

PARENTING WITH A DISABILITY BULLETIN

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PDN UPDATE



Spring Forward Through Empowerment: disABILITY Doesn't Have to Be a Barrier to Good Parenting By Nancy Barry and Carling Barry

On Thursday May 6th, the Parenting with a Disability Network held a one day conference entitled 'Spring Forward Through Empowerment: Disability Doesn't Have to Be a Barrier to Good Parenting'. The purpose of this conference was to educate and work together with service providers in the family, parenting and child service sectors on issues of parenting with a disability.

The day started out with a panel discussion comprised of parents with different disabilities, discussing their stories and experiences of being a

parent; including how and why they decided to become a parent, and issues they have faced with health care and service providers. This section of the conference was a very emotional piece that affected many people in the audience. From the expressions on their faces, it was easy to tell that many of them were trying to relate to the struggles that parents with disabilities encounter and that maybe through hearing these stories they would want to promote change and help to ensure that parents with disabilities have an easier time with issues that they have to face.

Followed by a catered lunch, the afternoon started

out with a guest speaker who is a Doula with a disability and whose clientele is mainly comprised of mothers with disabilities. She discussed her work and what made her decide to become a Doula, as well as some of the differences in issues faced by parents with disabilities working with



a health care provider versus a Doula. She ended her talk with an activity that got the audience thinking about what it feels like to be pregnant.

This led to a detailed discussion of a very important issue for many parents with disabilities that is so often



misunderstood by many service providers – and that was the topic of Nurturing Assistance. Nancy Barry discussed Nurturing Assistance: where the concept came from, what it is and what it isn't, and what needs to be done in order to make nurturing assistance more than just a concept. She did this by showing a video of parents with disabilities using adaptive equipment and creative ideas to make the act of parenting more accessible.

We ended the day with a discussion of the existing myths around parenting with a disability, where they come from and what we can do to debunk some of these myths. The conference was a great success and served as a great start to future collaborations to making parenting with a disability a more positive experience.



Mother's Day Event

On Saturday May 1st, the PDN hosted a Mother's Day event and it



was a smashing success. Although we had a small attendance, the décor, the food and the entertainment made it a fun-filled afternoon. We had a great en-



tertainer by the name of "Melody Mist", a female singer who sang hits from the 50's to today. Her music made you want to get up on your feet and dance to the music. Everyone just relaxed and enjoyed the show.

PDN Annual Picnic

Last year, due to the City strike, we were unable to meet for our annual summer picnic. This year, however, we reserved a spot in High Park so we can have our picnic this year. It will be held on Saturday August 14th, 2010. Stay tuned for further details. A flyer will be sent to all PDN Members in July.



The Maternity Information Gap for Physically Disabled People

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A UK study on physically disabled parents' experiences of maternity services reveals that physically disabled people embarking on parenthood face a number of challenges. In addition to working to provide the best start for their babies before and during pregnancy, through birth and into parenthood, they often also face a challenge in getting appropriate information and support to enable them to plan and prepare for birth.

The study was carried out by the UK information charity for disabled parents, Disability, Pregnancy and Parenthood International, as part of Empowering Parents, a three year initiative funded by the Department of Health.

In the study, we aimed to develop understanding of the information needs of physically disabled parents who

use maternity services, and also to investigate the scope of existing provision.

We use the term “physically disabled” in the widest sense to include those with mobility problems and other physical impairments, and also people with neurological conditions such as cerebral palsy, multiple sclerosis or epilepsy who experience physical access barriers. This may include people who are not generally considered by themselves or others to be physically disabled.

Participants in the study were gathered from people attending the launch meeting of the Empowering Parents Initiative, parents and professionals taking part in the steering group of the initiative, as well as those responding to questionnaires on pregnancy, birth and early baby care for physically disabled parents, which were circulated widely to parents and through a number of networks of health professionals. The following is based on contributions from 19 health professionals (including midwives, occupational therapists, antenatal teachers, and breastfeeding advisors) and 11 physically disabled parents.

Parents

Physically disabled parents were asked to describe their experiences of maternity services and their access to

appropriate and timely information. The following is a summary of the comments received. What they revealed was a lack of awareness and knowledge among many maternity and health professionals on integrating disabled parents' need for information and access to maternity services with their information and support needs as disabled people.

Lack of awareness and knowledge

Parents noted that many professionals knew little about the specific needs arising from their disability. They found it difficult to obtain information on how their medication might affect their baby. Hidden disabilities were often overlooked, with assumptions being made that people had no access needs. In addition, lack of continuity of care by midwives during the antenatal and postnatal periods often meant disabled mothers-to-be had to keep repeating themselves, in order to ensure their specific needs were taken into account.

Lack of knowledge of how, for example, particular birth positions might impact on parents with physical disabilities was also highlighted. A mother with scoliosis noted, “I wanted to have an active birth, but I ended up in stirrups, flat on my back on the bed. As a result my back pain was much worse afterwards.”

Negative attitudes still persist

“Why do you want a child if you are disabled?”

Some disabled parents reported some startlingly negative attitudes expressed by maternity professionals. These included:

- pressure to terminate a pregnancy because of health problems;
- pressure to have tests to assess if the baby had any disabilities;
- insensitivity of staff who refused to consider the access needs of disabled fathers.

Others reported patronising attitudes from their midwives who dismissed their concerns:

“everything will be OK”.

This closed down any discussion of concerns or additional needs.

Information gap

Parents highlighted a glaring gap in information relating to pregnancy and disability. While disability organizations provide information on particular conditions, and maternity services give information relating to pregnancy, parents often found it difficult to find information that bridged these two areas. Some disability organizations



had pregnancy-specific information available, others would put parents in touch with other parents with the same condition, some would refer parents to the dedicated information service provided by Disability, Pregnancy & Parenthood International, but some had no information on pregnancy and parenthood and did not refer parents to appropriate sources of information. In many cases parents have to turn to the internet, in particular online communities, for their information and peer support. Additional difficulties were noted around access to culturally appropriate information and information in languages other than English.

Normalising birth

Some physically disabled women found choices limited in terms of how they would deliver and care for their baby, with the assumption being made that they would have a Caesarean section and pressure applied to do so. Assumptions were sometimes made that physically disabled mothers would not breastfeed, or that they would have no additional needs when it came to breastfeeding.

Disabled mothers might also have additional support needs on the labour and post natal wards which a husband or partner may be keen and able to provide. Rigid rules about when fathers can visit wards created additional stress to some physically

Access

A disabled mother, acting as a user representative, carried out an audit of local maternity services, where she observed barriers to disabled people first hand. Problems she identified included: lack of accessible toilets and bathing facilities, inadequate space to manoeuvre wheelchairs, and lack of accessible equipment such as variable height cots. She also noted that improving such services for disabled women often also benefits all women in the later stages of pregnancy.

Professionals

Maternity professionals and health professionals working with physically disabled parents/mothers-to-be were asked to describe the main issues they faced or to highlight good practice. Health and maternity professionals were invited to contribute their experiences of working with physically disabled parents.



Time

One midwife noted:

“Due to lack of time it was difficult to spend more time with disabled mums teaching them normal mothering skills like feeding, holding.”

If the needs of disabled parents are to be met effectively, more time needs to be provided for their appointments. Catering well for disabled parents

requires a flexible appointment system. Planning in advance can also help to minimise the amount of extra time required.

Assessing individual needs and wants

An antenatal teacher noted that physically disabled parents are often labelled as ‘high risk’ simply because of their disability. She went on to add:

“The implications for labour and birth should be examined in partnership between the disabled mother, their midwife or other health care professionals on an individual basis and without an assumption of high risk as the starting point.”

A midwife noted,

“Delivery options were minimised with analgesia choices.”

This indicates that physically disabled mothers are, in some cases, being prevented from taking a full part in the decision-making about their birth because of assumptions about risk and inadequate time and attention being paid to allow for additional needs.

It was also noted that:

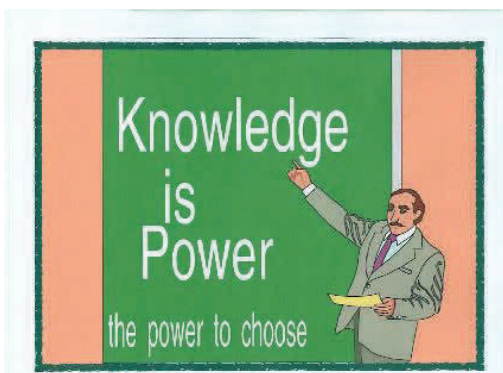
“Disabled people are often expert in their own situation and its medical implications, and well aware of what they can and cannot do, physically, so

often (as with other expectant parents) the main role of professionals is in building confidence and providing specific information on what to expect.”

Addressing the need

All expectant parents want to be able to make choices about how they bring their child into the world and care for them, but it seems that in many cases there are still many barriers preventing disabled people from doing this.

Through the feedback received from disabled parents and health professionals, this study shows that these barriers include negative attitudes from some health professionals, a lack of knowledge and information available for both parents and professionals, as well as poor communication between disabled parents and professionals. These factors, along with pressures of time and inaccessible environments, have led to inappropriate and inadequate care being given to physically disabled parents during pregnancy, childbirth and early parenthood.



Eight Tips for a Successful Adoption for Parents With Disabilities

© www.adoptivefamilies.com

1. **Talk with disabled adoptive parents in your area.**
2. **Honestly assess the age of the child you could best care for.** If you want to adopt a special-needs child, decide what type of disability you could reasonably handle and how much help you might need.
3. **Explore all options to determine which would most likely lead to a successful referral.** Contact public, private, domestic, and foreign agencies as well as those for private placement.
4. **Interview social workers to determine their views on disability as it relates to child rearing.** For your home- study, choose someone who can see past your physical impairment and accurately evaluate you as a potential parent.
5. **When preparing for your home-study, make sure your house is childproof and as safe as possible.** Contact Parents with Disabilities online at www.disabledparents.net for tips on child rearing and adaptive equipment. The better prepared you

are, the easier it will be to get a positive evaluation.

6. Be prepared to discuss strategies you would employ in an emergency and to describe your support system.

Emphasize your independence, perhaps even making a video that demonstrates it. Explain how you would handle various tasks, such as carrying, feeding, and changing a baby.

7. Before traveling to meet your child, prepare yourself. Look into accessibility obstacles you might encounter in another city or country.

8. Become as informed as possible by reading *You May Be Able to Adopt: A Guide to the Adoption Process for Prospective Mothers with Disabilities and Their Partners*, by Linda Toms Barker and Megan Kirshbaum, \$10 from Through the Looking Glass, lookingglass.org or give them a call at 1-800-644-2666.



NEW BOOK ON PARENTING

Maternity Rolls: Pregnancy, Childbirth and Disability

By Heather Kuttai

About the Author

Heather is a respected leader, administrator, coach, athlete, writer, and mother. She has been spinal cord injured for over three decades. She is a three-time Paralympic medallist and an experienced provincial and national team coach. She pioneered Disability Services for Students at the University of Saskatchewan, and in addition to being an advocate for students with disabilities and the creator of several student retention programs, she was also responsible for the development and writing of a University policy for this office. While at the U of S Kuttai worked on several research and writing projects.

A sought-after motivational public speaker, Kuttai is frequently asked to make public presentations on topics such as disability, dealing with adversity, parenting, and sport. She was recently inducted into the Saskatchewan Sport Hall of Fame and received a YWCA Women of Distinction Award for Leadership and Management.

About the Book

Heather Kuttai is a 40-year-old white, heterosexual woman. She is married and is the mother of two children. Living in a quiet, middle-class neighbourhood, her life is, in many ways, seemingly the quintessential picture of what many consider to be traditional. However, her life is not as conventional as it appears: she is a paraplegic and uses a wheelchair for mobility. Her disability dramatically changes the picture. Much of the writing about the experiences of women and mothers excludes the stories of women with disabilities. Established norms dictate that a mother's body be "healthy" and "whole." Because the body with disabilities is often seen for what it cannot do, taking on the role of mother can give the body a different value, status and worth.

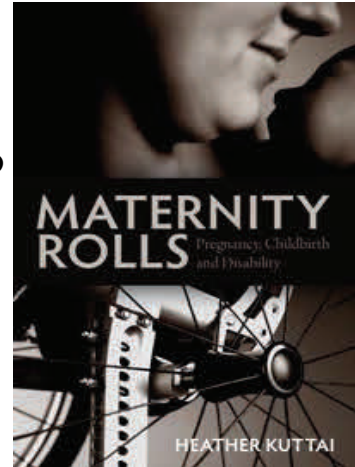
Heather's experiences as a woman with a disability experiencing pregnancy and childbirth offers insights into what is already known about women's bodies. The stories she tells of her life, her pregnancies and giving birth illustrate both her self-awareness and her awareness of our society's negative perceptions of disability.

"I do not know if I am always happily indifferent to the ones who have consistently been wrong about me, but I do know that I strive to be. Some days I get it right. Other days I struggle.

The autoethnographic process has made me realize that I am living an extraordinary life and that I have a

body worth celebrating. My body has done, and continues to do, incredible things. The lack of expectations that surrounded me as a woman with a disability were not ones I had to necessarily live with. I am an agent. It is hard work. But it is good work."

— from the epilogue



IMPORTANT NEWS FOR PARENTS & THEIR KIDS

Plan for Your Future: Invest in an RDSP

What is a Registered Disability Savings Plan (RDSP)?

The RDSP is a new federally registered savings plan that is delivered by the Canada Revenue Agency. It is designed to ensure long-term financial security for people with disabilities. Beneficiaries may receive the added benefit of government grants and

bonds. The RDSP, grant and bond are an initiative of the Government of Canada. Independent Living (IL) Canada encourages people to apply for RDSP's. This savings plan aligns with the Independent Living philosophy encouraging people with disabilities to plan for their long term financial security and the future costs of disability needs. Please contact your local Independent Living Centre for more information. Go to www.ilcanada.ca to find a local IL Centre.

Who can have an RDSP?

Any person can be a beneficiary as long as they:

- are eligible to claim the Disability Tax Credit (DTC)
- have a Social Insurance Number (SIN)
- are a Canadian resident
- are under the age of 60.

Did you know?

- Even with no financial contribution, you may be able to receive up to \$1000 annually to invest through the Canada Disability Savings Bond if you meet the criteria.
- If financial contributions are made by you, your family or your guardian you may be eligible for additional financial

contributions from the federal government through the Canada Disability Savings Grant Program.

- Grants and bonds are paid directly into your RDSP until the age of 49.
- The lifetime contribution limit is \$200,000 per plan.
- There is no annual contribution limit to an RDSP.
- Legally authorized parents or guardians can establish an RDSP on behalf of a person with a disability who is a minor or who is unable to enter into a contract.
- Having an RDSP does not impact Federal Benefits.
- In most provinces and territories, RDSP benefits do not impact existing provincial social assistance support programs.

Did you know?

- Growth of your RDSP contributions is not taxable until you take your money out (see the Canada Revenue Agency website for further details).
- When you decide to take your money out it can be used for any purpose.
- There are still incentives for some one over 49 years of age to open a plan:
 - You can contribute until the age of 60,
 - Save tax-free

- Depending on your province you may be able to access this money without impacting your federal or provincial disability benefits.

How to open an RDSP?

1. Identify the beneficiary. The **beneficiary** of the RDSP is the person who meets the above requirements and will receive the money in the future.
2. Identify the RDSP holder. The **holder** of the RDSP is the person or organization that opens and manages the RDSP (if required).
3. Contact a financial organization - several financial organizations offer the RDSP. To open an RDSP and apply for the grant and bond, complete a registration form.

Where to get an RDSP?

The following financial organizations offer the Registered Disability Savings Plan (RDSP), grant and bond:

- BMO Bank of Montreal:
1-800-665-7700
- Bank of Nova Scotia:
1-877-929-4499
- CIBC Securities Inc.:
1-800-465-3863

- Les Fonds d'investissement FMOQ inc. 1-800-641-9929 (Québec residents)
- The RBC Royal Bank:
1-800-463-3863
- TD Canada Trust (TD Waterhouse):
1-866-280-2022

Additional information:

Canada Revenue Agency -
www.cra-arc.gc.ca/disability

Disability Tax Credit -|
www.cra-arc.gc.ca/E/pbg/tf/t2201

RDSP -
www.cra-arc.gc.ca/tx/ndvdl/tpcs/rdsp-reei

Human Resources and Skills Development Canada - Grants and Bonds -
www.disabilitysavings.gc.ca

Service Canada Social Insurance Number -
www.servicecanada.gc.ca/eng/sc/sin

Planned Lifetime Advocacy Network (PLAN) - www.rdsp.com
info@ilc-vac.ca / info@vav-ilc.ca





UPCOMING EVENTS

People in Motion 2010

People in Motion is for people with disabilities, seniors with special needs, family members and friends, therapists, home care providers, facility managers, special educators and insurance representatives.

Everyone is welcome to this fun and enlightening event which features mobility aids, adapted vehicles, rehabilitation, home health care products, travel and leisure activities, corporate and government services, employment opportunities, computer aids, disability publications, associations and more.

See and compare everything under one roof at one time. **More than 120 exhibits!** If you have attended before, see it again! There are always new exhibitors with exciting new products and it is important to be aware of changes to existing technology.

MARK THE DATES ON YOUR CALENDAR NOW AND PLAN TO ATTEND PEOPLE IN MOTION 2010!!

**Friday June 4, 2010
10:00 a.m. to 5:00 p.m.**

**Saturday June 5, 2010
10:00 a.m. to 5:00 p.m.**

FREE ADMISSION!

- * Fully accessible building
- * Complimentary Show Guide
- * Attendant Services Available
- * Food and Beverage Area
- * First Aid On-site
- * Ample Parking
- * Some exhibitors will have products to purchase on-site!

**EMPLOYMENT
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For more information call 1-800-745-6555 or fax (705) 538-1988. Visit their website at www.people-in-motion.com.



THE CLASSIFIEDS

Please remember to share with us any used childcare equipment that you would like to get rid of and we can advertise it for you right here. To place a free ad call 416-599-2458, ext. 227.



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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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