SPECIAL NEEDS • MOVING ON

member to member

connection

Breaking through barriers for workers who have children with special needs

Nº 24 Summer 2012

My 22 year old daughter Brittney has been in the program for a few years and I feel it has helped quite a bit with expenses. As my daughter got older the sports were more competitive and maybe too competitive. Therefore my daughter, my son and I got involved with Special Olympics. Brittney plays and her younger brother and I coach. It's been a very big part of our lives and very fulfilling. I encourage everyone to involve themselves and their child, children or young adults to join and let them try it for a full season. Don't give up. Let them try. You will be surprised. Some athletes take longer than others but that's ok. It's the social opportunity they all need and is necessary to make our special people part of their communities and society. To find information regarding Special Olympics in your province go to website *www.specialolympics.ca*. Find your province and give them a call. The summer sports start end of May or the beginning of June and go until August. The fall sports start September/October and go until April/May, depending on the sport.

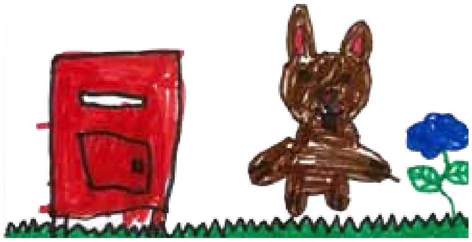
PO-4
Hamilton, ON

My daughter Madison is about to turn nine years old on May 13th. Madison has Down syndrome and has been through many challenges in her young life. She has already had two heart surgeries and there will be a third in the future.

The Special Needs Project has been with Madison through it all. With the help of this program Madison is able to receive the extra stimulus she currently enjoys.

I want to thank everyone involved in this project for the wonderful work you do. I'm including a picture of Madison so you can put a face to the little girl you have helped to blossom.

Letter Carrier
Cornwall, ON



“Horseback riding has given her a much needed boost in self-esteem and confidence.”

When I spoke to my advisor, I asked that my proposal regarding the funding provided by the program be examined. All funding should be transferred in the name of the person with special needs, as this would provide a greater benefit to each child or adult because they don’t have to pay taxes on these amounts.

I would like to be contacted regarding this matter. This would enable all members to use the full funding.

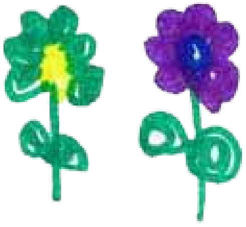
Letter Carrier
Cheneville , QC

Editor’s Note:

Thanks for asking this question. We previously investigated this idea with our auditors when we had a similar request from a member. At that time we were advised Revenue Canada considers the funding an employment benefit for the Canada Post employee/ CUPW member. It is therefore, deemed to be a taxable benefit and a T-4A must be issued. We recognize this is particularly difficult for many of our members already juggling additional financial pressures in meeting families needs.

Everyday I give thanks for the opportunities the Special Needs Project has allowed our Elizabeth (Lizzie). Recently she enrolled in the therapeutic horseback riding program at the Reaching Strides stables. It has given her a much needed boost in her self-esteem and confidence. In fact she is doing so well with the horseback riding she is hosting her 13th birthday at the stables and bringing along four of her friends to see her progress. Without this support we would not be able to afford these opportunities that help so much.

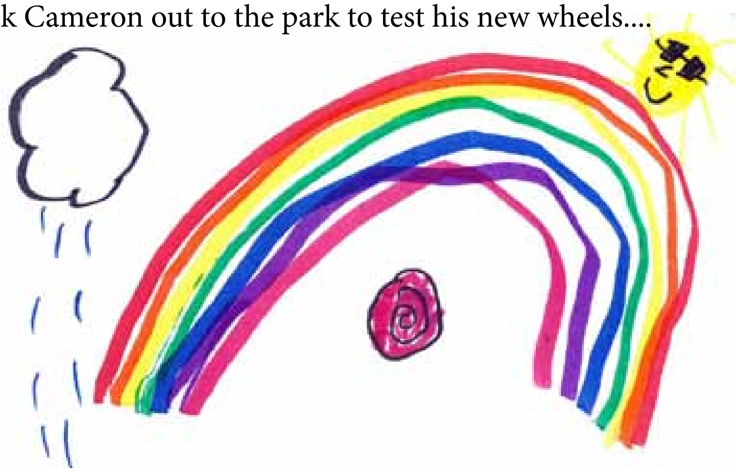
PO-4
Stellarton, NS



“I could not believe how fortunate my son was. “

Over the Christmas holidays Cameron got sick with pneumonia. Coming home from the hospital I decided to pick up some medical supplies at our local Motion Specialties Store here in Windsor. As Cameron was with me my plan was to run in and out in a few minutes. I sat Cameron down in the chairs and proceeded with my order. The clerk noticed that Cameron looked really sick and I told her that he had pneumonia. She asked if he had any siblings and I said that he was a triplet and that Cameron and his sister Chloe where both autistic and that Cameron also had juvenile arthritis. She then asked if he liked riding a bike. I said that he loved it but since last year he was no longer able as he got too big for his bike. I told her I was not sure what I was going to do this summer and that I would have to look at more options for him. She came around the corner and went to the sales floor. I didn’t think anything of it and paid for my items. When I turned around there she was with a special needs bike! Cameron immediately got on and started ridding it through the store...this little boy who was so sick just moments before lit up! She said, “Seems to me like he’s really enjoying it.” I said yes as I tried to find the price tag. She said, “It’s yours....Merry Christmas!!!” As I chased Cameron around the store to get his new bike and load it into the car, I could not believe how fortunate my son was. While Cameron was sick at home he would ride the bike around the house. On our first “nice” winter day we took Cameron out to the park to test his new wheels.... and he LOVES THEM!

Letter Carrier
Tecumseh, ON



Check out our website at www.specialneedsproject.ca

Special Needs
& Moving On
Projects of CUPW/UPCE-PSAC

Breaking through barriers for workers who have children with special needs ...

Members' favorite parts of the newsletter are the letters from their children.

What you told us

Early in 2012 we asked members participating in our Special Needs Project for feedback. This is what you told us.

Need help finding summer programs? *"Doing Okay."* say most members.

Seventeen percent did have concerns about finding summer programs. Most have children between 15 and 19 years with greater individual support needs, often requiring one on one attention. These members identified a lack of suitable and/or affordable programs as the greatest problems.

Need to book ahead to get the summer programs you want? *"Yes I do."*

One-third of members felt they could get the recreation programs they needed by booking one to two months ahead. Another third said it required three to four months lead time.

Need child care or respite? *"Family members helping out."*

While over fifty percent of members did not need child care or respite, thirty five percent did. Most of these members felt they needed to book a month or two ahead.

What can we do to help with summer programming? *"More funding wouldn't hurt!"*

Twenty-four percent were looking for additional support finding resources or information related to their child's needs. And some said additional funding would be helpful.

Member-to-Member Connection Newsletter

Do you like it? *"Keep it coming."*

Ninety-two percent of members looked forward to receiving the newsletter and found it to be valuable for them and their families. Even some of those who were ambivalent about the newsletter identified that they looked at the newsletter when it came.

Do you share the newsletter with others? *"It depends."*

Fifty-five percent of members shared the newsletter. More members were willing to share the newsletter with people in their community than with co-workers. One member identified that "*the new environment (at work) discourages sharing of information*". For others not sharing was a choice to keep their family situation private. Some only thought to share with a person who had a child with special needs or who had an interest in disability issues.

What do you like about the newsletter? *"Hearing from the kids."*

The three topics that members liked the most were: letters from children ; member letters; and health benefit information.

Do you feel represented in the newsletter? *"Not always."*

Only 24% of members have contributed to the newsletter. Almost two-thirds either did not have time to write or didn't feel they had anything to say that would be of interest to others. A few felt they would like to hear from more Quebec members and others wanted more information on transition to adult services.

"I am sharing this experience so other parents know that there is hope."

Almost 60% of members identified that they would be willing to share their story and ideas with the newsletter.

NOTE: We encourage you to contribute and look forward to hearing from you. We'll be following up with those who said they would like some help.

Do members who contribute to the newsletter get lots of people calling them? *"Not at all."*

Only eight percent of members contacted someone who had shared their contact information in the newsletter. Most of these said they called because they knew the member who had written.

Special Needs and Moving On Web-Site

Is the website helpful?
Most of you say *"Yes"*.

Over two thirds of members are aware the projects offer a web site. The majority of these members who visited the site found it helpful and easy to navigate. Most will return to the site again and all would recommend it to others.

Special Needs and Moving On projects website:
www.specialneedsproject.ca

Thank you to the children at First Avenue School-Aged Program at the Glebe Parents Daycare Centre in Ottawa for the drawings.

Many thanks to the CUPW Moving On Project for the generous funding. Aaron was diagnosed at age 13 with Pervasive Developmental Disorder – Asperger's Disorder. Aaron is a talented musician. He learned to play the violin and the clarinet all by himself. He can read and write music and chords instantly. He had a short stint with the Mississauga Symphony Orchestra as a second violinist but decided to quit and do more practice playing at home. They have told him he is welcome to come back anytime if he changes his mind. I am sharing this experience so all the parents who have a child with a handicap similar to Aaron's know that there is hope. You just have to be patient and work with your kid's capabilities. I know that it is easier said than done but the benefit will outweigh the difficulties once you discover your kid's real talent. I do believe that every kid with a disability has one special talent or ability. I am so proud to be an employee of CPC. Also, I would like to thank my Moving On advisor Kathleen B. for all her support.

Letter Carrier
Toronto, ON

"Almost every minute of their waking hours is either spent at work or caring for their children."

Surviving means thriving for this busy family

It's called "The Kids Survival Guide While Mommy and Daddy Are Away", and it has detailed notes for the people who looked after Chloe, Carter and Cameron Hodgins for a week in February, 2011—the first time in 10 years that their parents, Dave, a letter carrier in Windsor, Ontario, and Valerie were away from their children.

Every hour out of school is accounted for, from what each child eats for breakfast, snacks, lunch and dinner to their various after-school activities and routines. The schedule provides an insight into what a day looks like for a family with three children—except that the children in question are triplets, and all have special needs. Then there's the fact that there were four – not two – people caring for them for a limited time, with none of the specialist visits to Hamilton or London that occur on average every six weeks.

"*We literally need a third parent*," says Valerie, only half-joking. "*We are exhausted.*" The Hodgins' get extra support 12 to 16 hours a week from special services (ministry of child and youth services), but almost every minute of their waking hours is either spent at work or caring for their almost 10-year-olds.

Having three active children with special needs is expensive, so Valerie works full-time at a community centre, and has a second job at a hospital three days a week in the evenings until 11 p.m. and on alternate weekends. She is also the co-chair of the Parents' Multiple Births Association and a member of the special needs committee of her children's school board. Dave is the second vice-president of the CUPW Windsor Local. He prepares breakfasts and lunches before heading to work for 6 a.m., picks up Chloe and Cameron from school, makes dinner, and cares for the triplets most evenings with a support person until bedtime at eight. Valerie takes the children to school in the morning and picks up Carter from after-school tutoring at four before going to her evening job after supper.

"*It's just my daily routine, and my body has become accustomed to the schedule*," says Dave, who also does household chores after the children go to bed.

"I did not want to live alone. I need activities and friends to enjoy life."

An unexpected future

Finding out they were having triplets was a shock for Valerie and Dave, and it wasn't until several years after their birth that the children started to show signs of missing typical milestones. Chloe and Cameron were diagnosed with autism, and Carter with developmental delays. All three have asthma and Cameron also has juvenile arthritis.

"*You do go through a grieving process*," says Valerie, "*and they were diagnosed back to back. It was a very rough year.*"

Nonetheless, the parents have a positive attitude and are determined to provide opportunities for their children to grow to their fullest potential.

The children were in regulated child care when they were younger are now in a francophone school, where they are thriving and learning two languages. They are also involved in extra-curricular activities such as horseback riding, soccer, swimming and Boy Scouts.

The triplets can create their share of mischief, such as clogging drains with crayons, and figuring out how to defy the locks and home alarm system to escape while their mother grabs a quick shower. "*We have five different mechanisms for the door, and they got through them*," says Dave.

The children have brought their parents much joy. But the biggest challenge, says Valerie, is the fear "*of not being able to take care of them, so while we can we want them to have as normal a lifestyle as possible and do all of these things, and we will stretch ourselves to make it happen*."

My parents and I

would like to thank the Special Needs and Moving On projects for their help, which has allowed me to take part in activities that contribute to my physical development and well-being. I am 32 years old and have Down syndrome. I have been living in a supervised home for one year because my father is entering retirement this year.

Over the last several years the project has helped me get ready for group living. I did not want to live alone. I need activities and friends to enjoy life. Thank you and please continue helping those in need. I had a good advisor who cared about my well-being. Thank you to her too!

And to you parents out there, if you are running out of steam and need to share, write to me.

RSMC
Baie-du-Febvre, QC

"You can do small things that make a big difference in a person's life."

Normand Robichaud–New Brunswick advisor also a playwright

Special Needs and Moving On advisor, Normand Robichaud, estimates he's had 40 jobs during his life—from working in the Pizza Delight and Greco franchises founded by his family, to his current job as a worker at a special care home in Richibucto, New Brunswick. He has been involved in special needs issues since 1989, when he first opened a residence for people with developmental disabilities in a large home he had renovated in Shediac. Robichaud has been a volunteer and later worked for the Association for Community Living, has supervised an independent living centre for people with disabilities, and written four plays—two related to special needs.

The special care home where he now works, Manoir O'Leary Art/Café, is a renovated Victorian mansion that was once a country inn and is licensed for eight residents. "*It's an interesting concept*," he says. "*It has eight bedrooms for residents, with their own bathrooms and some with fireplaces and whirlpool baths. We are slowly trying to develop the artistic field, and there is a little coffee shop that is a micro-enterprise.*" The residents serve coffee, tea, cookies and muffins to the café's customers, and the proceeds go into an account for the residents' activities.

Robichaud has been working as a CUPW-UPCE Special Needs Advisor since around 2006. The 20 families in the Special Needs and Moving On projects he contacts all live in New Brunswick except for one in Prince Edward Island.

"*It feels good to do something that helps families and individuals*," he says. "*You can do small things that make a big difference in a person's life, so that's very rewarding.*"

Supporting project families

Robichaud sometimes draws on his extensive network of people with disabilities in New Brunswick – developed when he was a regional worker for the ACL – to support the families on the projects as well as find resources for them.

"*I sometimes tell them about other families who have gone through similar experiences and what it was that helped them. But sometimes the support you give is just in listening to people who are going through a difficult time.*"

Robichaud, a father of five and grandfather of five, is justifiably enthusiastic about his plays. One, called "Pizzaïolos", is about seven community college students in a competition for a marketing concept for pizza. The characters are based on the seven colours of the rainbow. "*One is a student with autism and he played Indigo, the colour of deep thought.*" When it was staged in Dieppe, five of the play's actors and crew were people with disabilities.

Another play, "Diaries from the Asylum", is the story of Mary Huestis Pengilly's experiences in 1883-84 in New Brunswick's mental health institution. "*When I read the diary it blew me away,*" Robichaud says. "*Mary was complaining about the same things you hear people who live in institutions complain about now—personal comfort, restrictions on what they can do, the attitude of some staff.*"

Robichaud and his twin brother, Armand, are now working on a play about children looking for treasure (and finding it in various museums in New Brunswick).

Single mother wins special leave grievance

"*Sometimes, you have to keep fighting,*" says Trudy Urquhart, a letter carrier in Fredericton, NB.

And that is exactly what this single mother of two did when Canada Post not only denied several of her special leave requests to care for her son when he became ill, but also threatened her job. She filed grievances, and won.

Urquhart's youngest, Jakeb, 15, has juvenile arthritis, an autoimmune disease that becomes acutely painful when it flares up. The flare-ups are unpredictable and can last for hours or days.

"*He [Jakeb] develops a high fever and it is almost like he has the flu, except that he's extremely sore,*" says Urquhart, who has worked for Canada Post for 18 years. "*His joints are so sore sometimes he can barely walk and I have to physically turn him over in bed.*"

Urquhart says the employer argued that she had taken special leave in excess of the limits, even though the leave has no cap, and that she should either take sick leave or be able to find alternative care. She uses special leave for the flare-ups and the quarterly visits Jakeb needs to make to IWK hospital in Halifax for blood work, checks on inflammation levels and regulation of his medication.

All of the programs she has investigated—on-call nursing at the University of New Brunswick, the Arthritis Society and the employee assistance program—are not set up to provide emergency care. Family members are also not an alternative: her parents and an aunt are elderly and face their own serious health issues.

"*I don't have another option. I felt frustrated because that's what special leave is there for and my number one priority is taking care of my son. I was quite upset. I have a child who's ill and I was afraid of losing my job. I cried a lot.*"

Stress all around

The stress also took its toll on Jakeb. "*They thought pressuring me might help but it makes things worse because if I'm stressed out I bring that home and then he worries about his mom.*"

His mom is also the person he needs most when he is ill. "*To be honest, although he is 15, when he's not well he doesn't just have a head cold, and he wants me, and I want to be there.*"

Finally, "*enough was enough*" and Urquhart decided to take on the issue by filing three grievances in April 2011 for separate special leave denials. The grievances went to arbitration, and in his October 11, 2011 ruling, arbitrator J.A. MacLellan found that the employer had unreasonably denied the leave and ordered reimbursement of the days that were withheld. As of April 2012, Trudy had yet to see the money she is owed.

Urquhart says the union was "*fantastic*" in its handling of the grievances and hopes the decision will help other parents facing similar problems. "*If I heard that someone else won grievances like these it would give me hope and encouragement to fight. They can't push us around just because we have to use special leave for our children with special needs.*"

"We believe that every child blooms in his or her own unique way."

Childhood disability LINK:
A bilingual website linking information and new knowledge on childhood disability to service providers and families

Enhancing your awareness and understanding of research on a variety of issues in childhood disability.

Services recommended are in Quebec. Online resources (listed under Service Providers) give the latest research results for a wide variety of diagnoses and themes.

Contact:
Marie-Linda Boghdady
Montreal Children's Hospital
Telephone: 514-412-4400 x22075 and x23578
Email: childhood.disability.link@gmail.com

Website:
www.childhooddisability.ca

ConnectABILITY:
Supports persons who have special needs, their families and support networks. This site offers valuable information on behaviour management, communication and much more. A virtual community that includes information, tools and workshops all in one place.

Website:*www.connectability.ca*

Inclusion:
Offers resources, training tools, articles and more on inclusion.

Website:*www.inclusion.com/inclusion.html*

Bright Beacon:
Provides a safe haven for parents/guardians of children with medical needs to meet and discuss their children, their children's medical needs, and perhaps even their own personal stories: their victories, defeats, joys and sorrows.

Website:www.brightbeacon.org

Exceptional Parent:
Helpful information to develop, translate, and share information as tools for change for the Special Needs Community.

Website:*www.eparent.com*

Boardmakershare:
Easy free way to create activities for your family, you can also find and share thousands of Boardmaker activities and connect with people who use them. Multilingual site– look at the bottom of the page to change the language.

Website:*www.boardmakershare.com*

BLOOM:
We believe that every child blooms in his or her own unique way.

Bloorview Kids Rehab created BLOOM to bring together the wisdom of families – reflected in firsthand columns such as Role Model, Parent Talk and Trailblazer– and professionals in childhood disability treatment, research, real-world programs and education at Bloorview and beyond.

BLOOM covers often unspoken or taboo topics that require specific "how-to" information. It focuses on issues that are common to parents of children with a variety of physical and developmental disabilities and highlights practical resources (web sites, books, videos, community programs) that support parents and their children.

Visit BLOOM at
www.hollandbloorview.ca/bloom

Care-ring Voice Network:
Care-ring Voice is a free, bilingual and confidential program that connects caregivers and families to information and support through the use of tele-learning. We host learning sessions by telephone and the web on a range of life-changing topics. Participants benefit from an amazing opportunity to learn from the healthcare professionals who lead the workshops and a chance to share with others in similar situations. Through Care-ring Voice tele-learning, caregivers and families take vital steps in ensuring their health and that of their loved ones.

www.careringvoice.com
info@careringvoice.com

To get immediate assistance by telephone, please call the toll free Care-ring Voice Info-line at **1-866-396-2433**. The line is open Monday-Friday from 9-5 pm (EST).

> "He's working in a way that he understands with his EA there to guide him."

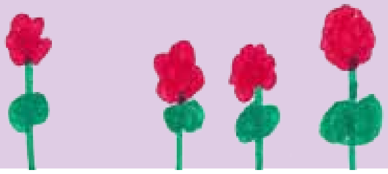
My daughter Steph would have never had a chance to do well in school without constant tutoring. She is ADHD, 24 years old, and in her 3rd year at college. It takes her longer to complete school, but she is trudging along. Thank you for the funding I have been receiving for Steeph since she was 7 or 8 years old. She is moving farther along the road to independence. Education is the key for her.

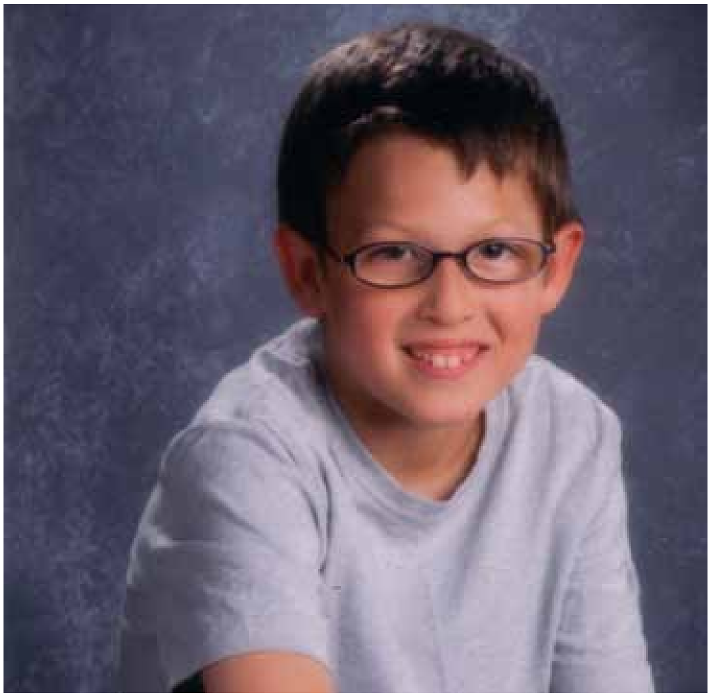
Jayden is doing well. He has ADHD and continues to be on a minimum amount of Ritalin. He was on 80 mg before I put him on Isagenix. His marks are about the same on ½ the amount, due to the detox formula removing toxins and giving proper nutrition daily. Thanks for listening. Call if you have questions.

Letter Carrier
London, ON

I would like to thank the Special Needs Project for helping my son Julian with the resources and support he needs. Organic products that are gluten and casein free are very expensive. On this diet my son has improved eye contact and is more focused. Also his esophagus-reflux is gone. As a parent with an autistic child, I believe that medication is not the only way to help our kids. The diet is very important to re-build their immune system and cleanse all the junk and poison found in some normal food. Muchas Gracias.

Letter Carrier
Lethbridge, AB





Brandon

We are very thankful for the help we get from the Special Needs Project. We have two boys, Logan who is 12 and in grade 7 and Brandon who is 9 and in grade 3. Brandon has a speech delay and some motor skills issues. He is also on 2 puffers every day as he has asthma. Brandon has glasses as he has a bad eye that turns in towards his nose. His glasses help him to keep his eye focused straight.

We are so thankful to Sherwood Elementary School. Ever since grade one Brandon has had the support he needs. He's come a long way. He has three educational assistants (EA), his homeroom teacher, a speech and occupational therapist and is given special attention in a resource room during the day at school. Brandon's EAs each have different times to be with him. He is in a regular class but on a modified program, so he's working in a way that he understands with his EA there to guide him. We are very pleased and grateful for everything that he has accomplished. The road has not been easy for Brandon. He is very special. On the days that feel long, he can make you laugh.

RSMC
Charlottetown, PEI

> "He has come a long way since the doctors said there was nothing that could be done."

I am attaching a picture of my son Fabio. Fabio suffered a brain injury in October of 2006. Doctors told my wife and I that he would be a vegetable all his life and that there was nothing that could be done. Fabio has come a long way since the accident, but he still has a long way to go.

Letter Carrier
Woodbridge, ON

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.