

## In the Stream

Spring 2008

### IMPORTANT NOTICE!

#### **Canadians with Disabilities Celebrate the Coming into Force of the Convention on the Rights of Persons with Disabilities**

People with disabilities and allies around the world, are celebrating their latest victory--the coming into force of the Convention on the Rights of Persons with Disabilities (CRPD) on May 3, 2008. As twenty countries have ratified the Convention, it now has the force of international law. Today, a special ceremony for the CRPD is taking place at the United Nations in New York, with participation from people with disabilities and our organizations as well as UN member states. Following the principle of "Nothing About Us Without Us", disability organizations played an integral role in the development of the Convention. Steve Estey, the Chairperson of CCD's International Development Committee and a staff person for Disabled Peoples' International (DPI) joined other colleagues from the global disability rights movement today at the UN ceremony to promote greater societal awareness of the CRPD, which provides guidance to countries on how to ensure people with disabilities experience full enjoyment of their human rights. Mr. Estey was a member of the Canadian delegation that participated in the negotiation of the CRPD.

"This is a very proud day for people with disabilities, because this international convention adopts an approach that has been advocated by people with disabilities for the last 30 years. Unlike some previous UN documents, the CRPD does not define people with disabilities as a constituency in need of medical care or social protection. The CRPD approaches people with disabilities as full citizens with rights who, as free and equal members of society, make decisions for their lives based on their free and informed consent," states Marie White, Chairperson of the Council of Canadians with Disabilities, Canada's chief cross-disability organization working in support of an accessible and inclusive Canada. "The Convention gives universal recognition to the dignity of persons with disabilities." The CCD is calling upon the Government of Canada to ratify the CRPD, fulfilling the commitment it made at the UN's March 2007 signing ceremony for the CRPD. In May 2008, the House of Commons unanimously passed a motion calling for ratification of the CRPD, following federal/provincial/territorial consultations—consultations where the Canadian disability community expects inclusion.

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## Medical Treatment and Disability

*By Sandra Carpenter*

As a person with a disability, I've always had a hate/love relationship with the medical community. Love because when they do things right, our lives are improved or often extended. Hate because when things go wrong, they go horribly and needlessly wrong.

We've all heard stories about the difficulties that people with disabilities face when they have to go to the hospital: Non verbal people who wouldn't be fed if a friend or attendant didn't visit regularly; medication that has been taken for years suddenly withdrawn because the attending physicians were focused on another problem, and the deaths that resulted because of massive seizures that resulted from this sudden withdrawal. Also, of people who die from a relatively minor problem due to misunderstanding of the impact that a minor problem for someone without a disability might have on a person with a disability. This is happening all across Canada.

What follows are a couple of personal accounts of recent hospital experiences – 'the problem'. We need to think about these accounts and seriously consider what the solution might be so that going into the hospital is not the frightening, life-threatening or even life- ending – prematurely – experience that it is for many of us.

This newsletter will also highlight other examples of solutions that some are trying to promote – 'the answer'. This is not to deny that some improvements have been made over the years and that the medical world hasn't learned from past mistakes, SARS being one of them. But we need to think systemically about solutions. Our fear is that, especially because in this day and age where nursing staff and physicians are totally overworked and where people don't even have their own doctor to advocate for them, people suffer and die needlessly.

Here we offer a couple of accounts to start everyone thinking. It's something that nobody wants to think about when they are not in the situation, but if we don't do this now, it may be too late when they are already in the situation. We all seem to be getting older. The aging demographic of the disability community is the same as the rest of society. Therefore we will need the benefits of the medical world, just like everyone else.

You are invited to share your thoughts with us, your experiences and some ideas that may become part of the solution.

This newsletter is dedicated to the memory of Steve McPherson.

## Hospital Hell

*By Vic Willi*

Most people with a significant disability eventually learn that hospital stays can be hostile. I have had a number of unpleasant experiences in hospital, each of which was unpleasant because staff did not understand my needs as a person with a disability.

Recently I was in a car crash and broke ten bones. I was transferred from Walkerton to the Royal Victoria in London, and then to St Michael's in Toronto, which occurred in the dead of night. The ambulance attendants pushed me through dark hallways in the old Bond Wing and 'dumped' me in a bed in an empty room. They started to walk away, leaving me on my back, with no call button, with no nurse, with nothing. I explained a number of my needs and eventually a nurse showed up. While still in shock, I had to direct her to hook me up to night drainage and explain what I needed and how I needed it done, all to a rather 'skeptical' professional.

Neglect was the theme for the first week that I was there until some friends hired two attendants to be with me during the night. Another friend miraculously arranged to have the Ethicist from St. Mike's come see me and then the medical staff. These two interactions changed everything and probably saved my life.

During the day I interacted with "PSWs" (Personal Support Workers), some of whom were extremely hostile to my self direction, but they made no apologies for their complete lack of knowledge, vis-à-vis 'looking after' a quad.

"Quit telling us how to do our job, Willi!" barked one lady. Another explained, "Willi, you have to think about our backs, and not about yourself". She was preparing me for sleep and I asked to be sat up again because I could not breathe properly. It turned out that I was drowning in my own fluids (I had punctured one lung and had contusions on the other). Desperate for help, I screamed at the top of my voice, "HELP"! The PSW's lecture to me stopped suddenly. Senior staff came in, they called the Respirologist and he diagnosed fluid on the lung.

The next morning they drained one and a half liters of pink fluid out of my right lung. It felt wonderful! I knew then that I had to stay in charge of my own 'care'.

Taking charge of my well-being involved figuring out how to breathe until the staff got their act together, diagnosing the fluid, and then draining my right lung. It was quite simple: I couldn't breathe lying down, so I decided to sit up at for least 48 hours. I knew that I was compromising the skin on my tailbone but it was a

calculated risk. Sure enough, I got my first bed sore in forty years. My masseuse, powerful and caring woman, grabbed my social worker and told her “You can’t leave him like that; he needs a special mattress to prevent a bed sore”. The social worker, a not too bright specimen, chirped “We have special mattresses for people with bed sores but Mr. Willi can’t have one because he doesn’t have a bed sore.”

Later at Bridgepoint Hospital, I asked one PSW to turn me – she rolled me on my side with my face scrunched up against the bed bars, my drainage tube twisted under my leg and she then started to walk away. I explained that I needed to be positioned. She did not know what to do. “Put your hand under my shoulder and pull me back”, I explained. She slid her hand under my shoulder and dug her long fingernails into my skin. “Not like that!”, I exclaimed. She then grabbed my shirt collar and literally dragged me back by my throat.

I heard later that those teaching the PSW course never address the concepts of Independent Living, attendant services, or self direction. Students learn the medical terminology, but have no clue how to turn someone with a disability.

In July and August, Bridgepoint Hospital was so cold that I sometimes wore a toque, long underwear and a wool turtleneck sweater during the day. Apparently this cold atmosphere was the perfect temperature for the mostly ‘hard working’ staff. Nothing I did could convince them to turn down the temperature. I now call Bridgepoint ‘Fridgepoint’.

It became apparent that about one third of the PSW staff disliked me because I was what they call ‘demanding’ and I was ‘heavy care’. To survive, I developed a technique by learning the first name of every PSW on staff, got to know them, and finally made friends with most of them. I discovered some wonderful people. The few bitter, angry hold outs however, still made my stay miserable at times. The hospital remained cold despite the suffering of many of the patients until I escaped in the fall. When it came down to it, I had to literally get into a loud, screaming argument, demanding that they help me so that I did not, for example, go into autonomic dysreflexia. It was the only way – unpleasant, but effective. You have to stand up to a bully!

On another occasion, in the 1990’s, I had a sudden onset of autonomic dysreflexia (a medical emergency whereby your blood pressure triples in a second and can cause a stroke or death). I scurried over to the Toronto General Emergency and explained my problem. I never got the sense that they believed me or were familiar with my condition.

I was lifted onto a gurney and catheterized by a young female resident. She suddenly inflated the catheter bulb in my urethra without telling me. My body heaved up in spasm and she asked, “Why did you do that?” I explained what she had done as the blood began to flow. She asked me to give her a moment and

disappeared out the door. The Chief physician came in, pronounced that I probably had a bladder infection and apologized for my bloody mess saying, "Mr. Willi, I am sorry, but we are just not equipped to handle people like you". It gets worse.

I decided it was best to get out of there before they killed me. I asked for a couple of male staff to lift me back into my chair. When they came, I gave explicit but friendly instructions on how to lift me, "... lift me under the knees and set my feet on the foot pedals". "Okay sir", the guy by my feet said as he lifted my legs by the heels. When my rear end touched the seat he let go of my heels four feet above the ground. "There you go sir", he smiled as my Achilles tendons smashed into the front edge of my foot pedals. I yelled at him and he smiled back. He disappeared out the door too.

When I got home my leg bag was filled with blood clots which had to be squeezed out like chunks of liver. My attendant was cool about it all and my friendly urologist, Doctor Bruce, told me to drink buckets of water, so I did. Later I had to laugh, realizing that I went to the Emergency with one problem and came out with three!

It is quite easy to see the origin of the hostility between the medical model of disability and the independent living model - some professionals (with some outstanding exceptions, thank God) tend to give little credence to the opinions of what, in their minds, are 'invalid patients'. Worse than that, we often know more about our condition than they do and that is threatening. In the future, we will have to correct this dysfunctional relationship.

## Hospital Nightmare

*By Bobby Sarlina*

In November 2007, I experienced the unfortunate set of events that took me to the Scarborough General Hospital. I had swallowed chocolate milk and it ended up going down into my lungs. I arrived at the hospital by ambulance and I was lucky enough to have an 'ILA' (Independent Living attendant) meet me there to assist me, as she knows me very well. The emergency room staff brought me around, that is to say, assisted me to breathe normally as I had stopped breathing properly.

The doctors suggested that I stay in the hospital for a few days and of course, I didn't really know that my stay would turn out be a nightmare. They moved me to a room which was not fully accessible. What was supposed to be a few days ended up turning into a week. If I would have known I was going to be in so much distress, I would have left as soon as possible.

The doctors immediately assumed, and this was while I was still in the

emergency department, that I could not make my own decisions, as the doctor asked the ILA what my wishes would be if there needed to be drastic intervention, such as a ventilator. He then proceeded to ask me afterwards. This makes me think that he wanted reassurance from the ILA, as it seemed that he did not believe that I had the capacity to make my own decisions.

They moved me to a room that was small and not really accessible for someone in a wheelchair. Hospitals don't really know what 'accessibility' means. You would think they would, but they do not. An IV was administered which seemed to me, was for their convenience, so that they wouldn't have to assist me too much.

Then the assumptions started, that I could not make my own decisions or function well enough to make everyday decisions. When a doctor or a nurse is confronted with someone lying on the bed, unable to move on their own, often times they assume that the person is not quite mentally capable. At one point, one of the doctors asked me if I wished him to contact my parent, and I told him that someone else would and at that point he insisted, and said that he would call anyway. I didn't know at the time, but he had called my parent, trying to persuade her to persuade me to have the G-tube. He did not know this would not happen as my mother knows that I can think for myself.

It shows his lack of respect for me as a person, and this doctor has breached my confidentiality. The doctor had no idea that this was totally inappropriate and unacceptable. I don't really know what he was thinking. He may have thought he was acting in my best interests, but obviously he was not, and this is where it is important to see that education and information needs to be addressed in the medical community.

Another issue that arose was the fact that the doctors wanted to administer a feeding tube, which I declined and at that point they made a decision not to feed me food. They informed me that I could aspirate again or even die. I told them, they could die too. No one knows when this will happen. It is a harsh reality. Medical personnel do not have the realization that persons with disabilities are living, breathing human beings that can make informed, logical decisions on their own. They often believe and think that ILAs, etc., are there to make decisions for the person who needs physical assistance. This is a systemic trait taken on by the medical profession while they are in training. I don't know where it stemmed from and how you get rid of it.

More over, there were medications being administered into the IV, causing my bodily functions go haywire. I informed them that this was not acceptable to me, but they did not listen.

To this point, I firmly believe that if I would not have left the hospital when I did, I would have been in a serious, life-threatening situation. The initial issue at hand was aspiration but kept escalating into a possible heart attack or a stroke due to

the fact that they did not listen to my requests, as I know what is best when it comes to my body. When I arrived home, my body went back to normal, as anticipated, and as I had suggested to the medical professionals.

I am suggesting that when given a situation such as a hospital stay it is imperative to have the support of your ILAs, etc. It is important because medical professionals still do not take people with disabilities seriously. As well, it is important to have ongoing education and ongoing information available for them. I believe that the education aspect should be done by person (s) with disabilities.

### Take Charge, Not Chances: A Portfolio for Users of Home Mechanical Ventilation, Their Caregivers and Health Professionals

International Ventilator Users Network, an affiliate of Post-Polio Health International, serves a unique group of people. In the Winter 2007 issue of their

Document	Responsibility for Action
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quarterly newsletter, "Ventilator-Assisted Living", they discuss a unique portfolio that they developed entitled, "Take Charge, Not Chances".

In the spring of 2006, the Ventilator Users' Medical Emergency Project of International Ventilator Users Network (IVUN) asked ventilator users with a neuro-muscular condition, their families and caregivers, and their health professionals how to improve the often traumatic outcome of medical emergencies. Surprisingly, all three groups cited the same three factors as most critical for fostering successful emergency care:

- Advance preparation by ventilator users,
- Open communication between all parties, and
- Education of medical staff about the unique needs of this group.

Thanks to funding from the Christopher & Dana Reeve Foundation, IVUN is pleased to present a portfolio of four documents which address these issues head on. They've called it, "TAKE CHARGE, NOT CHANCES".

You can take charge by doing the work of making these documents your "own", and by having the last two with you at all times. You can download the third document and customize it as needed. The other three are for use "as is", although they may be updated occasionally on IVUN's website at [www.ventusers.org](http://www.ventusers.org).

You may access any of the four documents on IVUN's website, as listed below:

Home Ventilator User's Emergency Preparation Checklist <a href="http://www.ventusers.org/vume/HomeVentuserChecklist.pdf">www.ventusers.org/vume/HomeVentuserChecklist.pdf</a>	Ventilator User completes it and, if desired, informs IVUN for recognition.
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Caregiver's Emergency Preparation Checklist <a href="http://www.ventusers.org/vume/CaregiverChecklist.pdf">www.ventusers.org/vume/CaregiverChecklist.pdf</a>	Caregiver(s) completes it and, if desired, informs IVUN for recognition.
Patient's Vital Information for Medical Staff <a href="http://www.ventusers.org/vume/PatientInfo.pdf">www.ventusers.org/vume/PatientInfo.pdf</a>	Ventilator User completes it for use by Medical Staff.
Treating Neuromuscular Patients Who Use Home Ventilation: Critical Issues <a href="http://www.ventusers.org/vume/TreatingNeuroPatients.pdf">www.ventusers.org/vume/TreatingNeuroPatients.pdf</a>	Ventilator User completes it for use by Medical Staff.

## My First Mammogram

*By Nancy Barry*

A few years ago, my doctor found something a little “out of the ordinary” in my left breast. Considering the fact that cancer is extremely prevalent in my family, she thought that I had better get it checked out. So she sent me for my first mammogram earlier than usual.

With it being my very first mammogram, I was a little nervous and I asked my Mom to come with me. When we first stepped into the office, the experience was already starting off on the wrong foot. I told the receptionist my name and what I was there for and she turned to my mom and asked, “Has she been here before?” I stared right into her eyes and replied, “No, I have not!” I just rolled my eyes in disgust, and proceeded to the waiting room.

After about thirty-five minutes, the technician came out and called my name. I drove my power chair into the examining room, and my mother followed. The technician seemed like a pleasant woman, but as the saying goes, “first impressions are often wrong”. That definitely applied in this situation. The room was tiny and there was hardly any room for me to move my chair. The technician asked my mom, “Can she get undressed by herself?” I replied, “Yes I can!” She left the room for a few moments while I changed.

Upon her return, the technician got the equipment ready and then asked me to “stand up”. I told her that I was unable to stand because I have Cerebral Palsy, and that was the reason I was in a power chair. I asked her if the mammogram machine lowered so that it could be at my height, but she said that it didn't. The technician seemed overwhelmed by my question as if were an impossible request. Obviously this technician had never done a mammogram on someone with a “mobility” disability in a wheelchair before.

Next, the technician asked if I could stand with assistance, and I said ‘yes’. So I proceeded to stand up, she moved my power chair away from me without notice and without my consent, so I almost fell backwards. Thank goodness my mom was there to catch me before I fell. So I was standing there, with my mom holding



on to my right arm and I was holding on to the table with my left hand. The technician was trying to place the mammography equipment as close to me as possible, but she said that she couldn't get me close enough. She went around behind me, and stuck her knee in my back so as to push me closer to the table. I was screaming in pain and crying at the same time. I don't know what hurt more, the physical pain of being stretched beyond my body's capacity, or the humiliation I was feeling inside.

At that moment, I demanded her to stop because I couldn't take the pain anymore. The technician left the room again to give me a rest. When she returned, she wanted to try again. I wasn't so keen, but I knew we had to get this done and I just wanted to get it over with. With some more pulling, pushing, kneeling in my back, we finally got it done! Her last words to me were, "I don't know how the films will turn out, as you couldn't seem to keep still long enough for me to take the picture." I looked at her with disgust and contempt in my eyes, and angrily responded, "Give it your best shot."

Ten minutes later, the technician returned and said that the pictures were quite fuzzy because of all of "moving around that I did", as if I were doing it on purpose. She continued, "But that'll have to do because I'm already late for my next appointment". At this point, I'd had more than enough of her attitude and I expressed my sheer disappointment and disgust with her demeanor. I asked if she had ever done a mammogram on someone in a wheelchair before, and she had not. I began to leave the room, but just before I made my final exit, I turned to her and said, "you have a lot to learn, lady, not just about people with disabilities, but how to become a human being that shows some signs of compassion", and I stormed out, never to return again.

This experience left me not only disillusioned with the medical arena, but also more adamant than ever to do something to change the way that these so-called 'professionals' view disability. Strangely enough, I felt empowered to do something so that other women like me didn't have to face similar barriers, especially those of an attitudinal nature. Sometimes, in fact, most often, it is those attitudinal barriers which hurt the most.

### Barriers in the Health Care System: A Summary of Researched Facts

Although disabilities are now more visible, people with disabilities are not completely accepted nor granted full participation in mainstream society. Many people with disabilities (both visible and invisible) continue to experience discrimination. However, women with disabilities increasingly experience

discrimination based on intersecting identities (i.e., gender, race, class, age, sexual orientation and disability). As such, it is essential that health care providers improve their knowledge of disability issues, as well as their practice of providing care to women with disabilities. Doing so could make a significant difference in promoting the health of a population that has traditionally been underserved.

Women with disabilities have the same health care problems and needs as the general population. However, women with disabilities often face specific barriers to care that other populations of women do not. Due to discrimination, past negative encounters with health care providers and individual lack of knowledge regarding health care issues, many women with disabilities do not seek out – and therefore do not receive – preventative health services.

Women with disabilities are often deprived of accessible, quality health services. As a result, many are routinely denied health information, services and options that most temporarily able-bodied women are not.

### **Models of Disability**

The medical model of disability has had an enormous impact on the way society thinks about people with disabilities. This model argues that disabled people's inability to participate in society is a direct result of their "impairment", rather than the result of features in our society that could be changed – the body, as a result, becomes the focus of attention. The medical model has also affected the ways in which people with disabilities how the body "should" look, move and feel. The social model of disability on the other hand, argues that disabilities arise from the disadvantages people experience as a result of think about themselves – most often in the form of negative internalized messages about societal beliefs about what it means to live with a disability. "Disability" according to this model, is caused by the reaction of society to a person's impairment and the extent to which people with disabilities are excluded from engaging in major life activities, rather than the (physical) inability of a person to do so.

### **Barriers to Care**

People with disabilities face numerous barriers to care in the forms of architectural (physical), societal and attitudinal barriers. These barriers keep many from entering the health care system. While much of our attention is focused on the physical barriers people with disabilities face, it is important to remember that not all barriers are physical ones. Interactions between health care providers and people with disabilities highlight the prevalence of societal and attitudinal barriers. Because each are socially constructed, they can be easily avoided by observing some basic rules of disability etiquette. Taking notice of one's own beliefs and behaviors about and toward people with disabilities

could yield greater results and more positive interactions between health care providers and clients with disabilities.

**Architectural Barriers** (or physical) barriers refer to those that keep people with physical disabilities from accessing facilities, receiving services and participating in social life. They are also the easiest to remedy. In the health care setting, architectural barriers may include: (1) Lack of access ramps, curb cuts, doorways, hallways, bathroom and exam rooms that can accommodate wheelchairs; (2) Lack of equipment – such as adjustable exam tables, platform scales and lifts – to assist people with mobility impairments or those who use wheelchairs in receiving adequate assessment and care.

**Societal Barriers** refer to the systematic exclusion of people with disabilities from mainstream society. They take the form of: (1) Invisibility and marginalization – able-bodied people often ignore, trivialize and render invisible those with mobility/physical impairments. Issues that address disability are often ignored, further marginalizing the disability community from mainstream society; (2) Infantilization – able-bodied people often believe that people with disabilities are not capable of communicating, have lower intelligence levels or are dependent on others for daily survival; (3) Charitable view – those who are able-bodied often ignore the ability of people with disabilities to live independently, leading to the belief that people with disabilities are deserving of pity and concern and should be “taken care of.”

**Service Barriers** refer to the lack of training and services that further contributes to the exclusion of people with disabilities from participating in medical and social services and activities. These take the form of: (1) Lack of training of health care providers – a very small number of nursing and medical schools include curricula on disability, which is often relegated to the margins of study, where it is offered as an elective or as part of a lecture. This absence leads to a lack of knowledge about appropriate, respectful and culturally competent treatment; (2) Lack of home health services – people with disabilities have difficulty finding qualified, competent personal care assistants and often find it difficult to pay for these services. Lack of access to employment and transportation keeps many at a higher risk for abuse and neglect because many may be reluctant to report an abusive caregiver when a replacement may be difficult to find; (3) Transportation – people with disabilities often find it extremely difficult to access transportation resources. Many services have to be made in advance, they may have to wait for rides and many may have to travel alone.

**Attitudinal Barriers** are much more difficult to remove than architectural barriers. They are often the root causes of societal, service and architectural barriers and are deeply informed by the history of disability. Attitudinal barriers the form of myths that our society holds about people with disabilities, and thus, impact the treatment that people with disabilities receive when they enter the health care system: (1) Focus on the disability – many times health care

providers define people with disabilities solely by their impairment, rather than treating them as whole persons with complex social, physical and medical needs; (2) “Buying into” the myths of disability - lack of education, experience with and awareness of disability issues makes health care providers susceptible to believing the myths and stereotypes about people with disabilities; (3) Belief in lower quality of life – health care providers often believe that the quality of life of people with disabilities is very low. However, research shows that the quality of life in people with disabilities is based on the same levels of social involvement and integration as it is for able-bodied people; (4) Asexuality – disabled women are often treated as asexual in health care and the society at large. Many believe that disabled women are not sexual beings, are not sexually active and are not capable of mothering, which keeps many disabled women from receiving appropriate gynecological care. Further, viewing disabled women as asexual reduces the likelihood that disabled women will gain access to sexually explicit materials, sex education and information on birth control.

### **Removing the Barriers**

There are actions that health care providers can take to create more accessible environments and services that engage women with disabilities as partners in care. Going beyond the minimum requirements set by law is paramount to achieving facilities and services that are universally accessible to the greatest extent possible. By meeting the needs of women with disabilities, health care professionals can provide enhanced facilities and services to all clients, while encouraging more women with disabilities to seek out services, increasing client bases and improving the general health of women with disabilities.

The following provides information on how health care providers can work to improve physical environments and personal interactions with clients with disabilities:

**General things to think about** – creating a barrier-free, disability-friendly environment is key to providing clients with high quality service. Become an active team member in planning for health care facilities and/or programs that target the inclusion of people with disabilities. Involve people with diverse disabilities to train providers on assessing facility accessibility and recommendations.

**Creating universal access** – ensure that all clients, regardless of ability, have access to environments, facilities, products and services. Install power door operators at interior and exterior entrances. Provide motorized, adjustable-height treatment and examining tables and chairs. Obtain mammography machines that can be used on a woman in a seated position. Provide more than one accessible toilet and dressing room. Provide a TTY phone for use by people who are deaf to make phone calls from health care facilities. Install a portable, amplified communication system at service desks and treatment spaces for people who

are hard of hearing. Arrange chairs for use by clients who cannot stand while transacting business. Clear spaces in waiting areas where wheelchair users can sit out of traffic areas with other people, disabled or not. Provide awareness and sensitivity training for all staff that interact with people with disabilities.

### **Specific Health Concerns**

Basic, routine health care is as necessary for women with disabilities as it is for all women. However, several areas of disabled women's health are neglected, as health care providers tend to focus solely on the impairment and associated issues, rather than on a woman's holistic health care needs. Incomplete interaction with a health care provider may put a woman at risk for developing otherwise preventable secondary conditions, if a woman is viewed as a whole person – and not as her disability – quality preventive care can be easily obtained.

### **Breast Health**

Women with disabilities have less access to breast health services than other populations of women. Even when women with disabilities schedule mammograms or clinical breast exams, they do not receive either service due to inaccessible health care facilities and medical equipment. Medical and societal biases impede proper treatment, as health care providers tend to focus on the area of the woman's body affected by the disability rather than encouraging disabled women to regularly examine their own breasts. Additionally, women with disabilities are often not identified as an underserved population, and therefore are not specifically targeted in education and outreach efforts by breast cancer organizations.

### **Reproductive Health**

The pelvic exam, a critical component of women's health, is often infrequent or nonexistent for women with disabilities. Reasons given by women with disabilities for not having regular gynecological exams include: not being aware of the need to have one; difficulty getting onto the exam table; being too busy; and, the inability to find a doctor who suits them or who is knowledgeable about their disability. In addition, health care providers often assume that their disabled clients are not sexually active, leaving the screening of sexually transmitted diseases and the performance of gynecological exams undone.

### **Sexuality**

Many women with disabilities do not receive adequate education about sexuality and reproductive health, which leads to a lack of understanding on sexual function and desires. Health professionals can help women with disabilities overcome physical barriers to sexual functioning by encouraging them to lead

sexual lives. More importantly, health care professionals can reassure the self-worth of women with disabilities by helping them understand that sexuality is an important aspect of their lives.

### **Tips on Providing Health Care**

There are steps that health care providers can take to create more appropriate and accessible environments and services for people with disabilities. The following are some tips that can enable culturally competent care for people with disabilities:

- Discuss health and wellness promotion with clients – two areas that have traditionally been ignored when discussing the health of people with disabilities.
- Carefully explain all procedures and exams.
- Always be patient and allow the client time to understand and ask questions.
- Always ask the client which positions are most comfortable for her, and ask if she prefers any assistance – she is her own best expert.
- Always provide accessible exam tables.
- Let the client set the pace in walking and talking – speak directly to the client rather than through a companion (whether the companion is an interpreter, family member or friend). When appropriate, always give the opportunity for a client to speak alone with you.
- Do not over-attribute symptoms to the individual's impairment. People with disabilities need regular check-ups, screenings and health education, as all clients do. Underlying causes of symptoms should always be explored.

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## Gateways to Cancer Screening: A Participatory Needs Assessment of Women with Mobility Disabilities

### **Background: Cancer and Screening**

Early detection and screening are seen as ideal areas of intervention in the cancer control continuum. For women with disabilities, access to screening and support has been a challenge due to multiple barriers:

- Women with disabilities have the same biological risks as other women for developing all cancers.
- These barriers include lack of knowledge among these women, neglect on the part of health care providers, and physical access barriers (Welner; 1998).
- Women with disabilities, in particular those who are older, are less likely to receive regular Pap tests and mammograms (Nosek & Howland, 1997).

### **How We Got Started:**

The Centre for Independent Living in Toronto (CILT) recognized the need to increase the level of awareness of screening for breast, cervical and colorectal screening among disabled women in the Toronto area. Partnerships were then developed with Mount Sinai Hospital and Canadian Cancer Society in order to write a proposal and seek funding.

### **Funding and Support:**

The project is funded and supported by the Canadian Cancer Society, in particular, the Diversity & Cancer Control teams. They provide in-kind support for the project, and ensure that the project reflects the diversity that exists in Toronto. Recommendations from the research will be carried forward in a meaningful and sustainable way.

### **Who are the team partners?**

- Centre for Independent Living Toronto (CILT) Inc.
- Mount Sinai Hospital, Marvella Koffler Breast Centre
- Canadian Cancer Society
- University of Toronto, Faculty of Nursing

### **What is the Gateways Project?**

The Gateways Project is a community-based participatory project that was carried out in the form of a qualitative needs assessment. We aimed to explore the experiences and needs of women with mobility disabilities when they access breast, cervical and colorectal cancer screening.

### **What is a Qualitative Needs Assessment?**

A Needs Assessment is an exploration of the way things are and the way that they should be. In qualitative needs assessments, the aim is to gain personal insight from individuals or groups as to the nature and impact of a particular situation (Kaufman, R & Fenwick, W. Needs Assessment: Concept and Application, Educational Technology Publications, Englewood Cliffs, New Jersey, 1979).

Initially, the Gateways Project working group considered taking the qualitative description research approach. Historically, researchers did not include members from the disability community in their work. The project team strongly believed in inclusion and consensus-based decision making at each stage of the project. We also wanted an action component, which therefore moved us to Participatory Action Methodology.

### **What is Participation Action Research?**

We chose this method of research because it included participation and most



importantly, an action component. The action component is where we take the knowledge from the focus group participants and transfer it to cancer screening organizations, raising awareness among service providers that could possibly lead to informed changes in practice. Focus group participants would also feel empowered through shared discussion and the fact that their voices were being heard and listened to. It was decided by the research team that for this particular study, the Gateways Project, focus groups would be the best way to collect data with peer facilitators asking the questions, because focus groups allow participants to build on each other's ideas that may not be obtained in a one-to-one interview. Approval was obtained by the Research Ethics Board at the University of Toronto, for consent forms, letters of invitation to organizations who provided support to women with mobility disabilities, recruitment flyers and research protocol.

### **Community Outreach:**

We deliberately attempted to hear from women from diverse communities, including women of colour, lesbian, bisexual, trans-gendered and trans-sexual communities, in order to truly reflect the diversity that exists in Toronto and make the resulting recommendations relevant to as many people in Toronto as possible.

Prior research on women with disabilities has implicitly assumed that either all women with disabilities are the same, or that disability is the singular central aspect of these women's lives.

Women with disabilities come from diverse sociocultural demographics, and these aspects of life impact the experience of disability and one's relationship with the healthcare system.

### **How We Carried Out the Needs Assessment:**

In total, five focus groups were conducted which were led by peer facilitators, with individuals who self-identified as women living with mobility disabilities. In order to participate in a focus group, each participant had to meet the screening criteria: no previous history of breast, cervical or colorectal cancer; they had to be at least 18 years of age and living in the GTA. Women were able to discuss their experiences with cancer screening and share insights, barriers and facilitators of screening.

### **How the Focus Groups Were Conducted:**

Each focus group was held at an accessible location, two at CILT, two at the Canadian Cancer Society, and we were asked to do one in the Region of Peel. At the beginning of each focus group, participants were given a written document, providing them with information on the background of the study, the purpose and design of the study, the length of the study, possible side effects and risks, possible benefits, compensation (each focus group participant received a \$50 honorarium for their participation in the study), description of the research team, the fact that their participation in the study was completely voluntary, and that they could refuse to answer any question at any time, and a confidentiality form which they were asked to read, ask questions about and sign.

Ground rules for confidentiality were mutually discussed by everyone before the actual focus group began. All participants were provided with attendant services, if required, and light refreshments.

### **Women's Health Presentation:**

At the beginning of each focus group, before getting into the actual focus group questions, a small Powerpoint presentation was given on Breast, Cervical and Colorectal Cancer information with the current screening guidelines set out by Cancer Care Ontario.

### **Peer Facilitation, Process Checking & Take-Home Info:**

Each focus group had two on-site transcribers using laptop computers, all focus group sessions were audio taped, and information provided by the participants was recorded on a flipchart as a method of validation. To ensure the emotional well-being of focus group participants, we ensured that a social worker or supportive staff person was available at each of the sessions if debriefing was required.

Each participant received a Canadian Cancer Society (CCS) bag with small gifts, and information about CILT, CCS, Cancer Care Ontario, Sherbourne Health Centre and cancer screening.

### **Goals of the Gateways Model:**

- To assess the needs of diverse women with physical mobility disabilities in accessing breast, cervical and colorectal screening services and determine the gaps and barriers associated with accessing these services.

- To develop a series of recommendations to be shared with the key stakeholders involved in the delivery of screening services.
- To focus on implementing these recommendations.
- To produce new areas of knowledge that can be effectively transferred to key cancer control professionals that benefit people with disabilities.

### **Key Themes and Focal Points:**

#### **“Bodies” in Relation to Screening:**

One theme we noted across all the focus groups was how participants fore-fronted their bodily experiences. Our approach to examining these “body” themes stands in contrast to existing literature and studies which has not looked at the individual bodily issues of disabled women accessing cancer screening. After reviewing some of the transcripts from the focus group sessions, the embarrassments, vulnerabilities and bodily predicaments experienced by the women during screening were quite evident.

Although it is well known that women with mobility disabilities frequently encounter architectural barriers to access, the focus group discussions illuminated many additional constraints. These ranged from subtle to obvious barriers, and often worked in combination to create complex, frustrating situations for women who sought cancer screening or other forms of health care.

#### **Barriers Created to Access by the Health Care System:**

Data collected from the focus group participants highlighted repeatedly that the health care system is structured according to normative assumptions about consumers. These assumptions govern all institutional arrangements, including a) referral, intake and appointment scheduling policies and procedures, b) type and placement of furniture within waiting rooms, c) expectations, attitudes and knowledge of health professionals, and d) design and use of specialized equipment for screening.

Many women in wheelchairs cannot transfer themselves or be transferred onto standard examining tables. Similarly, women using wheelchairs may be unlikely to find accessible mammography machines to accommodate them in their chairs. And women (including seniors) who have tremors, who experience spasms, or who lack the stamina to stand at an imaging machine also should be seated for accurate screening. Many healthcare providers who focus on the area affected by the disability might not encourage women to regularly examine their

breasts. Also, women with disabilities are often not identified as an underserved population for breast-cancer screening. Thus, they are not specifically targeted in education and outreach efforts by breast cancer organizations (BHAWD, Breast Health Access for WWD. Berkley, California.)

**Barriers to Access External to the Health Care System:**

The Health Care System was not the only source of barriers to cancer screening identified by the women. In order to connect with health services, other resources were required but could be frustratingly difficult to obtain or coordinate. These services were separate from the HCS, hence they presented additional layers of administrative complexity.

Transportation was a major problem cited by most of the participants. Wheeltrans and health services have several properties in common: they are both structured around the requirements of service providers, subject to unpredictable delays, and intolerant of lateness or last minute rescheduling. Women were late for appointments because of Wheeltrans delays or missed pick up by Wheeltrans because of long waits in clinics. Inclement weather intensified these challenges to intolerable levels.

Attendant services were often required for women to attend health appointments and manage self care. These arrangements also had to be carefully coordinated and scheduled. Access to attendant services and assistance with screening activities such as breast self examination or stool testing was limited by payment structures, job descriptions and scheduling restrictions. Specifically, colonoscopy screening preparation and stool testing designed to screen for colorectal cancer at home produces significant challenges for women using wheelchairs and requiring attendant support for using the toilet.

**Self Advocacy and Self Care:**

Despite – and perhaps because of – these multiple challenges, the women were proactive in protecting their health needs. While many were not engaged in regular cancer screening, they were knowledgeable about their own health issues and highly attuned to the shifts in their bodily wellbeing. They provided examples of strategies to avoid stress and protect themselves from illness. Strategies were learned through trial and error, active engagement with a wide variety of information sources, contact with peers, and, occasionally, tailored teaching by health professionals.

Focus group participants described efforts to communicate with and educate providers to ensure their questions and concerns were addressed and potential health problems were avoided. This was no small task, because the women's highly individualized knowledge was sometimes not recognized by providers, who seemed to value a more generalized form of information about disease

states and treatments. The women prepared in advance for health appointments by anticipating problems and coordinating assistance and transportation.

**Facilitators to Access Screening:**

The focus group participants also described positive interactions with the HCS and instances where screening was successfully obtained. Some women had connected with facilities that were uniquely structured around the needs of women with a variety of disabilities. Several had also found individual providers who had expertise and great sensitivity to their health needs. These settings and providers offered longer appointment intervals to reduce pressure, provide ample time for provision of care, and open space for discussion of health issues. Attendant services and special equipment were sometimes available to facilitate procedures such as cervical screening.

According to participants, positive attitudes and interpersonal styles of health care providers can make an important difference by creating a welcoming, rather than an intimidating, experience. Women sought care with confidence when they saw that their primary care provider had bothered to learn more about their unique health needs. They appreciated opportunities to ask questions, contribute their own opinions, and discuss merits of treatment options. Anecdotes told by participants indicate that they appreciated providers who treated them with respect and recognized their acquired self-care knowledge.

**Highlights of the Report & Recommendations:**

- More places with accessible exam tables and screening technology and on-site attendant care that are clearly publicized to the disability community.
- Strategic health messaging with disability-positive images and specific information for women with disabilities to support self- advocacy in accessing screening.
- More personnel to address disability-related needs and anxieties prior to screening procedures.
- On-site health education sessions for women with disabilities on screening guidelines, procedures and body-specific strategies for optimal care.
- Disability Training for Health Care Professionals and clinical staff at

- all levels on appropriate and clear communication, compassionate behaviour and best practices.
- Creating safe and positive spaces for women with disabilities from LGBTTQ communities, marginalized ethno-cultural communities, low socio-economic status and various ages.
- Patient-centred and integrated preventive cancer care that includes more options and less coordinating work for patients.

**To read the full report, please visit  
[www.cilt.ca/peersupport/Gateway\\_project.aspx](http://www.cilt.ca/peersupport/Gateway_project.aspx).**

### **Budget Leaves People with Disabilities in Poverty**

*© ODSP Action Coalition; March 25, 2008. Statistics provided by the Ministry of Community and Social Services.*

“Disability should not be a life sentence to poverty, but this budget does nothing to reduce the poverty of people with disabilities” says Denise Vernier of the ODSP Action Coalition. The Coalition, made up of people who receive income support under the Ontario Disability Support Program and organizations that work with recipients, is disappointed that there is only a 2% increase in social assistance rates.

While the Coalition is encouraged that the government is developing a Poverty Reduction Strategy this year, and has taken measures to address some of the issues affecting poor children, they are disappointed that people with disabilities have been barely mentioned. Eighty-six percent of people who receive ODSP do not have dependent children. Single people with disabilities need to be able to eat nutritiously, maintain adequate housing, and cover all of the other necessities of life too. A significant increase to ODSP income support in this budget would have been a strong indicator that the government is truly committed to lifting people out of poverty.

“People with disabilities disproportionately live in poverty compared to other Ontarians. We call on the provincial government to clearly indicate that it will include people with disabilities and the organizations that work with them, in their consultations on the Poverty Reduction Strategy”, says Nancy Vander Plaats, chair of the ODSP Action Coalition.

The Coalition calls on the government to implement an independent Social Assistance Rates Board to make recommendations on social assistance rates which would be adequate to pay for the average costs of shelter, nutritious food, transportation and other necessities. ODSP recipients who are able to work should also have access to the kinds of employment supports they need to overcome the barriers they face in the labour market. Those who are able to work should be allowed to keep all of their earnings, at least until they reach the poverty line. For more information contact Nancy Vander Plaats, chair, ODSP Action Coalition at 416-438-7206 or 416-801-4169; Denise Vernier, chair, Stormont, Dundas and Glengarry ODSP Action Coalition, at 613-330-3526 or 613-936-0131.

### NDP Gets Unanimous Support for Persons with Disabilities

On May 2, 2008, Parliament gave unanimous approval to an NDP motion calling for Canadian ratification of the UN Convention on the Rights of Persons with Disabilities. NDP Critic for Persons with Disabilities, Judy Wasylycia-Leis (Winnipeg North) introduced the ratification motion in the House of Commons.

“This motion sends a message to the world community and to Canadians living with disabilities that the Parliament of Canada fully supports the Convention and expects the government to move as quickly as possible to ratify and implement it,” said Wasylycia-Leis.

“All-party support for this NDP initiative demonstrates that Canadians of all political stripes are united in our commitment to the UN Convention,” Wasylycia-Leis said. “More than 20 other nations have already ratified and it’s time Canada reaffirmed our support.”

Canada signed the Convention over a year ago, on March 30 2007, but is yet to join other nations in ratifying it. Last month, the Convention received the required number of ratifications to bring the Convention into force.

Motion: “That, in the opinion of the House, the government should ratify the United Nations Convention on the Rights of Persons with Disabilities, signed by Canada on March 30, 2007, following requisite consultations and procedures with provincial and territorial authorities, and that Parliament and the Government of Canada take appropriate measures within their competence to ensure Canada’s full compliance with the convention.”

For more information, please contact: Chuck Brabazon, at the office of Judy Wasylycia-Leis, at 613-995-1988.

## CAILC's New Name and Identity

The former Canadian Association of Independent Living Centres or CAILC has re-branded to the shorter Independent Living Canada to better embed our identity and purpose throughout Canada.

Independent Living Canada is a national network of resource centres that supports individuals and their communities by changing the way in which people with disabilities view themselves and are viewed by others. Hence our slogan: "Promoting a new perspective on disability."

The staff and volunteers in our 28 cross-Canada IL Centres aim to reduce the attitudinal and environmental barriers that prevent the full participation of people with disabilities. The centres focus on information dissemination, networking, self-advocacy, independent living skills development, peer support, research and community development.

Independent Living Canada fosters and promotes the economic, political, social and cultural contributions of people with disabilities and by doing so we are creating a better Canada for all.

## COMMUNITY NEWS

### Out From Under: Disability, History and Things to Remember

The Royal Ontario Museum (ROM) is pleased to present a ground-breaking exhibition "Out From Under: Disability, History and Things to Remember" - April 17th to July 13th, 2008. Enter via the Bloor Street West Entrance of the Michael Lee-Chin Crystal. Organized by the School of Disability Studies at Ryerson University and the ROM. This exhibit chronicles the struggles, alliances and setbacks faced by people with disabilities in Canadian history and illuminates the proud history of resistance and survival.

Catherine Frazee states "Disabled people don't seek merely to participate in Canadian culture - we want to create it, shape it, stretch it beyond its tidy edges."

Admission:\$14/child,\$17/student,\$20/adult.  
Half price Fridays from 4:30 p.m. to 9:30 p.m.

### Turning Point: Summer 2008 Program in Toronto for Youth Who Have Acquired Brain Injury (ABI)



Turning Point is for young adults 16 to 25 years of age who have an Acquired Brain Injury and who want to become more independent and who are motivated to work on skills related to independence and are thinking about next steps to living on their own, and who also have the ability to participate actively within a group setting.

Turning Point takes place for six days and five nights - July 6, 7, 8, 9, 10, and 11, 2008 at Ryerson University Residence, Pitman Hall, 160 Mutual Street, Toronto. The cost is \$450.00 for five nights. Financial assistance is available.

Program topics include: social skills and independence, getting around the city, recreation and leisure and problem solving. Activities include community outings, making meals and final party planning. For more information, call Julie Osbelt at (416) 425-6220, extension 3298.

### Citizens With Disabilities – Ontario AGM

All CWD-O members are cordially invited to attend their 2nd Annual General Meeting (AGM) on June 19, 2008, starting at 7:00 pm EDT.

Two key activities for members at this year's AGM will be:

- The ratification of Bylaw No. 1, a bylaw relating to the general transaction of business and affairs of CWD-O; and
- The election of Directors for 2008-09.

At the AGM, the Nominating Committee will propose a slate (list) of Directors that represents Ontario's various regions, a cross-disability focus, and diversity within its membership. For 2008-09, Directors will be appointed for one, two or three-year terms (by random selection) in order to establish a future rotation of vacancies of one-third of the board each year.

Nominations of self and others are most welcome. If you wish to be considered for this slate, please forward your completed nomination form to: [membership@cwd-o.org](mailto:membership@cwd-o.org). Please feel free to browse their committee links at [www.cwd-o.org](http://www.cwd-o.org) for further information about our activities.

Participation at the AGM is enabled through IDEAL, an on-line conferencing system. Participants can type or talk on line (headset or microphone and speakers required). For information about how to log on to IDEAL, and for a schedule of training sessions, please contact [pat.seed@cwd-o.org](mailto:pat.seed@cwd-o.org). If you require an Interpreter or Captioner to participate online, please contact us as soon as possible so we can arrange for this accommodation.

Thank you for your interest in and support of CWD-O. Together, we are stronger! Citizens With Disabilities-Ontario (CWD-O) is dedicated to the full participation of all persons in the social, economic and political life of their communities. It actively supports and promotes the rights, freedoms and responsibilities of individuals to determine their own destinies. Key areas of activities are community development, social action, social development, referral, and member services. Its primary activity is to advocate on behalf of persons with disabilities and promote their personal participation in changing social and physical barriers that allow for full participation in the mainstream of society. CWD-O is an "Associate Member of Canadian Council of Disabilities".

### **Citizens With Disabilities – Ontario**

[www.cwd-o.org](http://www.cwd-o.org)

### **That Really Grinds My Gears!**

*By Nancy Barry*

In the last issue of 'In the Stream', we introduced our newest column, "That Really Grinds My Gears", a forum that allows us to release some of the frustrations that we face everyday as people living with disabilities. I think that releasing frustration can be a positive thing, as long as it's done in a way that doesn't harm others, but most importantly, that empowers us to try and find solutions to difficult scenarios.

Dorothy, from Oshawa, has decided to share some of the things that really grind her gears. Dorothy lives with her two best friends, one of whom uses a power wheelchair. These are some of Dorothy's thoughts:

- When you're at the mall and you're waiting to use the wheelchair washroom that's entirely on its own (not a stall in the main washroom) and a bunch of young teenagers who are clearly NOT disabled come out of it. I give them a really good tongue-lashing and report them to the security guard. In fact, last week we were coming out of that same washroom when we noticed two young guys and a young girl waiting to come in. They didn't make a move to enter until they thought we couldn't see them anymore. Then I quickly looked around the corner, catching them in the act, and yelled at them to get out, telling them they had no business being in there. The security guard later told me he'd view the film and if he could locate the teenagers he'd serve them with a trespass notice.
- Whenever I see someone clearly violating the use of a handicapped

- parking space, I politely tell them to move their vehicles. If that doesn't work, or if I don't see any of the people around the vehicle, I report the license plate number to the local bylaw office.
- We don't take the GO Train on a regular basis but let me just briefly share with you an experience we had last summer: one we won't forget for a long time. It took place during the CNE. We got on at the Oshawa station and the wheelchair car was quite filled up with a few other disabled folks but mostly families with strollers as we entered the Rouge Hill station. I noticed another person with a power wheelchair trying to board and asked others to make way for this person as the GO operator was nowhere to be found and this person was having a fairly difficult time boarding. I politely reminded folks that the car was for people with mobility devices first and eventually this person was able to get a spot. Then a young woman with a baby stroller told me that I was being very rude in telling her to move. When I asked why she thought that way she told me that she had a right to stay where she was because she had a stroller. I reminded her that the car was for people with mobility devices first and her stroller wasn't a mobility device. She then had the nerve to tell me that her stroller was the same as a wheelchair since her baby can't walk yet. I told her that her stroller is nothing like a wheelchair and she had the ability to pick up her baby, fold the stroller and go up the steps whereas people with wheelchairs can't do that. By this time the GO operator had returned and was watching all of this and not saying a word. Eventually her mother grabbed her and told her off. When I asked the GO operator what he thought about this, he said I should see what it's like during a typical rush hour run. He then told me that he couldn't really ask anyone to make way. I told him I couldn't understand that, as they're clearly in violation if they don't move. I later found out from another GO representative, that they're working on policies to get the operators to enforce that more (this was apparently a CN employee). I sure do hope that's the case.

Thanks for sharing, Dorothy. I can totally relate! I invite you all to share your grinds with us. If you'd like to share, please email a scenario that really grinds your gears to [peervolunteer@cilt.ca](mailto:peervolunteer@cilt.ca), or call me at (416) 599-2458, extension 27. I think this is a fun way for all of us to learn from one another.

## CILT NEWS

### Upcoming Workshops

*By John Mossa, IL Skills Trainer*

#### **Speak Up & Self Advocacy Workshop - Thursday May 29, 2008 1:30-3:30 pm:**

Having problems with getting services such as ODSP, transportation, and/or attendant services? Don't know what to do about it?

In this interactive workshop, you will learn some useful and necessary self-advocacy skills including listening, negotiation, problem solving, assertiveness and a step-by-step plan for self advocacy.

Come to our Self Advocacy Workshop at CILT (205 Richmond Street West, Suite 605). This is a FREE workshop. Attendant services and light refreshments will be provided. Other accommodations may be available upon request by no later than May 23, 2008.

If you are interested in attending, RSVP to John Mossa at (416) 599-2458, extension 38 or by TTY at (416) 599-5077 by May 23, 2008.

#### **Emergency Preparedness Workshop - Thursday June 12, 2008 1:00-4:00pm:**

Are you ready to be self-reliant for 3 days immediately after or during an emergency? Have you developed and practiced a family emergency response plan and emergency survival kit? Want to know more about being ready for all types of emergencies?

Join us for this interactive workshop featuring, Maxine Marz, Diversity Outreach Officer, Emergency Management Ontario, Ministry of Community Safety and Correctional Services. Light refreshments will be served. Attendant services will be provided. Other accommodations provided upon request before June 5, 2008.

RSVP by June 5, 2008 to John Mossa (ext. 38), Kimberly McKennitt (ext. 34) or Nancy Barry (ext. 27).

## BOOK REVIEW

By Susan DeLaurier

*Raising a Kid with Special Needs by Lisa Bendall*

You might not think a book about raising a child with a disability could be positive, enlightening, and also entertaining, but you'd be wrong. Lisa Bendall has managed to first acknowledge the shock and disorientation that parents feel when first told their child has a disability or disorder, and then to show how gradually, and with appropriate resources, things start to fall in place.

One of the most important things a parent can do is to accept that their child has a disability. This may sound self-evident, but unless this truly takes place, that parent may not look at all the resources that are available to help his/her child reach their full potential. Often there is a feeling of not wanting to "label" the child because he/she will become "one of them", but that "label" is just one aspect of the child's personality.

Once acceptance takes place, advocacy is the next step. The resources and different aspects of advocacy in this book, including a wonderful section of 'do's and don'ts', provide an excellent starting point for parents. While advocating for a child, Lisa also stresses that this child must be held to the same standards of behaviour as other children. Even if that child cannot speak, he or she can still convey a simple "thank you". Ultimately, this will increase his/her self esteem knowing how to get along with others. On a personal note, I have to say that this is most important.

Many years ago I had a neighbour whose little boy had cerebral palsy. His mom wanted him to be able to defend himself so she taught him to pinch others. This kid had strong fingers, he did it all the time, and it hurt! Needless to say, as he grew older, he had no friends and his Mom always thought it was because of his cerebral palsy. A little monster is not how you want your child to be thought of.

Each chapter in this book begins with one brief family story highlighting the subject of that chapter. There is also a unique "Gold Star Idea" – something that is not usually covered in other books, or is out of the ordinary. These ideas can easily be adapted for different families at different times. People dealing with disability issues for the first time usually have no idea of what's out there.

In the forward by Ian Brown, a Globe and Mail columnist, he says of the author, "she has thought of everything". This is an understatement. In addition to the obvious things like dealing with doctors and advocacy, topics such as schooling, adolescence, finances and family and marriage relationships are covered. The suggestions, lists of books and websites for each chapter will be a valuable

resource for any parent with a special needs kid.

In my opinion, the most important aspect of this book is its positive outlook. The future does hold all kinds of promises and possibilities. A 2006 Statistics Canada study shows that 86 percent of Canadians living with disabilities say that they are “pretty happy” or “very happy”, and this is what all parents want for their children.

Raising a Kid with Special Needs can be ordered through Amazon.com.

## INFORMATION & REFERRAL

### **Stylists On Call: Professional In-Home Hairstyling Service**

‘Stylists On Call’ offers a wide range of services from haircuts to perms, colour treatments to aesthetic services, and brings the beauty salon home to you.

In honour of all the special “moms” out there, Stylist On Call will be continuing their Mother’s Day celebration all month long and leading into Seniors Month this June, with their membership gift certificates at half price. True to their motto Stylist On Call “will make you look great” and they’ll come right to your door to do it.

For more information, call 416-630-5001 or visit [www.stylistoncallinc.com](http://www.stylistoncallinc.com).

## CLASSIFIEDS

FOR SALE:

### **2005 Toyota RAV4**

Asking \$25 000.

40 000 km, Silver Colour with Black Interior

Features:

4 wheel drive \* Extra wide tires \* Full spare tire \* Keyless entry  
Automatic 4 speed transmission \* Power doors and locks \* ABS brakes  
Air conditioning \* Heated leather seats \* Power mirrors \* CD player  
Fog lamps \* Roof rack \* Front air bags \* Over 2 years remaining on Toyota  
Warranty.

Accessibility Features: High vehicle – easier to get in and out.

Heated seats – relieves pain, stiffness  
Bruno scooter lift – scooter can be transported in rear of car.

Notes:

This is the last model year of the RAV 4 before the car was made larger and more expensive. The car is small and very maneuverable with good sight lines from the driver's seat. Gas consumption is quite low. A scooter can be loaded into the car with one rear seat tilted forward. With both rear seats removed (a simple operation) there is a very large cargo area for a scooter along with luggage, groceries, etc. Call Dave or Kari at 416-63-4684.

**Scooter for Sale**

The seller is asking \$2500 or reasonable offer. Scooter is a LX 2001, burgundy, in brand new condition with all the amenities. A viewing can be arranged in the Eglinton Ave. and Wynford Drive. Please call Julie at 416-967-3046 or e-mail [julie.crljen@mssociety.ca](mailto:julie.crljen@mssociety.ca) if interested.