democratic principles and values. One of the most important principles is that of self-representation.

The principle of self-representation expressed in various ways – “a voice of our own” in the Canadian context or “nothing about us without us” internationally – is a common thread in the history of persons with disabilities to secure our human rights. Its achievement has not always been easy or without friction, but it has always been a necessary element of progress. Without L. Braille’s insistent affirmation of his view and voice against the resistance of his sighted teachers, blind people would not have the valued reading and writing system that bears his name. Without the Coalition of Provincial Organizations of the Handicapped’s (CCD’s predecessor) inspired and determined political intervention at the time of the patriation of the Canadian Constitution, Canada would not have achieved inclusion in the *Charter* of protection of the equality rights of Canadians with disabilities. Such a failure would have deprived Canadians with disabilities of much of the progress we have made so far. It would also have deprived Canada of its status and reputation as an international leader in human rights, a status and reputation that makes Canadians, including our political leaders, proud, but a status and reputation that we must always endeavour to maintain and enhance.

It is in this context that I place my participation in the official Canadian delegation. It is this history that made it possible that wintery day in New York to invite in the safety and comfort of the Canadian Mission someone who was surprised at the unexpected access and inclusion.

This effort is still a work in progress.

# The Russia-Canada Exchange

By  
Rhonda Wiebe<sup>1</sup>

CCD has enjoyed the benefits of many international exchanges, and I was fortunate to be able to participate in one such venture involving the Canadian Centre on Disability Studies (CCDS), the University of Manitoba (U of M) and the Provincial Department of Family Services. The Winnipeg (Canada) - Stavropol (Russia) Social Development Project was launched in May, 1998 as a three-year project directed by CCDS which received funding from the Canadian International Development Agency (CIDA).

The Winnipeg-Stavropol Project arose out of a collaborative partnership between Stavropol and Manitoba organizations which began in 1995. It focused on disability issues, models and programs of Independent Living, aspects of social work, the health industry and social services. The major goal of the project was to promote the democratic development of Russian society and enhance the lives of Russians, with the emphasis on people with disabilities, their families and communities.

My direct connection came about when, as a coordinator of specific programs at the Winnipeg Independent Living Resource Centre, I was asked to representative NGO disability groups as a member of the Winnipeg-Stavropol working group. This involved hosting members of Russian consumer disability groups, university faculty, and government on two occasions when they came to Winnipeg. It also provided me with an opportunity to visit the southern regions of the province of Stavropol in Russia in 1999. I travelled with April D'Aubin (CCD), Len Kaminski and Harvey Frankel (University of Manitoba), and Norm Magnusson and Donna Bjore (Government of Manitoba.)

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<sup>1</sup> Rhonda Wiebe is currently a policy analyst with the Disabilities Issues Office of the provincial government of Manitoba and appointed by an Order in Council to the Manitoba Health Appeal Board. Her volunteer work includes co-chairing the Ending of Life Ethics committee for (CCD) and serving as a board/committee member for the United Way of Winnipeg, the Manitoba League of Persons with Disabilities, the Euthanasia Prevention Coalition, and Not Dead Yet. What is most relevant to her work is the perspectives she has gained as a person who has lived with disability since the age of thirteen.

My experience was rich! Most striking was the warmth, passion and generosity of the Russian people, and this impression contrasted so distinctly with the sparse circumstances in which the disability organizations had to accomplish their work. Scarcity of resources made it difficult for Russian people with disabilities to obtain the basic supports they needed to participate in their communities. Any information or role modelling we provided on the concept of human rights had to be translated into a message that was meaningful to them because of their complicated history of tension between the rights of the individual, the collective, and the state. It became obvious that there is no “cookie cutter” approach to human rights, and the overlaying of North American ideals, without significant acknowledgement of cultural context, will not work.

We visited orphanages, long-term care facilities for seniors, health care clinics, and “joint stock option” communities; we saw vivid examples of social isolation and extraordinary advocacy; we heard accounts of significant efforts by government and educational institution representatives to promote the interest of persons with disabilities.

It was a time to stretch, grow and reconfigure for our team of six Canadians. Every morning we would regroup to strategize ways we could be the most effective. This often meant setting aside our preconceived plans developed out of context back home. In the end, we recognized that our interactions with the Russian people were most fruitful when we shared stories, discussed ways to implement policies and plan strategically at government, educational and community organizational levels, and encouraged each other by celebrating the diversity of the human family.

# Nothing About Us, Without Us: Landmine Survivors Turning the Tide

By  
Mary Reid<sup>1</sup>

Imagine ...hesitating before walking across an open field in order to check for landmines; imagine teaching your children how to recognize a landmine where they are playing; imagine hearing the explosion that would result in a lifelong injury after stepping out your back door.

This is the world of people who live in regions where landmines have been used as a weapon of conflict. Landmines are known as antipersonnel weapons; they do not know the difference between a soldier and a child. Landmines are laid along roads, buried in fields or even tucked away in the homes of people who have fled. At least seventy percent of people affected by landmines are civilians and half are children. Thirty years ago, these weapons were manufactured and used in every region of the world. Today, they are rarely used, lands are being cleared and countries are starting to support the rights of people who have been affected by landmines.

In 1997, an international treaty to stop the use of landmines came into effect. Since then, landmines are no longer accepted as a weapon of war. As recent as fifteen years ago, 26,000 people were injured or killed by landmines each year. Today, this number has been reduced to less than 5,000. Areas contaminated by landmines continue to be cleared. And in the past ten years, countries are starting to assist and protect the rights of people who have been most affected by landmine explosions.

The Council of Canadians with Disabilities has been part of the work to eliminate landmines and to protect the rights and dignity of people affected by landmines. CCD is an active member of Mines Action Canada (MAC), an international leader in the effort to eliminate landmines, cluster munitions and other harmful weapons left behind by wars and conflicts.

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<sup>1</sup> Mary Reid has been a friend and supporter of CCD for thirty years.

In Canada, we have a lot to be proud of. It was our country that encouraged and led the world towards the international treaty on landmines. Eighty percent of countries around the world have signed what is known as the Ottawa Treaty. These countries have agreed to stop manufacturing or using landmines and to destroy mines they have stored away.

The Disability Movement also has a lot to be proud of. When people most affected by landmines, known as landmine survivors, joined the landmine movement, the tide was turned. Real change was created and bold steps taken towards getting rid of landmines. Landmine survivors carry a respected voice within discussions, projects and commitments about how countries will fulfill promises of the Ottawa Treaty.

The landmine movement is one where the “us and them” division is an ever-fading line as treaty negotiators; non-government advocates, government officials, and media personnel are themselves landmine survivors.

Support for people affected by landmines used to be focused on emergency assistance and occasionally health care. As landmine survivors joined the discussions, interventions broadened to see the person as a member of their community with a basic right to social and economic inclusion. Assistance has also broadened to include things like peer support, access to services with dignity, and self-directed programs.

The landmine movement doesn't just mirror the disability rights movement; it is part of it. The focus has moved from charity assistance, to medical intervention, on to social and economic integration, to today's focus of realizing the full and equal rights of each individual. The success of the landmine treaty is a testament to the power of “Nothing about us without us”.

Note: CCD is a member of Mines Action Canada (MAC), an international leader working to eliminate landmines, cluster bombs and other explosive remnants of war. Steve Estey, a leading disability rights advocate, served on the MAC Board of Directors from 2001 to 2007; in the role of Chairperson from 2003-2006.

