SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs

Nº 16 Summer 2008

In 2004 my husband and I welcomed our son Jacob into our lives. In 2006 he was diagnosed with autism. Our daughter, Hannah Rose, loves her big brother very much.

Jacob has fantastic ASW's (Autism Support Workers) who are part of our family. 20 hours per week are provided by government and we pay the rest (28-32hrs). Because of ABA, Jacob doesn't bite his sister now, his eye contact is AMAZING, and has learned what it means when he is asked 'Pick up book', 'clap hands' and is starting to help put groceries in the cart while we're shopping. Jacob also enjoys music lessons (which Hannah Rose invites herself to). He LOVES his music teacher. Jacob is enrolled in horseback riding therapy too. He LOVES horses!

My mother, my husband, my church, family and co-workers have been what keeps me going–to be a good parent to Jacob and Hannah Rose and to keep my sanity.

My husband and I will try and do as much as possible throughout Jacob and Hannah Rose's life to ensure it is enriched with special experiences. Respectfully,

Customer Service
Hanwell, NB

Very trying teenage daughters–

I thought the terrible two's were bad. As a parent I am learning lessons trying to deal with their personal issues, health issues and school. One thing is for sure - dealing with conflict and negotiating a compromise (happy medium) makes both daughters and myself feel better. As a parent I am learning many valuable lessons. Thanks CUPW Special Needs Project.

PO-4
Hamilton, ON

“Special leave is a right under the collective agreement.”

Life is full of surprises, some of them are good and some are not so good. I would like to share an experience in the hope that it may help other families through their ‘surprises’.

My youngest son Owen was diagnosed with cancer (lymphoblastic lymphoma B cell, stage 3) in September 2002. He was 12 years old and just starting 7th grade. The diagnosis came as a big surprise to us. Owen hadn’t been feeling well for about 5-6 weeks BUT THIS…it just couldn’t be true. This was one of those surprises where I wanted to say, “No thanks, I don’t want it.” A surprise by its very nature doesn’t work that way. Owen’s treatments lasted for two years. In that time there were many surprises:

- The strength Owen showed through it all.
- How supportive my co-workers were to me.
- Sick kids are brave.
- What a great health care system we have.
- The difficulties of arranging home schooling for Owen.
- Lots of strong and wonderful people can be found in hospital waiting rooms.
- Special leave is a right under the collective agreement and you CAN use it.
- The Special Needs Project is a tremendous support.

Owen is now 18 and graduating from high school in June 2008. He is well and ready to take on new challenges. The support we received from the “Project” and my Needs advisor through CUPW still surprises me! Thank you!

Letter Carrier
St. John, NB

My name is Marilyne Turcot, and I’ve discovered “power-chair football,” a new sport specifically for people in wheel chairs. My high school (Joseph-Charbonneau) is starting to develop this new sport.

Power-chair football comes from soccer. The rules and equipment have been adapted for people with reduced mobility. To do this sport, each player has a bumper on his or her chair so they can play in complete safety. The ball is 33 cm in diameter.

There was a power-chair football tournament held in Vancouver last July (2007). I’m happy to say I was one of the students chosen to go!

Our week in Vancouver was unforgettable. We played against teams that had been playing a long time. But our scores always were pretty close.

At the end of the tournament, we were recognized as having the best team spirit. The whole experience made us proud and confident.
To get more information, visit my school’s internet website, at www.csdm.qc.ca/joseph-charbonnea and go to the Power Chair Football section.

Thanks!

Marilyne Turcot, player #5 on the Blitz power-chair football team!

MSC
Montreal, QC

Transitions are a time of mixed emotions.

Growing Up Ready

Children go through many changes as they grow up. They move from family life to school, from elementary to high school. Then comes the big move from high school to the rest of adult life and all the paths and possibilities that life might offer.

For most parents these changes, or transitions, are a time of mixed emotions. If your child has a disability, this may be a very stressful time. As the parent of a child with special needs, you may be caught up in day to day survival. You may ask, "How can I think about tomorrow when I'm just trying to make it through today?" When you can catch your breath, it is helpful to be aware of those transitions and allow yourself to think about the future.

Acquiring life skills is not intuitive for young people with disabilities or for their families. Individuals with disabilities are often deprived of every day opportunities and life experiences as a result of the barriers they meet in their lives. As a result, young people with disabilities lag behind their peers in developing the skills required to successfully manage in the adult world.

To ensure your child has the opportunity to develop their skills, you need to start planning early. Your plans should be real and positive with shared expectations and hope for the future. It is important to keep your child's wishes and needs at the centre of the planning process. All children should be encouraged to do their personal best. Although children's abilities will vary, do not underestimate them. As a parent have expectations for your child and encourage your child to expect the best from themselves.

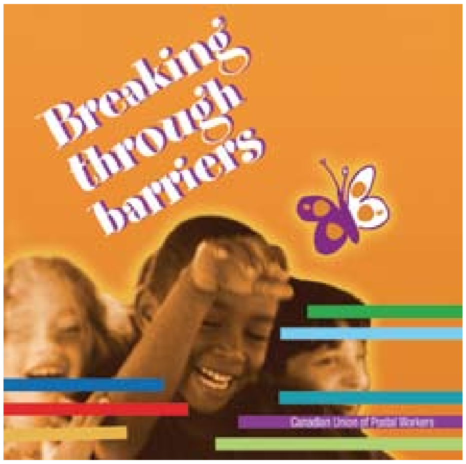
Who can you invite to a planning session that knows your child well – her peers, family, teachers? Include your child as much as possible in conversations where you dream about life ahead. Don't let roadblocks from your child's past stifle your creativity. What makes her happy? Where do his strengths lie? These could be areas your child can use to build the skills and experience they need.

One young man, challenged by autism, is running his own business today because those around him were creative dreamers. Without speech, and a habit of shredding anything in hand, his options may have seemed limited. But the dreamers saw his obsession as a passion. He began by working with a police detachment shredding paper. Today he owns his own shredder and his services are in demand.

It is important that you have support. Find another parent who has already been through the process. Contact an advocacy association in your area such as the Association for Community Living. Contact an organization that is linked to your son or daughter's disability. Ask your advisor for help when s/he calls. Contact the Special Needs and Moving On projects. We are working to help you find the support you need.

Thanks to Shirley McGuire, Susan Beayni, Bloorview Children's Rehab Centre and The Saskatchewan Association for Community Living for their input.

We would love to hear stories of how you and your child have managed the challenges of change. Your stories may help others as they face similar transitions. We would like to share them with other members through Member-to-Member Connection and on our website – ***www.specialneedsproject.ca.***



Contact your local union or the Special Needs Project office for a copy of CUPW's new DVD.

“CUPW not only looks after our welfare at work, but also cares about members’ family life quality.”

Our son Luke has just turned 11. He enjoys many sports activities as well as swimming lessons. This is only possible with the funding because the CUPW funds pay for most of the tutoring he needs. His tutor lives out of town and it’s a weekly commitment of a 40 mile round trip and a 1 hour tutor session that my husband or I sit in with Luke. Every day we practice what she has taught him to reinforce what he’s trying so hard to learn. We have seen this current tutor for 9 months and Luke has made great progress with her. She has a visual tutoring method. I will provide more information on his progress and his tutor who is a master practitioner of NLP (Neuro-Linguistic Psychology).

Letter Carrier
Bellville, ON

Gene was born a full-term healthy baby in April 1986. In November he was admitted to the hospital due to a brain hemorrhage. He underwent three surgeries to clear the blood clot in his head. He now suffers from acquired cerebral palsy.

Gene finished his education and is keeping busy while looking for a full time job. He participates in swimming, wheel-chair basketball, card games at the mall, Variety Village extreme sports as well as volunteering with the Salvation Army’s Thrift store, and Leisure World, a senior nursing home. He is also a devoted churchgoer.

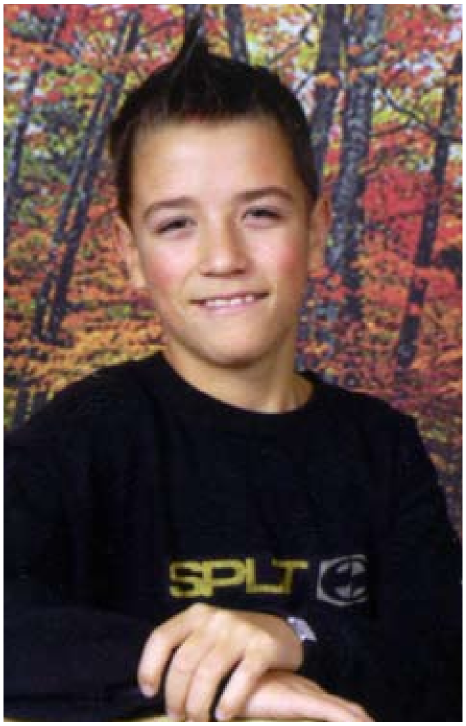
Gene has just finished a program called “Out and About” which gives him experience riding public transit to and from work and is currently enrolled in “Chef’s Delight” which provides hands on learning in preparing simple meals.

Gene has benefited from all the above-mentioned programs and training with the extra support from CUPW’s “Special Needs/Moving On” projects. CUPW not only looks after our welfare at work places, but also cares about members’ family life quality. This is one great union we are proud of.

PO-4
Scarborough, ON

A big thank you to the Special Needs/Moving On Projects. The funding helps our daughter (age 25) participate in many activities. Lesley-Ann is autistic and her love for music is extra ordinary. She attends Sing-a long, swimming and Hootenanny, which is great for her socialization. In the summer Lesley-Ann attended Rehoboth’s Christian Ministry Camp in Gull Lake Alberta where her first horse riding experience was exciting.

Letter Carrier and Patricia Gayder
Sydney, NS



Hello! We are a family of five. The Special Needs Project helps all of our three children's special educational needs. One of them has an attention deficit disorder and the other two are dyslexic. Remedial education teachers allow them to use some tricks to help them with their French. Because it's hard for them, I register them in sports they love.

I really appreciate your program, which helps them with their specific needs. Marc-Olivier, my eldest, uses it when he needs to. Because he's 16 years old, it's harder to help him.

Thank you so much!

Letter Carrier
Ste-Augustin de Mirabel, QC

Needs help finding resources in Quebec or Ontario

My son Nic has to deal with Asperger's Syndrome, Schizophrenia and obsessive-compulsive disorder. He is now 18 years old, has not finished school (stopped in grade 9) and cannot work or hardly leave home some days. The Special Needs Project has helped us with information on agencies that can assist us in many different ways and we appreciate all that they have done! We are looking at moving to Ottawa Region within the next year (I have requested a transfer) to be closer to friends and family members who live in Maine. We would probably live in the Gatineau Region. I would appreciate help with information from other members (UPCE or CUPW) with regards to resources available in Quebec or Ontario and the pros and cons of either region. This move would mean that we would have to find doctors and a psychiatrist for our son's continuing care. All members in a similar situation can feel free to contact me via phone or email to talk about their challenges and we can share tips, ideas, successes, etc.

Payroll Clerk
Edmonton, AB

Thanks for making things a bit easier for us.

I'd like to tell you a bit about my son, Julien. He was born on June 19, 2001 with only one kidney. It's possible to live normally with only one kidney, but there's a lot more to it than that.

When Julien was born, he stayed six days in intensive care for respiratory problems. Time went by and we noticed that he wasn't developing as quickly as he should. At the age of three and a half, he was diagnosed with moderate developmental delay.

This was soon followed by occupational therapy, speech therapy, and his condition entailed a great number of expenses, since getting public-health care means long waiting times.

In the spring of 2007, I learned that CUPW sponsored day camps on the North Shore. We wanted to register our daughter in the program and were greatly surprised to find out that our son could also register. But we had a lot of questions: Would Julien get the support he needed? Would he be safe around the pool? What about outings?

Ms. Doris Tremblay was patient and understanding, and she reassured us. She told us about the Special Needs Project. Julien enjoyed two wonderful weeks in the day camp. We were totally satisfied and enjoyed these two weeks of respite.

We are now getting funding to help our child's many needs. We'd like to thank the Special Needs Project and Ms. Tremblay for making things a bit easier for us.

Letter Carrier
Blainville, QC

Thanks for the support, which has enabled me to spend time with my other kids as well as by myself. It has also given my boys the social skills and interaction they needed.

I would also like to add after 18 years of having a son with autism, I just found out recently that we should never say our child is autistic because it appears to be a label instead we should say "I have a child with autism or is diagnosed with autism".

Thanks again CUPW for your help and support throughout the years.

S.P., PO-4
Ajax, ON

Any other famlies?

I would like to know if there are any other families that have a child with "Spinal Muscular Atrophy Type 2".

Letter Carrier
Victoria, BC

Doris Tremblay:
Quebec Special Needs Advisor

"I get a lot of satisfaction listening to parents and suggesting where they can find the resources they need," replies Doris, when asked about her role as Special Needs Advisor.

Doris has been an advisor for two years and in the past year has been answering the 1-888 line that takes calls from our Francophone members. Doris first heard about the Special Needs Project when she was hired by the ASGEMSQ, a Québec school-age association.

Having had special education training Doris took an immediate interest in the Special Needs Project. "I wasted no time applying when I learned they were looking for advisors."

Currently, Doris is a training advisor for the ASGEMSQ and coordinates their Quebec office. Doris also coordinates the CUPW/ UPCE-PSAC summer camp and school-age projects in the Quebec and Montreal regions often known as SAGA. She makes it a point to let people know about the Child Care fund. "I like to think that other labour organizations could follow CUPW's example and provide more help for parents. I believe that, as a society, we are all responsible for our children and that we should care about their future, which is our own as well."

Doris lives with her partner of more than ten years. An avid reader, Doris is never bored. She has a cottage in the country, where she spends a lot of time honing her gardening skills and bird-watching.

Doris appreciates all the support that the project office staff provides to the advisors. "Everyone is available to help us better serve the members and, because of the advisor conference calls, we also get the opportunity to exchange with other advisors. This helps us get ready for each new call period."

Doris finds a very high level of parent satisfaction with the Special Needs Project. "They're happy to hear from us, and very forthcoming in telling us about some of their concerns."

Doris gets a lot out of her conversations with parents. "I like thinking that I can continue working with children in this special way."

I have put my son through a program called "SNAP" for ADHD children to learn how to control their aggression. They provide family therapy, child therapy and tutoring. The children can use these services until they are 18. The kids realize they are with other kids with the same issues and the parents can bounce ideas off each other. It has been most helpful when dealing with Shaun's aggression. The SNAP stands for Stop Now And Plan. The short time we have been in the program my son's temper (and mine) has improved.

PO-5
Hamilton, ON

Best Buddies is dedicated to enhancing the lives of people with intellectual disabilities by providing opportunities for friendships. Best Buddies has programs in every province. To find out more contact:
Tel: +416-531-0003
Toll Free: 1-888-779-0061
info@bestbuddies.ca
www.bestbuddies.ca

Thanks to all members in the Special Needs Project for their participation in this work!

Voices on health and learning

Where do you go for health information?
Do you have difficulty finding health information?
What kind of health information do you need and want for your family?

In the Spring 2007, Advisors asked all our members on the Special Needs Projects questions regarding health information.

These questions were part of a project to identify health and learning issues and concerns for young children and their families by the Early Childhood Work Group of the Health and Learning Knowledge Centre. In addition to input from CUPW/ UPCE-PSAC members, the Work Group heard from parents, health professionals and early childhood educators through focus groups held across the country.

What did members say?

Parents use and prefer more than one source for their health information: contact with a health professional, internet/website and articles were the top choices.

Parents had several health concerns about their child during the past year: emotional health, social behaviour, intellectual development and nutrition were at the top of the list. Parents with children under six had more health concerns, including physical development and medication.

Parents are looking for health information on emotional health, social behaviour and nutrition.

What else was learned from this project?

Relationships between parents and professionals are “key” for sharing health information.

Mixed messages about health abound: on the internet, media and agencies/ departments.

Learning about the health practices of other cultures and providing health information in formats that are respectful of language and culture is crucial.

What now?

Information from the member survey can be used to develop the health section of the Special Needs Project website.

The Early Childhood Work Group will share the results of this project with parents, early childhood educators, health professionals and government officials, working for effective health information in communities.

A full report of this consultation, Voices on Health and Learning, is available on the Canadian Council of Learning website at: http://www.ccl-cca.ca under Health and Learning Knowledge Centre, Our Work, Working Groups, Early Childhood Work Group.

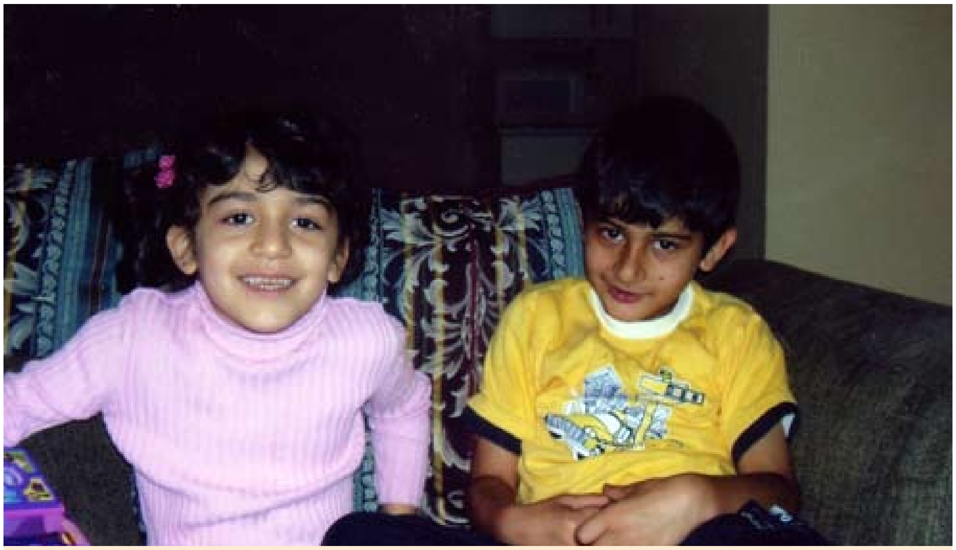
Thanks to all members in the Special Needs Project for their participation in this work!

"Whether you think you can or you can't, you are right."

Henry Ford

We are proud to announce the first public performance of the Filipino Canadian Autism Parent Support Group A+ Band last Oct 20th 2007. It is comprised of individuals with Autism and siblings. Five families have parents employed with Canada Post and members of Special Needs and Moving On projects. Thank you for your support to our kids.

PO-4
Mississauga, ON



The Special Needs Project has enabled me to purchase prescription medication for my son and hire a private tutor for my 2 children. It is helping me financially, psychologically, and emotionally. Now I can understand that I am not alone. I am very thankful for the support.

PO-4
Surrey, BC

"It has been a huge comfort to have support from family, friends and the hospital."

We would very much like to thank you for your kind words, thoughts and support.

In October of 2007 our 3 year old son Felix was diagnosed with ALL Leukemia. We were devastated. I was 7 months pregnant, already on a sick leave.

Felix did not show any obvious signs or symptoms. I took him to see the physician because he seemed "off" to me. The doctor examined him and said that his liver and spleen were enlarged and we needed to do some blood work. I went home thinking nothing of it, really it was just a little blood test.

I received a phone call from our Family doctor the very next afternoon. I could tell by the tone in his voice it was not good news. Immediately I was asking how bad is bad.

All I could manage to remember of this conversation was that I had to go to Sick Kids Hospital right away and that there was something wrong with his bone marrow. Felix was admitted in emerge and tests were begun to confirm the diagnosis. He did not cope well. The first few blood tests he tolerated but he began to feel like a caged animal and blamed us for letting the doctors hurt him. There were so many blood tests that his veins were collapsing.

In all of the shock and the dream like state we were in we still had to function. I called the CUPW Special Needs Project and their response was very comforting and very much appreciated.

Our third son Ollie (Oliver) was born 3 day's before Christmas and helped focus everyone's attention on something new and exciting.

It is very difficult to watch your child suffer from pain, exhaustion and all that comes with cancer of the blood. He has a very long and difficult road ahead of him. ALL Leukemia is the most treatable cancer with a very high success rate of total recovery.

As we struggle it has been a huge comfort to us to have all kinds of support from family, friends and the hospital. Our best wishes to all the families dealing with their own trials and tribulations.

Sincerely,

PO-4
Brampton, ON

Suggestions Appreciated

My son Calvin is 13 now and is going through the scary teenager issues that are dealt to him. He was born with cri-du-chat syndrome and behaviour is a big issue. Then the hormones are added to that. His main out burst is at school. His aids have so many concerns and questions about his actions but I can't always answer them. He is usually a very happy boy then out of the blue it turns. Any suggestions on this would greatly be appreciated.

My boy is my life and we will get through his obstacles one day at a time with the help of people like you guys that show you care. Oh ya the DVD *Breaking Through Barriers* was wonderful.

Letter Carrier
Fort St. John, BC

The Canada Disability Savings Grant will match contributions by as much as 3-to-1.

The Registered Disability Savings Plan (RDSP)

Families will soon have a new planning tool to assist them in securing the financial future for their relatives with disabilities. It's expected that the new Registered Disability Savings Plan will be available in financial institutions in December 2008.

The RDSP will provide a tax-deferred means for saving. Any person qualifying for the Disability Tax Credit can open an RDSP.

The Canada Disability Savings Grant will match contributions by as much as 3-to-1. Where people's incomes are less than $74,357 a contribution of $1,500 will result in a matching grant of $3,500. There is a $200,000 lifetime contribution limit and the limit on the Grant is $70,000 over the person's lifetime. Anybody can contribute to a person's RDSP.

The Canada Disability Savings Bond, for people with incomes below $20,883, will provide up to $1,000 per year for 20 years to a person's plan.

Federally, asset and income tested programs (tax exemptions or benefits received by people with disabilities) should not be affected. Provincially, BC and Newfoundland are the only provinces, to date, to have given the RDSP a complete exemption. This means that according to any of their supports, benefits, tax exemptions, pensions (any asset and income tested programs), the RDSP does not exist. People can accumulate as much as they want in the RDSP, and withdraw funds and spend the money in any way they want (no restrictions).

The remaining provinces have yet to announce how they are going to treat the RDSP. If you live outside BC or NL you need to monitor any provincial announcements related to the RDSP. It is expected that most provinces will announce something before the RDSP rolls-out in December. This will be a key factor for people deciding whether they want to set up an RDSP.

A couple of things need to be in place before your child can be eligible for the RDSP.

1. The individual with the disability has to be eligible for the Disability Tax Credit (DTC). Even if your child was rejected before, try again. The government has loosened the guidelines for the DTC.
2. Your adult child has to have filed an income tax return, even if they are not making any money.

Thanks to PLAN for their expertise in this matter. We will be posting provincial updates and links on our website at www.specialneedsproject.ca. You can also visit www.plan.ca for access to PLAN's RDSP blog, to sign up for their newsletters, or to get information on PLAN's free RDSP tele-learning seminars.

Jessica was described by the grade 12 (Special Needs) teacher as having difficulty following instructions or discussions. She talks constantly but does not monitor her comments. She has difficulty regulating her own behavior and when something goes wrong (e.g. losing her belongings) she becomes upset, screams, yells, and cries uncontrollably. Jessica's family has had difficulty coming to terms with her behavior and has been provided with support by the behavioral services, Trillium Health Centre.

PO-4
Mississauga, ON

“Our family situation has affected every aspect of my life..”

Dear sisters and brothers,

As CUPW’s newly elected 2nd National Vice President, I am very excited that the Special Needs and Moving On projects will be part of my responsibilities. These projects are widely recognized as models of support for working parents whose children have disabilities.

My partner Tammy Garrett is a letter carrier in the Ottawa local, and together we are foster parents to Jesse, Colin and Alec. We know first-hand what is involved in working and having children with special needs. Our family situation has affected every aspect of my life, including scheduling specialist, medical and school appointments, financial stresses, time pressures around homework, and providing emotional support for the kids

I have been on the CUPW National Executive Board since 1999, when I was elected 1st National Vice-President. Originally from rural Saskatchewan, I was a letter carrier in Edmonton. I was a member of the negotiating committee when the Child Care Fund was established.

I will work hard to ensure the Special Needs and Moving On projects continue to deliver the resources and services that have made such a difference to the lives of CUPW families who have children with special needs. And I will actively pressure governments and employers to provide much-needed support through programs, policies and benefits for workers who are trying to balance work and family life.

I look forward to hearing from you and to continuing to read your inspiring stories in Member to Member Connection.

In solidarity,

Lynn Bue

Lynn Bue

Member-to-Member Connection is the newsletter of the Special Needs and Moving On projects. It is produced by the Canadian Union of Postal Workers and the Union of Postal Communications Employees—Public Service Alliance of Canada.

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The letters you are reading have been edited in an effort to include as many of them as possible. Visit our website at **www.specialneedsproject.ca** to see all the letters we received in their complete form.