

CILT's Parenting with a Disability Bulletin

Volume 7 Issue 2
June 2004

PDN ACTIVITIES

PDN Annual Picnic

Sunday, August 8, 2004

11:00 to 2:00 pm

High Park, Area 3

Bring your hats.

Bring sunscreen.

Bring some food.

And bring the kids!!!!

Join us for some fun in the sun (and shade too!) in the beautiful and historic High Park.

It's a great time to get together with other PDN families and celebrate summer.

Kids can look forward to feeding the chipmunks, a nature walk, and running amok in the playground with our favourite child care workers. Also, \$3 will get them a ride on the famous High Park train if it's running on schedule.

This year will be a pot luck event so bring your favourite summer dish. The PDN will provide refreshments, snacks, and fruit. Let's make this the biggest bash yet! Attendant supports and child care will be available upon request.

RSVP by July 29, 2004 to Kimberly

Tel: 416-599-2458

Fax: 416-599-3555

TTY: 416-599-5077

E-mail: pdn@cilt.ca

New Support Group for Mothers and Prospective Mothers with a Disability

Over the past several months mothers with disabilities on the PDN have expressed their need for more peer support. In response, the PDN has partnered with the Anne Johnston Health Station (AJHS) to explore and identify practical support options by gathering information on issues and concerns relevant to mothers with disabilities.

A survey was sent out to 106 mothers and prospective mothers on the PDN in late April. A total of 20 surveys were completed and returned. Based on these

results we are holding three group sessions where we will explore the various issues that were raised. Through these peer support sessions, our aim is to empower our members by provide a forum to discuss and develop strategies to navigate the challenges of motherhood that are unique to women with disabilities.

The first session takes place on Saturday, August 21, 2004 at the Anne Johnston Health Station. The date of the following sessions will be determined at this meeting. Thank you to those who completed the survey. If you did not complete a survey but are interested in attending, please contact the PDN Coordinator at 416-599-2458 ext. 35; TTY: 416-599-5077; Fax: 416-599-3555.

At a later date, a similar survey will be sent out to assess and identify needs and support options for fathers with disabilities.

Coming Soon! New Online Group for PDN Members

In the coming months we are also looking to start up a new online group exclusively for mothers and fathers of the PDN. This will be a closed message-post forum where members can ask questions, provide information and share with others on our network. The success of this project will rely on the participation of members. If you have Internet access and would like to get involved, please e-mail the PDN coordinator at pdn@cilt.ca.

PDN Winter 2003-04 Questionnaire Results

With the October-December 2003 issue of the *Parenting with a Disability Bulletin* all members received a copy of the PDN Winter Questionnaire. Thank you to everyone who completed the questionnaire.

A total of 40 questionnaires were completed and returned. The results were split: half of all consumers and service providers responded that they were interested in workshops on nurturing assistance while the other half were not.

While half of all consumers indicated the need for physical assistance with parenting activities, only two service providers (Toronto's PACE Independent Living and Barrie's Simcoe County Association for the Physically Disabled) responded that they provide nurturing assistance. These results underscore the need for further information on and access to nurturing assistance.

With many consumers indicating that distance and transportation were barriers to participating in workshops - especially those who live outside Toronto and Ontario – it has become obvious that in order to meet the needs of parents with disabilities, there needs to be increased partnership with other centres and service providers. This became apparent when two PDN workshops were advertised and subsequently cancelled after receiving too few RSVPs.

If your organization or IL Centre is interested in partnering on workshops or information sessions concerning nurturing assistance, please contact the PDN Coordinator.

PARENT'S CORNER

Parenting Rights

By Savitha Thampi, Law Student Volunteer

This article originally appeared in the June 2004 issue of ARCH Alert. Reprinted by permission.

Child protection is an issue of fundamental importance in our society. Unfortunately for parents with disabilities, children are often taken from them in the name of “child protection.” Sometimes, the reason for taking children is simply because the parent lives with a disability. Courts, surprisingly, have not often examined whether this practice constitutes discrimination.

In Ontario, child protection is primarily addressed through the operation of the *Child and Family Services Act*. The paramount purpose of the *Act* is to promote the best interests, protection, and well being of children. The Supreme Court of Canada stated, in 1994, that the *Act* is one of the least interventionist child protection regimes in Canada. Since then, however, the interventionist powers granted to child protection organizations -- children’s aid societies – through the *Act* have grown. Correspondingly, the application of child protection laws to parents with disabilities has also grown.

Insidious biases are, disturbingly, operative with respect to child protection cases involving parents with disabilities. Parents with disabilities often face early state intervention due to previous involvement, because of their disabilities, with certain government agencies. Consequently, such parents are targeted more frequently than parents without disabilities in child protection matters.

The practice of predictive or presumptive unfitness also poses a difficult barrier for parents with disabilities to overcome. Judges often make an assessment of parental fitness that is not based upon empirical evidence of unfitness, but on the possibility that a parent may be unfit in the future. This involves a high degree of judicial speculation and subjectivity with the potential for serious inconsistencies. While the concept of an ideal parent remains undefined, the ideal of middle-class parents without disabilities is often used as a comparator group against which parents with disabilities are judged. This leads to inappropriate standards of parental fitness being applied to parents with disabilities. It is crucial for courts to keep in mind that while the manner in which parents with disabilities perform parental tasks may be different from parents without disabilities, performing tasks differently should not be deemed to constitute unfitness.

There are also social disadvantages, such as income insecurity, that disproportionately affect persons with disabilities and may be viewed to affect their ability to parent. When such social disadvantages are given weight by a court, there is a disproportionate impact upon parents with disabilities.

General social service agencies, which sometimes fail to provide accommodation to parents with disabilities, may also contribute to the problem, because the agencies may bluntly testify that their services cannot assist a certain parent with a disability whose ability to parent is put into question. Such agencies may dismiss the ability of an individual with a disability to parent on the basis of not learning certain parenting skills without ever considering whether, with accommodation in the form of extra time or repeated instruction for example, the parent is able to learn and benefit from the agency's services.

It is essential for courts to be diligent, in cases involving parent with disabilities, to ensure that discriminatory child protection practices are not operative. Courts should be cautious about accepting 'evidence' led by children's aid societies suggestive that because of disability, a person cannot parent.

One recent Canadian case that addressed the problems faced by parents with disabilities was rendered by the Yukon Territorial Court in 2002. In *R.A. (Re)*, the Judge stated that "[i]t is incumbent upon government, community and families of the developmentally handicapped to provide the support and resources to give practical significance to their rights to parent."

Parents with disabilities are clearly subject to discrimination through the application of child protection legislation. All parents should, however, be treated equally and respectfully. Addressing biases and practices that promote the differential treatment of parents with disabilities will result in the law being applied with fairness, and re-affirm our societal commitment to equality, while maintaining the state protection of children. It is essential for parents with disabilities to ask courts to decide, in future cases, whether the removal of their children constitutes discrimination, contrary to their right to equality under the *Canadian Charter of Rights and Freedoms*. With further judicial interpretation of the rights of persons with disabilities to parent, the more likely it will be that children's aid societies and the rest of the child protection system will be modified to work harmoniously with the rights of persons with disabilities.

RESP / CESG Update

In the last issue of the *Parenting with a Disability Bulletin* you read PDN member Rahime Juma's article entitled Canada Education Savings Grant for your Children - Collect it Today. Since then, the government has made some changes to this program. Stay tuned for an update by Mr. Juma on these changes in September's issue.

Living With Autism

By William (Bill) Mosher - PDN member, Toronto

As a single parent of my autistic son, Mathew, I have come to see the highs and lows of this disABILITY.

The highs of learning a new skill or interacting with a child playing a game.
The lows of not being able to have regular communication and to socialize with people.

Trying to find a place where he can be comfortable in his world and ours.
The following poem, "Between Two Worlds," may bring us a little closer to understanding the world of persons living with autism.

Between Two Worlds

I stand in a doorway, between two worlds,
A place where you're here nor there.
The outer world beckons, with people having fun.
A world of places, faces, and things to do,
But this world of reality slips away from me,
As my senses close in,
Sounds are distorted, lights and colors hurt my eyes,
And smells overwhelm me.
I hear a voice calling me, calm and serene,
Come back, come back home,
Home to the inner world, where you're safe and secure.
I'm drawn to this place, where I can escape,
But, I must always keep one foot in the doorway,
Cause, the door has a lock,
And I stay in this place, between two worlds,
Afraid to be trapped on either side.
I wish to join in your world, but it's hard you see,
I must always fight to stay,
Because I live between two worlds,
-----The world of the Autistic -----
Martine Stonehouse
1---2001

Autism: Parenting Means Litigating?

By Bill Holder, Staff Lawyer

This article originally appeared in the June 2004 issue of ARCH Alert. Reprinted by permission.

Parents of children living with autism are increasingly finding that being a parent necessitates constant advocacy on behalf of their children, including litigation. As was reported in the article, "Autism Litigation for IBI," much of the focus of the current autism litigation is on IBI (Intensive Behavioural Therapy). However, there are other issues of importance to families that compel them to litigate. One issue is the general inadequacy of supports and services - including respite - that are made available to families caring for children with high needs. Without sufficient supports and services, many families are forced to become the sole, around-the-clock, caregivers for their children, without much time for anything else. Madam Justice Kiteley, in the case of *Wynberg v. Ontario*, recognized how exhausting this can be: "I find that all of the parents have and continue to experience unrelenting and profound stress associated with providing appropriate treatment and education for their children." In the case of *Nieberg v. Ontario*, Madam Justice Benotto found that "[t]he evidence demonstrates the day-to-day struggles necessary to care for these children and the financial and emotional costs to the family."

In the *Nieberg* case, reported in the 2 April issue of the ARCH Alert, the Government of Ontario was ordered to re-make six funding decisions, made over the course of three years, regarding two families of children living with autism. The parents were compelled to go to court because of the way in which the Government was administering a funding program. For each of the three years in question, the parents made funding proposals to the Government for necessary supports and services. And, each year, they were "awarded a fraction of the proposal and no reasons were given." The Court found that the Government treated the families with procedural unfairness.

Compounding the difficulties faced by parents of children living with autism is the problem that arises when school boards refuse - invoking the *Safe Schools Act* - or otherwise fail to look after and educate their children during business hours. Some parents, in this situation have had to quit their jobs and have exhausted their savings because they can find no other way to ensure that their children receive care. The application of the *Safe Schools Act* to students living with autism is forcing even more parents into litigation, especially before the Ontario Human Rights Commission, to ensure that their children receive an education. This fall the Divisional Court will hear an application for judicial review of a Special Education Tribunal case, the facts of which involve a child living with autism who was excluded from school for five months because of the *Safe Schools Act*.

Other cases involving parents of children living with autism include two cases launched as class actions. However, in decisions rendered in June of 2003 and June of 2004, both cases were dismissed at the stage at which they sought certification by a court to proceed as class actions. Families who were involved in the cases must decide, given the negative certification decisions, whether to appeal or proceed independently (i.e., not together as a class of plaintiffs). Last week the Supreme Court of Canada heard the case of *British Columbia (Attorney General) v. Auton*, regarding the obligation of the British Columbia government to offer behavioural therapy to children living with autism. ARCH, together with co-counsel from Cavalluzzo Hayes Shilton McIntyre & Cornish, represented two interveners in the case: the Canadian Association for Community Living and the Council of Canadians with Disabilities. The interveners hope that the case will advance our understanding of the obligation, pursuant to the *Canadian Charter of Rights and Freedoms*, of provincial governments to provide general supports and services to children living with disabilities, including autism, and their families. The Court reserved its decision in the *Auton* case, meaning that it will decide the outcome and write reasons for decision in the next few months.

There are many problems that families of children living with autism are facing. Families argue that the Government of Ontario is not accepting its responsibility to educate their children and provide adequate supports and services. The families feel, consequently, that they are being forced into costly and unnecessary litigation against the Government. All families are awaiting the Supreme Court of Canada decision in *Auton*, therefore, hoping that a positive decision will convince the Government of Ontario to provide fair and comprehensive supports and services. The families look forward to a time when litigation becomes a less-necessary part of being a parent to children living with autism.

COMMUNITY

Geneva Centre for Autism

Founded on principles of partnership and skill building, Geneva Centre for Autism is committed to collaborative partnerships with families and professionals to ensure services meet individual needs. The Geneva Centre has become the most extensive resource and clinical centre in Canada.

The primary objective for all Geneva Centre for Autism services is to provide consumers with sufficient information and support to develop the skills needed to enhance the lives of people affected by autism and related disorders.

For more information about the Geneva Centre for Autism contact them at 112 Merton Street,
Toronto, Ontario
Tel: (416) 322-7877

Toll Free: 1-866-Geneva-9
Fax: (416) 322-5894
E-mail: info@autism.net
Website: www.autism.net

Autism Society Ontario

Autism Society Ontario (ASO) is the leading source of information and referral on autism and one of the largest collective voices representing the autism community. Members are connected through a volunteer network of 29 Chapters throughout the Province of Ontario.

ASO is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families, and the professionals with whom they interact. The Society and its chapters share common goals of providing information and education, supporting research, and advocating for programs and services for the autism community.

For more information contact the ASO at 1179A King Street West, Suite 004, Toronto, Ontario

Tel: (416) 246-9592

Fax: (416) 246-9417

E-Mail: mail@autismsociety.on.ca

Website: www.autismsociety.on.ca

The High Park Children's Garden Free Drop-in Events

The Children's Garden and Exploring Toronto programs invite children and youth to their **FREE** summer programming.

The Enchanted Garden Party

Sunday, July 18, 2004

12 noon - 4 pm

Enjoy fun activities including butterfly crafts and drama, herb sachets, a walk down the "magical staircase" across from the garden and lots more. All ages welcome. A garden harvest lunch will be provided while it lasts.

Foods of the World Garden Fiesta

Sunday, August 15, 2004

12 noon - 4pm

See how gardening and food are connected around the world with scavenger hunts, food mapping, nature crafts and much more. A multicultural garden harvest lunch will be provided while it lasts. All are welcome.

Harvest Festival

With Colborne Lodge and the HPCAC

Sunday, October 3, 2004

12 noon - 4:30pm

A great day of family fun including music, drama, storytelling, wagon rides, nature crafts and activities, traditional lawn games, seed collecting and a Children's Garden harvest lunch.

Thursday Morning Family Garden Drop-in Program at the High Park Children's Garden

July 18th - August 26th, 2004

10am - 12 noon

Join us for gardening and composting activities, garden games, arts, crafts and more! Open to 3-12 year olds. No registration needed but parental/caregiver supervision is required.

The High Park Children's Garden is located north of Colborne Lodge on Colborne Lodge Drive. Gardens have raised beds and areas are wheelchair accessible.

For more information about any of these events or programs, please contact Christine Klianis at 416-392-1329

E-mail: kidsgrow@toronto.ca

Website: www.toronto.ca/parks/programs/children.htm

AROUND THE WORLD

The Naked Truth

An announcement that a naked and very pregnant disabled woman will be displayed in Trafalgar Square has sparked a debate in London, England. Allison Lapper Pregnant, a fifteen-foot-high white marble sculpture by British artist Marc Quinn, is the first in a series of contemporary art pieces selected to occupy a vacant platform in the northwest corner of the historic square. It depicts fellow British artist Allison Lapper, born in 1965 without arms due to phocomelia, naked and 8 1/2 months pregnant with her son, Parys.

Critics of the decision, many of whom campaigned for a statue of the Queen Mother or Nelson Mandela, argue that the sculpture is an affront to tradition. As the site of Nelson's Column (which features Britain's most famous admiral missing the right arm he lost in a 1797 battle), they argue that Trafalgar Square should celebrate military heroes and historical figures.

In contrast, supporters of this piece and those slated to follow it on the platform suggest that contemporary and often controversial works like Allison Lapper Pregnant are essential to engaging viewers with modern art.

Often self-dubbed in her own art as a Venus de Milo, Lapper herself is ecstatic with the work and the message it sends.

"I regard it as a modern tribute to femininity, disability and motherhood," she said in a recent interview with Canadian Press. "It is so rare to see disability in everyday life, let alone naked, pregnant and proud."

For more information on Allison Lapper and the "Allison Lapper Pregnant," visit the following websites:

www.alisonlapper.com

www.fourthplinth.co.uk/marc_quinn.htm

www.bbc.co.uk/ouch/features/lapper.shtml

GET INVOLVED

New Support Group for Asians with Disabilities

Are you a consumer with a disability of Asian descent who is looking to meet with other consumers who share the same ethnic background(s)?

A local consumer named Gail Shimoda invites all consumers of Asian descent to join her new support group for Physically Disabled Asians.

Topics discussed in this group may include:

- Getting around in the city
- Personal interests and needs
- Housing
- Services
- Planning social events and activities

Place: Japanese Canadian Cultural Centre, 6 Garamond Court (Don Mills/Eglinton). Fully wheelchair accessible, with barrier-free washrooms.

Time: afternoon once per month

If you're interested in joining this group, or would like more information, please contact Gail at 416-739-9534; E-mail: gshimoda5213@rogers.com.

Come join the group for an informative & enjoyable afternoon session with other disabled Asians in your community. No attendant services provided.

UPCOMING EVENTS

Taking Care of Ourselves - Workshop for Women with Disabilities

Education Wife Assault and Women's Health in Women's Hands presents **Taking Care of Ourselves**, a **free** workshop for women with disabilities on setting healthy boundaries and having healthier relationships.

This workshop will provide an opportunity to talk about the impact and effects of unhealthy or abusive relationships, as well as, identify ways of coping in a safe and supportive environment.

When: Wednesday, July 21

Time: 5 PM - 8:30 PM (Dinner will be served at 5 PM)
Where: Women's Health In Women's Hands, 2 Carlton Street, Suite 500 (Yonge and Carlton)
Attendant Services and ASL Interpretation will be provided.
RSVP to Fran Odette at 416-968-3422 x30 by July 16.

Eaglewood Festival 2004

The 2004 Eaglewood Folk Festival is going to be held **August 27-29** in Pefferlaw, Ont. The Eaglewood Folk Festival is dedicated to the promotion of traditional and contemporary Canadian acoustic folk music and to making this art form accessible to all.

The annual three-day festival is held on the Eaglewood Resort whose aim is to provide accessible accommodation and camping, as well as recreational facilities for everyone.

All its programmes are in Braille, Large Type, and taped formats. American Sign Language (ASL) is provided during evening concerts. Workshop and daytime programming is presently being arranged. Accessible buses to and from the event are subsidized.

Ticket prices are low in order to provide this art form to all, regardless of individual economic circumstances.

For more information and to order your tickets, please contact Eaglewood Enterprises at (705) 437-1634 or e-mail: eaglewd@ils.net.

VoicePrint Canada: Accessibility Days

VoicePrint Canada, in conjunction with the CNE, is once again coordinating Accessibility Days to take place from **August 28-30, 2004**.

The three days will focus on 'accessibility,' and on adaptive technologies/methodologies. This year, the event will be located next to the Prince's Gate (east of the grounds). Both indoor and outdoor events can be scheduled to take place on the National Trade Centre premises. Partners and exhibitors will host a variety of interactive events throughout the Days and invite everyone to take part.

To participate in Accessibility Days 2004, please visit the official Accessibility Days website at www.accessibilityday.ca, or e-mail Pamela Muñoz at pamela@nbrscanada.com or Vanessa Carlisle at vanessa@nbrscanada.com. You can also phone 416-422-4222 x227 or toll-free at 1-800-567-6755.

Persons with a disability and their attendant get onto the CNE grounds FREE!

BOOKS

Book Review

By Susan DeLaurier - CILT Resource Librarian

Somebody Somewhere - Breaking Free from the World of Autism

Written by Donna Williams. Published by Doubleday Canada, 1995. ISBN: 0385255004

During the past 15 years or so, there has been much written about various forms of autism as this disorder becomes more widely known. Most of the available information is from teachers, parents and psychologists but rarely from a person who has been diagnosed with this. This is such a book. Donna Williams makes you feel what an autistic person does. The very fact that she can write so articulately about her perceptions is an amazing achievement. Her first book, *Nobody Nowhere*, was her first attempt to describe her world, and was widely read and admired.

This book cannot be taken as a generalized view of autism since it only focuses on one person's account and experience. However, the author has had contact with other people with autism, and some variations of the experiences are universal. One of the most fundamental characteristics of autism is that of knowing "my world" as opposed to "the world," and only feeling comfortable in the former. These worlds become integrated for Donna by the end of the book. Donna had been termed "echolalic" and "echopractic" because she always had the ability to mimic sound and movement. She realized that this is what she needed to do in order to live in the real world, although she also knew she had no true understanding of what she was saying or doing. She speaks of this as being "meaning-deaf and blind" to things and to herself. Donna always spoke to, at, or in front of people from an early age, but didn't know how to talk with someone in a natural conversation.

She often made mistakes in perceptions of others' facial expressions and this is often characteristic of people who have autism. She didn't see that frowning might indicate concern for her – she saw it only as a negative reaction. The meaning of knowing and feeling had no significance for her, because they weren't concrete objects and this led to great difficulties with personal relationships. Because her intelligence was obvious to everyone (she is highly educated and speaks several languages), her odd behaviour was seen as antisocial. She speaks frequently about her problems with friendships and how she learned the concept of having a friend.

Autism is a problem of processing information and has absolutely no relation to intelligence. Usually only a single mental input at a time can be tolerated and therefore, an autistic person may feel overwhelmed in a room with bright lights, a

turned on TV, and a person speaking at the same time. A common response to this much stimulation is to shut down completely and retreat to a private world. The author understands when this feeling of overload is coming and refers to it as going into the "big black nothingness." Now in her late twenties, she knows what she can do to bring herself back to the world. For Donna, getting information through print was always easier because she could take the necessary time to read at her own speed of comprehension, whereas in conversations she could not control the interaction. The aspect of choosing things herself gives her a sense of control.

For most people, processing information comes naturally and we can easily block out what is not necessary and concentrate on what we need to. Most of us have a threshold for stimuli, and when there is too much we will retreat in some way, either mentally or physically. For people with autism, however, all stimuli are equal and they retreat completely when overwhelmed.

If we were to meet Donna today, we probably wouldn't think she had autism, although she writes that when she was young, her behaviour was, at times, closer to what we think of as 'classic autism.' She talks about the peculiar repetitive actions, such as humming and tapping that are commonly associated with autism, and explains that these help to keep outside stimuli from coming in. She notes that this also prevents a person from doing anything else and she therefore defines autism as self-denial.

With the help of friends and a psychologist, Donna very gradually begins to find her world too confining and she begins to desire a more normal life with real interactions with others. She comes to realize that the difference between "my world" and "the world" is implied choice, and that autism stole that choice. This crucial understanding helps her to break through and she sees that there never was a "my world."

Donna doesn't believe she will be cured of autism, but she is confident that she'll be able to control it. This very gifted and artistic author has written a wonderful book for anyone wanting to know what autism really feels like and how to better understand their own perceptions. Reading about her gradual awakening and acknowledgement of the real world makes us more aware that there are many ways of experiencing the world.

WEBSITES

ARCH: A Legal Resource Centre for Persons with Disabilities

www.archlegalclinic.ca

Information on legal and advocacy issues, including a searchable database.

Toronto Public Health

www.toronto.on/health

Information on health related issues and free family programs such as At Home Alone, Ready or Not, Peer Nutrition Program and more.

Help! We've Got Kids

www.helpwevegotkids.com

Online directory for kids and families living in the GTA.

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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Website: www.cilt.ca

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Funded by: United Way of Greater Toronto

ISSN 1481-918X