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# CLT's Volunteer Vibes

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Volume 11 Issue 3

Fall 2011

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## Volunteer Program Update

We've had a few changes since our last newsletter. We have had to say goodbye to a volunteer, Farah Fatima, who had to leave her volunteer position temporarily, but will hopefully return soon. Crystal Bicknell, a past volunteer, will be returning in the New Year from finishing her post-secondary education.

We have also had two student volunteers in the past six months who volunteered with us to receive their 40 hour community service requirement in secondary school. We would like to thank our two students, Alexandra Monteiro and Florian Birkenhake, who helped us with so many mailings and data entry. We wish them the best in their years of high school.

## CLT Volunteer Holiday Hours

The holiday hours for volunteers begin on Monday December 19, 2011 to Tuesday January 3, 2012. We wish you all a joyous and happy holiday season. See you all in the New Year!



## Influenza (Seasonal Flu) and the Influenza Vaccine

©[www.toronto.ca/health/cdc/factsheets/influenza\\_factsheet.htm](http://www.toronto.ca/health/cdc/factsheets/influenza_factsheet.htm)

### What is influenza?

Influenza (the flu), is a virus that comes around each fall (making it seasonal) that causes fever, chills, muscle aches, headache, runny nose, cough, weakness and tiredness. These symptoms usually last from two to seven days. The cough and weakness may last for up to six weeks. Elderly persons may have the flu without a fever, and children may have stomach symptoms such as nausea, vomiting and diarrhea.

### Who is at risk?

Everyone is at risk of getting the flu. Although most people will not get seriously ill, some people may develop flu-related complications such as lung infections (pneumonia), ear infections, dehydration (loss of body fluids) and, in rare cases, death. People most at risk include: children less than two years of age; people 65 years of age and older; residents of long-term care homes or

chronic-care facilities; people with chronic health conditions such as diabetes, cancer, lung, heart or kidney disease; pregnant women; aboriginal peoples; and people who are obese.

### **How is the flu spread?**

You can get the flu if you are coughed or sneezed on by someone who has the flu. Touching hands, surfaces or objects that someone with the flu has touched and then touching your eyes, nose or mouth can all lead to getting the flu.

### **What can I do to prevent the spread of the flu? Get the flu shot each fall. Also follow these simple steps to protect yourself:**

- wash your hands frequently
- cover your cough and sneeze with something other than your hands
- stay home when you are sick
- drink plenty of fluids
- be physically active
- avoid touching your eyes, nose and mouth with unclean hands
- avoid close contact with persons who are sick with the flu
- stay well rested
- eat nutritious food



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### **What is the influenza vaccine and what does it do?**

Each year, the influenza vaccine (flu shot) protects against the three types of influenza viruses that are most likely to cause the flu that year. The flu shot cannot give you the flu because it does not contain live influenza viruses. The body needs two weeks to build up protection against influenza after the shot is given. Protection lasts four months or longer. The flu shot does not protect against colds or other illnesses with flu-like symptoms.

### **When should I get the flu shot?**

As the flu shot takes two weeks to provide full protection, the earlier you get the vaccine the better. The flu shot is available starting in October.

### **I got a flu shot last year. Do I have to get it again this year?**

Yes. You should get the flu shot each fall. The viruses that cause the flu change frequently. Protection from last year's vaccine has likely worn off. You need to get another shot to be protected this year.

### **Who should get the influenza vaccine?**

Everyone who is six months of age or older should get the flu shot, unless there is a medical reason that prevents you from getting the vaccine. If you are at

high risk for flu-related complications or live or work with people who are at high risk (e.g. healthcare workers and essential community services staff), getting the flu shot is particularly important.

### **How many doses of the vaccine do I need?**



Adults should receive one shot each year. Children between six months and eight years of age who never had a seasonal flu shot should receive two doses the first year they get vaccinated. These two doses should be received at least one month apart, and they need one shot each year after that.

### **What are the side effects of the flu shot?**

The flu shot is very safe. The most common side effects are soreness or redness where the shot is given, fever, headache or tiredness and achiness. Side effects usually occur one to two days after vaccination.

Severe side effects and allergic reactions are rare. In past years, a small number of people who received the flu shot developed oculo-respiratory syndrome (ORS). ORS can cause red eyes, cough, chest tightness, difficulty breathing, hoarseness, sore throat and swelling of the face. Symptoms occur within 24 hours and resolve within 48 hours.

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In very rare instances (about one in one million doses of vaccine), the flu shot has been associated with a temporary neurological condition causing muscle paralysis called Guillain-Barré Syndrome (GBS). Seek medical attention if you believe that you, or someone in your care, has had a reaction to the shot.

### **Who should not get the flu shot?**

- People with a severe allergy to eggs or any component of the vaccine (e.g., neomycin, thimerosal) or who had a serious allergic reaction to a previous dose of influenza vaccine.
- Babies younger than six months of age.
- Any person who has had Guillain-Barré Syndrome (GBS) or who has an active neurological disorder should speak with a doctor before getting vaccinated.
- Most people who have had oculo-respiratory syndrome (ORS) can be safely re-immunized with the flu shot but should discuss this with a doctor first.
- Anyone who is ill with a fever should delay receiving the flu shot until they feel better.

### **What should I do if I get the flu?**

Get plenty of rest and drink lots of fluids. Wash your hands often. Stay at home and away from children, the elderly and anyone with a serious illness until

you are feeling better. Ask your doctor about medication to reduce aches, pain and fever. Also ask about anti-influenza drugs that may ease your discomfort and shorten the length of your illness. Children should not be given medication that contains acetylsalicylic acid (e.g. aspirin) because it can cause Reye's Syndrome, a sickness that can lead to brain and liver damage.

### **Where can I find more information?**

Talk to your doctor or call Toronto Public Health at 416-338-7600.

## **The Canadian Foundation for Physically Disabled Persons (CFPDP): Changing the Way Canadians Think About Disability**

© [www.cfpdp.com/about/default.html](http://www.cfpdp.com/about/default.html)

*I*n 1984, Rotarian Vim Kochhar and The Rotary Club of Toronto - Don Valley members were asked to help raise funds for the Cheshire Homes Foundation to help build housing for the deaf-blind. The eventual result was the First Annual Great Valentine Gala which took place in February, 1985 in Toronto and raised \$230,000. It was supposed to be a one-time event, but within two years became so successful that a separate charitable

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organization to stage subsequent events and allocate funds was created.

That organization was the Canadian Foundation for Physically Disabled Persons (CFPDP), set up in 1987 by the The Rotary Club of Toronto - Don Valley with Vim Kochhar as Founding Chair. Its goal was to assist individuals with physical challenges to live fuller lives and raise awareness of their achievements and contributions to society. Since then, CFPDP has initiated dozens of important Projects & Events, raising over \$21 million.

Today, the CFPDP continues to initiate projects that help thousands of physically challenged people across the country. "We need to concentrate on things that really matter like character, compassion and community," says Kochhar. "Above all, we need to build awareness and keep promoting the message of inclusion."

Every year, CILT supports CFPDP by purchasing a table at the Annual Inductee Luncheon, and asking our volunteers to join us. This year, five more amazing individuals were inducted into the Hall of Fame: Archie Allison, Benoît Huot, Brian and Robin McKeever, and Celia Southward.



**Archie Allison(Builder):**

Archie Allison just might be the most popular guy in Toronto's diverse and far-flung disability community. Over the course of almost 30 years as a stalwart in the ranks of the city's world-renowned Variety Village, Allison's unfailing thoughtfulness and cheerful dedication have touched the lives of literally thousands of people, young and old, who live with disability. And, like the proverbial pebble in the pond, the ripple effect of Allison's attentions reaches far beyond the confines of 'The Village', giving heart and hope to parents and families, and spreading his message of inclusion and accommodation to thousands more students, educators and public spirited organizations across the province.



But this is the thing about Archie Allison, it all begins in the magic spark of personal connection. Archie Allison cares about people, and people respond. Beginning his career in 1984 as a kind of all-around sports and recreation instructor, coach, life-skills counselor and mentor, Allison's first order of business at Variety Village was helping people, many of whom encounter a lot of barriers in the wider community, find new and rewarding ways to feel active, involved and included. "Inclusion is so important," says Allison. "When I first came to Variety Village what I noticed was the

ability of people here and their tremendous desire to get involved and be active.

Variety Village offered them opportunities that were hard to find in the larger community." Allison specialized in accommodation, making participation in Variety Village programs available to everyone who wanted to get involved. An early and ardent proponent of the concept of reverse integration, he worked from the premise that you make provisions for disability first, then integrate the rest of the community. "We all have varied skills and abilities and experience. When you provide a venue that encompasses and understands these differences it creates access for everybody," says Allison.

Today, as Variety Village's Director of Access and Awareness, Archie Allison spends a lot of his time sharing this message of access and inclusion with the wider world. He also teaches courses in adapted sports and disability issues at the University of Toronto and local community colleges, reaching out to the next generation of educators and sports and recreation professionals. But don't worry, he's still an active and much loved presence around 'The Village'. In the words of one of his many devoted fans, "Mostly what I like about Archie is his personality. Archie seems to always be smiling and happy... It seems he always has time for us even though we know how incredibly busy he is and how much he accomplishes

every day. When Archie walks down the halls of Variety Village, members of the village gravitate toward him. By the time he reaches the front doors he has gathered a small crowd. He's a bit like the Pied Piper of Hamelin."

### **Benoît Huot (Athlete):**

Multiple world record setting swimmer and three-time Paralympian, Benoît Huot was born with a club foot. When he was seven days old, he underwent corrective surgery and spent the next year-and-a-half in a series of casts designed to realign his leg and foot. It was another three years before Huot began to walk and he wore a special orthopaedic shoe until the age of six. Like other kids his age, he also desperately wanted to play sports. "I was a huge hockey fan and I told my mother I wanted to learn to play and be a goalie like Patrick Roy and play for the Montreal Canadiens," remembers the Longueuil Quebec native with a laugh. His mother worried he was setting himself up for disappointment. Huot's right leg has a permanently underdeveloped calf and the foot is smaller with limited ankle flexibility.

Despite his mother's fears he headed off to the rink and gave it his best shot but the dream of hockey immortality was short-lived. Huot realized he was never going to learn to skate like the other kids. The next year he tried baseball and



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it was the same story. He just couldn't run fast enough. "Team sports were very difficult for me," says Huot. "The fact that I wasn't as good as the other players was hard. It was difficult to integrate myself in team sports – I didn't want the other kids to laugh at me."

It was in the swimming pool where Huot finally discovered an outlet for his frustrated athletic ambitions. Water proved to be the great equalizer. "In the pool I felt free, like a fish. I just felt better in the water," remembers Huot. He joined the local swim club and, with the support and encouragement of his coach and teammates, learned quickly. "After a couple of months swimming I really started to get better and I realized I had found my passion," says Huot.

For two years the young swimmer competed with able-bodied athletes, travelling twice to the Quebec Games and winning a silver medal in 1997. Then one night, at the age of 13, he was watching the Canada Games on television and caught an interview with Paralympic swimmer Philippe Gagnon, who was also born with a club foot. It was a revelation, recalls Huot, realizing for the first time that his disability had a Paralympic classification.

The following spring he attended the national trials and made the Paralympic team. Five months later, at the International Paralympic Committee World Championships, the 14-year-old

made his stunning international debut, taking two gold and four silver medals. Recognized today as one of the most decorated athletes in Paralympic sport, Benoît Huot has won 16 medals in three successive trips to the Paralympic Summer Games: eight gold, four silver and four bronze.

### **Brian McKeever and Robin McKeever (Athletes):**

When seven-time Paralympic gold medalist Brian McKeever earned a spot on Canada's Olympic cross-country ski team in 2010, the news quickly became one of the great feel-good stories of the Vancouver-Whistler Winter Games. McKeever, who is legally blind with only 10 percent vision, was the first Winter Paralympian in history to make his nation's Olympic squad and the amazing achievement captured the imaginations of sports fans around the world. Since 2006, McKeever had been totally focused on his dream of skiing in the Olympics, like his brother Robin in Nagano in 1998.



Then three days before his anticipated start in the Olympic 50k, the Canadian coaches informed McKeever he was being sidelined in favour of the team's top four starters. If the announcement was disappointing news for an awful lot of excited sports fans, it

was a devastating personal blow for the aspiring Olympian. "It's emotional, for sure," a tearful McKeever admitted the next day to a throng of reporters. "It was not something I ever wanted to hear. I'm very, very crushed by the decision, but I understand the decision. Our boys are racing so fast. They deserve everything they've got. I stand behind them 100 percent." It was a forthright and gracious performance from an athlete who had just suffered a brutal leveling. However, if McKeever was still labouring under the effects of his Olympic disappointment when he returned to Whistler three weeks later for the Paralympics, he found a way to put it all behind him.

Brian, and Robin who served as his sighted guide in Paralympic competition, would earn three gold medals in Whistler, turning in their best Winter Games in a career that has garnered nine Paralympic medals. "Everybody has something they have to overcome before they get to the starting line," says Brian. "The second you take the starting line and you don't have all the tools you know you need to win, then you're giving away a big advantage."

Facing down adversity is nothing new for McKeever. A promising young cross-country skier who represented Canada at the 1997 Junior World Championships, McKeever was diagnosed a year later with Stargardt's disease, an inherited condition he shares with his father that causes the loss of



central vision. Within two years he was legally blind and joined Canada's para-nordic program. Robin, an Olympian and 11-time national champion, retired from competition to serve as Brian's guide.

Focused, as always, on the challenges ahead, Brian McKeever's big goal is qualifying for the 2014 Winter Olympics in Sochi. "Hopefully this time I'll get a chance to compete. I'll just have to try harder, make sure I'm in better shape and maybe I can eliminate whatever doubts the coaches have about my ability to compete."

### **Celia Southward (Achiever):**

A one-woman powerhouse behind the growth and delivery of adapted sports and community accessibility in Windsor and across the province of Ontario and beyond, sports and recreation administrator Celia Southward has played a profoundly influential role in reshaping the range of opportunities available to Canadians who live with disability. When Southward joined the City of Windsor's sports and recreation department in 1976, consideration for adapted sports and recreational opportunities played virtually no part in the civic business of Canadian cities.



The whole idea of civic responsibility for accommodating

so-called special populations was built incrementally from the ground up by driven individuals with the courage and clarity of vision to press the case for change. People like Celia Southward. "Back in the day when people just didn't get it, I'd tell them, 'Look, is it sport in a wheelchair? Or is it sport and the wheelchair is just another piece of equipment?' And they'd look at me and say, 'What?' And I'd try to explain, I'm talking about SPORT," says Southward, biting into SPORT with the kind of emphasis that leaves no doubt in the listener's mind they want to pay close attention to what she has to say. Advocacy, of course, is only half the battle.

Southward also walks the walk. A perennially unflagging volunteer, it's hard to tell where Southward's job description leaves off and her personal contributions begin.

Over the course of 35 years of public service her unstinting ministrations have made their mark on so many diverse areas of community life it is impossible to offer anything more than a glancing overview. If you need a ramp for wheelchair bowling in Windsor, you call Celia Southward. She also founded the league that uses the ramps. She planned and implemented the City's first day camps for kids with disabilities and later expanded the program to include adults. She made it her mission to integrate people with special needs in all City



programs and in the workplace. She founded and ran Seniors Fun Field Day, a corporate challenge cup between the local nursing homes, retirement homes and chronic care wards. She is the founder of the Ontario Seniors Games and past president of the Ontario Cerebral Palsy Sports Association and the Ontario Wheelchair Sports Association.

A certified coach in hockey, track and field, and swimming, she has founded, managed and/or coached numerous sports organizations and established rigorous training and certification standards for all coaches and officials working with athletes in adapted sport. Asked to identify one accomplishment of which she is especially proud, Southward singles out the Windsor Classic Indoor Games, which she founded in 1982. Bringing together young athletes from around the world for four days of competition in all five Paralympic disability groups, the annual Games have become the largest indoor showcase for adapted sport in North America.



## Youth Canada: Volunteer Work

©<http://www.youth.gc.ca/eng/topics/jobs/volunteer.shtml>

**W**ork without pay? Yes! Volunteering may be one of the most valuable experiences of your life. It's a double win: your community or cause benefits from your work and you benefit from your experiences. How? Read on...

### The Basics: Why volunteer?

- Volunteering is a great way to get **work experience!** You learn new skills by trying new jobs.
- You might find something you'd like to do for a living, or discover what you would not want to do.
- Better yet, you can **meet people** who can give you guidance and possibly help you to find a paid job later on.
- Some volunteer opportunities involve travel across Canada or to other countries.
- Employers will be impressed that you took the initiative to **learn new things.**
- You can learn how a charitable organization works.



- Best of all, you will be taking action to promote what you think is important and probably be **helping someone else** along the way.
- Be the change that you seek!

### **Who needs volunteers?**

- Hospitals
- Charities
- Clubs
- Overseas development organizations
- Music and arts festivals
- Sporting leagues and events
- Children's camps
- Libraries
- Environmental organizations
- Crisis lines and peer counseling organizations
- Human rights organizations
- Religious organizations
- Political campaigns
- Government agencies (local, provincial, federal)

### **What are some of the things a volunteer can do?**

- Coach a Team
- Read to Children
- Raise money for charity (fight diseases, reduce poverty, help the sick and injured, etc.)
- Care for the Elderly
- Feed the Hungry

- Provide counselling and support
- Run errands and do deliveries
- Gather and analyze data
- Raise awareness of important issues
- Do clean-up and repairs in the community
- Build houses or playground equipment
- Care for animals
- Stage concerts, plays and other cultural events
- Protect the environment
- Plant trees
- Help-out with a political campaign

### **Where can you find volunteer opportunities?**

- Visit your community's volunteer bureau, community information centre, or town hall
- Call a service club
- Visit a hospital
- Ask family, friends and neighbours what they recommend
- Join an organization whose activities you support
- Consult the web sites of major volunteer organizations - some can be found through the links listed below:

### **Helpful Web Sites:**

- Find volunteer opportunities at a volunteer centre in your area by

visiting the Volunteer Canada Web site. <http://volunteer.ca/home>

- Browse the links at the Canadian Volunteer Directory at <http://www.canadian-universities.net/Volunteer/index.html> to find volunteer opportunities from across Canada
- Travel and do volunteer work in three communities in different regions of Canada by participating in the Katimavik program <http://www.katimavik.org/>

## Get Involved! Become a Virtual Volunteer

By: Heather Camlot;

<http://www.microsoft.com/canada/home/life-and-style/articles/get-involved-become-a-virtual-volunteer.aspx>

Sometimes finding the time to volunteer is hard. Perhaps you don't have one free moment between holding down a 40-hour a week job and caring for the kids. Or maybe there isn't an organization in your neighbourhood that has much meaning to you. If you want to volunteer, there is a way.



### Why volunteer?

Virtual volunteering allows you to donate your time and talent through the convenience of your computer and Internet connection. "I think it's a great

concept," enthuses Mohrea Halington, manager of Evergreen Printing Services Inc. in Langley, B.C. "[There are] no geographic limitations, I can do the work at home, and I decide when I can do it."

The only downside, she says, is the lack of face-to-face contact, but that hasn't stopped her from volunteering with Macdonald Youth Services, a Winnipeg-based treatment and support agency for children and families. She provides the organization with print-ready graphic files for their brochures or annual reports, which, depending on the project, can consume eight hours a week to two or three eight-hour days.

### Who is volunteering?

According to Statistics Canada's 2004 *Canada Survey of Giving, Volunteering and Participating*, Canadians donated a total of 2 billion hours a year (equal to about 1 million full-time jobs) to volunteering.

"Virtual volunteering is only now gaining popularity, so there may not be too many volunteer opportunities that are specifically listed as *virtual*," says Justin Ho, volunteer opportunities exchange administrator for Volunteer Canada. "So when you are browsing postings online or at a volunteer centre, read the descriptions carefully, and if an opportunity that interests you sounds like it could be done virtually, then you should approach the organization and suggest it to them."

While you may have the right technology and software, you also have to have the right attitude. “There’s actual work involved,” stresses Randy Tyler, virtual volunteer program developer for Macdonald Youth Services. “Virtual volunteers have to be able to work alone comfortably, be motivated, be committed and be able to provide continual reports on what they’re doing.” Ho adds that good time-management skills, excellent written communication skills and possibly a workspace with little distraction are also an asset.

Once you have some time to commit and the desire to volunteer, you can check various postings to find the position best suited to your skills.

### **Volunteer Canada**

Volunteer Canada offers information about onsite and online volunteering across the country. You can also browse available opportunities.

### **The Virtual Volunteering Guidebook**

Ho considers this American guide the best resource on virtual volunteering. It has information and tips for organizations and volunteers.

### **Charity Village**

The site has postings for volunteer and paid positions across the country and around the world. There is also a section on how to choose a charity, which is

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written for financial contributions but can be applied to volunteering.

### **Macdonald Youth Services**

Although the organization’s postings are elsewhere (try Charity Village and Volunteer Canada), the site provides a ton of information about where virtual volunteering is going and how it is bridging the gap between wanting to volunteer and actually doing it.

### **VolunteerMatch**

An American site, VolunteerMatch lists thousands of virtual opportunities divided by interest, such as environment and crisis support.

## **CILT News**

### **Gateways Gets Published Yet Again**

*T*he Gateways Team would like to announce that the Gateways Project has been published in The Journal of Cancer Education, Volume 26, Number 4, entitled ‘Access to Cancer Screening for Women with Mobility Disabilities’.

This scholarly article outlines the

focus group participants identifying the multiple and interacting institutional barriers to cancer screening. Their discussions highlighted the complex work of:

- (1) arranging and attending health-related appointments,
- (2) confronting normative assumptions about women's bodies, and
- (3) securing reliable health care and information.

These issues interact to shape how women with disabilities access and experience cancer screening. The article explores implications for redesign of cancer screening services and education of healthcare providers, providing specific recommendations suggested by Gateways participants and the findings.

## Gateways: A Recap and Update

By: The Gateways Team

*I*n 2006, the Centre for Independent Living in Toronto (CILT) Inc. recognized the need to explore and understand the cancer screening experiences of women with mobility disabilities. Partnerships were then developed with disability activists, university-based health researchers and health professionals in

Toronto:

- Centre for Independent Living in Toronto
- Canadian Cancer Society
- Mount Sinai Hospital
- Ismaili Cancer Support Network
- Springtide Resources
- Faculty of Nursing, University of Toronto



### Gateways I Project (2006-2008):

Purpose:

To explore the breast, cervical and colorectal cancer screening experiences and care needs of women with mobility disabilities in Toronto.

Methodology:

- Initially conceived as qualitative descriptive research
- Conducted as a community-based, participatory action research project (PAR)

Participatory Action Research (PAR):

- PAR involves all relevant parties examining together current action (which they experience as problematic) in order to change and improve it.
- PAR is not just research which is hoped that will be followed by action. It is action which is

researched, changed and re-researched, within the research process by participants.

- PAR aims to be active co-research, by and for those to be helped.
- PAR tries to be a genuinely democratic or non-coercive process whereby those to be helped, determine the purposes and outcomes of their own inquiry (much like the Independent Living philosophy). [Wadsworth, 1998]

### **Gateways I Project Results:**

- Focus groups were conducted by peer researchers with 24 women with mobility disabilities from diverse communities in the Greater Toronto Area (GTA).
- Key findings: women with disabilities face architectural, systemic and attitudinal barriers to effective screening.
- Recommendation: disability training for healthcare professionals and clinical staff who work in cancer screening on appropriate and clear communication, compassionate behaviour and best practices.

### **Our Current Initiative: Gateways II Project (2009-2012)**

In 2009, the Gateways Team applied for and received a community-

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based research implementation grant from the Canadian Breast Cancer Foundation for a new project:

### ***Improving the Breast Cancer Experience for Women with Mobility Disabilities: An Educational Intervention with Healthcare Providers (Gateways II)***

#### **Gateways II Team:**

- ***Mount Sinai - Principal Investigator***
- ***Mount Sinai - Project Manager***
- ***Mount Sinai - Research Associate***
- ***Mount Sinai - Curriculum Developer***
- Centre for Independent Living in Toronto
- Ismaili Cancer Support Network
- University of Toronto, Faculty of Nursing
- Springtide Resources
- Ontario Breast Screening Program

#### **Project Purpose:**

- Address barriers to accessing breast cancer screening for women living with disabilities.
- Improving the mammography experience for women living with disabilities.
- Develop, implement, evaluate an innovative, evidence-based education strategy for healthcare professionals to increase their



competencies when working with women with mobility disabilities.

## Representing Disability in Health

### Provider Education:

### Overcoming Ethical Challenges

In part one of Gateways, women with mobility disabilities were asked to participate in focus groups to discuss their personal experiences with healthcare providers when accessing cancer screening.



In part two of Gateways, focus groups were held with healthcare providers to hear about their experiences, concerns and feelings when screening women with mobility disabilities. In doing so, the Gateways Team wanted to find out healthcare professionals' learning needs about providing care for women living with mobility disabilities.

Focus groups were held with 43 healthcare providers from the Joint Department of Medical Imaging at three different academic teaching hospitals in Toronto: Mount Sinai, Women's College and Princess Margaret. Separate focus groups were held with clerical staff, mammography technologists, and radiologists from each hospital between

April and June 2010. Data was then analyzed from each of the focus groups

### Focus Group Questions asked:

- Icebreaker question: When I say the word 'disability', what comes to mind?
- Tell me about any experiences you have had while caring for people with disabilities?
- What have these experiences been like for you as a healthcare professional?
- What do you think these experiences were like for the person with a disability?
- What did you learn from the interaction?
- Based on your experiences, what are some ways to improve the experience for these patients?

Information gathered from all focus group sessions was coded and analyzed in order to come up with some underlying themes. For example:

- **Internal Barriers:** normative assumptions, healthcare providers' Attitudes and Knowledge, Architectural, Equipment, Human Resources, Systemic Constraints, Communication Constraints
- **External Barriers:** Transportation, Equipment, Support Constraints, Patients' Attitudes and Knowledge, Participation and Experience, Anxiety,



Communication Constraints, Past Negative Experiences

- **Facilitators:** Providers' Attitudes and Knowledge, Participation and Experience, Notice and Knowledge, Internal Communication, Patient Communication, Volunteer/ Caregiver Assistance, Systemic Improvements
- **Learning Needs:** Communication, Disability Education, Clinical Education



Results:

**I WANT TO HELP, BUT, WHAT DO YOU DO IN A SITUATION LIKE THAT?**

### Health Care Providers:

- Care about patients and empathize with the fear and anxiety patients may be feeling when they come for breast cancer screening.
- Recognize the need to treat patients with disabilities as people.
- Recognize that offering help, communicating well, being patient, and being encouraging to patients with disabilities is important for their comfort.
- Recognize that screening is a collaborative activity.
- Understand that patients with disabilities are knowledgeable about their own bodies; staff must ask questions, listen, and follow their lead.

### Examples of things Healthcare Providers do to provide appropriate care for women with disabilities:

- Book patients for less busy or longer appointment times
- Pre-book ultrasound in case it is necessary
- Expedite appointment (particularly if patient arrives by Wheeltrans)
- Direct patients to larger change rooms, assist with changing, toileting, and completing forms as necessary
- Communicate more deliberately and talk patients through the mammography procedure

### BUT WHAT DO YOU DO WHEN....

#### **WOMEN WITH DISABILITIES:**

- May vent their frustration over systemic Issues to HCPs (Healthcare Providers)?
- Respond to assistance from HCPs in a mixed fashion, which is ultimately confusing and paralyzing?

#### **HEALTHCARE PROVIDERS:**

- Experience general discomfort and uncertainty about respectful and appropriate communication/interaction strategies for patients with disabilities?
- Find novel care situations challenging?
- Are concerned about suboptimal

imaging?

Quotations from health care providers who participated in focus groups:

**“I guess maybe sometimes, because a lot of them value their independence, I don’t know how to ask certain questions without offending them. So, like, sometimes... you open a door for somebody and sometimes you get, like, ‘Thank you’, and then other times they’d kind of be like, ‘Well, I can open the door myself’. That kind of thing, you know? Them thinking that I feel sorry for them kind of thing.”**



**“So I have my experience, and I know what P3 (person above) was saying in terms of, like, you don’t want to cross the line and say, ‘oh, do you need help’ too much. And you do want to assist them. Sometimes at the desk, like when you’re checking them and you see the double doors they have to go through, and you’re sitting there. It’s like, you want to run and go open the door, but then you don’t want to... you know what I mean, you don’t want to cross the line by asking, ‘can you get the door?’. It’s a little bit hard.”**

Successful mammography screening requires good provider and patient interaction (active engagement and participation during procedure):

- Patients with cognitive impairments

may not understand or be able to actively participate in procedure, which is stressful and difficult for health care providers.

- Some patients will not actively participate in the procedure, which is stressful and difficult for health care providers.

### **Health Care Providers:**

- Make a lot of (stereotypical) assumptions about what patients are thinking, feeling, and experiencing: ex. anxiety and frustration is about fear of cancer, being a “burden”, the hassle of screening, and transportation issues, rather than other barriers and stressors.
- Receive little or no training about how to care for patients with disabilities.

When health care providers were asked how much training they receive on disability issues, some of them said:

**“There was no formal training about disability. I think I just learned... There was more, like, regulations and procedures. The rules of what you should do or not do. It doesn’t tell you, like, when you do one on one patient care, how can you help the patient the most. Or make them feel more comfortable or how to read their anxiety. That was just more like, ‘this is what the government says’. So**

that wasn't as helpful.”

### **Final Results of Gateways II:**

The final product of the Gateways Project will be a Disability Education Program which will:

- Bring the voices, needs, and lived experiences of service-users into the walls of an institution in the form of a training video;
- Assist healthcare providers to develop embodied empathy for women with disabilities
- Improve the mammography experience of women with disabilities who get screened for breast cancer; and to;
- Promote health equity for women with disabilities accessing cancer screening.

The Gateways Team has recently hired a well-experienced individual who has filmed many teaching videos. The DVD will be approximately 13-15 minutes in length and will include women with disabilities talking about their cancer screening experiences as well as a health care provider talking about their experiences around screening women with mobility disabilities. It's all very exciting. We will keep you updated as further results unfold.





*CILT's Volunteer Vibes* is a quarterly publication of the **Peer Support Program**. If you are interested in volunteering at C.I.L.T. please call Nancy to request a Volunteer Application Package.

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**Volunteer Vibes** is also available on audiotape upon request.

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*Promoting a new perspective on disability*  
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CILT is a member of Independent Living Canada

Supported by a Toronto Community Service Grant, United Way and Social Development Canada