

CILT'S "In the Stream"

Fall 2008

International Day of Persons with Disabilities - 3 December
2008 Theme: "Convention on the Rights of Persons with Disabilities:
Dignity and justice for all of us".

Dignity and justice for all of us is the theme of this year's International Day for Persons with Disabilities, as well as for the 60th anniversary of the Universal Declaration of Human Rights.

Dignity and justice for all persons are established universal principles. Since its inception, the United Nations has recognized that the inherent dignity and the equal and inalienable rights of all members of the human family are the foundations of freedom, justice and peace in the world. These principles, along with equality and non-discrimination, have guided the work of the United Nations for the past 60 years and are enshrined in various instruments such as the UN Charter and the Universal Declaration of Human Rights, as well as in treaties such as the International Covenants on Human Rights, and the Convention on the Rights of Persons with Disabilities. These instruments are among those which make up the International Human Rights framework, are complementary and reaffirm that all human rights are universal, indivisible, interrelated, interdependent and mutually reinforcing.

2008 is a significant year in the international human rights movement given the entry into force on 3 May of the Convention on the Rights of Persons with Disabilities and its Optional Protocol, legally binding instruments which set out the legal obligations of States to promote and protect the rights of persons with disabilities, as well as the 60th anniversary of the Universal Declaration of Human Rights (UDHR). Article 25 of the UDHR provides that each person has "the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control". Several articles in the Convention on the Rights of Persons with Disabilities expound on this right to security, including article 10 on right to life and article 14 on liberty and security of person. Article 28 is more specific in that it asks that States Parties take steps to safeguard and promote that realization of the right to an adequate standard of living and social protection, including ensuring "access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care". These instruments mark a clear reaffirmation that persons with disabilities have the right to full and equal enjoyment of their human rights. They also mark a clear reaffirmation of the principles of 'dignity and justice for all of us'. Around 10 per cent of the world's population, or 650 million people, live with disabilities. The

Convention promotes and protects the human rights of persons with disabilities in civil, cultural, economic, political, and social life. However, all over the world, persons with disabilities continue to face barriers to their participation in society and are often forced to live on the margins of society. They are routinely denied basic rights such as to equal recognition before the law and legal capacity, freedom of expression and opinion, and the right to participate in political and public life, such as voting. Many persons with disabilities are forced into institutions, a direct breach of the rights to freedom of movement and to live in the community.

Eighty per cent of persons with disabilities – more than 400 million people – live in poor countries and there is a strong link between disability and poverty. For example, the statistics on employment for persons with disabilities are staggering. In developing countries, 80 per cent to 90 per cent of persons with disabilities of working age unemployed and in industrialized countries it is estimated to be between 50 per cent and 70 per cent. The rights to education and health are also routinely denied. Ninety per cent of children with disabilities in developing countries do not attend school, says UNESCO. Approximately 20 million women acquire disabilities as a result of complications during pregnancy or childbirth. This continued marginalization against persons with disabilities highlights the need for all States to sign, ratify and implement the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

The United Nations and the global community must ensure that all its work is inclusive of persons with disabilities. The Millennium Development Goals will not be achieved if persons with disabilities are not included. Efforts to achieve the MDGs and implement the Convention are interdependent and mutually reinforcing.

On this International Day of Persons with Disabilities, as well during the year-long celebration of the 60th anniversary of the Universal Declaration of Human Rights, let us use “dignity and justice for all of us” as a rallying call, as these principles are far from being realized for everyone. Dignity and justice are embodied in the civil, cultural, economic, political, and social rights promoted by the Convention. Therefore, the International Day of Persons with Disabilities is a time to make a renewed commitment to the ratification and full implementation of the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

One of the fundamental obligations contained in the Convention is that national law should guarantee the enjoyment of the rights enumerated in the Convention. States Parties should thus consider the best ways of giving effect to the rights guaranteed by the Convention in domestic law. Implementing legislation should include the terms of the Convention or a specific reference to them, in order to indicate clearly that the laws should be interpreted in accordance with the letter and spirit of the Convention. Legislation alone will not ensure that persons with disabilities can enjoy their human rights. States will

need to formulate effective policies and programmes that will transform the provisions of the Convention into practices that will have a real impact on the lives of persons with disabilities. For persons with disabilities, as for all persons, the denial of one right can lead to the denial of other rights and opportunities throughout their lives.

Article 33 explains that States must set up national focal points governments in order to monitor implementation of the Convention's precepts. States must also set up independent monitoring mechanisms, which usually take the form of an independent national human rights institution.

The full participation of civil society, in particular persons with disabilities and their representative organizations, is essential in the national monitoring and implementation process. International monitoring is achieved via the Committee on the Rights of Persons with Disabilities and the Conference of States Parties. The first meeting of the Conference of States Parties will be convened by the Secretary-General no later than six months after the entry into force on 3 May 2008 of the Convention.

This International Day for Persons with Disabilities is a time to make a renewed commitment to these principles of dignity and justice and to ensure implementation of the Convention on the Rights of Persons with Disabilities. All human beings are not only entitled to rights, but also have the responsibility of making universal human rights a reality for all of us.

The annual observance of the International Day of Persons with Disabilities, 3 December, aims to promote an understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities. It also seeks to increase awareness of gains to be derived from the integration of persons with disabilities in every aspect of political, social, economic and cultural life. The theme of the Day is based on the goal of full and equal enjoyment of human rights and participation in society by persons with disabilities, established by the World Programme of Action concerning Disabled Persons, adopted by General Assembly in 1982. The official title of the Day was changed from International Day of Disabled Persons to International Day of Persons with Disabilities by General Assembly resolution 62/127 on 18 December 2007.

How the Day may be observed:

Involve: Observance of the Day provides opportunities for participation by all interested communities - governmental, non-governmental and the private sector - to focus upon catalytic and innovative measures to further implement international norms and standards related to persons with disabilities. Schools, universities and similar institutions can make particular contributions with regard to promoting greater interest and awareness among interested parties of the

social, cultural, economic, civil and political rights of persons with disabilities.

Organize: Hold forums, public discussions and information campaigns in support of the Day focusing on disability issues and trends and ways and means by which persons with disabilities and their families are pursuing independent life styles, sustainable livelihoods and financial security.

Celebrate: Plan and organize performances everywhere to showcase - and celebrate - the contributions by persons with disabilities to the societies in which they live and convene exchanges and dialogues focusing on the rich and varied skills, interests and aspirations of persons with disabilities.

Take Action: A major focus of the Day is practical action to further implement international norms and standards concerning persons with disabilities and to further their participation in social life and development on the basis of equality. The media have especially important contributions to make in support of the observance of the Day - and throughout the year - regarding appropriate presentation of progress and obstacles implementing disability-sensitive policies, programmes and projects and to promote public awareness of the contributions by persons with disabilities.

The City of Toronto and community partners
invite you to celebrate December 3rd:

Wednesday December 3rd, 2008 9:30 a.m.—1:30 p.m.
Villa Colombo, Salsa Caboto
40 Playfair Avenue (Dufferin Street & Lawrence Avenue West)

Celebrate Unsung Heroes
Displays
Imagination session
Invitation to Poetry readings
Refreshments

RSVP as space is limited
416-338-4756
TTY: 416-338-0889
cwong5@toronto.ca

Attendant services and captioning provided.

2008 Founder's Award Recipient: And the Award Goes To...

The Founders Award is an annual award given in recognition of individuals who have made outstanding contributions to the advancement of Independent Living for persons with disabilities.

Previous recipients are Sandra Carpenter, Karen Yoshida, Ron McInnes, Frank Wagner, Traci Walters, Gary Woodill, Judith Snow, Harry Beatty, Audrey King, Warner Clarke, David Lepofsky, Catherine Frazee and Marcia Rioux.

This year's Founder's Award was given to Tracy Odell. Tracy has always been a pioneer and leader of disability rights movement. She is a writer, volunteer, community activist, and parent with a disability.

Currently, Tracy is working for Ontario Ministry of Government and Consumer Services and serves as the Government Lead/Accessibility Specialist. Her home position is with the Ministry of Education where she has held various positions since 1987, most of them with special education senior management or policy.

In 2006, Tracy received a Masters Degree in Critical Disability Studies and a Bachelor of Education and Special Education both from York University. Her Major Research Paper for her MA was called- Not Your Average Childhood: Lived Experience of Children with Physical Disabilities Raised in Bloorview Hospital, Home and School from 1960 to 1989 (2005) and won our national Independent Living Canada's John Lord Award in 2006. This award recognizes excellence in research that reflects an accurate analysis of the social realities facing persons with disabilities.

Tracy has always been active in the disability community as volunteer and/or advocate. She has held many executive roles on board of directors for many different non profit or non-government organizations.

Currently, Tracy is Treasurer and Chair of the Finance Committee for Citizens With Disabilities – Ontario. Since 1994, she is also been on the board of Aldebrain Attendant Support Services of Toronto, Inc. She is founder and lifetime member Tobias House and Morrison Residence. She has volunteered for other organizations such as Access Apartments, DisAbled Women's Network and Project Work. She has written several Articles on education, labelling, segregation, and integration including:

- "It's Time We Learned" Canadian Woman Studies, York University
- "Where Have All the Children Gone?" in Companion magazine
- "Integration" Speaking Our Own Voice, Conference Report, Toronto Board of Education

She also has made numerous Film Consulting and Appearances on projects for Frontier College, Rogers Cable, Waterloo, CKCO Television, TV Ontario, and CBC's show Disability Network.

Tracy's other advocacy work:

Tracy Odell was one of several people who launched a human rights complaint against TTC Wheel-Trans - \$25 Registration Fee –which settled before going to Tribunal. She contributes news, information and advice to Wheel-Trans User Group on Yahoo! from time to time.

But Tracy is best known to CILT for her work on “Nurturing Assistance” - where she successfully promoted a new service for parents with disabilities who use attendant service, to receive assistance to care for their children independently. We credit her with founding the concept in our Parenting Handbook. It was CILT's honour to present Tracy Odell with CILT's 2008 Founders Award.

© The above article was excerpted from John Mossa's speech, who presented Tracy with this year's Founder's Award.

CILT's Board of Directors 2008-2009

This year, CILT is fortunate to introduce five new and fresh faces to our Board of Directors. Please welcome Miguel Aguayo, Harvinder Bajwa, Ken Conners, Judith Julien and Christine Stapleford to CILT's Board of Directors, 2008-2009.

Miguel Aguayo, M.S.W., R.S.W.

Miguel is the Manager of the Employer Outreach Secretariat, which is a unit within the Ontario Disability Support Program Branch (ODSP), Ministry of Community and Social Services. The Employer Outreach Secretariat's mandate is to build employers' capacity to recruit, retain, and integrate people with disabilities in their workforce. It does this by working with employers to help them identify and remove real and perceived barriers to hiring job seekers with disabilities.

Miguel's experience with disabilities and career management is extensive. As a Senior Human Resources Consultant with the Canadian Imperial Bank of Commerce (CIBC), he designed and led the CIBC Career Access Program, which was a diversity outreach and intake program. This program was an unprecedented for any private sector organization and helped CIBC become the first Canadian bank to achieve equitable workforce representation for people with

disabilities, aboriginal people, visible minorities, and women.

Before joining the bank, Miguel managed WORKink Ontario, which is a virtual employment resource centre for people with disabilities that provided online employment counseling and access to job opportunities. He also provided personal and vocational rehabilitation counseling through a private practice, which involved vocational assessments, disability management, trauma counseling, and disability accommodation provision.

Miguel, who became deafened at the age of 14 years, holds a masters degree in social work and a certificate in human resources management.

Harvinder Bajwa

Harvinder Bajwa is a person with a mobility disability, and she uses an electric wheelchair. Her chronic pain and breathing problems are major barriers in her life but her courage never let her stop from moving forward. She has been working for persons with disabilities for a long time (the last 12 years).

Harvinder believes in the philosophy of independent living. She loves to make a difference in the lives of persons with disabilities and her dream is to see them live a happy life and participate independently in society. She is a disability and accessibility activist. She has a lot of professional experience as a leader, founder, chair and a board member of the disability organizations. She is a Founder, Chair, Information Officer and Communication Officer for Canadian South Asians Supporting Independent Living (C-SASIL). Harvinder is also a vice chair of the Accessibility Advisory Committee -City of Brampton, a member of the Accessibility Advisory Committee – Region of Peel, board member of ERDCO (Ethno-Racial Disabled Committee of Ontario), event leader of the Brampton Rick Hansen Wheels In Motion and has been a member of the Centre for Independent Living in Toronto (CILT) since 1996. Harvinder holds a three-year college degree and has earned numerous awards for her work in the disabled community.

Ken Conners

Ken joined the CILT Board in January 2008 as an interim appointment to the Treasurer position which was vacated in December of 2007.

He has a wealth of experience with non-profit Boards and with filling treasurer responsibilities specifically for the Evangel Hall Mission and The Mariposa Folk Foundation. Evangel Hall provides a variety of services to homeless people in downtown Toronto. They have recently completed the construction of 84 units of rent-geared-to-income housing for the homeless and hard to house. He also volunteers at Christopher House in the annual income tax preparation program for seniors and people with low incomes.

Ken's professional experience includes self-employment providing accounting, financial management and day-to-day bookkeeping services to a variety of not-for-profit organizations in Toronto including; ONESTEP – the Ontario Network of Employment Skills Training Projects, CanadaHelps.org – a web site which encourages and facilitates donations to Canadian charities, and St. Matthew's Bracondale House – a not-for-profit, rent-geared-to-income housing and support services for seniors.

Since October 1999, he has also been providing payroll and bookkeeping services to people with physical disabilities who hire their own attendant care staff under the Self-Managed Attendant Services (Direct Funding) Program operated by CILT.

In the past, Ken has served as the Executive Director of Three Trilliums Community Place. Three Trilliums is a non-profit organization providing attendant services to adults with physical disabilities who wish to live independently in the community and direct their own care.

His international work has taken him to South Africa, where as a consultant, he facilitated a process of community economic development resulting in both a small business development strategy and the establishment of a local business service centre in Mdantsane (one of South Africa's largest townships, now part of the City of East London).

Ken also was Cooperant with the City of L'viv in the Ukraine for Partners in Progress – a people-to-people assistance program sponsored by Foreign Affairs and International Trade Canada. The program matches Canadian cooperants with requests for professional advice and assistance from the nations of the former Soviet Union. As a cooperant he presented a series of management seminars to senior managers at the City of L'viv; initiated and coordinated a project to translate written materials on Western management practices into the Ukrainian language, and assisted in the production of a "Profile of L'viv" and a new councilors" handbook.

Ken's background also includes work in the Northwest Territories for the Fort McPherson Incorporated Band Ltd., owned by the Dene Band and for the Northwest Territories Housing Corporation. His Education includes a Master of Public Administration, Master of Arts, Russian Literature, Bachelor of Arts (Honours), Political Studies, and The Society of Management Accountants of Ontario. He has been a great asset to the CILT Board and we consider ourselves very lucky to have his value added involvement.

Judith Allen

Judith Allen has served as a Director and Secretary of other Boards. She has over 30 years of volunteer and work experience with non-profit organizations providing service to persons living with disabilities, and has a deep sensitivity to the cultures of different disabilities.

She is involved in many community projects and committees, including the CNIB United Way committee, she has experience in planning Fund Raising Events, she has developed and implemented successful programs for the Blind and Deaf-Blind, and has also established and maintained contacts in different communities for disabled persons. (Deaf, Blind, Physical & Mental Disabilities). Judith is also a motivational speaker with regular engagements for the Canadian Council on Rehabilitation and Work.

Judith's work history includes working as Deaf-Blind Literacy Instructor for the CNIB, where she was also Tech Aids Clerk and Project Lead, she was the Administrator of a Computer School, an Entrepreneur ESL Teacher and Artist, an Investment Banker until she acquired her disability and a Special Education Teaching Assistant.

Christine Stapleford

Christine has worked many years in the field of social services. A Social Worker by profession, she has a Bachelor of Science Degree in Psychology and a Masters Degree in Social Work. She has experience working in the field of mental health and cognitive rehabilitation with adults, and has extensive

experience working with children and youth living with disabilities and their families, particularly in the areas of Spina Bifida, Hydrocephalus, and most recently, Autism.

Her particular area of interest has centered on the multi-faceted aspects of living with a disability, including “invisible disabilities”, and issues across the lifespan (increased risk of abuse, sexuality issues, aging, secondary conditions, substance abuse, social isolation and depression). She has also co-authored research articles relating to disability issues, including the experiences of fathers, social support, and self-esteem. Christine has been asked as a guest speaker on a variety of topics relating to disabilities, including self-esteem issues, facilitating independence in youth with disabilities, sexuality, and ethics.

Currently, Christine is working as the Social Worker for the LIFEspan programme, cross-appointed at Bloorview Kids Rehab and the Toronto Rehabilitation Institute, bridging the gap between the paediatric healthcare system and the adult system for young adults living with cerebral palsy or an acquired brain injury.

This Year’s Slate for CILT’S Board of Directors includes:

Beverley Elliott, President
Audrey King, Vice President
Ken Connors, Treasurer
Shannon Hill, Secretary
Miguel Aguayo
Harvinder Bajwa
Nancy Christie
Mary Louise Dickson
Judith Allen
Christine Stapleford
David Wallace
Heather Willis

Influenza Season 2008-2009

INFLUENZA VACCINATION CLINICS **TORONTO PUBLIC HEALTH**

Toronto Public Health influenza vaccination clinics are open October 27 to December 13, 2008 and January 5-8, 2009.

The flu shot is free for anyone six months of age or older who lives, works or attends school in Ontario.

Influenza vaccination is the most effective way to prevent getting the flu. It is important to get your flu shot each year. The flu vaccine is very safe.

Vaccination clinics are conveniently located throughout the city. No appointment is needed. We are open during the day, evening and weekend! (See insert).

Just a Few Facts:

What is influenza?

Influenza, often called the flu, is caused by a virus that circulates from October to April each year. People who get the flu may have a fever, chills, muscle aches, headache, sore throat, runny nose, cough, weakness and fatigue. The elderly may not get a fever. Children may have stomach symptoms such as nausea, vomiting and diarrhea. Symptoms usually last two to seven days. The cough and weakness may last for up to six weeks.

Who is at risk?

Everyone is at risk of getting influenza. Each year up to 20 per cent of Canadians may get the flu. Most will not get seriously ill. However, people 65 years of age and older, residents of nursing homes or other chronic care facilities, very young children (less than two years old), people with certain chronic health conditions such as diabetes, cancer, lung, heart or kidney disease, and pregnant women may become very ill from complications of influenza. Complications can include pneumonia, ear infections, dehydration and in rare cases, death.

For more info got to <http://www.toronto.ca/health/flu/index.htm> or call 1-877-844-1944.

Independent Living Canada AGM in Beautiful Victoria, B.C.

By Nancy Barry, Peer Support/Volunteer Coordinator

I was lucky enough to be invited to attend IL Canada's Annual General Meeting in beautiful Victoria, British Columbia, where I was asked to present on the Gateways to Cancer Screening Project.

Conference proceedings took place at Laurel Point Inn, and I resided for three days with my husband, who accompanied me as my attendant, at the gorgeous and luxurious Grand Pacific Hotel. I must say that I felt like a queen for three

days, in a five star hotel with all the amenities one could ask for. I was impressed with the conference, the hotel, the people and the lovely picturesque atmosphere that Victoria has to offer.

IL Canada (formerly, CAILC), had an exciting and full agenda which included a visit to the new storefront Victoria Independent Living Centre, formally called The Victoria Personal Supports Centre. Located on Fort Street, in beautiful downtown Victoria, the Personal Supports Centre (PSC) assists adults 18 years of age and older with disabilities to access information and/or personal supports from government, not-for-profit and private sector organizations. The centre is a single-window process to help connect people with disabilities to the resources and supports they need. The eighteen-month demonstration project will facilitate access to assessments, trialing of equipment and assistive devices and, where appropriate, training. Assistance is guided by the individual needing personal supports based on his/her goals. As an individual's needs change, the PSC will provide ongoing support if needed. This service is to support and enhance, not replace, the individual's efforts to manage their life.

A major theme inherent throughout the conference was that of Revenue Generation within the IL Centres; looking for money from places other than the usual funding sources. Mr. Burt Danovitz, Executive Director of the Independent Living Center in New York, talked about IL Centres developing partnerships with institutions that social service agencies would never think of creating. For example car dealers, banks and insurance companies who want your business would be interesting parties with whom to create partnerships. By giving something (\$\$\$) to the disability community, we would give something back by giving them our business. The whole platform is based on generating funds from sources other than the government, who basically never gives non profits sufficient funds anyway. While I found this to be an interesting concept, I'm not so sure that it would work in Canada. By large, the USA has many more IL Centres than Canada will ever see in one lifetime. For instance, there are 38 IL Centres in the state of New York alone.

Burt Danovitz is the Executive Director of the Resource Center for Independent Living (RCIL) located in upstate New York. With four locations spread over a dozen countries, the Center provides both advocacy and independent living services to thousands of New Yorkers making it one of the largest independent living centers in the United States. During his tenure at RCIL, Burt has been involved in a number of public policy and legislative initiatives including: voting rights, accessible transportation legislation, and consumer directed personal care attendant services (similar to our Direct Funding Program). Burt served on the New York State Senate's Medicaid Committee which resulted in legislation requiring New York to implement a nursing home transition program. Currently, legislation developed by RCIL is pending that will eliminate the institutional bias of all public dollars in New York.

In order to develop the resources necessary to support public policy initiatives, RCIL developed four new corporations including a for profit subsidiary.

Three projects from the Canadian Independent Living Centres were highlighted: one, which I am proud to say, was the Gateways to Cancer Screening Project, the Lifelong Education and Recreation Needs (LEARN) Program from the Calgary IL Centre, and the Investing in Futures RESP Program from the Thunder Bay Centre. Each was very well received by the AGM participants.

For more information on the RESP Program, visit www.ilrctbay.com and for further details on the LEARN Program from the Calgary Centre, visit www.ilrcc.ab.ca.

Food for Thought: A Pan-Canadian Initiative Addressing the Healthy Eating Goals of Persons with Disabilities

Overview:

Upon conducting a literature review it was clear that people with disabilities are more likely to experience reduced well-being because of obesity, or being underweight, malnourished. They face higher rates of dehydration, heart disease and diabetes than their able bodied counterparts. It also became evident that nutritionists and other educators and stakeholders lack information specific to the disability community.

With funding provided by the Physical Activity and Healthy Eating Contribution Program – Centre for Health Promotion, Public Health Agency of Canada, our initiative (to be completed by March 31, 2009) aims to build on the successful tools and resources that were created in our previous physical activity initiative “Healthy Lifestyles for Independent Living”. We will do this by adding new accessible tools on healthy eating including program models. We want to explore how food can also be used a vehicle to connect people, encourage physical activity and reduce isolation.

Objectives:

- To conduct participatory action research/national needs assessment to gather information on Canadians with disabilities and the issue of healthy eating itself.
- To establish cross-sectoral partnerships with a focus on healthy eating (i.e. nutrition educators, grocery providers, community agencies, food security organizations etc) and establishing an advisory committee to steer project and development of tools.
- To develop accessible alternate formats, plain language, bilingual

and user friendly healthy eating tools specific to the needs of people with disabilities based on the new food guide. (including a perpetual calendar).

- To host a Train-the-trainer event for all ILRC representatives (e.g. community ambassadors) whereby participants learn: the results of the national needs assessment; new accessible tools; and explore the implementation of various program models that improve and encourage healthy eating for people with disabilities.
- To pilot various consumer driven program models across Canada using healthy eating as a vehicle for reducing isolation of people with disabilities while promoting healthy eating habits.
- To create a handbook on the research, tools and lessons learned on healthy eating as a person with a disability, including tips for meal preparation for people with various disability issues.
- To evaluate the project and disseminate the results and the handbook throughout Canada.

To accomplish the goals of this project we will have an advisory committee comprised of individuals from both inside and outside of the network. These partners may include and is not limited to:

- ILRCs -Pilot Site staff
- Dieticians of Canada
- Active Living Alliance of Canadians with Disability
- Santropol Roulant

In keeping with the principles of IL, the Food for Thought Initiative will use Participatory Action Research (PAR) as the means of discovering what models work in various communities. This will be done by tracking a selected group of individuals with disabilities over the course of the initiative. Consumers will work with their local ILRCs while they test out various program models that encourage peer support and physical activities in 8 regions throughout Canada. They will also provide ongoing feedback to the project team to ensure that the project remains grounded in consumer needs and the developing model evolves in response to these stated needs. Although only 8 ILRCs will participate in the actual program pilots, the remaining 20 ILRCs will also participate in the training and provide healthy eating educational workshops for people with disabilities across Canada.

Please note that during the project we will produce communiqués and an online area on the IL Canada / Virtual ILRC website that will provide timely and relevant

information on the project. For more information contact: foodforthought@ilc-vac.ca

Addressing Disability in Cancer Care: CancerCare Manitoba/University of Manitoba

The purpose of this study is to document the experiences of people who experience disability and cancer and to explore how the cancer care system understands and addresses disability.

There are 4.4 million people with disabilities in Canada and close to one million cancer survivors, many of whom experience disability as the result of cancer and/or its treatment. There has, however, been very little research on cancer and disability in Canada.

Within the cancer care system, disability is not well understood and many cancer care providers are not well-informed about the care needs and issues of people who experience cancer and disability. Research in the U.S. has found that people with disabilities are often less likely to be screened for cancer, may not receive the most effective treatments, and have poorer prognoses and survival rates. Research in Canada and elsewhere has found that people who have had cancer are more likely to experience disability than persons who have not had cancer.

The leaders of the project are Deborah Stienstra and Harvey Chochinov. Deborah Stienstra is a Professor in the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba. Harvey Chochinov is a palliative care researcher at CancerCare Manitoba and a Professor of Psychiatry at the University of Manitoba. The study coordinator is Gary Annable of Cancer Care Manitoba. An advisory committee of people with disabilities and cancer care experts (oncology, palliative care, rehabilitation, epidemiology) provides guidance and advice.

The study is funded by the Canadian Partnership Against Cancer (CPAC) which is responsible for implementing the federal government's Canadian Strategy for Cancer Control (CSCC). The main objective of the study is to develop an understanding of:

- the barriers that people with pre-existing disabilities in Canada encounter when they experience cancer and the cancer care system;
- the challenges encountered by people who experience disability as the result of cancer and/or its treatment; and

- how the cancer care system in Canada understands and deals with disability.

Through focus groups, Cancer Care Manitoba hopes to hear the perspectives of people with disabilities, including those who experienced their disability both prior to getting cancer and as a result of cancer. They also want to hear from cancer care providers including oncologists, nurses, psycho-social specialists, palliative care specialists and rehabilitation specialists; they want to hear about experiences in the full cancer spectrum: prevention, detection, diagnosis, treatment, survivorship and palliation.

Definition of Disability:

The study is using a cross-disability perspective to identify things that are common to most people who experience disability and cancer. Disability is defined broadly according to the framework utilized for Statistics Canada's 2006 Participation and Activity Limitation Survey, and includes persons who experience limitations related to vision, hearing, mobility, agility, pain, memory, learning, development, and emotions/psychology.

Data Collection:

Separate focus group meetings with (1) people who have experienced cancer and disability and (2) cancer care providers will be held in seven Canadian cities during the fall of 2008. Independent living centres in each city is being funded to coordinate the meetings and recruit participants. The focus groups will be facilitated by at least one of the project leaders and the study coordinator.

Data Analysis:

The research team will prepare a draft report summarizing the findings from the focus groups, which will be provided to the study participants for review and comment in early 2008. A final report incorporating participant feedback will be published in the spring of 2009.

Ethical Issues:

The study has been reviewed and approved by the University of Manitoba's Health Research Ethics Board. People with disabilities will be offered a \$25 honorarium to compensate them for their time, transportation, parking, and other expenses they may incur to attend the focus group meeting. They will be offered another \$25 honorarium for reviewing and commenting on the draft report.

CILT is currently working with Cancer Care Manitoba in hosting two focus groups

in Toronto: the first one is for people with disabilities on November 13th, 2008 from 6:00 pm to 9:00 pm at CILT. The second focus group is for cancer care providers which is to be held November 14th at Sunnybrook. For more information, please contact Carling Barry at (416) 599-2458, or email her at carling.barry@cilt.ca.

COMMUNITY EVENTS

6TH Youth Weekend Retreat

A Life Skills Weekend Retreat Program offering:

- independence workshops
- recreation activities
- social opportunities

WHEN: Friday January 16 to Sunday January 18, 2009
WHERE: Salvation Army Jackson's Point Conference Centre
(in Jackson's Point near Lake Simcoe)
WHO: Youth with Physical Disabilities and/or Acquired
Brain Injuries ages 16-25 years
COST: \$225.00

For more information, or to receive an application package please contact:

Julie Osbelt

Bloorview Kids Rehab
416-425-6220, ext. 3298
Fax: 416-422-7037
josbelt@bloorview.ca

Lori Wood

Ontario March of Dimes
905-773-7758, ext. 6225
Fax: 905-773-5176
lwood@marchofdimes.ca

Abbey Royle

Ontario March of Dimes
Provincial Office
416-425-3463, ext. 7251
Fax: 416-425-1920
Aroyle@marchofdimes.ca

Application deadline:
Application acceptance:

Friday November 14, 2008
Friday December 5, 2008

CILT NEWS

We're Moving!

Closed December 4th – 8th

Open for business

December 9th, 2008



New address will be:

365 Bloor Street East

Suite 902

Toronto, Ontario M4W 3L4

**Phone numbers and email addresses
will not change.**

Introducing Carling Barry

Please welcome Carling Barry as the Peer Support Program Assistant, formerly a CILT volunteer. She will be assisting the Peer Support Coordinator with special projects related to peer support, including the Cancer Care Manitoba Project. She will also be assisting with general inquiries related to the Parenting With a Disability Network while Kimberly McKennitt is on an extended medical leave of absence.

Carling will be in the office two to three days a week, and can be reached by email at carling.barry@cilt.ca. You may also call her at (416) 599-2458, and leaving a message for her at extension 27.

United Way Fundraising Campaign 2008

The staff of the Centre for Independent Living are a generous and supportive group of people. We managed to exceed our goal of raising \$3,000.00 this year by a wide margin due to the efforts of all staff.

We had an amazing bake sale in the lobby of 205 Richmond St. West on October 9th during which staff managed to raise over \$400.00 from patrons in the building.

When combined with other small events & staff pledges, the staff raised well over \$3,300.00 which exceeded our goal by \$300.00 or 10%! This was an outstanding effort by all staff.

This year's committee Chair was Leisa DeBono of the Direct Funding Program, who was accompanied by her fabulous teammates Susan DeLaurier, John Mossa, and Victoria Pica.

CILT Members Have Their Say ...

This year, CILT had a 20.41% response rate to our Consumer Satisfaction Survey. Below is a summary of the results:

SECTION A: CILT Membership

Seventy-one percent of respondents are a CILT Member. Of those individuals, 64% have been a CILT Member for longer than 10 years.

SECTION B: CILT Programs

Seventy-one percent of respondents are familiar with the programs that CILT offers. The three most frequently accessed programs tend to be the Diner's Club, the Direct Funding Program and the Project Information Centre (PIC).

SECTION C: CILT Newsline

Fifty-seven percent of CILT members access the newsline. Twenty percent have had difficulty in doing so. Thirty-three percent have found the information on the newsline useful.

SECTION D: CILT Newsletter

Ninety-four percent of CILT members enjoy the newsletter.

What people like best about the newsletter:

Recent events
Easy to understand
Interesting articles
Information about government programs
Hearing from other consumers

What people like least about the newsletter:

It's too long
Not enough information on transportation
Formation of paper is difficult to read

What people would like to see more of in the newsletter:

Articles on transportation and travel
More events that are happening around the GTA
Employment opportunities
Articles on health, diseases and illnesses
More classifieds

SECTION E: CILT Website

Sixty-nine percent of respondents access the CILT website. Thirty-eight percent access the website at least once a month. The most common reasons people access CILT's website is for general information about CILT and the programs that we offer.

Thank you to everyone who responded to this year's Consumer Survey. Rest assured that all of your feedback is important to us and we will continue to work hard to implement that feedback into the work that we do at CILT. Thank you again to those of you who took the time to respond to our survey.

CLASSIFIEDS

FOR SALE:

Sling for Waverly Glen Track Lift

- New
- Medium size
- Best offer

Contact: Ann McQuaig at (416) 915-1491.

FOR SALE:

2005 Pride Legend 3 Wheel Scooter

Reclining high back seat and adjustable headrest, flat free tires, basket, lights, on-board 3 amp charger, viper blue. Barely used, asking \$3,800 or best offer.

Contact Julie at (416) 967-4554.