

# CILT's Parenting with a Disability Bulletin

Volume 6 Issue 4  
August 2003

## PDN ACTIVITIES

### PDN ANNUAL PICNIC

The 2003 Annual Picnic was a great success. 8 families attended the event on Saturday August 9<sup>th</sup> at High Park.

The children had fun running around the playground and exploring the park on a nature walk, while the adults relaxed and socialized. We enjoyed a delicious catered lunch and briefly discussed nutrition and healthy eating. Each family received an information package filled with facts, tips, suggestions and recipes for healthy living.

Many thanks to all who attended!

### PARENTING SEMINAR ON POSITIVE DISCIPLINE

Saturday September 27, 2003  
2:00pm - 4:00pm  
CILT  
205 Richmond St. West  
Suite 605

Would you like to learn effective discipline techniques? Develop your child's self-esteem, self-discipline, responsibility, cooperation and empowerment? Please join us for a 2 hour seminar featuring Pasquale Fulginiti, Early Childhood and Parent Educator, and author of the book [Kidstuff: How Positive Discipline Works Throughout Children's Lives](#).

The seminar will address common parenting issues and offer techniques, suggestions and alternatives for positive discipline. Attendant services and child care will be available upon request. RSVP to Kimberly McKennitt, PDN Coordinator at:

Tel: (416) 599-2458, ext. 35  
Fax: (416) 599-3555  
TTY: (416) 599-5077

***Members are encouraged to RSVP early. Space is limited for this event!***

## **Nurturing Assistance is On A Roll!**

*By Kimberly McKennitt - PDN Coordinator*

"If we can use the radio show to help fan the flame and get more people interested in doing something like this, we'd love to help out."

That's what Greg Smith, the founder and host of the weekly syndicated radio talk show On A Roll, had to say about the PDN and its Nurturing Assistance model. Just before Mother's Day, the PDN was surprised to receive a call from Mike Ervin, the producer of an American radio show called On A Roll. Mike explained that On A Roll is a live, weekly syndicated radio talk show on life and disability - the first and only one of its kind in the U.S. He and the show's host, Greg Smith, had come across CILT's website and were particularly interested in the Parenting with a Disability Network (PDN) and Nurturing Assistance. After a brief discussion, Mike invited me to speak about the PDN and a new model of service that provides physical assistance to parents with disabilities.

As a single father of three living on the gulf coast of Mississippi, Greg, who has muscular dystrophy, is the founder and host of On A Roll. He started the program back in 1992 on a local program out of Phoenix, Arizona and, to date, it airs on 40 radio stations across America and is broadcast live on the Internet. In celebration of Mother's Day, the tribute program kicked off with Greg and Mike sharing stories of their mothers and talking about the tremendous impact they've had on their lives. Greg expressed his gratitude to his mother not only for everything she has done in the past that helped shape who he is but also for the important role she plays in his life today, assisting with his personal daily care and the care of his three children. And Mike, who says his mother instilled a "naïve sense of entitlement" in him and his sister (both of whom also have muscular dystrophy), believes her attitude as a single mother and this unwavering approach to life are largely responsible for his many accomplishments.

As a father with a disability, Greg understands the need for organizations that support and offer services to parents with disabilities. Recognizing CILT's unique program for parents with disabilities, he asked me to explain the Parenting with a Disability Network and what the program offers.

Although familiar with the Independent Living philosophy, Greg had never heard of the term Nurturing Assistance before visiting CILT's website.

I described Nurturing Assistance (NA) and pointed out that CILT's NA model was developed for parents with physical disabilities who are able to direct their own care and the care of their child(ren). I outlined the role of the nurturing assistant and emphasized that all the tasks undertaken by the nurturing assistant are done so through the direction of, and in the presence of, the parent. It is not a

babysitting or nanny service nor is it intended for parents who require a break or rest.

We went on to discuss the fact that Nurturing Assistance is not widely available because it is not a well known or recognized service. Since many parents aren't familiar with this service or the possibility of it, most don't think to ask for it. I explained to Greg that the Nurturing Assistance project and model was funded by the United way of Greater Toronto and that, currently in Ontario, some parents have been able to establish nurturing assistance. These are parents who are already receiving attendant care services for themselves and who have been able to implement nurturing assistance into their service plans through their service provider.

By developing the model of nurturing assistance, I explained that we are hoping it will become recognized, more widely available and that our model will be a tool which parents, service providers and even funders can use and adapt to implement this type of service. Our research has proven that the need for support services like nurturing assistance exists and that by having access to such services, people with disabilities can fulfill their parenting tasks. It is also our hope that support services be established and available to all parents with disabilities, regardless of whether they require personal assistance.

Thank you to On A Roll's host, Greg Smith, and producer Mike Ervin for the opportunity to discuss the PDN and helping to spread the word about Nurturing Assistance!

On A Roll airs live every Sunday from 6-8 pm EST. Call in with your questions or comments to 1-800-510-8255 or visit the show's website at [www.onarollradio.com](http://www.onarollradio.com).

## **CHILD CARE EQUIPMENT**

### **Adapted Child Care Equipment Project for PDN Member Wins Tetra's Gizmo Award!**

In the April 2003 issue of the Parenting with a Disability Bulletin, you heard about the accessible crib project undertaken by the Tetra Society of North America's Toronto chapter for PDN member, Michele Gardner.

At Tetra's 2003 Gizmo awards, held on June 6th at the Queen Elizabeth Building in Toronto, engineer volunteer Ovais Gafhur, who worked with Michele, received the Gizmo award for this successful project. The awards are a celebration of the volunteers and participants of the Tetra Society in Ontario. Congratulations to everyone involved in this important project!

## PARENT'S CORNER

### Unable to Participate

By Rus Cooper-Dowda, PDN member - Florida, USA

*Reprinted with permission from Teaching Tolerance, Southern Poverty Law Center, Montgomery, Al. [www.teachingtolerance.org](http://www.teachingtolerance.org) / [www.tolerance.org](http://www.tolerance.org)*

November 8, 2002 -- I recall clearly the conversation between my son and another child, spoken while we were going to a local baseball card shop:

"Step on a crack, break your mother's back!"

"Too late for us, dude!"

The comment makes sense only if you understand this: Both boys had mothers who use wheelchairs.

Before my son was born, I'd dreamed of my future as a parent. I knew child rearing would be challenging, but I thought I was ready. The most difficult challenges we ended up facing, though, weren't about parenting; they were about the attitudes school officials and society hold against parents with disabilities.

Consider one of my earliest dreams, when, while pregnant, I pictured taking my son to his first day of school. Instead of my dreamy picture, we actually ended up boycotting his first day of school. Why? Because even though the district knew for seven months that we were coming, school officials didn't bother to fix the broken, rusted wheelchair lift -- a lift that had grass growing through its cracks.

Even after the lift was fixed, school officials insisted on storing outdoor play equipment in it. To use the lift, I had to throw woodchips at the school windows until someone noticed and moved all the toys.

### A Mighty Struggle

My son is a high school senior now, and it hasn't gotten much better. I've missed four autumn-semester open houses because the elevator to the second floor, where his classes are held, has been in disrepair.

I've struggled mightily to be the parent the schools say they crave. A former teacher, I've longed to be the classic cupcake-baking parent. But what I've encountered over the years has sent me a clear signal: Teachers at my son's schools welcome only the help of able-bodied parents.

To fight stereotypes and unequal treatment, I've sued one school district and battled the attitudes of those who think people with disabilities are contagious or dangerous to children.

Another school district wanted to put my son in special education classes, even though he didn't need it. We were told that was the only way classes could be accessible to me. It just wasn't on the school's radar that disabled parents could have able-bodied kids.

Here is what I've learned while addressing the rampant discrimination against parents with disabilities:

- More than 50 million Americans have disabilities.
- 1 out of 3 Americans has daily contact with someone they care about who has a disability.
- Anyone can become disabled at anytime due to genetics, accident or illness.
- 9 out of 10 disabilities are invisible.
- And as we live longer, more of us are aging into disability.

All of this means schools and other institutions for youth must make their space, events and programs accessible to adults with disabilities. One more bit of advice: Don't believe the argument that access is too expensive. Most groups that claim this have never actually examined or priced such changes.

Access provision can be free, cheap and worked into long-term plans. Independent Living Centers located in the same communities as inaccessible youth programs have been providing access for disabled parents on shoestring budgets for more than a generation. Schools and similar organizations should be talking to and working with their local Independent Living Centers, access consultants and, most importantly, parents with disabilities themselves.

"Nothing About Us Without Us" should be the working model for all such discussions. That motto, a South African slogan, became the name of a 1998 book by James I. Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment*.

### **Become an Advocate**

Others, too, can help fight barriers that keep parents with disabilities from classrooms and school functions. If you know a family with adult disabled members who have children in school, find out whether the whole family can get into the school. If they want to and can't, let the school board know you noticed and care. Most board members are elected -- let them know you vote, and keep letting them know.

Likewise, if you attend a youth program in a space where there are only stairs to get in, recognize that loving parents or guardians with disabilities probably missed that event because of physical barriers. Ask about access, and then complain as far up the chain of command as you can based on the answers you get.

In addition, help change societal attitudes. If you see a disabled parent and child in public:

- Don't speak to the parent through the child or ask the child what the parent wants.
- Don't assume the child is the parent's attendant.
- And help educate others who do any of the above.

So much work needs to be done, because the reality is that school and youth-program access continues to be an elusive hope for parents with disabilities. Society and its educational systems must begin to get their minds and hearts around the fact that people with disabilities can be active parents, too.

It has been the law of the land for more than a dozen years that parents with disabilities have the same program-access rights as able-bodied parents. Help make that law the mindset of your community, too.

### **Wheelchair Accessible Schools**

*The following is an excerpt from The Parenting Book for Persons with a Disability: From planning your family to raising adolescents (1999), Chapter 5, pgs. 104-106.*

The *Toronto District School Board (TDSB)* has a list of Toronto elementary and secondary schools in the former City of Toronto that are wheelchair accessible, meaning that all levels of the school and washroom facilities have barrier-free access. For details, contact Paul Lee, Project Administrator, Facilities Services Department at (416) 395-4595.

### **The Public School System:Accommodations for Parents with Disabilities**

Parents with disabilities would like to have physical access to their children's schools for the same reasons as anyone else: to attend open houses and parent-teacher conferences in the classroom, even to drop a small child off at the classroom door. Unfortunately, the majority of schools in the core city of Toronto are old, without access to floors above ground level.

In the current climate of unrest and underfunding in the public school system, it is difficult to have renovations made to a school to improve accessibility for a child with a disability, let alone a parent with a disability. There is no policy in place that supports parents with a disability who want to enhance the accessibility of their children's schools. There is, however, a process to follow in an effort to negotiate specific changes to your local school.

The first step is to approach the school principal with your request. Working with the principal and the superintendent of schools, without going further up the bureaucratic chain, is the simplest and most direct route.

However, if you don't receive any support at that level, try enlisting your local trustee. He or she can be an invaluable ally. If you don't know who your trustee is, find out by calling the TDSB at (416) 397-3061 or (416) 393-8809.

The next level to which you can appeal is the Toronto District School Board's *Special Education Advisory Committee* (SEAC). This is the committee to which student-related disability issues are referred, so it is the most appropriate contact point for disability issues in general. For more information, contact the current SEAC Chairperson, Pauline Ling, at (416) 393-8926; Fax: (416) 397-3114. [Note: you can also contact The Easter Seal Society's Manager of Special Education Services, Tina Shier, at (416) 421-8377 ext. 355; Fax: (416) 696-1035.]

Another forum you can approach is the *Parent – Community Network* (PCN). This group serves the TDSB in an advisory function only. It is a network through which issues that need to be explored further with the Board can be raised. Contact PCN at (416) 393-8892.

If you do not have any success at having modifications made to your local school, you can look into moving your child to the nearest accessible school. Within any "family" of schools, you would most likely find one that suits your needs, according to school trustee and [past] SEAC vice-chair, Suzanne Hall. Unfortunately, a parent's disability is not taken into account in approving a transfer. The reason for the transfer must be directly related to the child's needs, not the parents'.

There is one easy way to effect a transfer, however. Under the TDSB's "optional attendance policy," your child can transfer to a school out of your area simply if that school has the space. However, under these circumstances your child would not be eligible for bussing, free of charge, under the TDSB's student transportation policy. You would be responsible for your child's transportation to and from school.

If, because of your child's needs, he or she is eligible to be bussed to school, issues to consider include coordinating the bus schedule with your child care

arrangements and planning for someone to take your child to and from the designated drop-off point if you can't do it.

One factor to take into account when moving your child to a school out of your area is that you will probably have to put extra thought and effort into your child's social schedule. School friends will not be close by and your child may not easily get to know other kids in the neighbourhood if they are not interacting at school.

## COMMUNITY

### The Infant Hearing Program

**Toronto Preschool Speech and Language Services** provides free infant hearing service and speech and language services for infants, toddlers and preschool children.

The Infant Hearing Program is for children from birth to 30 months of age and offers the following:

- Universal infant hearing screening
- High risk monitoring
- Audiology services
- Family support services
- Communication development

Preschool Speech and Language Services is for children from birth to 5 years of age and offers the following:

- Assessment
- Consultation
- Support and information sessions
- Parent training
- Group and individual therapy

For more information, contact **Toronto Preschool Speech and Language Services** at 416-338-8255; TTY: 416-338-0025; e-mail: [info@tpsls.on.ca](mailto:info@tpsls.on.ca); website: [www.tpsls.on.ca](http://www.tpsls.on.ca).

### Child Disability Benefit comes into effect July 2003

The Canada Customs and Revenue Agency (CCRA) announced July 17, 2003 the implementation of the new Child Disability Benefit (CDB) for children who have a severe and prolonged impairment. The first payment of the CSB supplement will be issued with the March 2004 Canada Child Tax Benefit



(CCTB) payment and will include a retroactive amount from July 2003 to March 2004 inclusively.

The CDB is a tax-free supplement, for eligible recipients, to the CCTB and the Children's Special Allowance. It helps families with the cost of caring for children under the age of 18 who have a severe and prolonged mental or physical impairment. The CDB will provide up to \$133.33 a month in financial assistance for each eligible child.

The CCRA will automatically calculate and include the CDB in the CCTB payment in March 2004 for families who have already submitted Form T2201, Disability Tax Credit Certificate. They will not have to complete any other forms. To find out if your child is eligible for the CDB, please see the eligibility conditions outlined on Form T2201. Families with an eligible child who have not submitted Form T2201 are encouraged to apply as soon as possible to prevent delay when payment of the supplement becomes effective.

To get a copy of Form T2201 and for more information about the CDB supplement, the conditions for eligibility, and how to apply, visit the CCRA's Web site at [www.ccra.gc.ca/benefits](http://www.ccra.gc.ca/benefits), or call 1-800-387-1193.

## **UPCOMING EVENTS**

### **Education Wife Assault**

#### **AGM & Open House**

Come and celebrate another year of our accomplishments and help us *warm up* our fantastic accessible new space!

The Robertson Building  
215 Spadina Avenue, Suite 220  
Thursday October 23, 2003  
5:00 p.m. - 8:30 p.m.

5:00 Doors open. Meet our staff, students and program volunteers!

6:30 - 7:00 Business Meeting

7:00 - 8:30 Music and Refreshments!

Please RSVP to Erna by October 17, 2003 at

[eopena@womanabuseprevention.com](mailto:eopena@womanabuseprevention.com) or Voice: 416-968-3422, ext.22; TTY:  
416-968-7335; Fax: 416-968-2026.

This is a scent free event. ASL will be available.

## **Advisory Committee on Accessible Transportation**

The Toronto Transit Commission provides programs to improve the accessibility of both Wheel-Trans and the conventional transit system for persons with disabilities and for seniors.

To facilitate community input into the planning, development, and implementation of accessible transit, the Toronto Transit Commission has established the Advisory Committee on Accessible Transportation (ACAT).

Positions on the committee are open to residents of the City of Toronto who have disabilities, as well as seniors or others who have a knowledge of and an interest in accessible transportation issues and who are willing to make a commitment to attend and participate.

Interested applicants are invited to attend an orientation seminar at City Hall, 100 Queen Street West, to obtain more information about the Committee and its function. Seminars will be held in Committee Room 1 on Wednesday, October 15, 2003 from 2:00 p.m. to 4:00 p.m. and on Thursday October 16, 2003 from 7:00 p.m. to 9:00 p.m. ACAT membership application forms will only be distributed to attendees at the seminars.

Those interested in attending the seminars and require specialized services should call the Wheel-Trans office, weekdays, 8 a.m. to 4 p.m. at (416) 393-2462 or the TDD line (416) 393-4555.

## **WEBSITES**

### **Toronto District School Board**

[www.tdsb.on.ca](http://www.tdsb.on.ca)

Offers lots of information about the TDSB, it's programs, schools, and more.

### **Letterbox Library**

[www.letterboxlibrary.com/acatalog/DISABILITY.html](http://www.letterboxlibrary.com/acatalog/DISABILITY.html)

Offers a large selection of disability specific books for children. All listed titles in stock.

### **Safe Kids Canada**

[www.safekidscanada.ca](http://www.safekidscanada.ca)

Provides information on a wide range of safety topics to parents, caregivers, teachers and professionals.

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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Funded by: United Way of Greater Toronto  
ISSN 1481-918X