

CILT's Parenting with a Disability Bulletin

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PDN UPDATE

Mid Winter Gather 2009 By Carling Barry

It was a cold winter's day in late February. The date was February 21st , to be exact. It was our annual Mid Winter Gathering which happens every year around this time, bringing together two distinct groups; the Prime Timers and the Parenting with a Disability Network.

This was my first Mid Winter Gathering and hopefully not my last. We had a variety of food, much of it nutritious, including cheese, crackers, fruits and vegetables. And on the 'not so healthy' side, we had our annual cake that read 'Mid Winter Gathering 2009'.

It gave us all a chance to catch up, and see how everyone was doing in this horribly long and cold winter of unpredictable weather. Even though it was cold, many were still able to make it out to the event; we had each other surrounded by plenty of laughter and good company. We had our annual raffles, with lots of fantastic prizes including a set of sunglasses and watch, candle and oils from the body shop, games and puzzles.

The most fun part of the event was when we all sat around the table and played BINGO, where some yelled out 'bingo' without even being close to winning! We definitely had a bunch of competitive bingo players in the room that day!

This year's Mid Winter Gathering will definitely be remembered, for me, as a great time and I'm already looking forward to next year's event.

Stay warm, everybody! Spring will be here soon and I hope to see everyone out more when the weather is better!

Book Review

by Susan DeLaurier

Disability, Mothers, and Organization: Accidental Activists By Melanie Panitch

This book looks at mothers of children with disabilities and how they became activists. These women often struggled at home and in their communities against the demoralizing effects of exclusion. Gradually they recognized the importance of becoming advocates of change beyond their own families and helped toward building an organization, the Canadian Association for Community Living (CACL), that would take their concerns to a more public level.

Ms. Panitch's book tells how very ordinary women, often working as volunteers, became political leaders helping to change professional practices and public laws that have impacted on their disabled children. The author combines insights and methods from women's and disability studies to enhance our understanding of the history of both disciplines.

This book illustrates how three women challenged traditional expectations for being good mothers and became national leaders promoting de-institutionalization and human rights. These women are from diverse areas of Canada and bring into focus different local and provincial issues and perspectives. The mothers' accounts of their own experiences show that their grievances were internalized as personal failings. This was due, in part, to conventional literature which had put the onus on mothers for producing the disabilities in the first place or for failing to have a healthy child. These women received information attributing blame to pre-natal behavior, emotional problems, biological (waiting too long to have children) and other factors. All of these categories of blame have been used by social agencies to justify a less compelling right to aid and services for many mothers of children with disabilities. Mothers strenuously advocating for their children were seen as trouble-makers, hysterical and "bad" mothers. Cultural stereotypes put pressure on mothers to conform to professionals' ideas of who they 'should' be. For example, honest expressions of fatigue were interpreted in a negative way.

Panitch explains in great detail how CACL came into being in the 1960's and demonstrates how at the beginning, most of the women working at this organization were either volunteers or had very marginal roles and were significantly under represented at the board level. At that particular time, it was primarily men who ran organizations. It was only gradually when doors opened to them that they began to take on leadership roles.

The campaign to close institutions originated with the first wave of post-war mothers who resented the alternative of either giving up their child to 24-hour institutional care or keeping them at home with no community support. Included is a detailed discussion of some of the hostility between those who advocated for improving the institutions and those who wanted them shutdown.

The chapter discussing human rights documents how the Federal Human Rights Act became law in 1978 but without an amendment to include people with disabilities. Due to these activist mothers, in 1983 the Human Rights Act was fully amended to include people with disabilities. Panitch gives an extensive description of the process.

This erudite and enjoyable narrative demonstrates the necessary disciplines for the study of disability. Disability is often viewed as a narrow field of social policy, programs and services that leads to a set of parallel social arrangements that have isolated disabled people in segregated systems. By looking at the mothers of children with disabilities and their insights and researching their activism, it is hoped that disability will be viewed as a broad-based inquiry commanding social and political analysis.

This wonderful book would be a great addition to a library dealing with disability issues or anyone working with or studying how non-professional people, specifically mothers, become activists in local and national organizations. It can be purchased from Amazon.ca

The PDN is currently seeking submissions for the Parenting with a Disability Bulletin.

Submissions can include personal stories, articles, commentary on current issues, reports on disability events/issues/studies/books, parenting tips and strategies, etc. Anything related to parenting with a disability would be welcome!

If you have information or a story to share, send it to us at peers@cilt.ca, fax: 416-599-3555; or call 416-599-2458 extension 227.

NEWS FROM THE DISABILITY COMMUNITY

Doc Hotline may be the right medicine © Torstar News Service; January 26, 2009

Health Help is on the way for 500,000 Ontario residents without a family physician, who have generally been forced to go to walk-in clinics or emergency rooms when they need medical attention. Starting next month, a new hotline will help match people with a doctor in their area willing to take on new patients, the Toronto Star has learned.

The government will institute a special 1-800 number, where a Telehealth Ontario staffer will take down a health history and pass it on to a nurse who will help find a family doctor.

“This is a made-in-Ontario solution,” Health Minister David Caplan told the Star of the program to be launched in February. “We will be the first jurisdiction, I am aware of, that is doing this.”

Still, critics point out the program, called Health Care Connect, will not deal with the core problem: A shortage of doctors.

Dr. Douglas Mark, who practices in Scarborough, also wants to know where the doctors will come from to care for 500,000 people.

The Accessible Channel

The Accessible Channel, a national, English Language described and closed captioned basic HD digital TV specialty service.

On Tuesday, 24 July 2007 the Canadian Radio-television and Telecommunications Commission (CRTC) approved and supported an application from The National Broadcast Reading Service Inc. (NBRS) for a license to set up a unique English-language TV service — The Accessible Channel (TACTv). By regulation, TACTv will be part of the basic digital package of TV programming offered by all distribution companies — cable systems and satellite direct-to-home services.

The channel will acquire the most popular TV programs from conventional and specialty TV services and foreign-rights holders. All TACTv programs will be described and captioned so that at any time of the day they can be enjoyed by a viewer with low or no sight or low or no hearing - a world first. And viewers can access TACTv on the regular family TV set, allowing viewers with a disability to enjoy TACTv broadcasts in the company of their family, their friends, their neighbours and other acquaintances — a huge overall market.

NBRS was set up almost two decades ago. Its first licensed service was VoicePrint — a national audio program service. Just prior to going on air in late 1990, NBRS was granted charitable status by Revenue Canada.

In the years since, NBRS through a second division, AudioVision Canada, pioneered video description in Canada. Its unique approach to describing cinema-tographic works makes it suitable for open broadcast — and that’s why with the support of broadcasters across Canada, sighted and non-sighted viewers can watch the programming together without any loss of enjoyment by either.

You may contact The Accessible Channel at 1-866-509-4545 or visit their website at tactv.ca. The Accessible Channel Inc. is controlled by The National Broadcast Reading Service Inc.

Mona Winberg Dies at Age 76

Mona Winberg, long-time disability activist and known for her column on disability issues for the Toronto Sun, passed away on January 19th from pneumonia. Winberg was 76 years old.

Her writing career began when she was 16 years old when she started writing for the newsletter of the Ontario Federation for Cerebral Palsy, and in 1972, she was the first disabled person to become president of the organization. Winberg was known for her lobbying efforts with Wheel-trans and her public speaking engagements throughout Canada. She started writing for the Toronto Sun in 1986, in response to the fact that the paper never seemed to address disability issues. She wrote for the Sun for ten years.

Winberg was a recipient of many awards over the years, including the Clancy and Fred Gardiner awards, her induction to the Terry Fox Hall of Fame, and in 2001 Mona was named to the Order of Canada. She will be missed!

UPCOMING EVENTS

The Rights and Benefits of ODSP Recipients

Want to expand skills on advocating for yourselves or your clients? The ODSP Action Coalition presents a workshop on the Rights and Benefits of ODSP Recipients.

This workshop will help you to:

- Expand your knowledge of ODSP rights and entitlements
- Practice useful communication tools while participating in scenarios and interactive games
- Become better advocates in relations with ODSP!

The workshop is open to ODSP members, applicants, service providers and advocates. Tuesday, March 17th from 1:30 to 4pm at Birchmount Community Centre, 93 Birchmount Rd. (at Kingston Rd.) Free. Attendant services and free light refreshments will be provided. Please advise of any special needs related to attendant care. RSVP to David or Judith by Monday March 16th at 416-396-7606.

Poverty Reduction Working Group for People with Disabilities

Do you have recent lived experiences living with poverty? Are you a person with a disability? Do you want to raise awareness about the poverty issues that exist for Ontarians with disabilities?

ARCH (Advocacy Resource Centre for the Handicapped) is facilitating a working group to raise awareness about the impact that poverty has on people with disabilities. The group will work together to develop initiatives and activities to push the Ontario government to address the needs of people with disabilities in the government's poverty reduction plan.

The event takes place on Monday March 9, 2009 from 1:30 to 3:30 pm at 425 Bloor Street East (SE corner of Bloor and Sherbourne), Suite 110. Light refreshments will be served. This event is accessible and scent-free. Accessibility services including attendant care, note-taking, large print and ASL Interpretation will be provided upon request.

RSVP to Jenny Clement at 416-482-8255, extension 223.

Are You Prepared? Emergency Preparedness Workshop

Bellwoods Centres for Community Living Inc. is hosting a workshop on Emergency Preparedness for adults (16 years and older) with a physical disability.

Come and learn the latest in what constitutes an emergency, what to expect and how to put together your "72 hour kit".

The workshop is being held on Wednesday March 25, 2009, 2-4pm at Bellwoods Park House Lounge, 300 Shaw Street (Dundas & Ossington). Workshops are free of charge. Registration is required, as space is limited. Call Yoli at (416) 530-1448 to register. Attendant services are available upon request.

Bellwoods Centres is a pioneer in providing community-based, client-directed support services and education for persons with physical disabilities.

People in Motion 2009

People in Motion is for people with disabilities, seniors with special needs, family members and friends, therapists, home care providers, facility managers, special educators and insurance representatives.

Everyone is welcome to this fun and enlightening event which features mobility aids, adapted vehicles, rehabilitation, home healthcare products, travel and leisure activities, corporate and government services, employment opportunities, computer aids, disability publications, associations and more.

See and compare everything under one roof at one time. More than 120 exhibits! If you have attended before, see it again! There are always new exhibitors with exciting new products and it is important to be aware of changes to existing technology.

**MARK THE DATES ON YOUR CALENDAR NOW AND
PLAN TO ATTEND PEOPLE IN MOTION 2009!!**

Friday June 5, 2009 10am to 5pm

Saturday June 6, 2009 10am to 5pm

PARENTS CORNER

"Mommy, why do you walk with a cane?"

What you say in response to your child's questions or what you choose to tell them must be in line with their developmental stage in order to get the right message across. Also, it's best to give some thought to how you approach the subject. You will want to be up front and comfortable with what you are saying as you won't want them to grow up with a sense of shame about your disability.

Here is a general guide to discussing disability with your children adapted from How to Help Children Through a Parent's Serious Illness. This publication can be obtained by contacting the publisher. The reference for the book is: Kathleen McCue, M.A., C.C.L.S., How to Help Children Through a Parent's Serious Illness, New York: St. Martin's Press, 1994.

All ages - tell them:

- Mom has a disability
- The name of the disability
- Your best understanding of how your disability affects your abilities and activities.

Preschool age:

- explain the disability on their level
- Use dolls or puppets to help
- Don't go past their attention span
- Don't go beyond their ability to understand

School age - tell them:

- Nothing they did caused the disability
- They can't catch the disability from you
- Who will take care of their needs (if the disability is a progressive one)

Teenagers:

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

According to one mother, "When explaining disabilities to my children, I am open and honest and tell them what the disability is and what caused it. If I had told my children that I didn't carry the shopping, hang out the laundry, pick up heavy items, vacuum, etc., because I didn't want to, they would have grown up thinking that their mother was lazy and wanted them to do all of the work. Because they know the truth, they have an appreciation for my problem and do not feel indifferent towards me for it. I explained to them that perhaps their acceptance of disabilities may be a part of their career in the future."

Understanding Child Nutrition © Child Nutrition Basics

by Vincent Iannelli, M.D., "About Nutrition.com"

Proper nutrition in childhood can reinforce lifelong eating habits that contribute to your children's overall well-being and help them to grow up to their full potential and a healthy life.

Unfortunately, some parents over-think what to do about their child's eating habits, which give way to practices like forcing kids to clean their plates. And

some parents don't think about nutrition at all, letting their kids eat a lot of junk food and drink a lot of juice. So, it's important to find a balance.

In addition to contributing to the current childhood obesity epidemic, kids who don't have healthy diets as young children are likely to continue to make unhealthy choices as teens and adults.

Taking some time to understand the basics of child nutrition can help you avoid common mistakes, make healthy choices, learn about new things like probiotics, and teach your kids healthy eating habits.

Feeding Your Baby

You would think that you would have the easiest time when you are still feeding your baby, but you do have a lot of decisions to make this first year. Of course the big one is breastfeeding versus giving your baby formula.

There are still a lot of decisions to make later on though, including:

- when to start rice cereal
- baby food steps, including other types of baby cereal and baby foods, such as vegetables and fruits
- feeding homemade baby food versus store bought baby food
- when to give your baby water and juice
- starting finger foods such as Zwieback toast, Cheerios, and veggie puffs and then table foods
- switching to whole milk.

Understanding the Toddler Diet

Feeding a toddler can be frustrating. You may go from having an infant who eats a large variety of vegetables and fruits and three big meals a day, to a toddler who is a much more picky eater and eats much less. Surprisingly to many parents, that can be very normal — as long as their toddler is gaining weight and growing and developing normally, and isn't filling up on milk and juice. In fact, many toddlers simply eat one good meal each day, and then just pick at their other meals.

Your toddler's diet will likely be made up of about 16 to 24 ounces of milk (low fat milk once your child is 2 years old) and 4 to 6 ounces of juice, and be eating 2 snacks and 2 to 3 meals.

Even though your toddler may be a picky eater now or even go on binges where he will only want to eat a certain food, you should continue to offer a variety of

foods. This includes small amounts of fruits and vegetables, as he may eventually try them if he isn't pressured or forced into eating them.

Remember that this is a period in your child's development where he is not growing very fast and doesn't need a lot of calories. Also, most children do not eat a balanced diet each and every day, but over the course of a week or so, their diet will usually be well balanced.

Vitamins and Minerals

Parents often worry that their kids don't get enough vitamins, minerals and other nutrients from the foods they are eating. This often leads to their kids getting vitamins and other supplements. Although this can be okay, it is usually a much better practice to try and provide these nutrients to your kids through the foods they are eating such as high fiber foods, protein rich foods, iron rich foods, calcium rich foods, water with fluoride, whole foods, Vitamin C and foods high in potassium. Consult the Canada Food Guide to see which foods fall into each of these categories.

Fruits and Vegetables

Many parents have a very hard time getting their kids to eat few if any vegetables on a regular basis. Most experts advise that you can often get kids to eat more veggies if you start early by offering your older infant and toddler a large variety of vegetables, set a good example by eating vegetables yourself, offering a lot of choices, and mixing vegetables into a food that your child already likes.

Getting kids to eat fruits is often a little easier, but are your kids eating enough fruits each day? Do you know how many servings of fruits your kids should be eating each day? The food pyramid is a good place to learn. For example, a 3-year-old male who is fairly active should eat 1.5 cups of vegetables and 1.5 cups of fruits each day. If you consider that 1/2 of a large apple or one large banana is equal to a cup of fruit, then it shouldn't be too hard to get your kids to eat enough fruit each day.

Nutrition Facts

Food labels provide nutrition facts and information about the foods that your family eats. From the amount of calories, fiber, and total fat grams, to the food's ingredients, the food label is your key to the nutrition information in the foods you provide to your family.

Learning to read food labels can help you find healthier foods and help you find foods with the right amount of fats, carbohydrates, dietary fiber, vitamins and minerals, cholesterol, sodium and protein. Reading the ingredients list is also helpful in avoiding foods that your kids may be allergic to.

Healthy Diets

Proper child nutrition should usually include eating three meals a day and two nutritious snacks, limiting high-sugar and high-fat foods, eating fruits, vegetables, lean meats and low-fat dairy products, including 3 servings of milk, cheese or yogurt to meet your child's calcium needs. These healthy practices can also prevent many medical problems, including becoming overweight, developing weak bones, and developing diabetes. It will also help ensure that your child physically grows to his/her full potential.

The best nutrition advice to keep your child healthy includes encouraging him/her to:

- Eat a variety of foods
- Balance the food they eat with physical activity
- Choose a diet with plenty of grain products, vegetables and fruits
- Choose a diet low in fat, saturated fat and cholesterol
- Avoids foods with a lot of added sugar and foods high in salt
- Choose a diet that provides enough calcium and iron to meet their growing bodies' requirements
- Avoid a lot of fast food, caffeine, juices with added sugar and soda.

CILT NEWS

CILT's New Location

We have finally settled in to our new home at 365 Bloor Street East, Suite 902. It's a lovely place and everyone seems very happy. We are looking forward to showing all of you our new home very soon. We will be having a 'formal' open house in the early spring and we are hoping to see many of you at our new space.

Please note that aside from the address, most contact information has remained the same. However, staff telephone extensions now have a "2" in front of them. For example, if you're calling extension 27, you should now ask for extension 227. Feel free to contact us at any time. Stay tuned for details on our upcoming formal Open House some time this May.

Centre for Independent Living in Toronto
365 Bloor Street East, Suite 902
Toronto, Ontario M4W 3L4
(416) 599-2458;
TTY: (416) 599-5077
Fax: (416) 599-3555;
Email: cilt@cilt.ca
www.cilt.ca

Introducing Carling Barry: Peer Support Program Assistant

Hello everyone and Happy New Year! You may have heard about me in the newsletters or to RSVP to me for some of our events. I will now formally introduce myself.

My name is Carling Barry and I am the peer support program assistant. I work with Nancy on many things such as workshops, the volunteer program, newsletter, events and resources.

Before I got this job I was a volunteer with CILT, while taking three courses a semester at Ryerson University, in the Disability Studies Program and also volunteering at Rye Access and Access Centre.

I am in my third year of the Disability Studies Program and working here, so far, has given me the hands-on experience of what I am learning in class and in my textbooks. I feel very fortunate.

RyeACCESS is a Community Service Group of the Ryerson Students' Union that works to address the non-academic needs of students with disabilities. RyeACCESS offers resources, advocacy and support and develops educational campaigns to identify barriers on campus and push for the necessary awareness and change. RyeACCESS also provides student-centered services and supports to students with disabilities, according to the Ontario Human Rights Code, in order to facilitate academic success and access to the university.

As you can see from the activities just mentioned, I am a disability advocate and activist who fights to get equal rights, access and accommodations that are needed in this society that until recently, have not been on the agendas.

With a group of students at Ryerson, we put together a week of Disability Awareness on campus last year with a few events such as Barrier Labeling. The primary goal of the campaign was to create awareness about the physical barriers that students with disabilities face on campus.

We also had guest speakers come to discuss disability in many different ways. I put together an idea that if we want to change people's understanding and level of awareness of disability, we need to 'go big' - or 'go home'. So Rye Access and I 'went big', and we got the Honorable Lieutenant Governor, David C. Onley, to discuss disability.

The reason I thought that Onley would be the best for this job was because accessibility issues are important, and hearing from someone who's big in the media, with so much experience behind him, is vital to raising awareness. David Onley is in a position to talk more about accessibility-related subjects and help people with disabilities. He understands that we have voices as well.

Within my new position as Peer Support Program Assistant, I hope to continue to advocate for accessibility, help to break down barriers, and support independent living. I look forward to assisting Nancy in all that my job entails and I look forward to working with and meeting you all!

Nutrition and Healthy Living Workshop for People with Disabilities

- Want to get rid of those Holiday Left over pounds?
- Having trouble sticking to your New Year's resolutions?
- Want to get back into the healthy swing of things?

You can sign up for our interactive workshop providing information, strategies and resources from Eating Well with Canada's Food Guide.

The workshop takes place at our new location at 365 Bloor Street East, Suite 902 (Bloor & Sherbourne) on Wednesday March 25, 2009, 1:30pm to 4:00pm. Call 416-599-2458, extension 227 to register. Light and healthy refreshments will be served. Attendant services will be provided. Other accommodations may be provided upon request with sufficient notice.

Workshop Series for Women with Disabilities

CILT is offering a workshop series for women with disabilities this April. Topics include self esteem, healthy versus unhealthy relationships, how to become more assertive in our relationships with others, and coping with stress in our relationships.

All workshops take place at CILT's new location at 365 Bloor Street East (Bloor & Sherbourne), Suite 902.

The following is the scheduled workshop dates. All workshops take place from

1:00 pm to 4:00 pm on Thursday afternoons:

April 2, 2009: Self Esteem

April 9, 2009 Healthy vs. Unhealthy Relationships

April 23, 2009: Assertiveness

April 30, 2009: Coping with Stress

To register for the above workshops, call 416-599-2458, extension 227. Attendant services and light refreshments will be provided. Other accommodations provided upon request.

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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The PARENTING BULLETIN is also available in large print, on audiotape or by e-mail.

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