

CILT's Parenting with a Disability Bulletin

Volume 6 Issue 5
October 2003

PDN ACTIVITIES

HAPPY HOLIDAYS TO YOU AND YOUR FAMILY!

FROM CILT AND THE PDN

UPCOMING PDN EVENT

The PDN will host a social event in February. More details to follow. Watch for your flyer in the mail.

PDN Workshop Questionnaire 2003/04

Since the Nurturing Assistance Project began in 2000, the PDN has received an increasing number of calls for information on assistance with parenting activities and support. Many people were, and still are, under the impression that the PDN provides nurturing assistance or that we run a Nurturing Assistance Program. This is not the case. What the PDN provides in terms of nurturing assistance, is a guide that can be used by parents and prospective parents, service providers and even funders to set up this type of service.

When the project began, nurturing assistance (NA) was still a relatively new concept, although not a new need. Some parents were receiving this type of support but the numbers were still small. It was our hope that with the development of the model of NA that this type of support would not only be developed but also delivered through local service providers to parents who require assistance with child care tasks. It was also hoped that this need would be recognized by funders and all levels of government and that, ideally, a NA Program could be created.

Today not much has changed and these hopes have yet to be realized. Many parents are not getting the types of support and assistance they need. And families are struggling. Therefore, the PDN would like to develop a workshop or series of workshops in order to provide tools for parents and prospective parents as well as service providers to establish NA.

In an effort to determine the current needs of our membership, the PDN is asking you to complete the **Questionnaire** enclosed with this newsletter and return it in the self-addressed envelope provided. If you would prefer an electronic copy of this **Questionnaire**, please send your request by e-mail to pdn@cilt.ca. Thank you, in advance, for your cooperation and participation! Your input and feedback is extremely valuable in planning future workshops.

If you would like to receive information about nurturing assistance or would like to purchase a copy of the *Nurturing Assistance Guide*, please contact the PDN at (416) 599-2458, ext. 35; TTY: (416) 599-5077; Fax: (416) 599-3555.

Changes on CILT's Web site

Over the past several months there have been some changes to the CILT Web site.

The first major change was the addition of the new online version of the **Ontario Attendant Services Directory**, commonly referred to as the **Greenbook**.

Launched on Thursday September 18, 2003 at the CILT AGM, it is now available online in the Attendant Services section of our site at

www.cilt.ca/cilt_database_site/greenbook_system/green_book/intro.asp.

The second change was the relocation of the **Direct Funding** section. Direct Funding is now part of the Attendant Services section at

www.cilt.ca/Direct%20Funding/DF%20program.htm.

The third change was the addition of the new **Volunteers** section. This page was originally included in the Peer Support section but now has its own spot on the front page at www.cilt.ca.

Updates are added to our site regularly so visit often to find out what's new!

PDN PARENTING SEMINAR

By Kimberly McKennitt, PDN Coordinator

Many thanks to everyone who attended our Parenting Seminar on Positive Discipline held on Saturday September 27, 2003 at CILT.

The seminar was facilitated by Pasquale Fulginiti, Early Childhood and Parent Educator. Pasquale is a single parent with 3 children and the author of the book *Kidstuff: How Positive Discipline Works Throughout Children's Lives*.

The focus of the seminar was to help identify one's parenting style and to develop techniques and alternatives for positive discipline.

Here are some of the things that were discussed:

Consider your parenting style. A balance of structure and choice is the most effective way to foster a child's sense of responsibility, discipline, independence and self-esteem.

Give children choice that is age appropriate and within limits. Choice empowers children and helps them develop confidence, self-esteem and motivation.

CHOICES

- 2-5 years old: "Do you want A or B?"
- 5-8 years old: "Which of these fruits would you like to eat?"
- 8-12 years old: "What would you like to eat? Remember, it must be healthy."
- 12 years old & over: Take the hands off approach

Give children a voice and get them involved. By giving children an opportunity to voice their thoughts and feelings, you are promoting cooperation and empowerment.

Be specific and keep things simple. Give children information that is age appropriate. Tell them why you are asking them to do something or why something happened.

Focus on the behaviour and **not** the person. By separating the deed from the doer, children know how you feel about their actions and at the same time it reinforces your unconditional love for them.

Be consistent. Say it, do it, and mean it! All children need structure and they learn from experiencing the consequences of their actions.

Choose your battles!

Remember, everyone is unique. Do what is right for you and what works for you. For more information about Pasquale, his book and his seminars, e-mail kidstuffseminars@canada.com; call (905) 502-0066 or visit his website at www.kidstuffseminars.com.

Your suggestions are always welcome! If you have topic ideas for future parenting seminars, please contact the PDN Coordinator.

PARENT'S CORNER

Ready Or Not

By Pearl Jin, PDN member - Ontario

Being a parent is truly the most demanding, frustrating and yet most beautiful and rewarding project I have ever tried to do. At the risk of undermining my own hard work, I have to say that I often feel like an imposter.

I tire myself out attempting to answer "How are things going?" with a cheery reply. Sometimes I can give a truthfully happy answer but sometimes I wrack my brain grasping for anything seemingly normal to say. For example, at nine o'clock in the morning, how can I explain to anyone that I have been up since five o'clock attending to my child (fretful yelling and crying that I guess were remnants of bad dreams) and I already wish I could go back to sleep? But now I have to pay the bills, balance the chequebook (kind of), answer my phone messages, send birthday cards and presents, plan for lunch and dinner, get dressed and then take a deep breath and climb on my scooter to go pick up my son from Jr. Kindergarten. Little wonder that by noon I usually feel all burned out!

I am not heroic enough to wear my diagnosis of Chronic Progressive Multiple Sclerosis like a badge. However, my husband and I know we are truly blessed with a happy and healthy son. When we are not competing with a strong-minded little boy for *Power* or *Attention* or *Whatever Else*, we are amazed with this very intelligent and even helpful little person who reminds us what incredible things life brings; **Ready or Not here it comes!!**

Nurturing Assistance

The following is an excerpt from The Parenting Book for Persons with a Disability: From Planning your family to raising adolescents (1999), Chapter 3, pgs 47-48.

How do parents with disabilities apply for nurturing assistance?

When a parent with a disability applies for attendant services, nurturing assistance needs should be included in the application. When the consumer is accepted into a project, the service provider can make a one-time application to the Ministry of Health to cover nurturing assistance needs. Nurturing assistance funding is portable, i.e., if the parent with a disability moves, it's not necessary to reapply.

Nurturing assistance is available to individuals already receiving attendant services, or who are eligible to apply for attendant services. Both mothers and fathers with a disability are eligible for this service. If you are applying for

nurturing assistance, make sure you do so as early as possible. Make inquiries as soon as you know you are pregnant.

A key point to remember is that nurturing assistance needs have to be considered within the context of the consumer's total service needs. Nurturing assistance is one activity within a range of activities performed by an attendant. Service providers view the personal care needs of the parent with a disability as taking priority over the other needed services, and many service providers have limited experience with nurturing assistance. As well, some service providers may not have the resources to respond to the increased service needs of a new parent with a disability. Consumers must be prepared to explain and negotiate their needs with their service provider.

Keep in mind that there is no standard, easy process to follow when you are trying to arrange subsidized assistance. It is best to prepare your case ahead of time and present it in an assertive manner.

Are there any other similar resources available to parents with disabilities who do not qualify for attendant services?

There are no easily accessible, free services equivalent to nurturing assistance that are available to those who do not qualify for attendant services. One option for policy makers to consider in future would be for nurturing assistance to be funded separately from attendant services. In this way more parents with disabilities could benefit from this service.

People seeking nurturing assistance who do not easily fit into the eligibility requirements for attendant services may consider asking the health organization with which they are affiliated, a local politician at the municipal or provincial level, clergy, or other individuals/organizations to assist them to advocate for the services required.

There is a municipal *Homemaking and Nursing Services Program* for seniors and people with disabilities, which in some cases can provide limited child care services. This is a means-tested program, i.e., eligibility is determined by financial need. A person qualifies for assistance if he or she has income and assets below a specific level. If eligible, a person can receive help with light housekeeping, laundry and, possibly, child care. Clients are encouraged to be actively involved with child care, but this can be regarded as respite care if the person with a disability needs to take a rest. The average amount of service is only a few hours a month, but can be as much as a few times a week, depending on the client's needs. For more information on this Toronto service, contact the Intake Worker, Homemaking and Nursing Services Program, Homemaking Section, (416) 392-8545.

GET INVOLVED

Wanted: PDN members to share their experiences

Are you a parent with a disability with an infant or toddler and finding transportation a barrier? Are you currently using or have used Wheel-trans in the past with your child(ren)? A PDN member would like to hear from other members on the Network about their experiences using Wheel-trans with their infant. Contact Michele at (416) 368-3625.

Wanted: Pregnant women with disabilities

Are you pregnant? Moving On needs you!

CBC's Moving On, the award-winning national television show on disability issues, is looking for a woman in the early stages of pregnancy. If you are interested in being on camera several times throughout your pregnancy and after the baby comes, and talking about the joys, worries and issues you face, please contact us immediately!

Contact April Stevens at (416) 205-3360 or e-mail stevensa@toronto.cbc.ca.

Public Consultation on Strengthening the ODA for 2004

Ontario's Liberal Government announced December 3rd that it will commence a public consultation in the New Year on how to strengthen the Ontarians with Disabilities Act (ODA).

The Citizenship Minister, Dr. Marie Bountrogianni, and her Parliamentary Assistant, Dr. Kuldip Kular will conduct this consultation. No details are yet provided on how this consultation will be conducted. As we did when the previous Government was in power, we call for this consultation process to be open, accessible, and inclusive.

CILT and the ODA Committee encourage all consumers and allies to participate in this consultation process. Please feel free to contact the Citizenship Ministry directly by reaching Anne Boody, Minister Office, **416-325-6207**; or Tania Denesiuk, Communications Branch, **416-314-7386**.

The ODA Committee can be reached by e-mail at oda@odacommittee.net or visit their web site at www.odacommittee.net.

United Nations International Day of Disabled Persons

December 3, 2003, worldwide

This event aims to promote an understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities. The theme of this year's celebration is "A Voice of Our Own."

Find out more by visiting the official website at www.un.org/esa/socdev/enable/disid2003.htm.

UPCOMING EVENTS

See Me

The Building Bridges Project is holding a free weekly workshop for women with disabilities and differences. In the workshop, we explore relationships to our bodies and ourselves.

Using photographs and other art media we will:

- Tell our stories through images
- Remember moments of looking and being looked at
- Imagine new ways of seeing ourselves
-

You will be taking photographs using Polaroid cameras during workshop sessions. An artist will provide some training about using the cameras in the first session.

When: Four *ongoing* sessions,
Saturdays from 1:00pm to 4:30pm
January 24, 31 February 7, 14 2004

Where: 350 Victoria Street, Ryerson University

Facilitators: Esther Ignagni, Wendy Proch & Roseline Zarzecki
Attendant Services Available

No photography experience required

Participants will have a choice about the content of their pictures.

For information and registration, please call Hilde or Alessia at (416) 351-3702.

Building Bridges is a partnership project of AboutFace International and Regional Women's Health Centre (Sunnybrook and Women's College) by, for and with people of facial and physical differences.

Breast Health Workshop

CILT's Peer Support Coordinator is hosting a Breast Health Workshop in January. For more information, please contact Nancy at (416) 599-2458, ext 27.

Aging with a SCI

CPA and World Accessibility presents "Aging with a Spinal Cord Injury: Tales from the Trenches."

This is a Talkback Radio Broadcast© hosted by Roger B. Jones "The Ability Guy", with a special guest speaker each week.

The series on Aging with a SCI will air in 6 one-hour online broadcasts:

- * **Tues. Dec. 16, 2003 at 6 PM ET**
- * **Tues. Jan. 6, 2004, at 6 PM ET**
- * **Tues. Jan. 13, 2004, at 6 PM ET**
- * **Tues. Jan. 20, 2004, at 6 PM ET**
- * **Tues. Jan. 27, 2004, at 6 PM ET**
- * **Tues. Feb. 3, 2004, at 6 PM ET**

To register, e-mail scishow@worldaccessibility.com and tell CPA which shows you want to see. A CPA representative will respond with sign-in information.

The interactive nature of its Talkback Radio System is a great way for audience members to participate and provide live audio feedback. In order to listen to the show, all you need is a computer with an Internet connection and speakers or a headset. In order to interact verbally you will need a headset with a microphone. Space is limited so please register early!

MDAC hosts Healthy Living Symposium

Muscular Dystrophy Canada paired with Active Living Alliance for Canadians with a Disability is hosting "Healthy Living with a Disability: Conceptualization and Demonstration Symposium."

When: February 7 and 8, 2004

Where: Bank of Montreal Institute for Learning (Toronto)

Why: To educate and motivate people with a variety of disabilities to make healthy lifestyle choices.

Funded by: Health Canada

Physical activity, nutrition, and personal health practices will be discussed through workshops.

A variety of guest speakers will share their success stories to reiterate 'healthy living' is relevant to people with disabilities.

Limited space available

For reservation inquiries, please contact ASAP: **Leigh Vance, Healthy Living Project Coordinator, Muscular Dystrophy Association Canada (MDAC)**
2345 Yonge St, Suite 900
Toronto, ON M4P 2E5
Tel: (416) 488-0030 x155
E-mail: lvance@mdac.ca

WEBSITES

ABLEDATA

www.abledata.com/text2/parentin.htm

Contains parenting with a disability resources including products for parents that relate directly to child care.

Parent Voices

www.childcareadvocacy.ca/parent_voices/main-EN.html

A project of the Child Care Advocacy Association of Canada, Parent Voices is about working with parents to make the case for quality, affordable and accessible child care.

Invisible Disabilities Association of Canada

www.nsnet.org/idacan/

Contains information and resources on Chronic Fatigue Syndrome, Fibromyalgia, Environmental sensitivities and more.

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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