

CILT's Parenting with a Disability Bulletin

Volume 5 Issue 5
December 2002

PDN ACTIVITIES

Valentine's Day Party

The PDN and Prime Timers are joining forces once again to host a Valentine's Day Party on

Saturday February 8th, 2003 at CILT from 1:30 to 4:30 pm.

Mark your calendars and stay tuned for more details! A flyer will be sent out in January.

Please contact Kimberly at (416) 599-2458, ext. 35 with any ideas or suggestions for this upcoming family social event.

The PDN and CILT wish you and your family a safe and happy holiday season!

CHILD CARE EQUIPMENT

Meeting the Challenges of Putting Baby to Bed

By Sharon Jackson

PDN member - Westlock, Alberta

The simple task of putting a baby down for a sleep in a crib can be a real challenge for a wheelchair user. I researched different accessible crib prototypes, sure I'd find an ideal crib design. Unfortunately, the ideal crib design wasn't out there. Every design was problematic. One design I researched suggested splitting the side rail in half with each half swinging outward, much like a barn door. This posed a real problem. I'd have to back up in my wheelchair in order to clear the 'barn doors'. This would leave the baby unattended.

We came up with our own design that has proved ideal. We started with a standard metal hospital crib. The metal crib has the structural integrity necessary for modifications. A metal frame was first bolted to the wall. Then we cut the legs off the crib and mounted it to the metal frame, so that I could drive under it easily. The height that the crib is attached to the wall can be adapted to the clearance any particular chair needs to get under the crib. Next, we made the side rail move up rather than down so as not to obstruct my wheelchair from going underneath. We did this simply by inverting the rail. Metal cables were attached to the upper

corners of the rail. Pulleys and a ten pound weight were attached to the end of the wire. A ten pound weight can hold the side rail up at any height and allows me to have both hands free to attend to baby. Ten pounds is also about the maximum weight I can lift and pull down. Lifting the rail up is also made easier by using a silicon spray on the part of the rail that slides.

The design is perfect. I can diaper and put the baby to bed safely and independently.

Mothing, Law, Politics and Public Policy Conference

By Nancy Barry

When I was invited to attend the "Mothing, Law, Politics and Public Policy" Conference, I was ecstatic. I remember attending a similar conference a few years ago and, having enjoyed it very much, I was thrilled to attend once again. I went to the conference as a prospective mother with a disability. I met some very interesting people, quite a mixed group of people actually, including scholars in the field, service providers, mothers and daughters. However, while I was there it had appeared that I was the only one present with a visible disability. A couple of people came up to me and assumed that I was a student at York University (where the conference was being held). I thought it was interesting that people would assume that I was attending as a student (possibly studying motherhood or parenting) rather than as a parent or prospective parent with a disability.

There were many interesting topics presented by parents and professionals in related fields. Some of the seminars that I chose to attend included "Mothing and Work", "Mothing Challenges," and "Pregnancy and Work." Each of the seminars presented personal views and stories on each of the related topics. I was hoping to hear something about parents with disabilities somewhere in the discussions; however, when disability was mentioned, it was done so in the context in which the child had the disability and not the parent. I guess I wasn't all that surprised about this, as Parenting With a Disability is still a fairly new concept to many people. I felt that just my presence at the conference made a statement, in addition to some of the comments that I had offered during the conference. I like making people think and I would like to hope that I achieved that objective.

As someone with a disability who is not yet a mother but who is seriously considering it in the near future, I felt myself becoming quite emotional at times. Many of the women at the conference shared their personal stories, some of which were quite heart wrenching. Some of the issues made me think about my own situation and how I would handle some of those issues as a parent with a disability; issues such as post-partem depression, the challenges of being a working mother, breastfeeding and its effects on the emotions of a new mother. I

work full time and often wrestle with the question of whether or not I'll be able to continue working full time and be a mom at the same time. I am often very tired at the end of my days now and wonder if I'll be able to handle the challenges of both. Through my discussions with some of the other women, I discovered that my concerns were not very different from those of moms without disabilities. This kind of made me think that maybe there is a way to balance both. I am looking forward to becoming a mother one day and I am definitely ready for whatever challenges accompany my new bundle of joy.

Having a very supportive husband is a bonus. In the midst of some of my discussions with the other mothers at the conference, a lot of them had stated that they had wished their husbands had been there for them more when they were experiencing the challenges of being a new mother. Many of their husbands were off at work during the day, on long business trips, and in some cases the father wasn't in the picture at all. I feel very lucky that I have a very supportive husband who is very anxious to become a father. Together, I am sure that we can overcome the challenges that any parent experiences, with or without a disability.

GET INVOLVED

International Task Force on Parents with Disabilities and their Families

Through the Looking Glass has created a bulletin board for the National and International Task Force on Parents with Disabilities and their Families. Within the next couple of months, Through the Looking Glass will be organizing Task Force topic work-groups based on the discussions and priorities that emerge from this process. They invite you to go to the following website and post your ideas or comments. Repeat visits encouraged!

<http://www.lookingglass.org/phorums/>

International Day of Disabled Persons December 3, 2002

International Day of Disabled Persons occurs every year on December 3 and is intended to increase awareness and understanding of disability issues and trends and to mobilize support for practical action at all levels. The theme of this year's Day was "Independent Living and Sustainable Livelihoods." You can learn more at www.cilt.ca and www.un.org/esa/socdev/enable/disid2002.htm.

ARM to Toe!

By Kimberly McKennitt, PDN Coordinator

The Association for Research on Mothering (ARM) held its 6th annual conference in Toronto at York University, October 18-20, 2002. The topic of this year's conference was Mothering, Law, Politics and Public Policy and featured speakers from over 12 countries. It was an honour to have our proposal excepted and to be invited to present the Nurturing Assistance Model/Guide.

The conference was a first for me on many levels. It was my first official public presentation, my first opportunity to present Nurturing Assistance and the first time I broke a bone! But I'll get into that a little later. I was excited about this opportunity and thrilled that Enza Ronaldi, a member of the Nurturing Assistance Advisory Committee, PDN member, and a consumer of Nurturing Assistance, would be presenting with me (another first!).

On the first day of the conference I attended several sessions, including The Place of Birth in America, Mothering and Work and Mothering Challenges. As I listened to the presentations what struck me was the incredible strength that seemed to emanate from these women, all of whom came together from different backgrounds and different parts of the world to share their work, their knowledge and their experiences.

Another thing that struck me was the fact that, despite our differences, many of us were sharing the same challenges, frustrations, fears and guilt in motherhood. It was empowering to be surrounded by these women and to know that I had so much in common with them.

On the second day of the conference, as I was getting ready for a full day of sessions and networking, I had an accident in my house and broke my toe. I know it doesn't sound like much and, never having broken a bone before, I wouldn't have thought it was a really big deal. But let me tell you that it is! It probably didn't help that, in the process of breaking it, I also dislocated it! I'll spare you the details but let's just say it was one of the most excruciatingly painful experiences in my life, right next to child birth.

Having worked on our presentation for weeks, I felt so disappointed at the thought of losing this important opportunity. But with crutches in hand, some good pain medication and encouragement from my loving family, I decided that come hell or high water, I was going back to the conference to do my presentation the next morning.

The next morning I found that I needed help with almost everything: bathing, toileting, dressing, getting down the various sets of stairs inside and outside my house, etc. Anything that required the use of my hands while standing was pretty near impossible for me unless I could use my mouth. My husband eagerly

volunteered to help. Having had many years experience as an attendant it was easy for me to direct my husband on what I needed done. Despite his eagerness and my daughter's cooperation, getting ready and out the door took us a long time.

I was completely exhausted by the time I got into the car and wasn't sure how I'd manage the next four hours, let alone survive the car ride up to York. I experience motion sickness on a regular basis and was shocked at how intensified it was on the drive up to the conference while on pain medication. By the time I was dropped off, I felt so terrible that I was beginning to doubt my decision. But as I got settled in and the presentations started, I was determined to see it through.

The Mothering and Disability/Illness session began with two presentations on mothering children with disabilities, followed by two presentations on mothering with a disability.

Anna Kingston, from the University College Cork in Ireland, discussed the results of her study of mothers with children with learning disabilities in Ireland and the lack of services and supports for these families. Elspeth Ross, from the Fetal Alcohol Syndrome Association of Ottawa, discussed mothering children with Fetal Alcohol Syndrome. Corey La Berge, a student from the University of Victoria, discussed his research on mothering with Fetal Alcohol Syndrome/Effects. His presentation included a video documenting a number of mothers with FAS/FAE and their feelings and experiences as parents.

Finally, Enza Ronaldi and I presented the Nurturing Assistance Model/Guide. I started out by explaining that the Nurturing Assistance model developed by CILT is not for anyone but specifically for parents with physical disabilities, who receive attendant services for their personal care and who are able to direct their own care and the care of their child(ren). I provided a brief background about CILT and the PDN and gratefully acknowledged the United Way of Greater Toronto for its continued support of the PDN and for funding the Nurturing Assistance (NA) Project.

Enza continued with a detailed description of NA, and explained that its purpose is to physically assist parents to undertake the tasks involved in caring for their children and to help strengthen the parent-child bond. She described the role of the nurturing assistant as a paid employee, working under the direction and in the presence of the parent with a disability. Using photographic illustrations, Enza went on to discuss the various Nurturing Assistance activities such as diapering, bathing, changing, lifting and nursing . She shared some of her personal experiences using NA and the impact that NA has had on her and her family. I then turned to the Project process which included an advisory committee, interviews with consumers and surveys with service providers. From this process it was found that, although there is a growing need for NA, it is not a well known

approach, it is not well defined and it is not uniformly delivered. I explained that NA is currently delivered in Ontario through agency delivered services or through self-managed services but that only a limited number of parents have been successful in establishing this service for themselves.

I then presented the results of the project (increased debate, awareness, consensus and clarity about NA and our working model Nurturing Assistance: A Guide to Providing Physical Assistance for Parents with Disabilities). PDN information packages were distributed to all who attended along with a copy of the slide presentation.

A lively round of questions took place following our presentation that could have gone on for hours but our moderator, ARM president Andrea O'Reilly reminded us that our time was up! I was pleased with the feedback from our audience and felt that our presentation had been a success!

Thank you to Enza for presenting NA with me and thank you to ARM for giving us the opportunity to spread the word about this important new model of service for parents with disabilities!

The next few weeks weren't nearly as successful. I continued to experience major pain, not only in my toe and foot but throughout my entire body. The pain literally debilitated me. And after more than a week of constantly having to ask for assistance from my husband and daughter I slowly began to realize that only now did I truly understand some of the needs of the clients I had served as an attendant. I had often heard about the stresses caused from having family members assist with one's personal care but now I was actually experiencing it, albeit on a temporary basis.

As the days grew into weeks, the pain persisted and my need for assistance continued. There were so many things that I still couldn't do and I was really missing our old routine. I felt constantly stressed and knew that things were beginning to take their toll, not just on me but on my family. Finally after over five weeks of healing, I slowly began walking again and was able to resume many of my duties. After another few weeks, my family and I are now back to our old routine and I feel I have a new perspective on many levels. I look forward to the opportunity to participate in more conferences and you can be sure that I will be more careful with my feet in future.

UPCOMING EVENTS

Continuing Education Seminars at York University

The Association for Research on Mothering (ARM) and the Toronto Women's Bookstore are pleased to present FIVE Continuing Education Seminars at York University on the topic of MOTHERING AND MOTHERHOOD.

Location: York University: Room: TBA, Cost: \$45 per seminar, \$200 for the full series.

Light refreshments provided; please bring lunch. A Certificate of seminar completion & Reading List are provided.

ONE: Changing Societal Views of Motherhood: From Goddess Figurines to Contemporary Parenting Magazines.

This one day seminar will explore how the mothering role and cultural attitudes on motherhood have changed throughout history in response to changing economic and social forces. SATURDAY JANUARY 25, 11am-3pm.

TWO: Mothers and Daughters: From Estrangement to Empowerment
This one day seminar will examine how mothers and daughters today are challenging accepted views of the mother-daughter relationship so that this important relationship in women's lives may be experienced as a site of empowerment for mothers and daughters alike. SATURDAY FEBRUARY 22, 11am-3pm.

THREE: Mothers and Sons: New Ways of Raising and Relating with our Sons
This one day seminar will investigate the various ways mothers today are confronting traditional ways of raising sons through connected and close mother and son relations and nonsexist childrearing practices. SATURDAY MARCH 29, 11am-3pm.

FOUR: Mothering Today: Beyond the Myths
This one day seminar will examine contemporary myths of the 'good' mother and how mothers' lives are shaped by these myths and how mothers may challenge these myths. SATURDAY APRIL 26, 11am-3pm.

FIVE: Motherhood and Feminism: Challenges and Possibilities
This one day seminar will explore how the relationship between feminism and motherhood has been viewed and experienced over the last thirty-five years paying particular attention to how motherhood may benefit feminism and how feminism in turn may enrich motherhood. SATURDAY MAY 31, 11am-3pm.

For more information e-mail aoreilly@yorku.ca, visit ARM's website at www.yorku.ca/crm or phone (905) 775-3684.

COMMUNITY

Just for Dads and their Kids!

Drop-in at the LAMP Family Centre
185 Fifth Street Etobicoke, Ontario
Come visit Brian, our resident Dad.
Every Thursday from 6:00 to 8:00 pm
Dads... make a play date with your kids and meet other dads.
For more information, call Brian at (416) 252-9701, ext. 278

BOOKS

ANNOUNCING: The Temperament Guides, Volume 2: Activities for Early Intervention Professionals and Families

by Kate Andersen, M.Ed., with Sean C. McDevitt, Ph.D. Published by Behavioral-Developmental Initiatives.

RELEASE DATE: October 1, 2002.

The Temperament Guides, Volume II - Activities for Early Intervention Professionals and Families is a very practical workbook to help parents understand and cope with the temperament of a two to twelve-year old child. It offers a step-by-step approach for learning new and positive ways of responding to temperament-related behavior and mild behavior problems. The principles and strategies in the workbook apply to any temperament profile. The workbook can be used as back-up material for families undertaking a program of individualized temperament guidance, such as that outlined in our first volume, The Temperament Guides: Resources for Early Intervention Professionals, or it can be used on a self-help basis by parents. The workbook is also very suitable for professionals who are seeking additional material to supplement the principles and practices outlined in the first volume.

Over 40 new exercises have been developed for this workbook. Exercises which match parent handouts in the first volume are marked TTG 1, followed by the number of the page on which they appear in that guide. In the workbook, parents reflect on their hopes and dreams of parenting, consider briefly the situational stresses in their lives as well as their own childhood role models, explore their emotional and behavioral responses to challenging behavior, and learn about the distinction between behavior stemming from temperament and behavior which represents secondary problems. Parents are provided an arsenal of positive ways of responding to temperament and are introduced to a set of research-based tools for reversing true behavioral problems.

To order by mail, send a check or money order, stating that you are ordering Volume 2 of the Temperament Guides, to:

Behavioral-Developmental Initiatives

14636 North 55th Street

Scottsdale, AZ 85254, U.S.A.

Tel: 1-800-405-2313

Fax: (602) 494-2688

Cost: \$39.95 US. (Please note that there is a special price for ordering both Volumes I and II at the same time: \$89.95 US).

To order online, go to www.b-di.com/shoppingindex.html.

For further information, email us at Behavioral-Developmental Initiatives at bdi@temperament.com.

CHILDREN'S CORNER

Kids Advice to Kids...

WHAT DO YOU THINK YOUR MOM AND DAD HAVE IN COMMON?

Both don't want any more kids.

Lori, age 8

WHAT DO MOST PEOPLE DO ON A DATE?

Dates are for having fun, and people should use them to get to know each other. Even boys have something to say if you listen long enough.

Lynnette, age 8

On the first date, they just tell each other lies, and that usually gets them interested enough to go for a second date.

Martin, age 10

WHEN IS IT OKAY TO KISS SOMEONE?

When they're rich.

Pam, age 7

The law says you have to be eighteen, so I wouldn't want to mess with that.

Curt, age 7

The rule goes like this: If you kiss someone, then you should marry them and have kids with them. It's the right thing to do.

Howard, age 8

WEBSITES

Temperament.com

www.temperament.com

A clearinghouse for research and practical information about temperamental characteristics to be used by parents, students, professionals and others who have an interest in temperament.

HealthyOntario.com

www.HealthyOntario.com

A consumer health web portal containing health and health service information, feature articles, expert columns, daily health news, health tools and medical databases for details on health conditions and drugs.

The 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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Toll-free in Canada: 1-800-354-9950

E-mail: pdn@cilt.ca

Website: www.cilt.ca

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.

The opinions expressed in this newsletter are those of the contributors and may not reflect the views of *CILT*.

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