

CILT's Parenting with a Disability Bulletin

Volume 6 Issue 3
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PDN ACTIVITIES

ANNUAL PDN PICNIC

Due to the on-going concerns of SARS, plans for this year's **Annual PDN Picnic** have not been finalized. The picnic has been tentatively scheduled for **Saturday, August 9, 2003 at High Park.**

We would like to proceed with this event, but screening for SARS will likely be necessary so we NEED your input on the following questions:

1. Do you want the picnic this year?
2. Will you be able to attend?
3. Do you want the PDN to screen all attendees for SARS?
4. Would you prefer that people be responsible for screening themselves

[For example, asking yourself: Have you been exposed to anyone with SARS? Have you recently attended a hospital or health care facility? Do you have a temperature above 38 °C (100.4° F)? Or are you experiencing symptoms such as muscle aches, severe headaches, unexplained fatigue or illness, cough, shortness of breath, or fever?].

We are asking PDN members to contact us and let us know what you think. Please contact the PDN by no later than July 10th at (416) 599-2458, ext. 35; TTY: (416) 599-5077; E-mail: pdn@cilt.ca.

POT LUCK SUPPER

Many thanks to everyone who came out for our **Spring Pot Luck Supper** on Saturday May 24th in the CILT boardroom.

As usual it was a huge success, attended by many of our regular members, a few new faces, and even a couple of surprise international guests! With a buffet table fit for royalty and an exciting raffle filled with unique prizes, it was an intimate, social afternoon and a perfect way to welcome in Spring. Thank you to peer support and volunteer coordinator Nancy Barry and to attendants Sharon Robertson and Asif Syed for a job well done!

GET INVOLVED

Peer Support Volunteers Needed!

The Parenting with a Disability Network (PDN) is all about peer-support and information-sharing. Quite often the best information and support is through other parents and prospective parents who are, or have been, in a similar situation and who can share their experiences, joys and challenges. And let's face it: we all need someone to talk to from time to time. That's why we are currently recruiting volunteers for our **Peer Matching Program**.

If you are interested in sharing your time and experiences with other PDN members, either by telephone, e-mail or in person, then we want to hear from you! Contact Kimberly at (416) 599-2458, ext. 35; TTY: (416) 599-5077 or E-mail: pdn@cilt.ca.

International Women's Institute on Leadership and Disability Conference

Mobility International USA (MIUSA) is hosting the Second International Women's Institute on Leadership and Disability (**WILD 2003**) conference from **September 17 to October 5**, in Eugene, Oregon, USA.

Women with disabilities from around the world who are new and emerging leaders are invited to apply for this opportunity to strengthen leadership skills, exchange wisdom and strategies, create new visions and build networks of support to improve the lives of women and girls with disabilities internationally. E-mail development@miusa.org or fax: 1-541-343-6812 for more information.

PARENT'S CORNER

Being a Mum

By Indra Beharrysingh, PDN member--Ontario

The following speech was presented at the Canadian South Asians Supporting Independent Living (CSASIL) third annual Diwali (Festival of Lights) event, November 2002.

We have a precious little angel whose name is Shivani. Michael and I were married for 10 years when we decided it was time to start our family. We had talked about having a family before we got married and had both agreed that we wanted children. Over the course of those 10 years we would talk about children, somewhat wistfully agreeing that it wasn't the right time. Because of the cause of my illness, a small part of me was a little concerned about getting pregnant. I have fully recovered from the illness that caused my disability 24 years ago, but

my treatment involved chemotherapy and radiation at a young age, and I worried that this might have affected my chances of getting pregnant. Another thought that crossed my mind before we got pregnant with Shivani was that we could be one of the over half a million Canadian women and men that are affected by infertility - these are non-disabled people.

Generally, my health is fine; I just don't walk. Mikey's health is fine; he walks. Walking and having children are not related in any way. The cause of a disability might possibly have an effect on fertility in that certain treatments might affect one's ability to conceive or certain types of disability might make it more of a challenge to conceive. But not being able to walk has nothing to do with having children or the ability to have children.

Once we made the decision that we were ready, we were pregnant within a few months. It was the most exhilarating feeling to know that there was a little person that we had created about to come into our lives. The pregnancy was relatively simple. Not knowing what to expect, I took a lot of things for granted and was unsure as to whether things were normal or whether to be concerned. I was sick for the duration of the pregnancy - for the first 4 months with morning sickness that lasted all day and then, once Shivani started growing, with indigestion caused simply because there wasn't room for food to digest properly. The medical staff following me prepared me for a nightmare of a delivery. My OB felt that I might be able to have a natural childbirth but said we couldn't be sure until the baby was ready to come. I was told that an epidural wasn't an option because my curved spine might mean that it wouldn't work properly and because an epidural would definitely mean having an I.V. and we had run in to some difficulties with IV fluids and congestive heart failure. The alternative to natural birth was then a caesarean under a general anaesthetic in which case I would miss my baby's birth and Mikey would too as he would not be allowed to be there, unlike a section under epidural. The reason - his role at the birth was to support me and if I was out cold he had no role. The mere fact that he just happened to be the father and it might be important to him to see his child come into the world didn't count! Still, our main focus was bringing our child into the world safely.

When the time came it was a breeze! Shivani was a little anxious and came to us a couple of weeks early. I waited until the contractions got a little uncomfortable before waking Mikey at 6 a.m. January 8, 2002. We arrived at the hospital around 9 a.m., and the attending OB was someone unfamiliar with my history. I was admitted to Labour & Delivery and hooked up to all of the paraphernalia while the OB read my chart. Meanwhile, I knew Shivani wanted out and had decided this had to be done without intervention if I wanted to experience it and be aware of it. The doctor, fearing the worst based on my chart wanted to send me downtown to Mount Sinai so that I could be in ICU and have a line inserted in my chest in case I went into heart failure - something that had

occurred twice in the past week due to the doctors ordering excessive intravenous fluids .

One of the most disconcerting things, for me, was because I did not know what to expect I became totally reliant on the medicos and I was hesitant to draw attention to much of what I was feeling for the fear of it being interpreted as complaining or whining. So, I didn't ask many questions and I found out later that perhaps I should have spoken up at times when I did not. In any event, the ambulance was waiting to take me to Mount Sinai; Mikey would have to follow behind. After almost 2 hours of being admitted, the OB got through my chart and came to see me to see how much I was dilated and to send me on my way. I could have told the doctor I was ready to have the baby. By this time I was in considerable pain. He checked and looked at the nurse and told her we were going to have the baby NOW and not to bother with the ambulance. I was going nowhere. Mikey tells me the doctor put his hand on the baby's head to stop her from coming out any further until the doctor could don his robe. Within minutes and only 3 pushes Shivani entered our lives on the outside in a normal and natural delivery, free of drugs and interference, and after only about 1- hours of intense labour pains.

Life has never been better. I like to say I have never been so happy in my life and never been so tired. It is not easy, but I have a sneaky suspicion that if you ask any parent they will say that. When I was asked to say a little something here, I kept thinking that most of what I have experienced as a Mum is probably what most other Mums experience. Perhaps there are things that I face because of my disability - physical barriers - but, as with most things, one gets past the obstacles and moves on.

Our home is not fully wheelchair accessible and so there are frustrations that I faced before Shivani came along that, at times, seem to be more of a challenge now. There are things that I have had to work out on my own, certain logistics, but I am not alone, I have Mikey. We work as a team - a family. I'm not sure we would do things so very differently if I did not have a disability. I can't bathe Shivani on my own. Our bathroom is too small for me to have an area where I could fill her tub and bathe her. Carrying a filled tub is not an option, so her Papa bathes her. Many Mums, Mums without a disability, have told me bathing is something they leave for the Dad. Considering that Mikey doesn't have the equipment for nursing her, which is something she sometimes does a lot of although now that she is on solid food it has lessened somewhat, bathing gives him a chance to interact with baby. Some might interpret bathing Shivani as something I need help with, but bathing Shivani is something I might have handed over to Mikey even if I could do it!!! The other thing I have not been able to manage is getting Shivani in and out of her rear facing car seat and carrying the car seat with Shivani in it is too heavy. So for now, we don't go out alone. It is just a matter of time before Shivani is in a forward facing seat and walking and

she will be able to help me help her. Other than those two things, so far, I can care for my angel despite my so-called disability.

I do as much for Shivani and with her as I can - I love being her Mum. I have to try to remember that other people might want to spend time with her too. I have been told that perhaps I spend too much time with her, holding her and not wanting to leave her. My reply is that that is my role, to Mother her and be with her. I have been given 52 weeks away from my paid job to be with Shivani and I am not about to relinquish more of that time than I have to. I absolutely love being with her. She is my joy. There will come a time when she does not want me to hold her, and won't need me as she does now.

I am getting better at asking for help when I need it. My parents were somewhat denied an opportunity to care for Shivani in the beginning because I insisted on doing it all my self, only allowing Mikey to care for her as an alternate. I wanted her all to myself and yes I did wear myself out after a time.

Someday we hope to add to our family and give Shivani some siblings. Looking back now, I think I might accept more help where help is offered if, by the Grace of God, I go through it again. I have heard that some cultures prescribe that new Mothers stay in bed for 30-40 days only feeding the baby, no housework permitted!!! Next time, I will learn to turn a blind eye to some of the housework and only admit visitors who bring food or will put on a load of laundry or run the Hoover over the floors or mop them! I did and perhaps, still do get a bit bothered by some of the things that I leave undone because I prefer to be with Shivani; dust accumulating on the piano, and windowsills; a lovely meal I didn't get around to preparing! But the house is far from dirty and we still eat, even if I don't always make it at home! In the beginning I expected I could and should be a Super Mum - having the house in immaculate condition, looking and feeling like a million dollars, a freshly made four course meal on the table in the evening and a hale, hearty and happy baby. Someone told me that being a Super Mum is a myth and that either I have everything looking good in the house and miss out on time with my baby or let the housework wait and spend those precious moments with the baby while I can. I choose to heed that advise now! I can be a Super Mum, but not by neglecting my baby to attend to unimportant things. I can be a Super Mum by providing a safe and happy environment for Shivani and giving as much love in me to give. So, if you come to see me, don't expect gleaming floors, sparkling mirrors, polished surfaces and elaborate meals. But expect to see Shivani and I hale, hearty and happy - most of the time anyway.

There are people who stop and stare. People did it before I had Shivani. Now the look is "A girl in wheelchair with a baby. I wonder, is it hers?"

A couple of things I must say in closing. First, for most individuals who are trying to get pregnant and are under 35 years of age there is a 25% chance each month of achieving a pregnancy. The chances of becoming pregnant increase to

60% within three to six months and up to 85% after one year. Given the odds, a child, to those of you with *and* without a disability, is a miracle. Second, there is a misconception that people with disabilities don't have the same desires, wants, dreams, goals, call it what you like, that non-disabled people have. I am thankful for parents who raised me with love and enough wisdom and integrity to treat me as their child plain and simple, not their *disabled* child. They expected nothing less of me than they did my brother and I learned to expect nothing less of myself. My disability was seen as incidental, not part of who I am.

As a young girl I dreamed of the things I think most girls dream of. These were mine: (1) Meeting someone extraordinary and special to share my life with - I met Michael. (2) Having a family - we have started with Shivani. (3) Having a fab, highly paid job or winning the lottery - for me being a Mum or parent is the noblest job I can think of and while the pay is not monetary it's the most rewarding, and higher than any salary I could ever hope to earn. As for the lottery, looking at my beautiful child and loving husband, I know I've got the jackpot. I don't feel like a Mum or parent with a disability. Perhaps that is because to Shivani, I am and hopefully always will be, simply her Mum.

Parenting teenagers: growing up ...and moving on

This article originally appeared in the Disability, Pregnancy & Parenthood international, No. 42, Spring 2003. Reprinted with permission.

Parenting teenagers brings new challenges and rewards for all parents and issues vary from family to family depending on individual circumstances and personalities. Many factors influence family dynamics such as ethnicity, education, employment, income, social support and so on. In the context of disabled parenting there are great variations in types and levels of an individual's impairment and in family experience of disability.

A young person may have grown up in a family in which a parent has always been disabled. Or a parent may have a progressive illness or have acquired an impairment suddenly, as the result of an accident for example. Much can change within a family during the years when a child is growing to adolescence and parents have mixed experiences.

"In some ways I find this stage of parenting easier than when the children were younger because it's more about talking with them and giving moral support and it's less physically arduous," comments one parent of teenagers, who is a wheelchair-user.

Despite the many strengths of disabled parents, raising teenagers can be heartbreakingly difficult at times particularly when linked to restricted access to services, resources and money, and complicated by other people's assumptions.

Research shows that having access to appropriate resources and support can, for example, help parents manage discipline and behavioral problems more effectively.

This feature gives a brief overview of various issues and highlights some experiences of disabled parents.

Building self-reliance

Children of disabled parents are often encouraged to be self-reliant from an early age, which has both positive and negative consequences.

"I can't access my eldest daughter's room so even if I wanted to attempt to tidy it I can't. All I can do is nag or withhold pocket money. As a disabled parent I have to be more willing to 'let go' and let them grow up fast. They have a lot more independence, which is positive, but it can be stressful too. If I tell them to be home by 11pm and to ring me if they're not, and they don't ring, what do I do? If they did have a problem I wouldn't be able to go and get them. I would have to ring someone in my network of mates, but these friends are likely to be disabled too." Poppy Hasted

Communication and trust

Disabled parents often comment on their efforts to develop open and trusting relationships with their children.

"I've had to learn to be 'laissez-faire' and have a fair degree of trust that normally I wouldn't have. For example when my wheelchair was broken I had to give my daughter my bank card so she could withdraw money and do the shopping. Giving my daughter extra responsibility has resulted in us becoming good friends. But it's not easy. I don't say 'don't' in the main. I'd rather they do things – I may put a restriction on it but I find it easier to know what they are up to rather than suspect it and not know and not be able to do anything about it. I know they drink and smoke occasionally and I allow it. My daughter says that if I say 'no, don't do it', then she knows I mean it because I say it so rarely – so she doesn't do it! There's a much stronger element of trust." Poppy Hasted

"You have to make them aware that you can't run after them in a physical sense. If she didn't come in when I told her to I'd go and look for her - I'd be standing out in the road trying to see her but my night vision is very poor. She quickly became aware that I had to know if she was going to be late." Chris McMillan

Accepting new situations

Adolescence today is very different from what most of today's adults experienced. Childhood is growing shorter. Young people and their families have to face pressures about appearance, dieting, dating, peers and independence at a much earlier stage.

"Hazel has much less patience going shopping with me now. There's no time in her life for woolly thinking! When she was younger she was more likely to walk around and wait while I decided what I wanted. She won't do that now she's older. I've no choice... she's in command and she's the one with the wheels giving up her time. You've got to put yourself in her shoes. Hazel left school at 16 and went to college so she became a young adult earlier. As soon as she got a car she got the independence she needed and I had to learn that I was not going to be ferried around. You have to stand back and realise they've got their own lives." Chris McMillan

"Rebecca is a normal teenager and she is doing so well at school. I try to help her with homework but most of her work is very hard to follow because of my British Sign Language. I try to listen and talk with her rather than shouting at her. I always ask her to tidy up her bedroom, if she won't I just shut the door, to avoid getting cross with her! Not easy!" Sarah Ivey

Financial headaches

Disabled parents are more likely to have a low income than their non-disabled counterparts. A significant number of disabled parents are also lone parents. There is no benefit that takes into account the extra cost of parenting as a disabled person. For some families this means extra hardship during the teenage years.

"School trips are more expensive when children are teenagers and funding them can be difficult. I'm a single parent of two daughters aged 14 and 17 and their school trips cost £300-400. Their clothes are more expensive as they need adult-sized everything. It's so easy to get into the 'resentment routine' when I have to keep saying 'sorry, no, I can't'. Luckily I'm working, but for disabled parents who aren't it can be a nightmare."

"Non-disabled parents would not only know their child's friends but also their parents. I can't get into their houses so don't meet their parents nor do I get up to school often. I go to parents' evenings but not social events as a taxi costs £40." Poppy Hasted

Seeking external help

When researching her book, *Disabled Parents: Dispelling the Myths*, Michele Wates spoke to a number of disabled parents with teenage children. Three out of their seven older children had received or were receiving child guidance. Should this high proportion be seen as evidence that children of disabled parents are more likely to have emotional problems? Not necessarily, argues Michele. "Young people whose parents have continuous contact with health and social services are more likely to come to the attention of service personnel. By the

same token, this group of parents may be better informed than the general population about the range of services which are available. Also, in part because of their sense of responsibility, they may be less inclined than non-disabled parents to let things ride or to deny the existence of problems."

However, getting help can be difficult for disabled parents, both in dealing with emotional and relationship problems and also when trying to seek support for parenting.

"...Because we are Deaf we are far more restricted in who we can turn to for help...we had a lot of trouble to find a therapist and counsellor who would be able to communicate with Marianne and me and who would also understand my disability." Vicky D'aoust, Bigger Than the Sky

Caring tensions and leaving home

Disabled parents usually try very hard not to put undue personal demands on their children. Nevertheless, difficulties in accessing mainstream support services can mean disabled parents relying on their children for help with certain tasks. The 'young carers' debate is complex and can only be touched upon in this feature. Tensions arise when considering what tasks or household chores any teenager would be expected to help with (and the trials and tribulations of eliciting co-operation) versus what is inappropriate and the result of lack of appropriate support available for disabled parents. But what happens when children want to leave home?

"I try not to impose too much on my daughters because of my impairment. However, as a single parent they can't, for example, both go and stay with their grandparents at the same time. I need one to stay with me unless I go and stay elsewhere. My eldest daughter was concerned about applying for universities away from home and is going to do a two-year gap to see her younger sister through 'A' levels before she goes." Poppy Hasted

"My impairment certainly didn't deter my son from going to university. However, when he comes home he immediately takes the car keys from me and insists that he drives to avoid me getting tired." Beverley James

Teenagers' attitudes

It has been said that in families where one or both parents are disabled, and differences are discussed, lived with and valued, children may have a better chance of developing an open mind about diversity.

"When Melanie wrote her college essay, she wrote about me. She said that as a young child, she had been embarrassed to be seen with me, but that as she matured it became easier. She did not like the stares that accompanied us wherever we went, and she did not like having to explain about my disability,

which is cerebral palsy. As she grew older, she admired me for always trying new things and never giving up on what I wanted." Laureen Summers

"My disability means I can't walk far. On family holidays my sons got used to the fact that I stayed behind while they went off canoeing or whatever with their dad. But they never resented me." Beverley James

Developing suitable responses to deal with negative attitudes is something most parents of teenagers have to contend with. Each family's perceptions, circumstances, challenges and responses are unique.

"I don't want you coming to the parents' evening' said my teenage son, frowning at my wheelchair. 'I shan't allow your prejudices to prevent me from meeting your teachers', I retorted. For a couple of days I worried about Ben's attitude to me, until hearing a number of non-disabled mothers reporting similar conversations with their sons reminded me that it was a pretty standard adolescent reaction. If his objection hadn't been on the grounds of my being in a wheelchair it might have been on the grounds of the make or age of my car, or my dress sense."

"A friend asked her teenage son if he felt embarrassed about having a disabled mother. 'Course not' he replied cheerfully. 'You're ma mum. You just embarrass me full stop.'" Michele Wates, *Disability Now*

"My two don't think I'm embarrassing (they told me this recently) because, apparently, I wear reasonable clothes, let them smoke and drink if they want to and if they stick to reasonable limits, don't yell if their friends smoke, like the right sort of music and (most importantly) went to a 'Black Sabbath' concert in my youth and saw Ozzy Osbourne live!" Poppy Hasted

"...Like most teenagers he grumbles a bit about chores, especially taking out the garbage. I asked him not too long ago if he thought he had missed anything having two parents with disabilities. 'Like what?' he said. Enough said." Vickie Beck

Source material

Disabled Parents: Dispelling the Myths. Wates M, 1997, London: NCT

Bigger Than the Sky: Disabled Women on Parenting. Wates M and Jade R, 1999, London: Women's Press

Parenting Teenagers. Disability Now, Wates M, May 2000

The Parenting Book for Persons with a Disability. 1999, Canada: CILT

UPCOMING EVENTS

Eaglewood Folk Festival

August 22-24, 2003
Eaglewood Resort
9715 Morning Glory Rd.
Pefferlaw, Ontario

The Eaglewood Festival is an annual family-oriented event, featuring performances by gifted Canadian songwriters and musicians, children's programming (afternoons), all day workshops, crafts and camping. The festival accommodates people with disabilities by providing accessible washrooms, paved trails, ASL signing and alternate format programs (Braille, large print and audio tape). Large tents suitable for wheelchair access are also available on a first-come, first-served basis. Local girl guides also available for babysitting

For more information contact Doug McArthur at (705) 437-1666;
E-mail: dougimac@sympatico.ca; Web site: www.eaglewoodfolk.com.

COMMUNITY

WindReach Farm

Celebrate Summer! Come to WindReach Farm where there is always lots to do. Experience the great outdoors in a wheelchair accessible environment. Book your visit now to enjoy all the wonders of Summer at WindReach Farm.

FARM MUSEUM: Groups can visit our century old barn and discover historical farming equipment. They can even learn more about wool at a spinning demonstration

FARM TOURS: Groups can visit the petting zoo, barn, feed various animals, and take a seasonal short hike around the boardwalk

HAY WAGON RIDES: Groups can take a hay wagon ride around the facility and see all of the animals on the outskirts of the farm. (Weather permitting)

RECREATIONAL FIELD: Groups can use the recreational fields to play games, and sports. There is also a playground, which is accessible for all participants.

LUNCH FACILITIES: We have indoor/outdoor facilities for lunch, which can include cooking facilities like a kitchen, BBQ and picnic area. Also, indoor facilities can be used to play games, arts and crafts, and work on projects.

POND TO POND TRAIL: Wander over the pond to pond trail and discover all of the wonders of nature. We will soon have interpretive signage that our visitors can explore to learn more.

OTHER DETAILS: WindReach Farm is a charitable organization especially designed for the accessibility of our visiting participants. Our recommended donation is \$5.00 per visitor and \$2.00 per support staff. All visits are by appointment only. So, book your tour quickly!

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WEB SITES

STAY ALERT... STAY SAFE (SASS)

<http://www.sass.ca/sassfact.htm>

Stay Alert... Stay Safe (SASS) is a street-proofing program geared to children 7-10 years old. In reality, however, SASS is about a feeling - a feeling of being smart and in control. Our tips and the messages of our program are applicable for all ages.

The Stay Alert... Stay Safe mission is to develop an on-going, national street-proofing program actively involving both children and adults, that aims to make them aware of and alert to potential dangers, by building situation understanding and, more importantly, children's confidence in handling such situations.

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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:

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The PARENTING BULLETIN is also available on audiotape or in Braille.

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