

# CILT's Parenting with a Disability Bulletin

Volume 7 Issue 1  
March 2004

## PDN ACTIVITIES

### PDN Winter Questionnaire

With the last issue of the *Parenting with a Disability Bulletin*, all members received a copy of the PDN Winter 2003-04 Questionnaire with a self-addressed return envelope.

If you haven't already done so, please complete the Questionnaire and return it as soon as possible. If you would prefer an electronic copy of this Questionnaire, please forward your request to [pdn@cilt.ca](mailto:pdn@cilt.ca).

Your input is important in determining future activities of the PDN!  
A report of the survey results will appear in the June issue of the *Parenting with a Disability Bulletin*.

### Attention! Important Bulletin Update

The *Parenting with a Disability Bulletin* has gone quarterly and will now be published 4 times a year!

The new distribution dates will be:

- March
- June
- September
- December

### SUBMISSIONS WANTED!

If you have an article, story, poem, tips/strategies, photos or anything related to parenting with a disability that you'd like to share, the PDN wants to hear from you!

Send your submissions to Kimberly at [pdn@cilt.ca](mailto:pdn@cilt.ca); fax: 416-599-3555; or call 416-599-2458 ext. 35; TTY: 416-599-5077.

## Upcoming Nurturing Assistance Workshop

### *NEW DATE!*

Thursday, April 22, 2004

5:30-8:30 pm

Centre for Independent Living in Toronto (CILT)

205 Richmond St. West

(at Duncan St.)

Suite 605, Toronto

A workshop for consumers, service providers and anyone interested in Nurturing Assistance!

This 3 hour workshop will offer:

- practical information
- demonstrations
- a panel discussion
- question & answer period

Registration for this workshop is required by no later than Thursday, April 15, 2004.

To register call Kimberly at 416-599-2458 ext.35; TTY: 416-599-5077; E-mail: [pdn@cilt.ca](mailto:pdn@cilt.ca).

Pizza will be served.

Attendant services and child care will be available upon request.

## PDN Winter Social Event

*By Kimberly McKennitt, PDN Coordinator*

Thank you to everyone who made it out to our Mid-Winter Get Together on Saturday February 21, 2004 in the boardroom at CILT.

It was a great opportunity to socialize and beat the winter blues! In fact, many people commented that they find February to be an extremely difficult month and that they were happy to get out and spend the afternoon with friends.

Here's what a couple of PDN members had to say about the event:

"Thanks for a great party at CILT!"

"Thank you for a wonderful party! After such a cold, long winter, it was refreshing to get out of the house and talk with peers in a warm and friendly environment."

Stay tuned for details of the next PDN social event in the June issue of the *Parenting with a Disability Bulletin*.

## IN MEMORIUM

### PDN loses valued member

*By Kimberly McKennitt, PDN Coordinator*

It is with great sadness that we announce the passing of Yolanda Rodriguez on December 23, 2003 due to complications arising from her disability. Yolanda had lupus and hemiparesis.

A mother of a teenage son, David, Yolanda was an active PDN member since 1998.

Yolanda will fondly be remembered as a loving, caring, dedicated parent. She had a great love of children, especially her own; her son was the focus of her life. She was kind and generous, and regularly volunteered her time at CILT. She was someone you could count on for a smile, could usually find humour in situations where others could not, and was always willing to share a laugh. Yolanda was the first PDN member I met. I remember the warm welcome she gave me and her eagerness to find out my plans for the PDN and how she could contribute.

Yolanda would often talk about her son and the joys and challenges of raising a teenager in today's increasingly complex world. During one of our weekly conversations she told me about her son emailing a 'friend'. Admittedly concerned because she wasn't familiar with computers and the Internet, I referred her to one of the many courses offered through the Toronto Public Library. So it was no surprise that, as someone always interested in and willing to learn new things, she came into my office one morning a few months later and proudly announced she had just completed the course. Now, she said, she would be able to keep up with her son and discuss what, exactly, he was doing on the computer.

A dedicated PDN member and a regular participant of our social events and workshops over the years, I will truly miss Yolanda and her great love of life.

## PARENT'S CORNER

### It's a Girl!!

Congratulations to PDN member Virginia Guo and her husband, Gerald Cui, proud parents of Jingyuan (Claire) Cui, born at Mt. Sinai hospital on January 29, 2004, weighing in at 6 lbs, 4 oz. Both mom and baby are doing well!

Virginia's pregnancy and delivery was followed by *Moving On*, a documentary program about people with disabilities.

*Moving On* airs on CBC on Sundays at noon. Their new season starts April 4<sup>th</sup>. Watch for Virginia's story in an upcoming episode.

### **Canada Education Savings Grant for your Children - Collect it Today.**

*By Rahime Juma - PDN member, Kingston*

It has come to my attention that children of disabled parents are much less prone to attend post-secondary school. Of course many of us are also "poor," and it is well known that the poor attend post-secondary schools at a lesser rate than others in society; however, we seem to be particularly challenged in this regard. According to statistics Canada, a child born today will be looking at about \$100,000 for a four year post secondary program.

My interests in this started 3 \_ years ago when my daughter was born and I somehow managed to start saving for her education in a Registered Educational Savings Plan (RESP), which is a government tax shelter for educational savings initiated in 1974.

RESPs work differently than RRSPs in that money going into a RESP is after-tax money. What this means is that when the plan is complete the principle amount is returned to you (the subscriber) tax free. The interest on the principle is withdrawn in the child's (nominee's) name. While the nominee is attending school the tax implication to her/him is minimal, if any at all. You have therefore, in essence, grown your money tax free.

WAIT, it gets better.

The government will top up your contribution by 20% to a yearly maximum of \$400 and a lifetime maximum, per child, of \$7200. This is known as the Canada Education Savings Grant (CESG), and has formed part of the RESP initiative since 1998. The grant portion of the program ends at age 18, but there are ways of catching up for missed years. Not taking advantage of this opportunity is lost money that could be giving your child a step up in this world - that step being education. The projected lifetime earnings of a university graduate is 300% (3 times), more than that of an individual who stopped with their high school diploma. The real cost of a post-secondary education is not having one. An RESP can be opened at any participating CESG/RESP promoter. They can be opened by parents, grandparents, aunts, uncles, etc. It's a great gift idea; monthly contributions can be as low as a few dollars. More information about the plan and the grant is available from the following Government of Canada web page: [www.hrdc\\_drhc.gc.ca/cesg](http://www.hrdc_drhc.gc.ca/cesg).

## **What to watch out for**

Your money can be invested in various financial products. Watch for hidden fees! Ask for the fees upfront. Is your original investment guaranteed? Mutual Funds are good investments but they can fluctuate significantly. If you need the money at the bottom of a cycle, this could be a problem. GIC's and bonds are great because they are safe, but the return is so low that taking inflation into account, you may be losing money. Pooling your money in group programs specifically designed for RESPs and CESGs is a great idea, but again be careful. Will you only get back your principle if your child does not attend post secondary school? Some plans offer above average returns; be weary of this and ask why. Don't get involved in a plan with overwhelming limitations. The major plans are pooled group plans, family plans and pooled individual plans. I recommend the pooled individual plan for the great majority of us.

All of these group plans are heavily regulated by the government in a national policy. They can only invest in safe vehicles such as government bonds. By pooling the money they can get returns on bonds that as individuals we could only dream about.

Make sure that when your child starts post-secondary school, it is you that has control of how much money you can withdraw and when. If you have more than one child, make sure you can transfer the funds to the next child if the first does not attend school. Remember all plans will allow you to rollover the taxable proceeds into your or your spouse's RRSP, space permitting.

There is much more I wish I could convey, but this would turn into a book. I am licensed with the Ontario Securities Commission and would love to provide you with information and tips personalized to your situation and needs. My e-mail and phone number are listed below.

I am sure I am not alone in wanting my child to get a post-secondary education. We all want better for our children. I know first hand that it is hard to focus on their tomorrow when their today is such a challenge; but if we don't, what will tomorrow hold for them? I feel very passionate about this. Spread the word - collect the grant - CESG. Don't Miss Out!

For more information, contact Rahime Juma by e-mail at [rahime@globalresp.com](mailto:rahime@globalresp.com) or call 613-545-0707 (call collect).

## **Parenting with a disability: The challenges and the joys**

*By Annie Atkinson*

*This article originally appeared in Toronto Rehab magazine, Spring/Summer 2003, pgs. 12-14. Reprinted by permission.*

Six-month-old Simon gurgles with delight as his Mom lifts him high above her head, then swoops him down until they are nose-to-nose.

"This guy is so important that I have another calling in life now," says April Ferguson, 32, of Uxbridge, Ontario. "I'm motivated to be the very best parent I can be. Simon and his siblings will be my great accomplishment-my contribution to the world."

April is one of the growing number of Canadian adults with disabilities who are choosing to become parents. In addition to this group are able-bodied parents who, due to illness or injury, sustain a disability and then make the transition to being a parent with a disability. Disabilities can be visible or invisible, and include physical, visual, hearing, intellectual and emotional impairments, and chronic health conditions.

"There's a myth that people with disabilities don't have sex and don't have children," says Rita Mabrucco, a social worker in Toronto Rehab's Spinal Cord Rehabilitation Program. "It's important for the public to know that people with disabilities are capable of having children and being parents."

"People with disabilities deserve the right to decide if they want to become parents or not," agrees Kimberly McKennitt, Coordinator of the Parenting with a Disability Network, a program of the Centre for Independent Living in Toronto (CILT) Inc. "It's becoming a more realistic option because it's better recognized now that people with disabilities can be parents-and they can be really great parents. With the right supports in place they can have a fulfilling experience and raise great children, just like anybody else.

"If an adult with a disability requires and directs their attendant services, then they can extend that to the role of parenting," explains Kimberly. "Just because a parent can't brush a child's hair doesn't mean they can't be a good parent. If they ask the attendant to brush the child's hair, they're still being the parent. They're still in control and in charge."

Nine years ago, April never would have imagined that being a parent would become her focus in life. Her mind was firmly fixed on her upcoming marriage, a move to Alaska and a career in limnology, the study of fresh water biology. All that changed in September 1995, days before her wedding, when April sustained multiple fractures and a traumatic brain injury after she was hit by a car while riding her bike. She spent 28 days in a coma, and the next five years-including a two-month stay at Toronto Rehab for intensive rehabilitation-recovering from paralysis, speech impairment and a variety of cognitive problems.

The brain injury robbed April of her memory of the previous four years, including her courtship and the knowledge she had gained while obtaining her Master's

degree. It also diminished her strength, and her ability to process information quickly and to multi-task. But she and fiancé Jamie rebuilt their relationship and married in 1996, and April's life again changed gears as she focused on outpatient rehabilitation and then eventually on having their first child.

"I spent five years trying to regain whatever I could," says April. "I wasn't ready to share my life with a baby until now. I would give this advice to everyone-not just to people with disabilities: wait until you're really ready to have children. It's tough to be a parent when you are not ready and you haven't done the things you want to do for yourself. But once you are ready, it's really worth it."

The key to April's success as a new parent with a disability lies in the support she has organized for herself. Jamie works from a home-based office so that he is nearby if April needs him. April has arranged for a private company to assist her with laundry and some of Simon's care several mornings a week. "Until Simon is more independent, that's the way it is. Sometimes it takes me a little longer to do things and he has to wait," she says. "So patience, I'm hoping, will be one of his virtues."

Support and information are what parents with a disability need most and what the Parenting with a Disability Network is all about, according to Kimberly. Founded on the philosophy of independent living-that people with disabilities have the right to examine their choices, make decisions and take risks-the network provides information resources and peer support to parents and prospective parents with a disability.

Information is available on a range of topics-from adaptive equipment, such as side-opening cribs appropriate for parents in wheelchairs, to nurturing assistance, a consumer-directed service that provides physical assistance to parents with disabilities who have young children. The network's peer support program matches parents and prospective parents with other parents to gain and give support, advice and information, either by phone or in person. "Who better to help one another than parents going through similar things?" says Kimberly. "We need to rally service providers and funders to provide more practical, concrete supports for parents with disabilities. We need to raise the level of awareness among the general community, so that parents with disabilities are an integral part of our community and we welcome them."

Part of that wider acceptance comes with addressing broad issues such as accessibility, says Rita. "Do parents with disabilities have access to their children's schools so they can attend special events and teachers' conferences? Can a parent in a wheelchair make it into the park to supervise their children at play?"

For David Lostchuck, 43, of Bolton, the father and step-father of six children ages 5 to 18, the transition from being an able-bodied parent to a parent with quadriplegia who uses a wheelchair has been "very difficult." While accessibility,

housing and limited physical abilities have been challenges since he sustained a spinal cord injury in a car crash in 1998, David's main hurdle has been learning to communicate more openly with his children.

"I had always parented by example," says David. "Before my injury, I used a 'do as I do' approach. Now my biggest challenge is to become a communicator. "I had a hard time thinking I could enforce anything," David says of returning home to be an active parent after being in hospital for a year. "It's hard one minute be the parent and draw the line with the kids, and the next minute to say to the older ones, 'Oh, by the way, can you put me to bed?' It's not necessarily bad because it equalizes things, but it sometimes does make disciplining the kids a bit different. I think we're slowly adjusting.

"Parenting brings life to me," David reflects, "a world of experiences that I'm thankful for. I'm glad we're doing it."

"There are lots of joys and lots of challenges," agrees David's wife Leslie. "It's just that our challenges are different than other people's.

*Annie Atkinson writes for Toronto Rehab magazine. Toronto Rehab is Canada's largest hospital that provides adult rehabilitation services and complex continuing care.*

## **Rationale for Nurturing Assistance**

*By Tracy Odell*

*The following is an excerpt from Nurturing Assistance: A Guide to Providing Physical Assistance for Parents with Disabilities(2002), Part I, Chapter 2, pgs 12-14.*

As a life-long disability advocate, I was overwhelmed by how "disabled" I felt when I had my first baby. Although my baby was fairly small (5 pounds, 6 ounces), I did not have the power to lift her. At the best of times, I can lift only a few ounces of weight. My baby was fussy and squirmy. I could not hold her in place for nursing, without being afraid she would wriggle and fall off my lap. My husband had to attend every nursing session (and I nursed the baby on demand), just to make sure I could hold the baby safely. It was some time before we figured out a way to prop pillows and wedge them between me and a table, so there was literally, no "wiggle room" to endanger our baby.

It was also overwhelming to be so much at the mercy of other people's energy levels. As a new parent, my sleep was shortened, interrupted and disrupted-even when baby slept through the night. I feared she had stopped breathing! My husband was similarly sleep-deprived, as he had to get up to bring the baby to me to nurse, get us into position, and do the constant, compulsive, new-parent



checking for both of us. He had little energy or patience left to help me do things for the baby my way during waking hours.

One of our first "big" fights was over whether or not to make the baby wear socks. I felt frustrated that, even though I was my baby's mother, I did not have the final say about what she would wear and how she would be cared for. I was heartbroken if my daughter cried and could only be comforted by someone else, as I looked on. My role as my baby's mother was being eroded, as I had to give that right over to the people who were "helping" me, because they were doing the best they could, within their own energy limits, and because they could ensure my child's needs were met.

I felt I needed someone who could help me care for my baby, my way, on my own terms. Just because I did not have the strength to lift her, it did not mean I had no interest in holding her, comforting her, dressing her or playing with her. Yet to do all these things meant getting someone to help. Even family and well-meaning friends aren't really helping if they just take over. I was feeling disenfranchised. I was feeling like a stranger who did not know the likes and dislikes of my own child. I wanted to be, and needed to be, a parent to my child in my own right.

Infants need to be held by someone who loves them. A mother's love is not diminished by the fact that she happens to have a physical disability, even if that disability prevents her from holding her own infant. Gradually, I began to come up with the idea of having assistance to care for my child, similar to attendant support that helps me care for myself. If there was someone available, for some time each day, where I would be totally responsible for my child's care, I believed we would both benefit. My baby would benefit from having more intimate contact with a loving mother, and I would benefit from having a stronger relationship with my own child. There would be some time in every day where I could be the person to pick out what my child would wear. I could be the person to make my child laugh and giggle while I played with her, and learn about her ever-changing likes and dislikes.

Nurturing assistance, the phrase I used to describe this type of help, would do all this. Nurturing assistance would help me to interact and bond with my child, and be a mother in every real sense of the word. It would liberate my husband from my insistence on doing things my way (although he was the one doing them); it would liberate me from feelings of uselessness; and most importantly, it would strengthen the mother-child bonds by having real interaction and involvement between my baby and me.

Children have needs on both physical and emotional levels; so do parents. The nurturing assistant helped me not only to meet my child's physical needs without an unhealthy dependence on other family members, but also helped us both to meet some emotional needs at a very emotional time. I needed to feel involved in

my baby's upbringing. I needed to feel I was having an influence in her little world. I didn't need a contest of wills with other adults in our lives over every little decision—like whether or not to wear socks.

Now I have two girls, ages 11 and 13. As we enter these turbulent and stressful teen years, I trust that the time I spent in direct interaction with my children as infants, through the nurturing assistance I had, will see us through, and with loving bonds stronger than ever.

*2004 update: The girls are now 13 and (almost)16! - ED*

## **COMMUNITY**

### **The Tetra Society of North America**

#### **What is Tetra?**

We are a non-profit organization that utilizes skilled volunteers to design and build customized assistive devices for people with disabilities allowing them to live life to its full potential.

#### **How can you benefit from Tetra?**

- Increase your independence, live a healthier life
- Improve your self esteem
- Reduce your need for attendant care
- Share your input in the design
- Achieve a more fulfilling life and enhance your contribution to the community

If you or someone you know could benefit from a customized assistive device, contact us at our toll-free number: 1-877-688-8762. Please check our website [www.tetrasociety.org](http://www.tetrasociety.org) to find a local chapter near you!

### **Arts Events Program for Consumers with Disabilities**

Arts Carousel has a program called "Arts Events" where it arranges visits to fully-accessible sites for people with disabilities. Places include museums and live theatre. This program is open to all consumers in the Toronto area. Family and friends are encouraged to attend.

Arts Carousel provides attendants for consumers, if required. Costs are partly subsidized. Flyers are mailed out about a month in advance.

To be put on the mailing list, or if you're interested in attending an event, please contact Arts Carousel at 416-391-2086. Trip ideas or requests are always welcomed.

## **GET INVOLVED**

### **Volunteers Needed Immediately at CILT!**

CILT is currently looking for volunteers to assist staff with:

- mailings
- filing
- assembling information packages
- photocopying
- ...and more
- 

If you are interested in volunteering at CILT, please call Nancy Barry, Volunteer Coordinator, at **416-599-2458 ext. 27** for more information.

### **Critical Disability Studies Program at York University**

The Critical Disability Studies (MA) program at York University is accepting applications for its second year of students, following its first academic year in 2003. The graduate-level program's purpose is to contribute to research examining the systemic social, political, legal and economic barriers to the full societal inclusions of people with disabilities.

For information on the kinds of courses offered, the faculty associated with the graduate program, and admission details, please contact **416-736-2100 x44494** or e-mail [gradcds@yorku.ca](mailto:gradcds@yorku.ca). You can also visit its Web site at [www.atkinson.yorku.cda/cdis](http://www.atkinson.yorku.cda/cdis).

### **SCCC Swim & Social Program 2004**

The Scadding Court Community Centre (SCCC) invites consumers to participate in its Swim and Social Program. If you are an adult with a physically disability who is looking to swim with the aid of a volunteer and would like to make new friends then this may be the program for you.

Any interested swimmers are required to bring a swimsuit, towel, soap and shampoo, and a lock for your locker.

Social events planned for the year include BINGO nights, Arts & Crafts nights, Movie nights, Card nights and Board Game nights.

If you are a consumer with a physical disability, or would like to come work as a volunteer in the program, please contact Mohsin Khattak or Walter Quan at **416-392-0335**. The program is held at **707 Dundas Street West** (at Bathurst) on **Monday and Thursday nights from 6-8:30 PM**.

The SCCC is wheelchair accessible with ramps and an elevator. The program is FREE of charge.

## UPCOMING EVENTS

### Mother's Day Conference

The Association for Research on Mothering invites you to attend our 2004 Mother's Day conference on: "**Grandmothers and Grandmothering**"  
**April 30-May 1, 2004**  
**York University, Toronto, Ontario**

Registration deadline is April 15, 2004.

For more information or to register, contact The Association for Research on Mothering (ARM) at 416-736-2100 ext. 60366; E-mail: [arm@yorku.ca](mailto:arm@yorku.ca); Website: [www.yorku.ca/crm](http://www.yorku.ca/crm).

### CMHA Toronto 50<sup>th</sup> Anniversary Mental Health Week

Canadian Mental Health Association (CMHA) Toronto is hosting its **50th Anniversary Mental Health Week from May 3-9**.

The main event, "**Spring Free of Stress**," will be held **May 2** from 1:00-4:00 PM, at the North York Civic Centre.

The event will feature:

- Interactive seminars on stress, dealing with loss and achieving life balance
- Kite-making
- Face painting
- Story time for children
- 

To RSVP or to get more information on the Mental Health Week, please contact **416-789-7957 x237** or e-mail: [csnoddeon@cmha-toronto.net](mailto:csnoddeon@cmha-toronto.net).

## WEBSITES

### 211 Toronto

[www.211toronto.ca](http://www.211toronto.ca)

Community Information Toronto has relaunched its online 211 service. The site was redesigned to provide users with quicker access to key topics and fewer details to surf through. Enhanced features include a power search, print-and-go Mini Blue Books, contact lists, monthly updates on important changes to services, etc.

## BOOKS

### **The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness**

Written by Cory Silverberg, Fran Odette and Dr. Miriam Kaufman. Published by Cleis Press, 2003. ISBN: 1573441767

A self-help sex guide providing encouragement, support, and expert information on sex toys. The book also examines the myths about disability and sex and features a resource guide.

## EMPLOYMENT OPPORTUNITY

### **Program Coordinator Wanted (Full Time) for CILT's Project Information Centre**

Deadline for application: April 22, 2004  
*Position starts ASAP after May 1, 2004.*

A challenging position exists at a Toronto based information/resource centre for people with disabilities. If you have a strong customer service focus and are proficient in data-base management, particularly Microsoft Access, as well as other office based computer applications, then this position may be for you. You have the demonstrated ability to multi-task and work under pressure, possess top interpersonal and analytical skills and have experience working with members of the public as well as both community and government representatives. Knowledge of the disability community in Toronto is essential. Excellent written and verbal communication skills are required. Candidates must possess a degree in a related discipline to be considered. Competitive salary offered with a range of benefits after 3 months.

*The Centre for Independent Living in Toronto is an equal opportunity employer.*  
**NO PHONE CALLS PLEASE!**

Apply in writing by April 22 2004:  
Sandra Carpenter,  
Independent Living Program Manager  
205 Richmond Street West  
Suite 605  
Toronto Ontario  
M5V 1V3

Re: Project Information Centre Coordinator  
For more information about CILT and the Project Information Centre, visit  
[www.cilt.ca](http://www.cilt.ca).

### **New Energy Fund - Helping Individuals and Families Stay Warm I U A L S**

The Energy Fund, sponsored by Enbridge Gas Distribution, provides energy grants to low-income households in the **City of Toronto** that are having difficulty making ends meet, including heating their homes. The fund will provide eligible applicants with financial assistance for natural gas utility bill payments. The Energy Fund is delivered through Toronto's Rent Bank program. Inquiries and applications are being processed from February through April at the following community access centres:

- Albion/Etobicoke Housing Help Centre -North Office - 416-741-1553
- South Office - 416-252-6471
- North York COSTI Immigrant Services 416-244-0480
- East York Housing Outreach 416-698-9306
- Scarborough Housing Help Centre 416-285-8070
- Woodgreen Community Centre 416-469-5211
- York Community Services 416-653-5400
- Neighbourhood Information Post 416-924-2543
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For general inquiries, call 2-1-1 or Neighbourhood Information Post at 416-924-2543.

*A joint initiative of United Way of Greater Toronto and Enbridge Gas Distribution.*

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

205 Richmond St. West, Suite 605, Toronto, Ontario M5V 1V3

Tel: 416-599-2458  
Fax: 416-599-3555  
TTY: 416-599-5077  
E-mail: [pdn@cilt.ca](mailto:pdn@cilt.ca)  
Website: [www.cilt.ca](http://www.cilt.ca)

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