

CILT's Parenting with a Disability Bulletin

Volume 6 Issue 2
April 2003

PDN ACTIVITIES

ANNUAL PDN PICNIC

Planning for the Annual PDN Picnic is now underway. Stay tuned for more details to follow!

Your ideas and suggestions are always welcome! Call (416) 599-2458, ext 35 or e-mail pdn@cilt.ca if you'd like to get involved in this year's picnic.

PRIME TIMERS SPRING POT LUCK SUPPER

The Prime Timers cordially invite Adults from the Parenting With a Disability Network (PDN) to join them for a POT LUCK SUPPER!

Saturday May 24, 2003

4:00 pm to 7:00 pm

Centre for Independent Living in Toronto

205 Richmond St. W., Suite 605

(Richmond & University)

Bring a dish to share! Choose from the following list of options:

Salads, Hors d'oeuvres, Sandwiches

Finger foods, Main dishes/entrees,

Desserts

Beverages will be provided

THIS IS AN ADULT ONLY EVENT!

Please RSVP by calling (416) 599-2458 and speaking to either Nancy (ext 27) or Kimberly (ext 35) by "no later than" May 16, 2003. Please also let us know what dish you plan to contribute to the Pot Luck!

CILT will make every effort to have an attendant available for this event, however we are unable to guarantee that one will be present. Those who must have an attendant with them to fully enjoy this event are encouraged to bring their own.

Introducing... Prime Timers

Prime Timers is a new social club for adults over 35 years of age with physical disabilities.

- Are you in this age group?

- Do you have a physical disability?
- Do you want to meet people in this same age group?

Then maybe this group is for you!

Prime Timer Events include:

- Educational Workshops that work for you
- Dinner Outings
- Coffee Chats
- Bingos
- Day Trips
- Pot Luck Suppers
- Movies
- Social Gatherings
- And much much more

If you are interested in finding out more about the Prime Timers, please contact Nancy at (416) 599-2458, ext. 27 or e-mail peervolunteer@cilt.ca.

GET INVOLVED

Gardening Program

The Scadding Court Community Centre (SCCC) at 707 Dundas Street is planning to host a program for consumers with disabilities interested in gardening!

The gardening community invites those consumers who rarely have a chance to experience gardening to participate.

The SCCC is providing "raised planter beds" for people using mobility devices. For more information, please call Krista Fry at (416) 392-0335, ext. 243, or Sam Savona at ext. 247 (Wednesdays only).

CHILD CARE EQUIPMENT

Tetra Aids PDN Parent

By Kimberly McKennitt, PDN Coordinator.

Like many expectant first-time moms, Michele started planning for her baby's arrival early in her pregnancy. One of the items that would be essential for Michele was a wheelchair accessible crib. She had an old crib acquired through a friend which, if it met standards, she knew would require modifications. She

also needed to find someone willing and experienced enough to make the changes to meet her needs and make sure it was safe.

Michele began working with an occupational therapist to determine if there were any types of assistive equipment she might require in order for her to maintain her independence and care for her baby.

Although some ready-made store bought products can be used or adapted, assistive baby care equipment is generally not available on the open market. Often individual needs vary and many parents end up making or having equipment made for them. Enter The Tetra Society of North America. An organization dedicated to assisting people with disabilities, Tetra's purpose is to recruit skilled volunteer engineers and technicians to create assistive devices or environmental modifications designed to promote greater independence. Michele contacted Tetra's Toronto chapter (one of six in Ontario) and asked if they could modify her old crib.

To start the process, Michele had to fill out Tetra's "Request for Assistance" form. Then arrangements were made to conduct an assessment at Michele's home in order for Tetra to see where the device would be used. Tetra had never done a project of this kind before, so issues of safety and liability needed to be explored to determine whether or not they could proceed. The crib in question was old and there were concerns about safety standards. It was agreed that Tetra would send letters to major department stores across the GTA requesting the donation of a new, ready made crib for this project. Everyone was pleased when Toys R Us responded and agreed to donate a crib and mattress.

Michele then discussed her needs with Tetra's Ontario Coordinator, Glenn Barnes, and they shared ideas about how to modify the crib. Glenn says that there are 3 main aspects to consider when undertaking any project: the consumer's needs and level of mobility/dexterity; the actual space where the device or aid will be installed (if applicable) and used; and any restrictions that need to be considered. In addition, Glenn says that Tetra consults with consumers on the issue of aesthetics, hoping to make devices blend in to each environment.

Next, Michele met with engineer volunteer Ovais Gafhur. In preparation for this project, Ovais researched all the available information before meeting with Michele. Glenn says that he chose Ovais for this project because "he is meticulous... a dedicated volunteer."

During their meeting, Michele had a chance to see the crib and describe her specific needs to Ovais and show him where the crib would go. She needed to be able to pull her wheelchair right up against the crib with room for her legs to fit underneath. She also needed a side opening that would allow her enough room to transfer the baby in and out without fear of the baby slipping or rolling off the edge. Ovais took measurements, discussed the modifications that were needed,

and offered some suggestions. Michele was pleasantly surprised when he recommended a change table that could be mounted to the side of the table that the crib sits on, making the unit into an L shape that she would be able to configure in three different positions.

Suggestions and input were also sought from other Tetra staff and volunteers. In this case, Tetra looked to their administrative assistant who is an experienced mother and has a disability. They also sought advice from the volunteer engineers and technicians on locking mechanisms. For safety, they decided on 3 different locks. They also had Michele sign a letter of agreement, which is something they don't ordinarily do, stating that Tetra will maintain the crib, make any necessary repairs or further modifications and that, when Michele no longer needs the crib, she return it to Tetra.

Once the modifications were completed, Ovais installed the unit and, on a subsequent visit, returned to finish the change table surface, as it needed padding and a cover. Michele says she currently has the crib and change table fully extended, as this was the best option to give her full access to both the crib and the change table. Pleased with both the functional and aesthetic design, she feels confident using the unit and doesn't worry about safety.

As for Tetra, I asked them if they would be willing to do this type of project again. Glenn says that, yes, they would consider it if the situation was right. But Tetra encourages parents to look at what is already available and points out they cannot design products that are already subject to copyright laws. If parents aren't sure about making adaptations, give Tetra a call and they will discuss what they can offer. If they cannot assist with a project they will provide parents with resources and/or referrals to catalogues, stores, etc. To contact the Tetra Toronto Chapter call (905) 274-8584, fax (905) 274-2550 or visit www.tetrasociety.org.

Finally, during this project Tetra was contacted by the television show Body and Health. Curious to know of any significant projects that the organization was involved with, Glenn suggested they might be interested in the crib modification project as a life changing event. Michele agreed to allow Body and Health to film the process and the segment aired in early December. For anyone interested in viewing the tape, please contact the PDN.

A valuable resource for parents and prospective parents looking for assistive devices is Through the Looking Glass's publication [Adaptive Baby Care Equipment: Guidelines, Prototypes & Resources](#). Contact Through the Looking Glass at (510) 848-1112 (voice); 800-804-1616 (TTY) or visit their website at www.lookingglass.org.

PARENT'S CORNER

It Takes a Whole Village to Raise a Child

By Lisa Jones, PDN Member -- Ontario

This article originally appeared in Connections, Winter 2003. Reprinted with permission.

My philosophy is that even if I wasn't disabled -- and maybe because I am -- it takes a whole village to raise a child.

My name is Lisa Jones and I'm raising two girls -- Laural, 10, and Emily Grace, 4 -- on my own. I think my role as a parent is to guide my daughters and help them along, but my family and friends also play a huge part. When parenting with a disability, I think it's important to embrace the fact that we are all interdependent and we each have different skills to contribute in raising happy, healthy children. I have cerebral palsy and work as a health planner. I use a power wheelchair and have limited use of my hands.

When I was growing up, I always knew I wanted to have children. I knew I had a lot of stuff to pass on to a child and that I could help a little person become a really good individual. I wasn't exposed to the common stereotypes that suggest a person with a disability is somehow less of a parent, so it came as quite a shock when some of my relatives expressed these sentiments after I became pregnant with my first child.

They said I didn't have the right to have children because I was disabled, and that if I did have a child, I wouldn't be able to care for it. They questioned how I could expect to have a fulfilling life when not only would I not be able to do things for myself, but I wouldn't be able to do them for my child.

In spite of this opposition, I believed in myself and, since my children were born, I've rarely dealt with attitudinal barriers. The greatest challenges I've faced involved caring for my girls physically during their early years. Because I have poor fine motor skills, I couldn't easily lift my children when they were babies, support them as they began to toddle about, or push a stroller.

I met each of these challenges through problem-solving, trial and error and the fervent belief that I would be able to work something out. Many of the adaptations I came up with were based on simple ideas. For example, when Laural was born, my father built a crib with a side that slid away so that I could wheel right up to the crib. The crib was at a perfect height so that I could feed and change her there. In order to lift Laural, I would roll her up in a receiving blanket, then grasp the sides of the blanket and pull her onto my lap.

I couldn't push a stroller, so in order for us to go for a walk, I figured out a way to carry Laural -- who was then seven months -- on my lap while I pushed my wheelchair. I made a padded apron that I would wear, and which Laural could lean against. It included a fabric strap that fit around Laural's chest. Then I had my wheelchair repair store make an extra long seat belt that fit around Laural and me.

When Laural was first walking, I took her out wearing a harness with a long strap that I held. I would take her to enclosed playgrounds so that she could run freely without any danger of running away.

What I found, over the years, is that my daughters are incredibly resourceful, adaptable and safety conscious because they know that I can't rescue them like other parents can. I've noticed that able-bodied parents are very protective of their children. I can't be, so my children have become very good at self-managing. They understand -- at a level far beyond any other child -- that if they take a physical risk, they're on their own. I support them by giving them the confidence that they can figure out situations, and by allowing them to participate in decision-making.

For example, I remember when Laural was about 18 months, she climbed up on the back of our couch and began inching along the narrow top. I said "You better be careful, because Mom can't get you down, and if you fall, you'll really hurt yourself." I couldn't scoop her up, like other parents, all I could do was sit beside the couch and talk her through it. I could see her reasoning it out, figuring out whether she could move a little further, then deciding it was a bit too scary. She pulled her legs back over the front and was able to fall safely onto the couch. What has made the difference in my ability to raise my daughters has been the support of my family and friends. Transportation is a big issue, as I don't drive. One of the ways my parents help out is to drive my children to school and to other activities. One of my friends picks my kids up after school and that's her contribution to my "little village." I do things for my girlfriend's children in exchange, such as helping with French homework. It's that interdependence with other people that is so essential in raising children. Everyone has different skills, but we share what we can give.

During Emily Grace's first year, I received five hours of attendant services each day. Today, I receive two on weekdays and three to four on the weekend. Our attendants primarily meet my personal care, grocery and cooking needs, although they do help the girls with small things like braiding their hair. When the girls were young, the attendants spent more time helping them with bathing and dressing.

When Laural was a baby, it used to bother me that I couldn't do everything for her. I missed the feeling of being able to lift my baby up easily to my shoulder, or of being able to dress her when she was tiny. What I've learned is not to sweat

those things. I focus on what I am able to do, and I do it as often and fully as I can. I know my kids won't grow up with a complex because I didn't wash their hair when they were three months old, or because someone else tied their shoes. Regardless of who's braiding their hair, they know that I'm their mother. They come to me when they're hurt, when they want direction or when they want a hug.

I've always been open and honest with my daughters about my disability and talked about why I do things differently. In turn, I've also given them the license to do things in their own way.

I think my disability has given my children the ability to be hugely independent, adaptable and able to reason for themselves. It's also given them a strong sense of social justice. Laural and Emily Grace don't see disability or diversity because they just accept that everyone does things differently.

As a parent, I've gained a real sense of peace, fulfillment and purpose. I know that I'm raising really good girls -- not in terms of them being well-behaved, but in terms of them being good people at their core. I hope that in hearing my story, parents of children with disabilities will see that their child can have a full, rich life -- one that might even include children.

How to Build Self-Esteem in Kids

By Pasquale Fulginiti. This article originally appeared in the Toronto Star, Saturday March 1, 2003, pg. K7. Printed with permission by the author. Studies show that children who think little of themselves may perform inadequately in school. But those who believe in themselves can really excel. Children with high self-esteem are willing to try something new. They are willing to tackle tough problems. And they keep on trying.

Here are 10 easy ways parents can help children develop self-esteem.

- Eliminate the word "can't" from your child's vocabulary. When children say, "I can't," they mean "I don't know how to," "I am not able to" or "I don't want to." When a child begins a statement with "I can't," he or she will not put any effort into the task at hand. Eventually, this leads to a negative self-image. "I can't" develops into "I'm inadequate," "I'm not capable" or even "I'm stupid."
- Parents' expectations shape a child's belief that the child can do well, the child will probably think so, too. But sometimes expectations are too high. Anticipating that every school assignment will be perfect or comparing your child with others may harm self-esteem.

A parent should give age-appropriate tasks and praise the child for his or her efforts. For example, my daughter had not made her bed the way I wanted her to, but at least she had made an effort. So I stated: "Honey, your room really looks

different with the bed creatively made." I did not want to make a negative comment like: "You call that a made bed?"

- Teach your child to see the positive side of his or her inadequacy. Find something the child can discover from his or her errors. Ask: "What would you do differently next time?" Let the child contemplate and untangle his or her own dilemma. And let your child know you are proud of him or her for trying. Say: "I think you are a success because you built up enough courage to go back and try to correct the mistake."
- Let your children "accidentally on purpose" overhear you talking about their achievements. When they hear you talking on the telephone about what a good job they did cleaning their rooms or how much their reading has improved, they will believe it.
- Exhibit your child's finest work. I'm convinced students at our day-care centre had high self-esteem because of our hall of fame, where their work was exhibited for all to see. Do the same at home, with a school paper, drawing or photo.
- As your children grow older, give them more responsibilities and independence. Parents tend to become more rigorous as their children enter adolescence. At least once a year, reassess the house rules. Ask your children what they think is fair. You will be surprised at what the kids come up with.
- Never compare siblings: contrast them. This helps each child discover his or her own strengths. Comparing kids harms their pride. Try not to say things like: "Your brother always brought home straight A's. Why can't you?"
- Place two unique photos where your child will see them a few times a day, either on the child's desk or near his or her bedside.

The first should be a family photo. It will remind your child that he or she is loved. (If the parents are separated, have a recent photo of the child with both parents or two separate photos.) The second photo should show your child doing something he or she loves. (We have a photo of my daughter making pasta with her grandmother.)

Change the photos often and watch your child's self-esteem develop even more.

- Some parents make such an effort to help their children to be successful that the kids do not learn from their mistakes. Whether their kids are doing homework, making the bed or developing a new skill, these parents jump in with comments like: "Here, let me do that for you," or "Is that the best you can do?" The message they are really sending is "You are not efficient at doing this by yourself. I must help you or you will fail." If this sounds like you, try taking a hands-off attitude and let your child experience successes and failures.

In the winter of 1998, my son tried to skate for the first time. My daughter told him he might fall. She then added, "But if you do, this is the easiest way to get up," and demonstrated. When he did fall, he was able to get up without help. I was the one who thought he wasn't capable of getting up all by himself.

- Speak to your child in a tone that confirms your faith in him or her. For example, when my daughter was studying for a Grade 2 spelling test, she found a few words challenging. Instead of saying "We'll see if you can remember all those words," I said, "Knowing you, I know you can remember these words." She went to school the following day knowing that someone had faith in her. She said that made her feel confident.

Pasquale Fulginiti conducts parenting seminars and is the author of the child-rearing book Kidstuff. Visit his website at www.kidsstuffseminars.com.

UPCOMING EVENTS

People in Motion 2003

People in Motion -- Canada's Premier Event for Persons with Disabilities, Special Needs and Professionals Working in Related Areas, is coming to the Queen Elizabeth Building at Exhibition Place on Friday, June 6 (10 am-7 pm) and Saturday, June 7 (10 am-5 pm).

The show features 63,000 square feet of exhibits, including transportation and mobility, barrier-free design, health care products, accessible travel, leisure activities, technical aids, employment information, corporate services and government programs.

People in Motion is Canada's most comprehensive exhibition for people with disabilities of all ages, as well as their families and friends. Admission is free. Attendant services, First Aid, ample parking and refreshments are available.

For more information, please call (905) 702-1121, Fax: (905) 702-1244 or visit www.people-in-motion.com.

CHILDREN'S CORNER

Toronto Public Library's Dial-A-Story

416-395-5400

Children of any age can hear stories over the phone in 6 languages, 24 hours a day.

Dial-a-story is available in the following languages:

- English
- French
- Italian
- Spanish
- Portuguese
- Cantonese

Children can choose to hear a story for younger children (7 and under) or for older children (up to 12).

For more information about the Toronto Public Library's wide range of services, visit your local branch or call (416) 393-7131; TTY: (416) 393-7100; website: www.tpl.toronto.on.ca.

WEBSITES

Tetra Society of North America

www.tetrasociety.org

A charitable organization that recruits skilled volunteer engineers and technicians to work one to one with people with disabilities to make assistive aids or modifications to their environment so that greater independence can be achieved. Find out about Tetra projects, chapter locations, online request for assistance forms, links and more.

Ouch!

www.bbc.co.uk/ouch

A disability news web-zine operated by the BBC and staffed by reporters and columnists with disabilities. The main aim of Ouch! is to reflect the experiences and thoughts of people with disabilities, and to present alternative viewpoints on issues that are important to PWDs. It also aims to expose the absurdities of the portrayals of PWDs from the mainstream media by tapping into the realities of life in the British and international disability communities.

The PARENTING BULLETIN is also available on audiotape or in Braille.
Articles on products, agencies or services are for information only and are not meant as endorsements.

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