

# Prime Timer Focus

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## New Executive Direct for Centre for Independent Living in Toronto (CILT) Inc.

The Board of Directors are pleased to announce the appointment of Ms. Sandra Carpenter to the position of Executive Director, Centre for Independent Living in Toronto (CILT) Inc.

Sandra is well known within Toronto region's disability community and its supporters including academics, and nationally within both the independent living and consumer movements. She directed CILT for a time in its very early days, and returned to CILT over seven years ago as Program Manager.

Throughout the 90's and the early 2000's, CILT has operated primarily within the network of Independent Living Resource Centres and with the Canadian Association of Independent Living Centres. The net result is that we have remained close to our roots and consumer issues within Toronto and Ontario, providing resources for people with disabilities.

Sandra is a person who can lead CILT to a new level of effective community engagement, working with health care, service provider and activist partners. We have every confidence that Sandra will continue to build on the relationships she has forged and develop new and effective partnerships as we move forward for the future.

Please join us in welcoming Sandra to her new role.

## 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 where the Canadian disability community expects inclusion.

For more information contact Laurie Beachell, CCD National Coordinator, at 204-947-0303, or by Cell at 204-981-6179.

### 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 take 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. 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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## Reach a City Beach with a Free Beach Wheelchair!

Do you have limited mobility but want to explore the beaches at Woodbine, Ashbridge’s Bay or Kew-Balmy? Toronto Parks, Forestry & Recreation has two beach wheelchairs available for free short-term loan this summer.

### **What are beach wheelchairs?**

They have large balloon tires, allowing easy movement over dry or wet sand and along the water’s edge. They come equipped with an umbrella. They require assistance – beach wheelchair users need a helper to push the chair and assist with transfers and personal care. They are designed for use on land only, though they can be pushed through no more than 15 centimetres (6 inches) of water. They can be borrowed for up to 2 hours per visit. They are available during beach lifeguard hours. To borrow a beach wheelchair, reserve a chair up to 24 hours in advance by calling (416) 392-7688.

A second chair is available on a first-come, first-serve basis at Donald D. Summerville Outdoor Pool, 1675 Lake Shore Blvd. East (foot of Woodbine Ave.) – vehicle access is via Queen St. East / Kippendavie Ave. / Kew Beach Ave. Dates and times available in 2008:

June 14 to 25: weekends, 11.30 a.m. to 6.30 p.m.; Monday to Friday, 4.00 p.m. to 6.30 p.m.

June 26 to August 31: every day, 11.30 a.m. to 6.30 p.m.

Exchange your mobility aid for a beach chair at the Donald Summerville Pool reception area (accessible washrooms available). Remember to bring a buddy to push the chair. Be sun safe and be prepared to have fun on the beach!

## 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, 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.

### Diner's Club is Taking a Break for the Summer

There will be no Diner's Club event for the months of July and August. All Diner's Club activities will resume in September. We have found that in the past, not many people attend during these two months due to summer vacations. We are currently looking for hosts beginning in September. We have had a few volunteers call already. That's great!

Enjoy the Summer! If you have any questions about this, please call CILT at (416) 599-2458, extension 27 or by TTY at (416) 599-5077.

### Toonie Movie Night

We have been receiving many calls about the Toonie Movie Night, from people wondering if it's ever going to happen. The concept first originated in the Winter. A movie night was scheduled on three different occasions, and each time we had to cancel due to weather conditions. Thus, we decided that it was best to wait until the Spring. However, once Spring arrived, CILT has been very busy preparing and participating in many different events, projects, community partnerships, etc.

It is our hope that we can re-visit the idea of Toonie Movie Night in the Fall. In order to make it fair, and give different people the opportunity to attend a movie night, we will be holding the events on different days of the week, at different times. You will be notified by mail as to when the events will be held. If you are unable to come to one event, hopefully you will be able to attend the next.

### Joint Annual Disability Community BBQ

ERDCO, CILT, C-SASIL & Wholenet Technology cordially invite you to their first Joint Annual Disability Community BBQ Saturday August 9, 2008 12 noon - 5 pm High Park - Areas 4 & 5 Toronto Volunteer Escorts available at Main Entrance for those needing assistance getting to the Picnic.

Water, Vegetarian and Halal Food provided. Attendant and Child Care available. Other accommodations provided upon request. RSVP to 416-657-2211 or Email to erdco\_ca@yahoo.ca.