

CLT's Parenting with a Disability Bulletin

Volume 7 Issue 3
September 2004

PDN ACTIVITIES

PDN Annual Picnic

Many thanks to everyone who attended the 2004 Annual Picnic on Sunday August 9th in High Park! Although our group was small this year, that certainly didn't stop us from having fun! The weather was beautiful and we enjoyed relaxing and dining on a tasty pot luck lunch, catching up with old friends and getting to know new ones.

The children had a wonderful time playing and exploring the park with our favourite ECE worker, Helina. In fact, they were having so much fun looking for chipmunks, eating ice cream and chasing squirrels that we had to send out a search party to bring them back for lunch!

If you have ideas or suggestions for next year's picnic, I'd love to hear from you. E-mail Kimberly at pdn@cilt.ca or call 416-599-2458 ext. 35.

Upcoming Workshop for PDN & Prime Timer members!

The Parenting with a Disability Network and the Prime Timers in partnership with Education Wife Assault Present...

Taking Care of Ourselves: A Workshop For Women with Disabilities

This workshop will focus on:

- What is a healthy relationship?
- What is an unhealthy relationship?
- Setting boundaries and taking charge

When: Saturday November 27, 2004

Time: 11:00am - 4:00pm

Location: Centre for Independent Living in Toronto (CLIT)

205 Richmond Street West, Suite 605

To register for this event, please call (416) 599-2458, and ask to speak to Kimberly or Nancy or by TTY at (416) 599-5077 by "no later than" November 19, 2004.

Pizza and refreshments will be served. Attendant services will be provided. Other accommodations may be available upon request.

A Toronto Community Service Grant, United Way of Greater Toronto and Human Services Canada support CILT's programs.

The Government of Ontario, through the Ontario Women's Directorate, provides EWA's funding for this workshop.

CILT NEWS

Consumer Attendant Roster now online!

CILT and the Project Information Centre (PIC) officially launched the online edition of the Consumer Attendant Roster (CAR) on September 23rd at CILT's 20th Annual General Meeting.

CAR Online is a free, interactive and participant-driven Web-based system designed to build employment relationships between consumers and attendants.

Consumers can post employment opportunities for attendants or browse the database of attendants seeking employment. Attendants can post their resumes on a database and search employment opportunities posted by consumers.

The launch of CAR is the latest development following the recent implementation of the online Greenbook (Ontario Directory of Attendant Service Providers).

For access to CAR Online visit the Attendant Services section of CILT's website at www.cilt.ca/PIC/PIC%20-%20home.htm and click on the heading 'CAR Online' located near the top left hand side of the screen.

If you have any questions about CAR Online or would like more information, please contact Rolita Siu, PIC Coordinator at 416-599-2458 ext. 34 or by TTY at 416-599-5077.

PARENT'S CORNER

But I Didn't Help You Up

By Ora Prilleltensky, former PDN member

It was a bitterly cold winter morning in Winnipeg, the sort of morning you want to stay in a nice cosy bed. Of all days, my husband had an early morning meeting at work and could not take three-and-a-half year old Matan to pre-school. I would have to take him on my way to work. There was only one child to be dropped off and the pre-school was immediately next to our home. However, this seemingly simple task was not easy for me as a disabled mother. There was no parking right next to the building so I decided to walk Matan to pre-school and then come back for my car.

Matan was somewhat fussy that morning; young children have a special talent for taking their time when they sense parental pressure to hurry. We left later

than we should have, I walked faster than I should have and promptly found myself on a cold, snow-covered ground. For a moment, I felt a mixture of irritation and concern. I was irritated with my husband who had to leave early, and with my young son who took his time. Befittingly, my knee-jerk reaction was: "We should have left earlier." However, Matan's question of "Is it my fault mommy?" quickly dissipated my irritation. I assured him that he is in no way responsible and that we will find a solution. I was still on the ground, however, unable to get up unassisted. Concern took over. It was -25 and there was no one in sight. Several cars past by; however, I doubted that they could see us behind the colossal snow banks that separated the sidewalk from the road. Matan extended his little arm: "I'll help you get up, mommy." I explained as best I could under the circumstances, that he is not strong enough to lift me up; only an adult can do that. I felt the chilling wind and noticed that Matan's face was getting red from the cold. Doing my best to stay calm, I told him to walk to the building and ask someone to come and help me. He took several steps forward and then backtracked. "But the door is too heavy for me, I won't be able to get it open." He was on the verge of tears; I did my best to reassure him as I considered my next step.

Another few cars passed by and the two of us waived at them frantically. I breathed a big sigh of relief when I noticed a car slowing down. I was further relieved when I saw a woman getting out; I always feel more comfortable getting this type of assistance from women. I still remember the petite and cheerful teacher who lifted me to my feet. I was impressed that a woman so small could be so powerful. We thanked her and ever so carefully, walked to the school. We came in, got Matan out of his boots and snowsuit and into the class. His teacher was very sympathetic and helped me comfort my clearly distressed child.

Along with my concern for Matan, I started to think about the meeting at work that I would undoubtedly be late for. I was a clinician in the school system and on that morning, arranged to meet with a parent and with the school. The mother was highly reluctant to come to the school. It took some convincing on my part to get her to agree to the meeting. I had assured her that I would be there. I phoned the school to inform them that I would be late and slowly, carefully, walked to my car. Luckily, I had an extra set of car keys in my wallet, as my key holder was buried somewhere under a pile of snow. When I arrived at work, I was relieved to hear that the mother called to say that she would be late. After phoning the pre-school to hear how Matan is doing, I sat down in the staff room for a cup of coffee. Finally, I had a few moments to think about the impact that this experience had on me. I could not deny that it had left me shaken.

Safely at home at the end of the day, Matan and I told dad what had happened. The distress no longer there, Matan was nonetheless bothered by the incident. "But I didn't help you up," he kept repeating. I sat him on my lap and explained that he did the best he could. Following my instructions as well as he did was the best help he could have provided. A little later, Matan came up to me with some of his little toy cars. He wanted to play what had happened. "One car goes by, and doesn't stop. Another car goes by and doesn't stop. Another car goes by and

stops." He demonstrated with his cars as he spoke. Going along with his game, I said: "This must be the nice lady who came to help us." Matan raised his head from his cars and looked up at me with his big brown eyes. "No mommy, this is me when I'm big. I get out of the car and help you up."

This submission first appeared in:

Prilleltensky, O. (2004). Motherhood and disability: Children and choices. New York: Palgrave/Macmillan.

Update: Matan is currently 17 years old and has had multiple opportunities to fulfill his wish and help mommy up!

Getting around in TO with an SCI

By Suzanne, CILT Volunteer, Toronto

I have Arterial Vascular Malformation (AVM). For most, this usually occurs in the brain but for me it's in my spinal cord. My disability causes me to have problems with balance, strength, stamina, coordination and dexterity.

As my condition progressed, it became really difficult getting around the city with my infant and toddler so I thought it was time to look into Wheeltrans services. I had heard that it was near impossible to be eligible for service unless one used a wheelchair or scooter, and since I didn't use either, I decided to rent a scooter.

Having a scooter was both fun and challenging as I negotiated getting the three of us around. I zoomed up Yonge St. with both of my children sitting on my knees. I used my left arm to hold my 9-month-old infant on one knee. My 2-year-old toddler sat on my other knee and I used my weaker right arm to operate the scooter.

This was an incredible experience for me. Everyone who saw me stopped in their tracks, mouths gaping open. You could think that they were disapproving. However, I chose to see it a different way. I felt that people were impressed and this was empowering for me.

I love to challenge peoples' assumptions. I felt that I was doing just that by taking my young children out with me on the scooter.

As the novelty of the scooter wore off and my toddler became tired of sitting I would let her walk beside us. If she veered away I'd stop motoring and say, "stay with mommy." It was important that I be very clear and direct about what I expected and wanted her to do. I would usually say things like "here we go to the elevator" so that she knew where we were going and which way to walk. If she was not where I wanted her to be I'd simply stop and wait while she circled around me. When she was back safely on my right side, we'd set off again. She learned quickly.

My Wheeltrans appointment went well and I was later accepted. The woman who interviewed me observed my gait and watched while I dealt with the children. It was obvious to her that I needed Wheeltrans services.

When I used Wheeltrans the driver never knew what to do with the car seats. I could not carry my baby and a car seat. I'd have to ask strangers to carry the car seat from the bus into the doctor's office. Everyone eagerly helped since I arrived by Wheeltrans.

Another difficulty for me was securing the belt straps of the car seat. I didn't have strength in my fingers to lock in the belt nor could I push the button to release it. I had to get the driver to do this for me.

In the past I used an infant sling with my newborn. When she became too heavy for the sling I used a front carrier. Once she reached 12 lbs, I found the front carrier too heavy so I used a backpack carrier. I was able to use this until she reached 9 months. When the backpack carrier became too heavy, I used a wagon and pulled her behind me.

Picking up the baby was another challenge for me but I developed a strategy: I would lay her on the floor and, using my strong arm, pick her up by her overall straps. This worked very well. I would ask my toddler to pick up the baby's coat, which I would purposely leave on the floor for easy retrieval with her help.

I would be forceful with the children when necessary in ways that others might see as abusive; they weren't, they were just different. For example, because I was not fast enough with my hands, I would use my legs instead to stop my toddler. I did this in a way that would not injure or hurt her.

When not using a scooter, I found a MacClarens double stroller easiest to use. It was lightweight and easy to push and maneuver with one hand. The only difficulty I had was folding it and reclining the seat.

I must admit that I am unconventional. I would ask strangers to carry my children for me and to help do up snaps and buttons when needed.

All parents need help and parents with disabilities need extra help - some more than others. Be confident and know that there are different ages and stages. Children constantly change and as parents, disabled or not, we adjust to meet their needs. Little people are very adaptable too!

Teaching Disability 101 to your child

The following summary prepared by Don Barrie and Mary Ocampo is based on the chapter entitled "Discussing disability with your child," taken from The Parenting Book for Persons with a Disability: From planning your family to raising adolescents (1999).

This summary originally appeared in Volume 4, Issue 6 of the Parenting with a Disability Bulletin.

A person whose mother had a physical disability once said that when she was really young, she thought everyone's mother used a wheelchair. And when life expanded to include the outside world, she did indeed start to realize otherwise - not without her confusion, fears and anger.

Maybe it will come as an innocent question posed about why you can't walk or about why you use the services of an attendant. Or maybe it will come out in a tantrum or a sudden avoidance of you in public places. However it comes, there will be a time when parents with disabilities have to address their children's concerns about those disabilities.

How do you do this? Well, the contributors of *The Parenting Book* offer suggested approaches in talking about disability with your child.

One of the things that the parent needs to consider is the type of disability he/she is living with. Dr. Arlette Lefebvre, a child psychologist at the Hospital for Sick Children, points out that the issues that one needs to deal with in helping a child understand a parent's disability are different depending on the type of disability involved. If the parent has always been disabled, for instance, then there is no risk of losing the parent to the disability. If the parent becomes disabled later in life, but the disability is a stable condition, changing family roles may become an issue. The parent who has a fluctuating illness (e.g. lupus) or who has a genetic, slowly progressing disability, or who has an illness involving personality changes (e.g. Huntington's disease, brain tumors or cancer) are harder to deal with as a family, because the disability is invisible and unpredictable, and its outcome cannot be taken for granted. Understanding how the type of disability and the issues that may come up for your children related to it will help you understand their needs.

Another thing to consider is that, as Dr. Lefebvre points out, the child's cognitive development, personality, and past experience with chronic illness may influence how to approach disability to a child. Moreover, another psychiatrist suggests that internal and external resources within the family may also determine how well a child copes with a parent's disability.

While all of these factors may vary, the child will most likely have questions to ask related to the subject of disability, getting more sophisticated as the child gets older (e.g. "Can the disability be inherited?").

Kathleen McCue discusses in her book *How to Help Children Through a Parent's Serious Illness* the three common concerns that children may have. They are:

1. Feelings of guilt for a situation outside of their control (e.g. a parent becoming gravely ill)
2. The fear of "catching" a serious illness like cancer
3. Questions like "Who'll take care of their needs - who will do the 'Mommy things' or the 'Daddy things' now?"

McCue recommends handling these concerns head-on. She recommends giving brief answers to the first two issues, and advises giving as many details as possible on the third.

McCue also has come up with some general guidelines to discussing disability with your child at various development stages:

All Children, All Ages

Tell them these three things:

- Mom or Dad is seriously ill (or has a disability).
- The name of the disease (or disability).
- Your best understanding of what may happen (or how this affects your abilities and activities).

Preschool Age

Explain the disability on the child's level:

- Use dolls or puppets to help.
- Don't go past the child's attention span.
- Don't go beyond the child's ability to understand.

School Age

Tell them three things, and keep telling them:

- Nothing they did caused the disease (or disability).
- They can't catch (it) from you.
- Who'll take care of their needs (if the disability is a progressive or fluctuating one requiring the child to adjust to changing roles within the family).

Teen Age

Give lots of detailed information and answer every question fully. Make sure there is someone outside the immediate family with whom they can talk on a continuing basis. Be prepared for anything.

"The way in which a child views his or her parent(s) disability(ies) can change over time," says Susan Forster, a parent with a disability. "Discussing this issue will likely become a recurring theme in our lives."

Issues surrounding a parent's disability often surface during the mid-school and early teen stages. The early teen period may be less stressful, especially if the parent's condition has existed for quite some time and the child has adjusted to it. Other causes of trouble may arise if conditions have changed in the parent or in the family environment (e.g. a new job, town or home).

Talking to your children about disability involves a great deal of thought and consideration to the factors that influence your children's needs, such as the nature of your disability, their level of cognitive development/age group and the type of supports that they have. But the discussions should never be avoided. The late Karen Blackford advocated for good communication about disability. "If a parent's disability (is) kept secret or not talked about at home, then the child (is) left to feel isolated and along with those fears. It is through caring and communication that children get to know what a disability is."

Debbie Howe from King City was quoted in *The Parenting Book* as saying, "My children have a greater awareness than their peer group about people with disabilities. They realize that just because someone has a cane, wheelchair, bent back, etc. that they are just as important as everyone else..." What better a lesson to learn from your parent?

COMMUNITY

Beat the flu - get the flu shot!

It's that time of year again.

Free flu shots are available from the City of Toronto, from October 28 to November 30, 2004 and January 10 to January 13, 2005.

Toronto Public Health flu vaccination clinics are open to individuals who work, live or attend school in Ontario.

Vaccination clinics are located throughout the City. No appointment is required.

For information on flu clinic locations visit www.city.toronto.on.ca/health/flu.htm or call 416-338-7600 / 1-866-358-6968.

GET INVOLVED

Ombudsman Ontario Information Session!

The Tobias House Resource Centre invites people with physical disabilities to an information session with Ombudsman Ontario - working to ensure fair and accountable provincial government services.

- Are you receiving Ontario government services such as ODSP, ADP, student loans, OHIP, CCAC?
- When dealing with an Ontario government service, do you feel:
You have been treated in a way that is unfair, mistaken, unreasonable?
 - That nobody returns your calls
 - That it seems to take forever to get results

Don't give up. Maybe there is something you can do. After all you are entitled to a fair, timely delivery of service.

Come find out how Ombudsman Ontario may be able to help you.

Wednesday November 10, 2004

2:00pm to 3:15pm

Tobias House, The Recreation Room

695 Coxwell Ave., 6th Floor, Buzzer 104 (at Coxwell and Danforth)

Due to limited space, please RSVP Constantine at 416-690-8804 by Wednesday November 5th.

Coffee, tea and cookies will be served. Attendant services will be available.

Free forum on Innovating Research, Strengthening Communities

Community-based staff, community leaders and funders are invited to a free forum called "Innovating Research, Strengthening Communities" that is part of a community-based research project on the health status of ethno-racial groups in Toronto.

In this forum, you will have an opportunity to learn more about the process of community-based research and provide feedback on research ideas.

"Innovating Research, Strengthening Communities" will take place on **Thursday November 18, from 1-8:30 PM, at OISE** (Ontario Institute for Studies in Education of the University of Toronto), **252 Bloor Street West** (near St. George St.).

Free Refreshments and Vegetarian Friendly Dinner will be served.

Childcare, TTC tokens, translation services, and other supports needed will be provided upon advance request, before November 4th.

Access Alliance Multicultural Community Health Centre has obtained funding from the Canadian Institutes of Health Research to lead the project in partnership with other community organizations, community members, academics and institutions.

For more information, or to register, please contact Mary Roufail at Access Alliance, at 416-324-0927 or mroutail@accessalliancemhc.on.ca.

This forum is funded by the Canadian Institutes of Health Research.

Adult Inter-Active For Adults with Disabilities What is the Adult Inter-Active?

The **ADULT INER-ACTIVE** (formerly known as the "Social Adult Drop-in") is a series of focused social gatherings for adults with disabilities, offering a great opportunity to meet people, learn skills, have fun and get caught up with what's happening in the community.

ADULT INTER-ACTIVE events take place on a bi-monthly basis at various wheelchair accessible locations around central Toronto. Attendant services and refreshments are provided at each event.

The Adult Inter-Active is a collaborative project among the following community agencies:

- Anne Johnston Health Station
- Birchmount Bluffs Community Centre
- Centre for Independent Living in Toronto(CILT)

- Ontario March of Dimes
- Spina Bifida & Hydrocephalus Association
- Tobias House Resource Centre

Who Can Participate in the Adult Inter-Active?

Adults with disabilities who are looking to meet new people, and would like to become more socially active and involved in the community.

There is a \$2.00 fee that everyone is asked to contribute to each event to cover the cost of refreshments. The fee may be waived for those who are not in a position to pay.

If you are interested in joining the Adult Inter-Active and would like to receive regular mailings, please contact Nancy, CILT's Peer Support Coordinator at 416-599-2458 ext. 27 or by TTY at 416-599-5077.

UPCOMING EVENTS

Broken Speech: A Play with Words

"Broken Speech: A Play with Words," is an original play about communicating when you can't speak. It is written by Tony Diamanti, David Lam and Vivian Luong, and directed by David Lam.

A performance of the play will take place **Thursday, November 4, at 7 PM, in Room 140 of the Rehabilitation Sciences Building**, 500 University Avenue.

Tickets are available in Room 1066 of the Rehab Sciences Building, or contact **416-978-6890** or speakingdifferently@fastmail.fm.

Tickets cost \$8 in advance (\$10 at the door), students \$5 in advance (\$7 at the door). Tickets include a one-year membership in Speaking Differently Art Show (free) featuring the works of persons with severe and physical disabilities in the lobby from 6-7 PM.

A Q&A session with the actors and crew will follow after the play.

Note: Contains some strong language and mature themes.

"Broken Speech" is brought to the stage by Speaking Differently. Sponsored by the Trillium Foundation of Ontario and the University of Toronto Rehabilitation Sciences Sector.

Women's Connection for Women with Physical Disabilities

The "Women's Connection for Women with Physical Disabilities" is a workshop facilitated by Fran Odette, a well-known author on issues concerning women with disabilities. At this workshop, she will talk about body image, believing in you, sexuality and many other issues.

"Women's Connection" will take place **Saturday, November 13 from 1-4 PM, at the Party Room of Surveyor's Point, 1st Floor, 111 Agnes Street, Mississauga** (located 1 block NW of the Hurontario and Dundas intersection)- **Buzzer #219**. Attendant services will be available as well as refreshments.

For free registration, call France Tolhurst at **905-755-9157** or email france.tolhurst@sympatico.ca. Your registration will be confirmed by phone or e-mail.

THE CLASSIFIEDS

Epiphany Design

Epiphany Design's mission is to create innovative ways of giving people freedom and self-reliance.

Epiphany Design offers attractive, specialized clothing designed for people with limited range of motion and/or muscle control. Epiphany Design's products give people with mobility disabilities solutions to the day-to-day challenges of life and leisure. They are functional and effective, bringing new options to people's lives, colourfully and stylishly.

For more information about Epiphany Design's products, visit www.epiphanydesign.ca or contact Joe Ross, proprietor at 416-410-2243 or toll-free at 1-888-410-2243.

WEBSITES

PARENTS WITH DISABILITIES ONLINE

www.disabledparents.net

A site full of resources, information and offers support through their Parent Empowerment Network.

PARAMOM

www.Paramom.com

A site created and maintained by a mother with a disability.

PARENTING WITH A DISABILITY BULLETIN is a publication of the *Centre for Independent Living in Toronto (CILT) Inc.*

To become a member of *the Parenting with a Disability Network (PDN)* or to submit an article to the PARENTING BULLETIN, contact *CILT* at:

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TTY:416-599-5077

E-mail: pdn@cilt.ca

Website: www.cilt.ca

The PARENTING BULLETIN is also available on audiotape or in Braille.

Articles on products, agencies or services are for information only and are not meant as endorsements.

The opinions expressed in this newsletter are those of the contributors and may not reflect the views of *CILT*.

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