SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs

Nº 17 Winter 2008/2009

I have worked with Canada Post as a letter carrier for the past 7 years. Our youngest son Colton, who is 5 years old, was diagnosed with autism. Our ongoing journey to help Colton reach his potential has been challenging at times. Colton has an older brother Luke, who is 8 years old. The love and support Luke gives Colton has always been a source of inspiration and encouragement for our family. The financial demands incurred to help Colton have been a concern along the way. The support received from the Special Needs Project have been greatly appreciated. Colton is now speaking and is integrated into the kindergarten program at our school. Our little boy is very loving and a true blessing to our family. Many thanks for your kindness and support along the way.

Letter Carrier
Pickering, ON

Hi! My name is Marie Guest and I'm a letter carrier in Peterborough P.O. My husband is also a letter carrier in Lindsay. Since our son Brendan is ADHD, we use the money from the Special Needs Project for tutoring. It is my son Brendan who benefits but the cheques can not go out in his name. I have been looking at different ways to help with the income tax that we have to pay on our funding from the project. As both my husband and I are CUPW members the cheques and T4A slip can be split equally between us. Also I learned that I can claim all of Brendan's tutoring under medical expense. The following conditions apply: 1. The tutoring services must be used for primary education of a person with learning disability or impairment. 2. The tutor must be in the business of providing such services and cannot be related to the person being tutored. You have to get a yearly receipt from your tutor. Every tax year a medical practitioner must certify in writing that these services are necessary. If the doctor charges you for the note you can claim this under medical expenses. Also see Medical and Disability Related Information Booklet for 2007 pg.12. If this applies to you and your income tax is already filed for 2007 you can always write a letter to the tax office requesting an adjustment. I hope this will help someone else.

Letter Carrier
Ennismore, ON

“We are so proud of what Chris has accomplished and will continue to accomplish.”

My son is 16 years old now. He is going through puberty and there have been many problems these last few months because of it. We’ve been seeing a specialist on and off. We had planned to go to Disney World before these issues occurred. I hesitated to travel with him but we went. I couldn’t believe what I saw. There were no problems at all with my son. He really enjoyed the holiday. It was a different Myles. He was happy and enjoyed every theme park in Disney World. I think this was a kind of therapy for him.

PO-4
Surrey, BC

On November 26, 2007, brother Luciano DiBacco was in a serious car accident. He is still struggling to recover and support his family, including his child with special needs. We hope that his recovery is swift and complete. Our thoughts are with you and your family.

Special Needs and
Moving On Projects
members and staff

I just wanted to let you all know that Chris is doing fine. He has had a lot going on. He’s graduated from high school with honours. He is now attending NBCC (Business Admin/Accounting). We are so proud of what Chris has accomplished and will continue to accomplish. Chris has had one operation on his legs and is getting ready to have another one done. We are hopeful that this will be the last one he has to have. We would like to thank the Special Needs Project, and all the members, for all your help and support.

Letter Carrier
Moncton, NB

My wife and I would like to thank the Special Needs Project for their funding assistance which has enabled us to purchase a smart vest airway system for our daughter. The price of the vest is $10,000 American. Sabryna was born on Jan 21/95 and shortly after was diagnosed with Cystic Fibrosis. This disease has no cure and requires artificial enzymes to digest food. Daily therapy is done to loosen and remove congestion in the lungs. Then at 12 years old she was also diagnosed with CFRD – Cystic Fibrosis Related Diabetes. She now has to take enzymes and inject herself with insulin before each meal. Her sugar levels need to be tested and monitored 4 to 5 times a day. All of this requires time. Using the smart vest airway system will save us half an hour (of therapy) a day. Thank you very much.

Letter Carrier
Renfrew, ON

Does your child with special needs have a story s/he wants to tell? *Or, does another child in your family want to share the joys and/or challenges of being the sibling of an individual with special needs? Please send us their stories for the next newsletter.*

Many members are struggling to find the resources needed for their adult daughter or son.

Moving On Interview Results

In April 2008 our Moving On Project Advisors talked to their members.

Here's what you told us…

About your Health Benefits:

The overwhelming majority of the seventy-five members we talked to are covered by the Great West Life extended health care plan. The majority (73%) of the adult children were eligible for coverage on their parents plan either because of age or disability. About seven adult children are using the vitamin benefit.

About the Web Site:

Twenty-one percent of members have visited our website. Others indicated they had either forgotten, didn't know about the website, were not a "computer person", or they had no time.

Of the members who visited the website 75% of them thought the information was easy to understand with 69% identifying they found the website interesting and easy to find. All who had visited the site said they would go back again.

About what interests you:

We gave you a list of workshop topics and asked you which ones were of greatest interest. Eighty percent of members said they were interested in workshops. Your top six choices, in order of priority are:

Registered Disability Savings Plan	61%
Wills, Trusts & Estates	49%
How to plan for and secure the housing needed for your family member with disabilities.	45%
Planning to Secure a Good Life – exploring the elements of a good life.	39%
Caring for the Caregiver – ideas to prevent burnout	37%
Facing the Future together – assisting family members in creating a clear plan for the future.	36%

The workshop format that suited the most members is a combination of on-line and teleconference.

About organizations you recommended:

When asked to recommend an organization that offers workshops 1/3 of the members suggested the Association for Community Living. Other recommendations included organizations specific to the adult son or daughter's disability.

Advisors indicated that many members are struggling to find the resources needed for their adult daughter or son. We will continue to look for ways to support your needs and will be expanding the resource list on our website to assist you in finding appropriate and helpful organizations, groups and information.

> “The support and information we receive is truly making this world a better place for Teresa.”

I would like to take a moment to thank the Special Needs Project for my son being able to continue his special gluten and casein free diet. Without your help it would be almost impossible to meet the requirements and follow up for Julian. The gluten and casein free diet is helping Julian with his reflux as well as with focus and concentration. Julian still has hyperactive behavior but at least our blessed son can keep his food down. God bless all of you. I wish the best for your children.

Letter Carrier
Lethbridge, AB

Words can never express my thanks to the Special Needs Project. Having the opportunity to place Teresa into dance, camp, tutor and other activities has inspired her endlessly. These opportunities have allowed Teresa to love, learn, grow, push herself and most importantly love herself. The support and information we receive from the Special Needs Project is truly making this world a better place for Teresa. Teresa will be undergoing another surgery on June 30/08. The biggest and most positive influence in Teresa’s life is the Special Needs Project.

Thank you!

PO-1
Toronto, ON

We would love to include drawings created by your children. Please mail us the drawing and include the child’s name, age and title of the drawing.

I want to thank the Special Needs Project for helping my son Sean to develop a passion for soccer and guitar. I would not have been able to afford this on my own. Being Autistic (aspergers) noises and crowds would normally bother Sean but he is learning to overcome this. His greatest passion is his guitar and writing songs. I have seen his self-confidence go from nil to bragging about what he can do, to having friends, to expressing how smart he is. This is a big, big step for my son. With the help of the Special Needs Project Sean has blossomed. He is still struggling with academics issues but having friends is very very important to him. He is now looked upon at school as being cool (somewhat, instead of being weird or odd). Sean even got his first job last month. Taking direction is difficult for him but this job doesn’t require that much. He seems to be on his way.

Letter Carrier
Halifax, NS

"The changes have filled his, and my life, with hope."

Thanks so much for the information on transitions. My daughter Claire will be entering middle school in September and anything to help that move is much appreciated. Recently my daughter has been accepted as a client with the Ministry of Children and Families of BC, under the ARC program. Our referral originated with our pediatrician but clients can self refer if they need to.

This program provides support for children and families with special needs and serves to link families with programs and services that they may not otherwise hear about. As a result we have had help in planning for the transition to middle school. Thanks to this program, my daughter is also able to access filial play therapy and will now be able to attend a summer camp for kids with special needs.

PO-4
Kelowna, BC

We have a child 12 years old who is severely autistic and developmentally delayed because he has brain and nervous system injuries. He has strengths that are proper at his disability and age. Gabriel has greatly improved in many areas and with little assistance. He can communicate with some basic sign language and also uses pictures to say what he wants. I am including a picture where he is doing the sign to go to the washroom. He was very happy when he found that people could understand him. I know he feels happy because finally he can communicate and I feel good too. It is wonderful!! Thanks a lot for your support. The changes have filled his, and my life, with hope. Thank you very much.

Letter Carrier
Toronto, ON

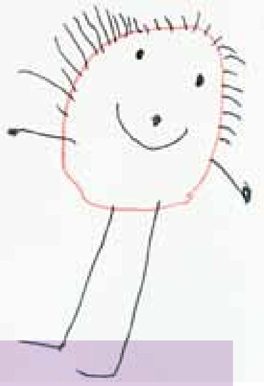
"When he is 19 years old where does he live? Does he work?"

My son Calvin is now 14 years old. He was born with a rare syndrome called 'cri-du-chat'. He just finished Grade 8 and is doing very well. We are going through some rough anxiety behaviours (mostly at school). For the most part he amazes me everyday with the knowledge that he has. His memory is unbelievable. I just want to share with you a project the school district did for Calvin.

They called it 'Calvin's Pathway of Success'. Being that he is a teenager now and moving toward adult hood they wanted us to plan where we think his future is going. In attendance were my family members, Calvin's aides and teachers, his physiotherapist and the process facilitator. We talked about Calvin's path 'now'. We all took turns telling about things he enjoys, dislikes or is good at now. We then talked about what we are going to do to 'enroll' - to make certain things better. For example - I was appointed to make a Doctors appointment to get Calvin referred to a pediatrician to see if there is any medical help to reduce anxiety and get blood work done. Everyone had a role that they were assigned. Then we talked about 'strengthen' - what we wanted Calvin to really work on. For example - working on a calming routine (worry rock – stress ball), dealing with transitions and the ability to make choices and accept changes. We then went to 'goals' for Calvin in the future – Life skills, communication, friendships, and work experience, distressing outings, transition to high school and other (money management skills or a personal digital assistant PDA). Throughout the session we did 'dreaming' about Calvin. When he is 19 years old where will he live? Does he work? What does he do for fun, leisure time and so on? It took a lot for me to think about Calvin's future and where I think he might be in 5 years. Once I heard everyone else's dream for Calvin I got into it!

I guess it is hard for me to think 'my boy' is now growing up and I will have to let go a bit! All in all I was very happy we were asked to do this and thought I would share it with some of you. And again thank you very much to the Special Needs Project.

Letter Carrier
Fort St. John, BC



I have a three-year-old boy who has autism. This is very difficult for my family. We are doing everything we can to help him. Luckily my co-worker informed me about the Special Needs Project. The project provides funding, information and advice. We are very thankful to have such a wonderful program.

PO-4
Vancouver, BC

"Some families don't think they can challenge the system and ask for more."

Making a difference, one call at a time

For Lesley-Anne Cook-Kay, the best part of being a Special Needs Advisor is the personal connection she makes with the CUPW and UPCE families on the project.

"When you call someone three times a year for seven years you really get to bond with them and know a lot about their lives—how things are going—and that's the big piece," she says.

As a longtime community volunteer and a resource teacher for children with special needs for the last 23 years, Cook-Kay "lives and breathes" inclusion issues. She has a daytime agency caseload of 24 children with special needs aged 18 months to six who are in child care programs in Ontario's Niagara area. In the Special Needs Project she works with 16 families.

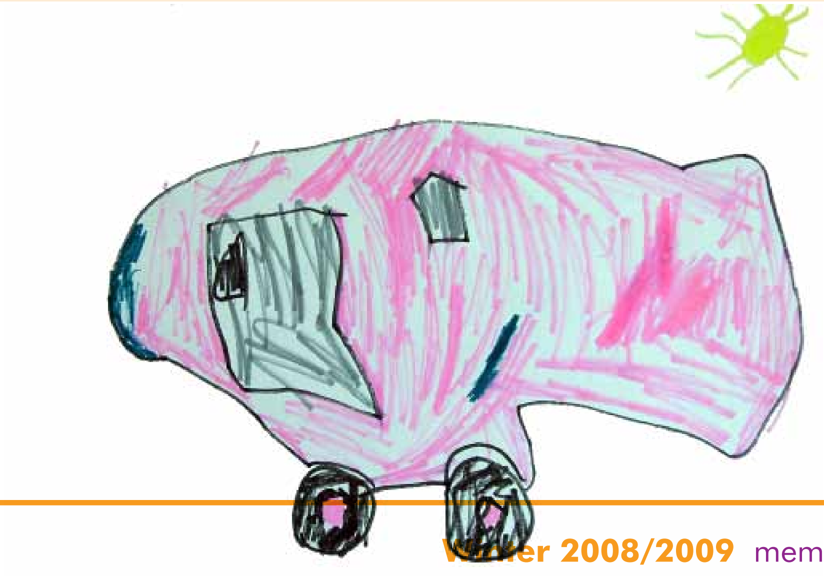
One of the aspects Cook-Kay stresses with the postal worker families she calls is advocacy. "Some families don't think they can challenge the system and ask for more than they're getting, and I really try to boost up that advocacy part."

She also tries to give parents "food for thought" regarding services and other options they can pursue to locate resources that will support them and their children. "I give them homework and I ask them about it the next time I call them."

Another major part of the job is being there for parents who are having an especially difficult time. "Sometimes you live through their marriage break-ups with them or a death in the family. You are a person they can vent to, who doesn't know them but is compassionate and will listen."

Cook-Kay says she feels the project has evolved since she started working as an advisor in 2001. While the job has more or less stayed the same, "there's more to offer, more places to send people, there's the Moving On Project [for adult sons and daughters with disabilities] and the project web site."

Her original motivation for becoming an advisor has not changed. She just wants "to make a difference—big or small—in people's lives. This is right up my alley. I'm doing what I love."



“You want to protect her but at the same time let her grow to become more independent.”

What did you say…

Special Needs End of School Year Interview 2008

We talked to over 415 members our last round of interviews. You talked about your experience with transitions. Many of you shared transition stories, both positive and challenging.

Many stories of positive transitions identified a change in the child’s social network. “*My son was accepted immediately by his peers at his new school. His negative behaviors have decreased, he’s more settled, is sleeping better and less touchy.*” One member identified that implementing family meetings allowed their son to communicate openly about his feelings and eliminated his apprehension.

Your greatest challenges included:

Being overwhelmed	52%
Finding educational support needed	49%
Trouble getting my child’s cooperation	47%

Many of your stories of challenging transitions spoke to the difficulty parents have working with the school to access the support needed. “*When my son went to the new school he no longer had specialized supports. He was easily frustrated and would do things that he shouldn’t.*” “*The people who make the decisions don’t know the child.*”

Members also spoke of the challenges of parenting a child with special needs. “*We try to motivate our daughter but not overwhelm her. Because of her comprehension difficulties we never know if we are pushing her too much or not enough. You want to protect her but at the same time let her grow to become more independent.*”

Many parents talked about their major concerns leading to the next transition in their child’s life. The primary issues highlighted were:

Lack of educational support	45%
Lack of social network for their child	34%
Trouble getting child’s cooperation	35%

Most members were aware of resources in their communities (59%) but they wanted to learn more about how to best prepare for transitions (63%). Advisors identified that sending members resource information in their packages would be helpful.

"I sincerely appreciate all of the members who share their joys and struggles with Advisors as part of this project."

"Thank you" to members

I have been an Advisor with the Special Needs Project since the project began over ten years ago. Many times I have heard members express their appreciation for the project. And now I want to express my appreciation to members.

Last week I was talking to members during the fall interview and completing the "End of Summer Interview 2008." I called Kathy S, who usually is one of the last members I speak with during an interview period (she is a busy person and out many nights). I have been talking to Kathy for over ten years now. She remembers when my baby was nursing during those first interviews. I remember how excited she was when she was able to take a Mexican holiday with her girlfriend. She remembers when my daughter was changing schools. And I remember her sorrow when her dad passed away.

I know how much homework Kathy's worked on with her daughter over the years, and how she welcomed the tutor from the project. I heard how her heart ached when children weren't always ready to befriend her daughter at school. And how thrilled she was when new school friendships were formed. And I know the love, concern and effort that she and her husband have provided to both of their children.

Kathy's children are a few years older than mine, so I learned lots of the "secrets "(especially of the teen years) from her. Kathy taught me how important it is to help your child find their way, even though their path may have many twists and turns, and be covered with prickly bushes at times.

And Kathy's daughter is turning 19 next month. This was our last interview. Kathy really didn't have to do the interview, but she did. We talked about all the things she did to smooth the transitions between preschool and primary school and high school and after for her daughter. The interview became a testimony to all that Kathy has done to support her daughter along the way. And as an Advisor in the project, I have had the privilege of knowing Kathy and her family. I sincerely appreciate you, Kathy, and all of the members who share their joys and struggles with Advisors as part of this project. You are all amazing! Thank you.

My name is Ryan Mogridge, I am 11 years old. I played in the Special Olympics at my school and I got lucky. 8 ribbons in 8 different events. Yahoo!

PO-5
Dundas, ON

Season's Greetings

from your friends at the Special Needs and Moving On Projects

Special Needs
and Moving On
Advisors:

Bernadette M.
Lisa B.
Shirley M.
Donna M.
Debra Jo P.
Valerie D.
Marie-Josée L.
Christine D.
Roberta M.
Suzanne C.
Pam M.
Arlie R.
Anne G.
Sylvie G.
Pat M.
Heather N.
Sheila O.
Ellen M.
Sheila S.
Lesley-Anne C.
Nancy B.
Agnieszka G.

Sue M.
Brenda G.
Sharel S.
Enna M.
Norma C.
Janet M.
Betsy S.

Catherine D.
Kathleen J.
Donald G.
Susan B.
Doris T.
Gary C.
Normand R.

Lawana S.
Diane M.
Cora B.
Melynda C.
Genevieve P.
Theresa A.
Debbie W.
Trina S.
Karen W.
Debbie D.
Julie S.

Family Place:

JoAnna LaTulippe-Rochon
Gail Holdner
Dorothy Keigan
Cary MacDonald

CUPW:

Lynn Bue
Jamie Kass

UPCE-PSAC:

Richard L. Des Lauriers

May there be peace in your hearts and homes,
and in the world, now and in the new year.

The federal government has exempted the RDSP from affecting any federal support programs.

Registered Disability Savings Plan Overview

The Registered Disability Savings Plan (RDSP) is a long-term savings plan for persons with disabilities that will allow funds to be invested tax-free until the time the funds are withdrawn. Contributions to the plan can be made by anyone, including friends and family, and must be received before the beneficiary's 60th birthday. The maximum contribution that friends and family can make is $200,000.

In order to provide an incentive for people to set up an RDSP and contribute to the plan, the Government of Canada has created the Canada Disability Savings Grant and the Canada Disability Savings Bond. The Grant was designed to encourage friends and family to put money in by providing matching federal government contributions. The Bond was designed to help those who may not have any friends and family in the position to contribute.

Establishing and Managing an RDSP

Anyone who is eligible for the Disability Tax Credit can set up a plan. To find out whether you are eligible for the Disability Tax Credit you can contact the Canadian Revenue Agency or visit their website.

ENG: www.cra.gc.ca or call 1-800-959-8281
FR: www.arc.gc.ca or call 1-800-959-7383

In the case of a minor child, a parent or guardian can establish and direct the RDSP. In the case of an adult setting up a plan, they can set up a plan or can have a plan set up for them by a parent or legal guardian.

Impact on Federal and Provincial Benefits and Programs

The federal government has exempted the RDSP from affecting any federal support programs, such as CPP/QPP, OAS and GIS. So far for anyone living in British Columbia, Newfoundland, Manitoba, Ontario, Yukon, and Saskatchewan, the plan is an exempt asset. Individuals are free to use any income from their plan in whatever way they choose without affecting their income assistance.Although Quebec has identified the RDSP as an exempt asset it will tax an individual who withdraws more than $300/month from the plan. The money will be considered income and may disqualify or cause funds to be clawed-back from current benefits.

Getting Ready for the RDSP

A Registered Disability Savings Plan is a trust arrangement between a holder and an issuer (a trust company in Canada). With the RDSP expected to become available from financial institutions in December 2008, people should do two things in order to take full advantage of this plan.

1. The individual with the disability has to be eligible for the Disability Tax Credit (DTC). Even if your adult son or daughter was rejected before, try again. The government has loosened the guidelines for the DTC.

2. The adult beneficiary has to have filed an income tax return, even if they are not making any money.

* Net income refers to a family's combined net-adjusted income while the plan beneficiary is a minor. When the beneficiary is an adult, net income refers to an individual's net-adjusted income, and includes that of his/her spouse or common law partner.

Based on information provided by Planned Lifetime Advocacy Network - PLAN. Check PLAN's RDSP Blog at http://rdsp.wordpress.com

Check out our website at www.specialneedsproject.ca

“This could unleash a process that will destroy public service and impact job security and benefits for postal workers.”

Dear Sisters and Brothers,

I wanted to write about a pressing issue facing postal workers and their families. CUPW and UPCE-PSAC are very concerned the government initiated Strategic Review of Canada Post could recommend deregulation of the post office. This could unleash a process that will destroy public service and impact job security and benefits for postal workers.

In our vast, sparsely populated country, the exclusive privilege for the post office to deliver certain types of mail has been necessary to keep an affordable service. Rural and remote communities would be most vulnerable to cuts in service or increased prices following deregulation. This has been the experience of other countries following deregulation.

Many community groups across the country recognized the threat and wrote to the Review Panel:

Many choose to live in their rural communities because they believe that a non urban community is the best place to live and raise a family. We have seen a steady decline in services to rural remote and northern communities in the past years. We have lost our banks, hospitals, doctors, schools and many of our post offices already. For you to further erode what we have is just another example of government saying rural residents do not matter. This is unacceptable. Rural Voices (a national support network supporting early learning and care)

We work to support families having members within the CUPW and the UPCE unions across the country. These members all support families having children with special needs. It is clear that good employment and adequate benefits is critical to being able to provide solid support to children who are challenged in this extraordinary way. Deregulation brings with it the potential for lower wages, job loss, and the erosion of much needed health benefits. JoAnna LaTulippe-Rochon (Executive Director of Family Place, Cape Breton)

The loss of good quality postal service would tear a huge hole in the fabric of this community. Without it, this project, and many other small businesses, would have to move. Moving one small business creates a ripple affect impacting negatively on many others in the community. I ask you to consider the true cost of deregulation, who does it truly benefit? Gail Holdner, Coordinator Special Needs and Moving On projects

We expect the Review Panel to report by December. Please keep checking our union’s bulletins and our websites. This is an issue that can affect both you and your family.

In solidarity,

Lynn Bue   Richard L Des Lauriers

Lynn Bue   Richard Des Lauriers

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.