



CAILC News Bulletin

CANADIAN ASSOCIATION OF INDEPENDENT LIVING CENTRES

Information sharing, national initiatives, federal policies, and political decisions affecting the Independence of Canadians with Disabilities and their Independent Living Resource Centres

WINTER 2005 ISSUE

"TIME TO ACT—END 3,000 DAYS OF LIBERAL INACTION" NDP CAMPAIGN ANNOUNCED

VOLUME 10 NUMBER 1



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It is no secret that the disability community in Canada has grown impatient with the slow pace of change with respect to the design and implementation of inclusive and empowering disability policy in Canada. Disproportionate levels of poverty, abuse, and unemployment, as well as a lack of adequate income supports continue to prevent many persons with disabilities from full and equal participation in their communities. However, recent developments may indicate disability issues are finally getting the political attention they deserve, and many are hopeful that real and lasting change may finally be on the horizon.

On December 3rd 2004 (the UN International Day of Disabled Persons) the NDP launched the "Time to Act" campaign to draw attention to what they believe to be the Liberal governments' inaction with respect to recommendations tabled by the Task Force on Disability Issues in their October 1996 report 'The Will to Act.' The campaign was launched by the NDP's Member of Parliament for Burnaby-New Westminster and NDP Critic for people with disabilities. Peter Julian draws attention to the 3,000 days since "The Will to

Act" was tabled, and what many believe to be a frustrating lack of progress on disability issues since that time.

The campaign was launched by the NDP's Member of Parliament for Burnaby-New Westminster and NDP Critic for people with disabilities. Peter Julian draws attention to the 3,000 days since "The Will to Act" was tabled, and what many believe to be a frustrating lack of progress on disability issues since that time.

According to Julian: "In 1996 the Liberals claimed to have the 'Will to Act' – now is the 'Time to Act'... four million Canadians or roughly 13% of the population have a disability. They are our neighbors, friends and family and it's time the government empowered people with disabilities to escape poverty and improve their quality of life... It's been 3,000 days since the Task Force brought forward recommendations aimed at empowering Canadians with disabilities and ensuring their full participation in our communities... It's time the government took this report off the shelf and, with the involvement of the disability community, actually acted on it."

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Time to Act...(continued from page 1)

In addition to the 'Time to Act' Campaign a new parliamentary subcommittee on people with disabilities has also been formed. This new subcommittee, formed in November 2004, is comprised of members from all parties represented in Parliament. Although it is a relatively new subcommittee, information on its membership, activities, meeting schedule, and disability issues being addressed can be viewed online:

http://www.parl.gc.ca/committee/CommitteeList.aspx?Lang=1&PARLSES=381&JNT=0&SELID=e27_&COM=9237

Hopefully these new initiatives signal that the voices of persons with disabilities are finally being heard and their political clout is growing. For more information on these initiatives, or to share your thoughts and concerns with those involved, please visit their online sites.

More information on the NDP's 'Time to Act' Campaign can also be found at:

<http://ndp.ca/newsdetail/nid-2362>

'The Will to Act' can be viewed at:

http://www.sdc.gc.ca/en/hip/odi/documents/scottTaskForce/00_toc.shtml

FEDERAL BUDGET 2005:

ANOTHER DISAPPOINTMENT FOR THE DISABILITY COMMUNITY

On February 23, 2005 Minister of Finance Ralph Goodale delivered the eighth consecutive balanced budget. However, for the disability community, there was nothing balanced about this budget as the disability agenda was once again pushed aside. Indeed, rather than announcing funding for initiatives identified by persons with disabilities as essential, disability issues were all but absent from spending announcements, and again the theme of any disability related budget promises was tax measures. As many within the disability community have noted, tax credits benefit those with taxable incomes, and thus fail to address the needs of a community with disproportionate levels of unemployment and poverty.

Independent Living Resource Centres are on the front line providing supports and services to enable the full participation of individuals with disabilities across Canada, and have survived on basically the same levels of funding since 1988. As we are all well aware, our community does not enjoy the same level of citizenship as many non-disabled Canadians and along with other disability organizations we continue to fight to secure the rightful place of persons with disabilities in

Canada. Yet, once again, this budget illustrates that we are not getting the recognition or financial support we deserve from the Federal Government.

Although small and predictable, there were some crumbs in the budget for the disability community. With respect to the Disability Tax Credit (DTC), it looks like most of the recommendations from the Technical Advisory Committee on Tax Measures have been addressed including:

- Greater clarification on how legislation will conceptualize impairments, and life-sustaining therapy.
- Extending eligibility to include individuals with multiples restrictions. This is significant as it will increase the number of individual who will benefit from the DTC.
- Allowing a greater number of health practitioners to certify individuals for eligibility for the DTC.

Building on the disability supports deduction announced in the 2004, this budget also proposed to expand the list of eligible expenses (i.e. to include things like reading services, note takers, and job coaching). In

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WINNIPEG 20TH ANNIVERSARY DINNER AND DANCE

By Anna Quon

It was the last day of the CAILC Annual General Meeting (AGM), a time for celebration and reflection for the many exhausted delegates in attendance. The Winnipeg ILRC, marking their 20th anniversary, hosted a dinner and dance as a finale to the week's events. It was held in a cavernous conference room at the Winnipeg Convention Centre.

I made my way past the guest book, took a Stroll Down Memory Lane (with photo albums of the last twenty years), and stopped before the Wall of Honour, where prominent people with disabilities connected to the Winnipeg ILRC, such as Allan Simpson, were remembered. Then I chose a seat at one of the tables which flickered with candlelight.

The only other occupant at the table was a consumer I had seen the night before at the Winnipeg ILRC's wine and cheese reception. As we talked, he told me about his struggle to get compensation from a former employer, where he felt his supervisor's treatment of him had contributed to a possible disability of mental illness. As a mental health consumer myself, I understood the way that poor relationships put stress on the mind and emotions. In fact, I had been feeling a little insecure and awkward during the CAILC AGM, attended by so many people I didn't know from across the country, that I was glad to meet someone with whom I felt I shared a common experience.

Gradually, the seats around our table filled. We were all intrigued by the centerpiece, a candle floating in a glass vase of water, surrounded by pebbles, "in a composition that leads the eye around the table to acknowledge our companions and then up through earth's elements toward the future," according to an accompanying card. There were also a white spruce seedling, (Manitoba's tree) and a pin shaped like a grey owl (the provincial bird), at each place setting. The sapling represented

growth and the owl symbolized the power of flight, "more an act of courage than it is an act of magic," the card said, and the Winnipeg ILRCs journey from past to future.

It's funny how magic and courage entwine with one another to bring people closer together. It might have been the eloquent and humorous key note speech by Reg Alcock, President of the Treasury Board or the sumptuous supper (and free and freely flowing wine), that reminded us to take pleasure in being together. And it may have been the candlelight, representing as it did for me the ancient campfire that compelled the people at my table to tell their stories. Whatever it was, people opened up with tales of difficult families, friendships forged in illness, and epiphanies about disability that pried open the shell of our separateness.

And then we danced. The band Aphrodisiac Smile played for all they were worth in a corner of that huge room. A group of young women in black dresses went barefoot, women in wheelchairs spun around together on the dance floor. And one young man in an electric wheelchair danced by himself, turning and twisting his chair to the music. It was bittersweet, that even among us, there are people who dance together and those that dance alone. But at least we were dancing.



Anna Quon accepting the Volunteer of the Year Award from Paul-Claude Bérubé, President of CAILC and from Lois Miller, Executive Director of the ILRC Halifax, NS

INDEPENDENT LIVING IMPACT PROJECT - FUNDED BY SOCIAL DEVELOPMENT CANADA (SDC)

Last year, CAILC produced “The Independent Living Business Case: A Strategic Investment into the Human and Economic Potential of Canadians with Disabilities.” The inclusive process that enabled us to develop the business case also helped define our strategic priorities for the next five years. The national office/board selected 3 areas from the more detailed activities within the business case to build the foundation for implementing the business case.

With the overall goals of the business case in mind, last year CAILC developed and submitted a proposal for an Independent Living (IL) Impact Project that has since been approved for funding. This project has been designed to build a credible, sustainable, pan-Canadian framework for analysis, information gathering, story telling, and measuring the participation in IL related activities, services, and supports. This project will enable us to document our success stories and provide a historical account of the impact of the IL movement in Canada.

This project will:

1. Create and implement a national IL information collection system that will provide reliable statistics, reports on supports for Canadians with disabilities, document evidence of quality of life issues, and the economic benefits of the Independent Living model;
2. Improve standards and approaches to Independent Living Resource Centre (ILRC) core programs through the creation of principles, strategies, and document practices;
3. Provide a historical and up to

date account of the impact of IL on individuals, their communities, and Canadian society.

The project will achieve the following outcomes:

Creation of an IL based national information collection system that will allow for comprehensive data and information collected for all ILRCs. The information gathering system will incorporate appropriate indicators and descriptors enabling a more accurate illustration of socio-economic realities for Canadians with disabilities and their overall quality of life;

Improved standards and approaches to core programs within the ILRCs, which will include principles and strategies, internal tools for assessment, an IL web site with an effective practices forum, and a public resource centre with descriptive, human interest stories, and testimonials about inclusion of people with disabilities in communities;

Publication of a book that will provide a historical account of the impact of IL by incorporating narrative inquiry and storytelling to ensure the power and effectiveness of IL is articulated through the voices of people with disabilities.

We have the good fortune of having John Lord as a project consultant throughout this 3 year initiative. Jihan Abbas, CAILC’s Policy and Research Consultant will be the project manager, Michael Horne will act as the Team leader for the improved standards component, Susan Forster will act as the Team leader for the national information and data collection component.

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Independent Living Impact ... (continued from page 4)

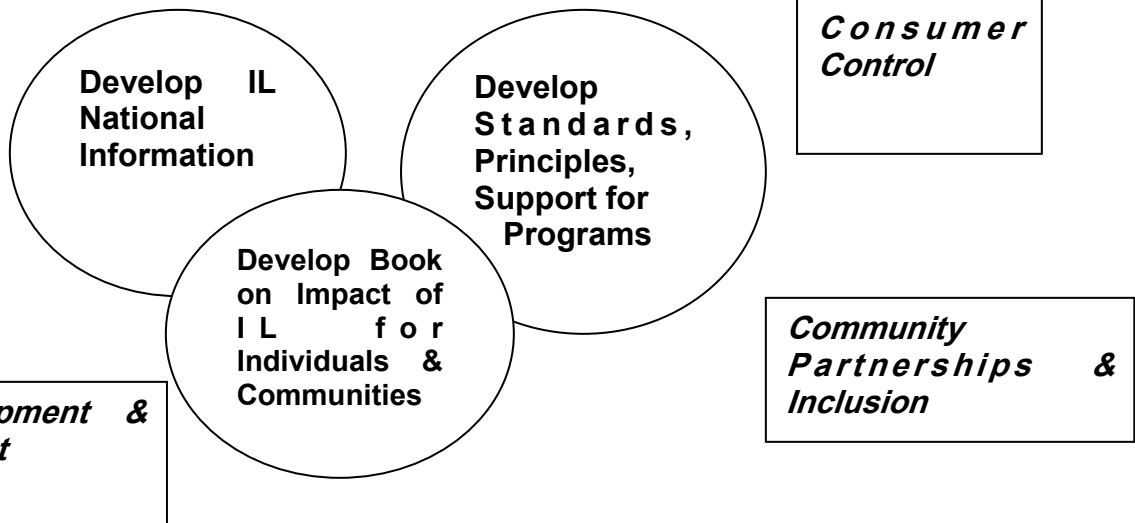
We intend to sub-contract both of the later components to ILRCs and a call for proposals will be sent out sometime in the spring. We will also help consumers who are interested in writing their own personal stories for the IL Impact Book and we will have a peer writer who will oversee these consumer writers and help

with editing. All consumer writers will be paid for their work.

More details about the project will be sent out once it is up and running. If you require any further information please do not hesitate to contact Jihan or Traci.

PRINCIPLES AND APPROACHES TO PROJECT IMPLEMENTATION

- 1. An IL Lens Guides, All Project Processes, Activity Development and Methods.***



- 2. The three Project Components are Inter-Connected, in Terms of Methods, Approaches, and Learning.***

- 3. The Project is Consumer Driver, and Involves ILRC's in the Development, Implementation, and Evaluation***

- 4. Adult Education, Action Learning, and Participatory Research Principles Guide Approaches to All Research, Resource Development, and Education***

DECEMBER 3, 2004: FEEDBACK FROM ILRC DELEGATES ATTENDING CAILC'S INTERNATIONAL DAY OF DISABLED PERSONS CELEBRATION

CAILC subsidized one representative from three ILRCs to be present for the December 3rd events in Ottawa, in order to celebrate the International Day of Disabled Persons. Here are their impressions on that day.

TROIS-PISTOLES, QC

It was very gratifying for me to be selected to participate in the December 3, 2004 activity highlighting the International Day of Disabled Persons. It was also an opportunity for me to share my opinions and experiences and to meet other people from different backgrounds. At the same time, I was asked to be the francophone voice for a television spot promoting independent living in Canada. So on the morning of December 3, I headed to an Ottawa studio to record the spot. This brought back warm memories because of my previous work experience in the communications field. Next year, I think it would be positive to retain this same format so that other people involved in the independent living movement can gain such experience. It would also be valuable to give these people the opportunity to speak during the event on what independent living means to them. In closing, I would like to thank everyone who made it possible for me to take part in this wonderful experience.

By Denis Lévesque

PARRY SOUND, ON

It was rewarding of spirit and heart to be at the CAILC December 3rd Event. To meet hundreds of persons with all types of disabilities, celebrating their own lives, and the great support CAILC and their own ILRC Centres have given these persons on their road to independence.

The CAILC Board Members, and Staff welcomed me, as the newest Board Member at Large. I had the opportunity to also meet members of our Canadian Government and persons supporting the ILRC goals of Research, Information, Support and Empowerment.

By Linda Anne Thompson

HALIFAX, NS

I was invited to join the Board at the Independent Living Resource Centre a year ago and felt that I may be able to help by bringing some of my first hand experience to the group. My aim is to help inspire other persons living with disabilities to believe in themselves and to never give up on their goals. Originally from a small town in NS, to head to Ottawa for this event was very exciting! I had never been to Ottawa before. I had the very exciting opportunity to meet Ken Dryden and have my picture taken with him as well.

There were many exciting announcements made including the partnership between CAILC and the weather network, where the weather network produced two public service announcements showing that people with disabilities live and work in the community. The PSA were shown on the weather network during the month of December. Also, the Access to Entertainment card announced by Famous Players/Cineplex/ and various disability organizations that beginning in March will allow support persons to attend a movie free of charge or for a nominal fee. Also Ken Dryden acknowledging that his department is committed to working with the disability community to set standards.

Once again this was a very exciting opportunity to be a part of and I was honored to be there.

By Michelle Mahoney

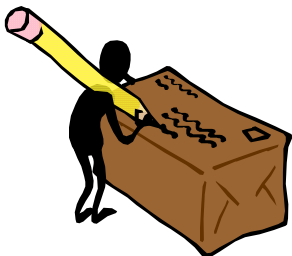
SPOTLIGHT ON VOLUNTEERS

If you have spent anytime in CAILC's national office, you probably know how valuable and dedicated our volunteers are. Given their outstanding contribution to the national office and leadership as volunteers, this volunteer spotlight on Richard and Valerie Guertin is much deserved.

Richard and Valerie have been volunteering at CAILC for the last 5 years. They enjoy the work, say it keeps them alert, and hope to continue doing it in the future. Both Richard and Valerie have invisible disabilities. Richard and Valerie help coordinate mass mail-outs to the Centres, do a number of services such as answering the phones, help receive and send parcels, keep the CAILC library organized, and help CAILC prepare for seminars, conferences, and national events. This happy couple has also been with the Ottawa-Carleton Independent Living Centre for 16 years, and helps the Ottawa ILRC with their quarterly mail outs and attend workshops and events. Richard has even been Santa Clause at the annual Christmas Party!

In addition to being model volunteers, Richard and Valerie's teamwork and commitment to helping each other is to be admired. As they often say: "It was our destiny to be together – we go everywhere together and we are hardly ever apart - we grew up together and are lifetime friends." Both are also committed to justice and inclusion for all persons with disabilities.

Richard and Valerie are an integral part of CAILC's day-to-day operations and we thank them for their continued service and commitment. In fact, if you are reading this Newsletter chances are very good it made its way to you because of Richard and Valerie's hard work!



Federal Budget 2005...(continued from page 2)

In addition, the budget also expands items eligible for the Medical Expense Tax Credit and extends eligible expenses to include those costs incurred through operating equipment (i.e. the cost of electricity). The maximum Child Disability Benefit is also being increased from \$1,681 to \$2,000.

For more information on the Federal Budget visit:

<http://www.fin.gc.ca/budtoce/2005/budliste.htm>

For more analysis of the Federal Budget through an Independent Living Lens, visit the "What's New" section of CAILC's website at www.cailc.ca

AWARDS FOR PERSONS WITH DISABILITIES

CENTENNIAL FLAME RESEARCH AWARD

In January, the Subcommittee on the Status of Persons with Disabilities announced they are accepting applications for the 2005 Centennial Flame Research Award. This annual monetary award (\$4,000 for the 2005 competition) will enable a person with a disability to conduct research and prepare a report on the contributions of one or more Canadians with disabilities to the public life or the Parliament.

For more information on this award or how to apply (deadline is April 2005) please go to:

<http://www.parl.gc.ca/committee/CommitteePublication.aspx?COM=9237&SourceId=97737&SwitchLanguage=1>

SKILLS DEVELOPMENT OPPORTUNITIES

BRUSH UP ON YOUR PROPOSAL WRITING SKILLS

Proposal writing is often an unfortunate and time consuming reality for ILRCs. The turnover time between a call for proposals being issued and the submission deadline often seem unrealistic to already overworked staff. Although not specific to the grants and contributions streams ILRCs and other non-profits often apply for, Contracts Canada's free regional workshops that on doing business with the Federal government may give you an

edge come proposal writing time!

For more information on the seminars being offered, timetable, or regional workshops, visit Contracts Canada's web site: <http://contractscanada.gc.ca/en/sem-e.htm>.

While visiting the Contracts Canada site, be sure to also check out their online resources and tips for better proposal writing: <http://contractscanada.gc.ca/en/writin-e.htm>.



SPOTLIGHT ON PARTNERSHIP

HIV AND INDEPENDENT LIVING CENTERS: MAKING THE CONNECTION BY AINSLEY CHAPMAN, CANADIAN AIDS SOCIETY

I would like to introduce you to the Canadian AIDS Society (CAS), a coalition of over 120 community-based AIDS Service Organizations (ASO) across Canada. Since 1986, CAS has served as the national voice for the community-based AIDS movement. We have received a call from our members to reach out to other groups who share some of the experiences of people living with HIV/AIDS, and to find ways of working together to challenge common barriers to independent living such as discrimination, poverty and the high cost of illness. Our members are often interested in building partnerships and networking with other service providers in their area. These partnerships can be formal projects and co-sponsored activities, while other types of networking such as referring clients and keeping updated on what other resources are available in their neighbourhood.

There are many ways that Independent Living Resource Centres (ILRCs) can benefit from connecting with their local ASO. Depending on what services a local ASO can provide, a neighbouring ILRC may want to access:

- Training for ILRC staff and volunteers on HIV/AIDS in work environments (including issues around safety, supporting the needs of people living with HIV/AIDS and legal issues around disclosing HIV status);
- Training for ILRC staff, volunteers and consumers on HIV transmission and

prevention;

- A network of resources to refer ILRC clients who may live with HIV or who would like to get tested.

By working with an ASO, you can find out:

- How HIV affects your community;
- How to support someone in your community who lives with HIV;
- How to reduce some of the economic challenges that often come with living with HIV/AIDS.

Most importantly, by discussing these issues you are challenging the stigma and discrimination that often keeps people living with HIV from seeking support. This year, make one of your goals to become an HIV-friendly environment! As leaders in service delivery and advocacy for people living with disability, ILRCs can also support ASOs by offering themselves as one more resource that is available to people living with HIV/AIDS.

If you want more information about HIV/AIDS, how it affects your community and what partnership or networking opportunities are available in your region, you can contact us, toll-free: 1-800-499-1986, visit our website www.cdnaids.ca, or email me ainsleyc@cdnaids.ca. You can also contact your local AIDS Service Organization (listings are available through our website, filed under Contacts and Links, Members and Associates).



EXCITING NEW OPPORTUNITY FOR THE INDEPENDENT LIVING MOVEMENT: *CENTRE-RESSOURCES POUR LA VIE AUTONOME, RÉGION BAS-SAINT-LAURENT* RECEIVES SUPPORT FROM SOCIAL DEVELOPMENT CANADA

On January 28 2005 the Minister of Social Development, the Honourable Ken Dryden, announced \$440,932 in funding for the Centre-Ressources pour la Vie Autonome region Bas-Saint-Laurent. This funding, through Social Developments Partnership Program – Disability Component, is being provided to help enable and support the full participation of persons with disabilities in Canadian Society.

The project, entitled “Impact des représentations sociales sur l’emploi” aims to increase the inclusion of persons with disabilities in the workforce. The project will achieve this through joint research within the IL network and with other stakeholders, the inclusion of persons with disabilities in the research process, working to change perceptions of persons with disabilities, and transformation of current employment

practices and barrier removal.

Minister Dryden noted “the Government of Canada is committed to working with our partners to promote the full inclusion and active participation of all Canadians in the social and economic life of our country.” Daniel Bilodeau noted that “this project will advance research into the integration of persons with disabilities in the workplace.”

As employment needs and barriers to participation in the paid labour market have been identified time and time again by persons with disabilities as an urgent social issue, this funding is a welcome acknowledgment of both the need of persons with disabilities and capacity of the Independent Living movement to address these needs and identify solutions based practices.

SPEECH BY DANIEL BILODEAU, CRVA BAS-SAINT-LAURENT AT THE PRESS CONFERENCE BY THE MINISTER OF SOCIAL DEVELOPMENT CANADA
JANUARY 28, 2005

On behalf of the *Centre-Ressources pour la Vie Autonome : Région Bas-Saint-Laurent* [Independent Living Resource Centre: Lower St. Lawrence Region], based in Trois-Pistoles, I wish first of all to thank the Minister of Social Development Canada, the Honourable Ken Dryden, for travelling to our region to announce this important funding for our agency.

Our project, entitled “*Impact des représentations sociales sur l’emploi*” [Impact of Social Representations on Employment], was submitted under the Social Development Partnerships Program, Knowledge Development for Social Inclusion. We wish to highlight the

sense of long-term vision that the federal government has demonstrated in this field by providing significant funding for research on persons with disabilities in Canada.

This funding will allow us to conduct more than two years of research on the social representations related to work and persons with disabilities in the Lower St. Lawrence and in New Brunswick’s Acadian Peninsula, with the findings being disseminated in the spring of 2007

This participatory-type research will be conducted in conjunction with the *Comité de*
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Speech by Daniel Bilodeau... (continued from page 10)

concertation et de consultation des travailleurs et travailleuses handicapés du Bas-Saint-Laurent [Lower St. Lawrence disabled worker cooperation and consultation committee], Quebec and New Brunswick university researchers, the *Centre-Ressources pour la vie autonome de la Péninsule acadienne à Shippagan* [Independent Living Resource Centre, Acadian Peninsula in Shippagan], and the Canadian Association of Independent Living Centres. It is recognized that people with disabilities are often excluded and isolated from society; much work has been conducted attempting to explain the related mechanisms. In Canada, the Declaration on the Rights of Disabled Persons, policies, and various funding and intervention programs all constitute initiatives designed to improve these persons' participation in community life. One of the fundamental goals of these programs has been for persons with disabilities to achieve independent living by taking steps such as entering and remaining in the labour market.

Despite incentives and ongoing efforts by various support and intervention groups, results have been significantly below expectations. This issue must be approached from a new perspective by studying "handicap situations" in a more all-encompassing and interactive way, i.e. by focusing on the relational dynamic between persons with disabilities and their social environment. This project is designed to explore the social representations of employers and disabled persons in two Canadian provinces, namely Quebec and New Brunswick.

Through this project, it will be possible to acquire additional knowledge on poorly understood aspects of the mechanisms that exclude persons with disabilities from the labour market, and to better understand the inconsistencies that are undermining the success of the extensive efforts already underway to integrate disabled persons into the working world. The

project will help reduce disabled persons' isolation, marginalization and poverty by significantly increasing their level of participation in the workplace. Upgrading their employment qualifications and reducing the psychosocial barriers to hiring them and keeping them in the workplace by enhancing employers' and employees' social representations of them will be the approaches used to achieve this objective. We are proposing to examine this social reality in all its complexity in order to identify the underlying dynamic and be able to subsequently disseminate the findings across Canada.

The project will develop a valid and relevant model and tools for evaluating the interactions between disabled persons and employers and build effective intervention strategies based on a more integrated vision of all the components in play. Social and community workers, specialized trainers, adapted work centres, agencies promoting and defending rights, as well as the subsequently trained service planners will be better equipped to support disabled persons' efforts to find work and join and remain in the workplace. These parties' new knowledge will allow them to comprehend the full complexity of disabled persons' interactions in order to identify the underlying dynamic and intervene more effectively so that independent living becomes more and more accessible.



From left to right in the back: Traci Walters, Patricia Larrivée and the Hon. Ken Dryden, in the front: Daniel Bilodeau, Denis Lévesque and Thérèse Gagné

RESEARCH CORNER

THE JOYS OF A GENUINE PARTICIPATORY RESEARCH PROCESS

AUTHOR: HAZEL SELF

Several years ago a small group of us met to define a research project question - it is one of the most important questions that medically-based rehabilitation needs to consider: - ***“What is the consumer perspective of their early rehab experiences and what are their recommendations for change?”***¹

Our group consisted of two University of Toronto professional research scientists, Dr. Rebecca Renwick, O.T. and Dr. Karen Yoshida, P.T.; a service provider - Laura Forma, O.T. manager of Gage Transition to Independent Living and two individuals with physical disabilities - Audrey King² and myself.³ We also employed two administrative assistants, Francine Odette and Leslie Fell.

We all worked together, from the preliminary “idea” stage where we formulated key questions and methods for obtaining information, to reviewing and analyzing the vast amount of data generated from interviews with 80 spinal cord injured consumers in five areas of Ontario, to writing the results, holding a public forum, and presenting the feedback and recommendations at conferences, locally, nationally and internationally. Each of us participated at all stages, consulting, discussing and sharing various tasks and roles.

Working on this project has been one of the most satisfying and rewarding experiences of my life. As a “Participatory Research” group we laughed together, toiled together and ambitiously “took on the world.” We all learned some practical considerations when including consumers in the process such as, the timing and location of meetings, budgeting for attendant services and accessible transportation. It takes a teachable heart to

embrace others' experiences as equally valid. Rebecca, Karen and Laura (all able-bodied) were individuals who genuinely *lived* their conviction that all people are worthy of respect and the ***lived experiences of people with disabilities are an essential contribution to the research team.***

Karen and Rebecca, our research experts, were always willing to explain process and terms and as all members listened, questioned and learned from each other, an environment of trust and appreciation grew; fertile soil indeed for enthusiasm, creativity, integrity and innovation to flourish.

There is no question that it's very much easier to influence participatory research when you work with able-bodied researchers within a health care or educational setting and you yourself carry the “triple credentials” of being disabled, active ambassadors of Independent Living, and an educated healthcare professional yourself. However, anyone with a passion for the importance of this kind of research can exert a major influence by getting to know researchers and bring important research issues to their attention in a collaborative, encouraging way.

We believe we have contributed an important piece of knowledge which will make a real difference in effecting positive and constructive change. Both Audrey and I thank our able-bodied counterparts for enabling us to give of our talents and our expertise and for sharing theirs so generously with us. The result was participatory research at its finest.

¹For more information on the research project contact karen.yoshida@utoronto.ca

²Audrey, disabled by polio at age 9, earned her B.A and M.A degrees in developmental psychology at Carleton University before working for 30 years with disabled children and youth at Bloorview MacMillan Centre in Toronto; she has served on many government and community committees over the years, and is currently a board member of the Centre for Independent

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The Joys of ... (continued from page 12)

Living in Toronto. Audrey is an artist, advocate, writer and presenter on disability issues. A frequent traveler, she recently returned from a tour of Japan where, as the guest of the Japanese Ventilator User's Network, she spoke on issues relating to independent living with a ventilator

³Hazel Self worked as a registered nurse until she had a C6 spinal cord injury in 1978. After several years of volunteer work in disability-related fields she became employed at Gage Transition to Independent Living, a program of West

Park Healthcare Centre; she also enjoys painting and has had the opportunity to travel and present internationally.

For more information on Participatory Action Research please visit CAILC online:

http://www.cailc.ca/CAILC/graphic/awards/lor d/award_e.html

GOOGLE SCHOLAR: NEW SEARCH ENGINE FOR FINDING RESEARCH

One of the most daunting tasks for anyone starting a research project is finding out what research already exists on a certain topic. Thankfully, the folks at Google have introduced a whole new search engine geared to scholarly works and published research.

Searching the site for authors, subjects, or keywords brings back a long list of results and articles (some web based and accessible this

way). The site also seems to allow users to search for texts in different languages. This new site will allow researchers to compile a list of relevant articles, sites, and books before heading into the library.

To give Google Scholar a try visit: <http://scholar.google.com/>

FUNDRAISING CORNER

The Ottawa Carleton Independent Living Centre's Grand Slam: The 8th Annual Baseball/Ball Hockey Tournament - a \$20,000. Success.

From humble beginnings, as a simple baseball tournament with seven teams in 1996, the Ottawa Carleton Independent Living Centre's baseball and ball hockey tournament just keeps getting better and better. The last two years have seen 32 teams, with each team paying an entry fee of \$250.00. The tournament has become so popular that last year one team had to be turned away in order to ensure an even number of teams for a round robin format. Run by the Ottawa ILRC staff and numerous volunteers, the event was a huge success.

The players in the Kids Ball Hockey

Tournament are an integral part of the event as each player receives a pledge form and needs to have a minimum of \$25.00 in pledges. In addition to the games, there was also a cash bar, a snack bar, BBQ and a silent auction with over 100 items. The auction provided the Ottawa ILRC with networking and outreach opportunities, and showcased the generosity of the local community. Auction items ranged from gift certificates, paintings, t-shirts, a Harley Davidson motorcycle rental, and a weekend for two at a hotel. In total, the Ottawa ILRC raised over \$3000 on the silent auction alone.

Aside from the fundraising that will benefit the Ottawa ILRC, this event raised morale and the profile of the Independent Living movement. Momentum is also building and the Ottawa ILRC has set a goal to raise \$25,000 for the 2005 tournament.

DISABILITY ON THE WEB

DISABILITYPOLICY.CA - NEW WEB SITE FOR CANADIAN DISABILITY POLICY

<http://www.disabilitypolicy.ca/>

DisabilityPolicy.ca looks at the issues and concerns surrounding disability-related policy in Canada.

The site was built by a group of committed volunteers from several different organizations, including: Canadian Association of Independent Living Centres, and various Independent Living Resource Centre groups, the Canadian Association for Community Living, ARCH: A Legal Resource Centre for Persons with Disabilities, the Council of Canadians with Disabilities, and National Federation of the Blind: Advocates for Equality.

The disabilitypolicy.ca web site was designed to meet or exceed all current website design accessibility standards. If you have any suggestions that will help make the site more accessible, please feel free to contact:

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devilevie@hotmail.com

NEW ONLINE CBC COLUMN TO

SHOWCASE WRITERS WITH DISABILITIES

http://www.cbc.ca/news/viewpoint/vp_disability_matters/

The CBC has a new section of their website called *Disability Matters* that will feature the contributions of three writers with disabilities. This new column will provide persons with disabilities with the opportunity to comment on disability issues including: rights, inequity and discrimination, self-help and consumer advocacy. Given that disability is often reported on in the mainstream press by non-disabled writers, this site is a welcome addition.

CANADIAN REVENUE AGENCY – ON LINE LINKS AND TAX RESOURCES FOR PERSONS WITH DISABILITIES

<http://www.cra-arc.gc.ca/tax/individuals/segments/disabilities/menu-e.html>

This site links visitors to a number forms, resources, documents, and regulations concerning persons with disabilities and the taxation.

CANADIAN HUMAN RIGHTS COMMISSION – PREVENTING DISCRIMINATION RESOURCES

http://www.chrc-ccdp.ca/preventing_discrimination/educational_resources-en.asp

This site links visitors to information, tools, and resources about preventing discrimination. Although not disability specific, there are links to resources on barrier free workplaces.

ANOTHER INTERESTING WEB SITE:

It is a government of Canada web site which focuses, among other things, on Accessible Transportation, Adaptive Technologies and Mapping for the visually impaired. There is also an Employment section. It is called www.pwd-online.ca

UPCOMING CAILC EVENTS

NATIONAL SAFETY SYMPOSIUM: CRIME PREVENTION AND INDEPENDENT LIVING APRIL 28-30, 2005 – WESTIN HOTEL – OTTAWA

The time is fast approaching for our National Symposium on Crime Prevention and Independent Living. The program has taken shape and we are excited about the interest this event has generated in both the crime prevention and disability communities.

Throughout the preparation for this event, it has become clear that people with disabilities are very concerned about issues related to safety, security and crime prevention in their communities. CAILC and several of the Independent Living Resource Centres across Canada are aware of this concern and have worked hard to develop programs and resources for the disability community. The Symposium offers the IL movement the opportunity to showcase this work and introduce our crime prevention tools and resources to first time responders, police, community leaders and service and support agencies. We have invited these groups and organizations to come to our Symposium, to learn about IL, and the safety of persons with disabilities in their communities.

One of our guest speakers is Dr. Michael Kendrick, an international consultant who is familiar with the issues affecting the personal safety persons with disabilities and Independent Living. Dr. Kendrick will address the nature of vulnerability, the function of intentional safeguards and the role of persons with disabilities in making changes. He will also facilitate an open session on how to build inclusive crime prevention communities.

Breakout sessions will feature tools to facilitate Independent Living and other community tools for disabled persons, police and first responders, as well as workshops to develop an inclusive community strategy. Panel discussions will include police partnerships with IL Centres, Fetal Alcohol Syndrome Disorder, and personal care and abuse. The key plenary session is about building inclusive communities to prevent crime led by expert Michael Kendrick.

We have also invited speakers from the government and the disability community. Our consumer panel will include Sandra Carpenter from the Independent Living Centre in Toronto who is an expert on personal care abuses, and Jim Derksen a disability and human rights consultant. The Symposium will also provide us with the opportunity to come together under the guidance of Cam Crawford from The Roeher Institute to develop recommendations for a national strategy on crime prevention, Independent Living, and persons with disabilities.

In addition, our partners, The Ottawa Police Services, will be celebrating their 150th anniversary and will be hosting a gala dinner for all delegates and the community on the Friday evening. If you are not able to be with us in April, please view the Crime Prevention section of CAILC's web page in May where we will post speaker notes and pictures from this important national event



OTTAWA POLICE SERVICE
SERVICE DE POLICE D'OTTAWA

Working together for a safer community
La sécurité de notre communauté, un travail d'équipe

THE GOVERNMENT OF CANADA RELEASES THREE NEW DISABILITY PUBLICATIONS

On December 3rd 2004 (UN International Day of Disabled Persons) the Government of Canada released three new publications addressing issues related to persons with disabilities. The following new publications are all available on line:

- 1) *Advancing the Inclusion of Persons with Disabilities 2004* - This is a follow-up to the 2002 Government report of the same name. This updated report presents information on persons with disabilities and the barriers they continue to face in Canadian Society as well as the progress made towards barrier removal.
- 2) *Canadian Attitudes Towards Disability Issues* – This national opinion poll looks at

public awareness and attitudes towards disability. Of particular interest to the IL movement is that over 80% of those surveyed agree to some extent with providing public funds to support initiatives that promote independent living rather than institutional settings.

- 3) *Frequently Asked Questions* – This guide provides readers with answers to the questions most frequently asked by persons with disabilities and caregivers.

All three of these new documents can be viewed online or ordered by visiting:

<http://www.sdc.gc.ca/en/cs/comm/sd/news/2004/041203.shtml>

NEW RESOURCES



Fire Safety for People with Disabilities(2004) The Canadian Paraplegic Association

This impressive plain language, cross-disability training kit on fire prevention and safety for persons with disabilities is now available to order through the Canadian Paraplegic Association (CPA). This educational kit includes:

- Case studies on persons with disabilities and fire prevention and emergency preparedness;
- Information on fire safety and the persons with disabilities;
- Fact sheets on disability and fire;
- Sign Language for emergencies;
- A checklist for organizing accessible public

education sessions on fire safety.

The information in this resource will benefit a broad range of safety stakeholders including: individuals with disabilities, disability service providers and organizations, building owners and landlords, fire services, and workplace health and safety representatives.

For additional information or to order a kit (\$20 + GST) you can contact CAS at:
 230-1101 Prince of Wales Dr., Ottawa, ON K2C 3W7
 Phone: (613) 723-1033 ,
 Email: info@canparaplegic.org
 Website: <http://www.canparaplegic.org/>

WELCOME TO THE CAILC BOARD

Congratulations to: Dave Kehler, Winnipeg, MB and Linda Anne Thompson, Parry Sound for their appointment to the CAILC Board.

BOOKS:

From There to Here Stories of Adjustment to Spinal Cord Injury (2004) edited by Gary Karp and Stanley D. Klein PhD, Foreword by Marcie Roth.

This book is a collection of 45 personal stories of people living with spinal cord injuries that explores how people with spinal cord injuries live with their disability. As a person born with a physical disability myself, reading this book gave me a greater of the rehabilitation process, the recovery process, and the journey towards independence.

This book is currently only available in English.

By Mary Jane Clinkard

INDEPENDENT LIVING SUCCESS STORIES

SUDBURY ILRC SUCESSFULLY CREATES PUBLIC AWARNESS ON THE NEED FOR DISABILITY SUPPORTS & FUNDING

Despite a growing need for the services and supports offered by Independent Living Resource Centres (ILRCs) in Canada, their significant contributions to their communities and the overall quality of life of persons with disabilities in those communities, ILRCs continue to receive little federal support for the work they do. In recent years, CAILC and ILRCs have tried to communicate to the government and Canadian public the need for public investment into the ILRC network and the vast socio-economic benefits of such an investment.

CAILC and ILRCs know that they provide a unique and much needed service. According to results of recent government of Canada public opinion survey over 80% of those surveyed agree to some extent with providing public funds to support initiatives that promote independent living. However, despite the clear

need for increased support, and overwhelming public support, ILRCs have yet to receive an increase in federal support. Clearly, the ILRC network needs to do more to raise awareness of funding issues to educate their Members of Parliament (MP) who will, in turn, question the federal government about the funding crisis facing ILRCs.

Recently, the Sudbury ILRC ran a successful media and public awareness campaign to pressure their MP and the federal government. This campaign, which came just before the 2005 federal budget, was well timed and well executed. In addition to local print and television coverage, a petition to the local MP and Minister of Social Development, there was also a local online poll showing 97% of respondents agreed that core funding should be provided to ILRCs across Canada. The Sudbury campaign illustrates the kind of public and political pressure necessary to pressure the federal government for a viable investment in Independent Living in Canada.

ON THE MOVE: FOUR NEW EXECUTIVE DIRECTORS

Georgie Davis, North Saskatchewan ILC, Saskatoon, SK
 Barry Galloway, Independent Living Resource Centre, St. John's, NL
 Ella Huang Disability Resource Centre –Richmond, BC (Acting)
 Earl Hubbs, Independent Living Resource Centre of Calgary, Calgary, AB

NEW FACE AT CAILC

Sara Jarvis is the Executive Assistant to Traci Walters, joining the team in February 2005. Most of her career has been spent in the charity/not for profit sector, although she has also spent some time working in several eclectically diverse fields including exercise jockey for racehorse trainers in the UK and providing administrative support to some of Canada's best known bands and comedians. Her work in the charity sector has encompassed database management, event organisation, fundraising and project coordination. Her skills include research, writing, administration and organisation.

In her spare time, Sara works as a stained glass artist and recently established her own business, Jara Glassworks. The focus of her artwork is to provide unique custom and commissioned stained glass panels, suncatchers, lighting and objets d'art to meet the personal needs of her clients. She also enjoys watercolour painting and hanging out with her cats

Welcome Sara. She can be reached at
exec-assistant@cailc.ca

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Sara Jarvis, Executive Assistant, exec-assistant@cailc.ca

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 We would like to thank SDC for making this newsletter possible through their ongoing financial support to CAILC and our member Centres. Without them, this type of citizenship engagement would not be possible.

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*Indicates Provincial Delegate

OPINIONS EXPRESSED ARE THOSE OF THE CONTRIBUTORS AND DO NOT NECESSARILY REFLECT THE VIEWS OF THE CANADIAN ASSOCIATION OF INDEPENDENT LIVING CENTRES (CAILC)

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