

SPECIAL NEEDS • MOVING ON

# member to member connection

Breaking through barriers for workers who have children with special needs  
N° 33 Winter 2016

## *Branden, my 17*

*year old son,* is very athletic but using a wheelchair makes it harder to find clubs close by. With the Special Needs project helping out it has been financially easier for Branden to drive to Edmonton for wheelchair basketball and wheelchair rugby. And because of getting to play in local clubs in Edmonton Branden has been invited to Toronto many times for NEXGEN Team Canada wheelchair basketball as well as invited to prospects camp for Team Canada Rugby. Wheelchair Sports Alberta has welcomed Branden and he's made the basketball, rugby and track teams. Thanks for helping us get Branden to Edmonton (510 km round trip) as often as we can for practices (about once a week). Branden has brought home medals in every sport he plays now from Canada Summer Games, Canada Winter Games and Wheelchair Rugby Nationals.



**Branden (middle).**



**Branden**

**Letter Carrier**  
Lloydminster, SK





**The story starts** on July 2, 2015. My 13-year old son had no energy, and was listless and unhappy. He had suicidal thoughts.

So I took him to the hospital and, once there, the whole process started: medical examination, psychologist, social worker, youth psychiatrist and all kinds of specialists.

He did not go to school all year long, because he was scared of being bullied and all the stress that would cause him. He spent two months in Hôtel-Dieu du Sacré-Coeur hospital. As he had severe behavioural problems, he was placed in a youth centre. He has been there for a year. He is beginning to feel better because of his medication.

Diagnosis: personality disorder, ADHD, mixed anxiety disorder and tics, for example, he pulls out his hair, picks up everything and eats all the time.

In short, someone at work talked to me about the help I could get, and I called (the Special Needs Project). I would have liked to know about it sooner, but that's how it is. The costs for youth centres are very high. I only pay half and, with the medication, it costs me between \$350 and \$450/month. Imagine!

**Letter carrier**

St-Brigitte-de-Laval, QC

**Thank you** for your continuous support to help our son Cooper attend activities that are improving his condition. A week ago we all saw the neurodevelopmental pediatrician. He told us Cooper has Developmental Coordination Disorder and is behind in his motor skills. We are waiting for a call from the Occupational therapist recommended by one teacher at school. We want the OT to assess Cooper's gross and fine motor skills and tell us what needs to be done. The doctor also said Cooper

is a very smart boy that has pretty much caught up with his peers. He is doing well for his age in terms of learning. The doctor still wants to monitor Cooper and will give us a report in about a month. We are super proud of Cooper. We are sure that arranging activities to overcome his motor skills problems will help him. Boys are boys and in the future we would not want his motor skills to have repercussions on his social life. Thanks so much once again!



**Cooper**

**VHE 9**  
Bolton, ON



**Clay and Cooper**

## Advisor passionate about her work

**Pat** is in the middle of a busy morning, but she takes it all in stride and has no problem making time to talk on the phone, even if it means heading out to her car for some quiet.

“I really enjoy the people I work with as advisor,” says Pat. “I just wish I had more time. Everyone is much busier today. It’s really changed. I’m hoping that when I retire I’ll be able to talk more. I’ll have more free time and it might be easier to schedule.”

Pat has worked in the area of special needs for close to forty years, since she finished her degree in psychology. She has been Special Needs Project advisor for Nova Scotia for almost 19 of those years, since the project began. When Sharon Hope Irwin asked if Pat would be interested in taking on the role, she jumped at the chance: “I said I’d love to and have been involved ever since. I’ve been very lucky. They’re very good families. It’s been a great a ride.” Pat also works as an inclusion coordinator for a daycare program in Halifax.

As you may have guessed from her career trajectory, Pat is passionate about working with families with special needs. Having raised two children with high needs herself, she finds it very easy to sympathize with the families she speaks to: “When I talk to a new family and find they have some of the same struggles that we had, it’s almost a relief to them to hear that someone else has gone through the same thing... although it’s not much of a relief to hear that some of the struggles are the same as they were twenty years ago—that’s rather discouraging.”

Pat remembers a lot of high points in her work with the Special Needs Project over the years, like hearing



families’ success stories. And she’s always amazed to hear the things that members are doing for their children: “People are amazing. Families are amazing. What they’ll do for each other.”

Pat also really enjoyed the Special Needs Project advisor conference that was held last November. “None of us had ever met face to face. It was such an incredible event. I’ll never forget that.”

Outside of work, family is enormously important to Pat. She and her husband have three kids and five grandchildren, and they also brought up their nephew, who has just started university. “We gather every Saturday to have supper at our house,” says Pat. “There are a lot of us so it’s not that easy, but we try to do things together as much as we can.”

Pat’s other passions are going to the theatre, movies, reading, going for long walks, and anything to do with the human mind. “Crazy or not, I love going to conferences,” says Pat. “I went to a three-day one two weekends ago that was all on the brain. I loved that.”



“Social stewards will be trained to provide support to members in the workplace.”

# Child Care Fund Update

## Social Stewards, Disability Support and More!

### *Social Steward Network*

Delegates to the 2015 Convention directed CUPW to support and train a network of social stewards similar to our social steward networks in Quebec. In late October 2016, the first 5-day training course for social stewards took place.

Social stewards will be trained to provide support to members in the workplace. They will be there to listen, to help identify problems and find solutions for members facing problems at home or at work. Social stewards will allow CUPW to provide assistance to members as equals – help offered to members by members.

Part of the social stewards’ training included a session on the CUPW Child Care Fund. With the help of our new social steward networks, we hope to get much more information to members about the Fund and about our child care projects, Special Needs and Moving on projects.

### *Evaluation –*

### *Special Needs and Moving On*

We are working with the Canadian Centre on Disability Studies (CCDS) to evaluate our Special Needs and Moving On projects. The evaluation will look at how well we are doing and recommend ways for us to do even better. Project members will be invited to participate in the evaluation through an interview with their advisor in early 2017.

### *Important Resources for You*

Too many parents have a hard time finding good child care they can afford. Check out the [www.findingqualitychildcare.ca](http://www.findingqualitychildcare.ca) website if you are **looking for quality child care options in your area**. This web site has up-to-date information to help improve your chances of finding good child care you can afford.

Check out [www.specialneedsproject.ca](http://www.specialneedsproject.ca) to find the Resource Guide: Special Education Navigation Tool. This Guide makes it easy for parents of school-age children with special needs to navigate the public education system in your province or territory. You can **learn about what your school-age child is entitled to** and how you can advocate for them.

### *Child Care – Mini Hub*

Members who live or work in rural or suburban areas, or who work part-time or irregular hours often have the hardest time finding good quality child care.

In trying to support these members, we are getting an exciting project underway in British Columbia. Working with three locals in the Lower Mainland of BC, in partnership with BC211 and West Coast Child Care Resource Centre, we will assess the feasibility of setting up mini hubs that would connect and house small child care centres with information and referral services, family resource programs and family home child care.





***Hello everybody.*** My name is Surria and I feel very proud to say that Umaima is my daughter, my princess, and my party girl. I think autism is more challenging than the other exceptionalities. A child with autism faces many problems and influences family, too. Research indicates that mothers of children with autism are at greater risk of mental health issues and their siblings often have to take a back seat as they are forgotten and so much attention is directed to the child with needs...I would like to share my story through my poem.

I love you Umaima  
But you don't know  
When you will know  
I don't know

I always had these thinkings  
In my mind and soul  
Whenever I thought about  
My little lovely doll.

How long I waited for the day  
When my little princess  
Will come from school  
And has something to say.

I remembered whenever  
Umaima made a large mess  
I seek help from my children  
And I said help me, help me

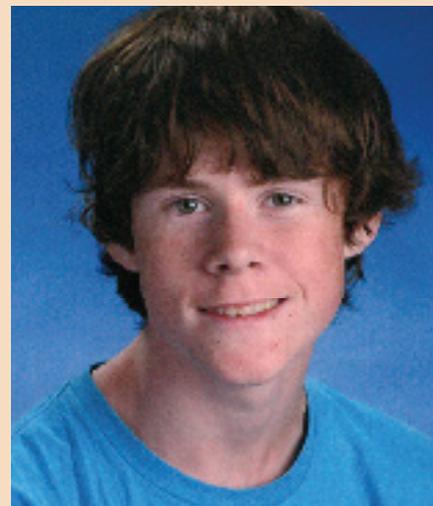
It is a test  
Mahrona said  
What kind of test  
To clean the mess  
I want to tell her  
Umaima makes no more mess  
And we have passed the test.

I remembered my bitter culture  
My relatives and friends said  
She is a curse from God  
For all my bad deeds  
I want to tell them  
She is a gift from God  
For all my good deeds.

She is loving and caring  
And never screams  
It is her first step  
To her life of my dreams

She sings sweet song  
And I pray for her life long  
Everyday she has something to say  
And helps others in her own way.

**PO-4**  
Ottawa, ON



***Our son Lucas*** was born early at 28 weeks and weighing in a little over 2 pounds. At birth he suffered a brain injury and has a learning disability. At four years old Lucas was diagnosed with multi focal osteomyolitis that is painful at times but manageable. Lucas is resilient and perseveres.

With the help of the Special Needs Project we have had the extra money for tutoring, medications, transportation and independence and social skills building.

Math and language have always been challenging for Lucas. He is 15 years old now and last month he won a Merit award for Grade nine language. I couldn't have been more proud. Without the funding for all the tutoring he has received this would not have been possible. The support and information from our advisor is invaluable, as she has clarified IEP's and helped with getting technological support for Lucas in school.

Thanks to everyone who is involved in this amazing program.

**Letter Carrier**  
Orangeville, ON



**Umaima and teacher**



## Jacob is 18 years old

and loves to write and read. He enjoys history, political science and theology. One of his hobbies is writing poems and stories. Here is one of his poems.

RSMC  
Halifax, NS

# The Spirit Within

by Jacob

**There once was** a man well along in years, who had trouble with his eyes and trouble with his ears.

Through the long day he found it hard to walk, and with his loving family he found it hard to talk.

Then one night he wanted to rest his head, so he climbed up the stairs and into his cozy bed.

He went to close his eyes and to turn off his ears, and so went to sleep the man well along in years.

He woke up to a light he had never seen before, he got up without a fright and saw something to adore.

It was a little boy with big cute eyes and big cute ears, and there was no doubt about it he was very young in years.

He wondered where the boy came from, unaware what had been done, and into, his bedroom why had that boy come.

Until he looked at the boy with some recollection, so he brought up the past a specific selection.

He stood and he thought until to his mind, the memory was brought of a time much more kind.



Jacob (left) with his mother and father

He looked at himself at an earlier age, when the book of his life was at an earlier page.

He thought to himself how this could be, he thought to himself is this boy really me.

When there came a voice he had not heard before, a powerful voice that made his soul soar.

“Do you not know who you now see, are you unaware of who this could be?”

Then to his great delight he knew who this boy was, with face so bright.

Again came the voice, “To be who you were or to be who you are, this is your choice it should not be too hard.”

“What do you mean?” asked the man very keen.

“To be who you were and not who you’ll be, that is your choice, given by me.” Said the voice.

The man thought to himself, “How could this be, how could this little boy I see be me?”

“For I am now old, well gone in years, so how can I be this boy with cute big eyes and cute big ears?”



Again came the voice. "It is not the face the eyes and the ears, but the spirit you can bring back after all of these years."

"For this my child can be a great aid, to be who you were it was how you were made."

"Yes you are old and well gone in years, with creaky body parts like rusted old gears."

"But the spirit within cannot be easily changed, unless you yourself allow it to be rearranged."

"And so you have done it becoming old in heart, you've changed your spirit into an old rusty part."

"But now you can change back into your young self, and I do recommend it for it is good for your health."

"This sounds very good and I think that I would, if only you show me how I now could." said the man.

"Wake up!" said the voice. "Seize this new day, and let your young spirit inspire you to play. Go and have fun, and whatever you do don't let your body say you're not young, for that is simply not true."

And with that awoke the man well along in years, with his troubled eyes and his troubled ears.

To return to his body he had some regret, but the message he got he would never forget.

And so now he lives with rusted old gears, but a spirit within still young in years.

***We are a nice family*** with 4 handsome boys. Our eldest has three labels on his back. He is dyspraxic, ADHD and ASD. When we found out we had to get in touch with the social worker at Centre de réadaptation Marie. When we found out that our child was different and that he will remain so for the rest of his life, we had to grieve the loss of the "perfect" family. Time lessens our pain and makes us understand that, basically, these are only labels that we will be able to modify over time as our child evolves at his own pace.

Our son attends an international school and is getting average grades even without additional support. To assist our life, I started a business whose mission is to ease the daily life of families with children from birth to the age of twelve. I develop educational materials from recycled objects that help make the daily life of families more harmonious. This business enables my son to attend an international school. This school works well for him because everyone around him is aware of their precise role.

The business is called SOPS Action.

[www.sopsaction.com](http://www.sopsaction.com)

[facebook@](https://www.facebook.com/sopsaction)

[sopsaction](https://www.facebook.com/sopsaction)

Thank you.

**Letter carrier**

Ville D'Anjou, QC



**Family**

English ▾

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

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

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# What You Said

## about your disability support needs and experiences

During the End of Summer Interview 2015, Advisors spoke with parents in both the Special Needs and Moving On Projects about disability supports – the resources, programs and services members use and want for their children and family.

You told us about the disability supports you currently use and want to keep using, and those you would like to get for your son or daughter in the future. Table 1 shows the top 5 types of disability supports parents in the Special Needs and Moving On Projects want to get and keep.

Parents in both projects want to get future planning and supported employment supports. Parents in both projects want to keep funding & government aid and therapy.

Top 5 types of disability supports parents want to get a keep in each CUPW project (with number of patients in each project and percentage of parents identifying each type of support)				
	Special Needs Project		Moving On Project	
<b>Want to get</b>	Future planning	22%	Housing options	30%
	Planning for transitions	20%	Future planning	26%
	Supported employment	18%	Financial planning	25%
	Funding & government	18%	Supported employment	23%
	Counseling for family	16%	Social skills training	19%
<b>Want to keep</b>	Education-related support	40%	Funding & government aid	49%
	Funding & government aid	31%	Respite	30%
	Therapy	30%	Day programming with supports	27%
	Tutoring	28%	Counseling for adult children	23%
	Assessment	27%	Planning for transitions	21%
			Therapy	



You shared your overall experiences in finding the disability supports you need for your son or daughter and family:

**30% of parents in the Moving On Project and 26% of parents in the Special Needs Project experience difficulty looking for disability supports.**

You voiced the reasons why you have experienced difficulty finding disability supports:

- **Over 60% of parents in both Projects experience difficulty because there is little or no availability of disability supports; this was the most common reason for reported difficulty.**
- **Half of parents in both Projects experience difficulty because of long wait lists.**
- **Nearly half of parents in both Projects experience difficulty due to lack of information.**
- **40% of parents in the Special Needs Project and over 50% of parents in the Moving On experience difficulty due to lack of time.**

## **What's Next?**

Now the Special Needs and Moving On Projects plan to address the need for more information about disability supports in two ways:

- Developing a disability support information online searchable portal. We will partner with 211 services and plan to have a pilot project for members in Ontario and Nova Scotia in the New Year.
- Hiring a Support Navigator in the New Year to join the Special Needs and Moving On Project team. The Support Navigator will be available to all members in both projects to assist in finding information about the disability supports you need for your son or daughter.

We sincerely thank you for all of the information you provided during this and all Advisor interviews. We will keep you up-to-date about this work through e-news bulletins, information on [specialneedsproject.ca](http://specialneedsproject.ca), the Member-to-Member Connection Newsletter and Advisor interviews.



211 is Canada's primary source of information on government and community based health and social services. 211 services include a telephone help line (2-1-1) and an online database of health and social services information.

211 services are currently available to 60% of Canadians. Residents in all communities throughout Ontario and Nova Scotia can call the 2-1-1 helpline to find health and social services information, and access the online database from the 211 Ontario and 211 Nova Scotia websites.

211 services are growing in other provinces. Residents in many of the communities in British Columbia, Alberta, Saskatchewan, Quebec and New Brunswick have access to an online database of service information and/or the 2-1-1 telephone help line.

Check out the website of 211 in your province to find out what services are available in your community!

- **211 BC** - [www.bc211.ca](http://www.bc211.ca)
- **211 Saskatchewan** - [www.sk.211.ca](http://www.sk.211.ca)
- **211 Nova Scotia** - [www.ns.211.com](http://www.ns.211.com)
- **211 Alberta** - [www.ab.211.ca](http://www.ab.211.ca)
- **211 Ontario** - [www.211ontario.com](http://www.211ontario.com)
- **211 New Brunswick** - [www.211nb.ca](http://www.211nb.ca)
- **211 Quebec** - [www.211quebecregions.ca](http://www.211quebecregions.ca)



**"I am his biggest fan."**

**My son Jayden** will graduate from high-school this year. He has done really well with all the support through his IEP in school. I really thank this school program. He is going on in school to be a minister. He has to take a reduced workload in university though as it will be so very hard. He will not have all the help he has had in high school. He is unsure if he wants to do a victory lap or a half load at Kings College. Hope all goes well for us. I am his biggest fan. And his Dad is now diagnosed with prostate cancer and it's all through his lymph system. This will impact his feelings of being so unsure.

**Letter Carrier**  
London, ON



**Samuel**

**Samuel is** a 12-year old boy suffering from dyslexia, Gilles de la Tourette syndrome and severe ADHD. He manages, thanks to the Special Needs Project, to realize some great achievements in hockey, soccer, deck hockey, horseback riding and many others. Through these programs he is in direct contact with other youth and is learning to live with his peers. This enables him to work on his self-esteem through his great accomplishments.

Thank you very much for the support given throughout the years. Without you, none of this would be possible – Maria and Samuel.

PO-4  
Ste-Catherines, QC

## **Busy Times at CUPW – Bargaining and Postal Review!**

### **Bargaining**

This year, CUPW was locked in a very difficult round of negotiations with Canada Post Corporation, which wanted to force postal workers out into the street during a critical federal review of the postal system.

Union representatives went on the road to talk to members and to prepare strike votes. During the summer, negotiations came to a head and tentative agreements were reached for both rural and suburban members and urban unit members. At the time of writing, these agreements are undergoing the ratification process.

Our Special Needs and Moving On programs were gained through the struggles of postal workers at the bargaining table. Our union will keep up its ongoing fight to improve our working conditions and benefits, and to keep these vital programs for all members.

### **Postal Review**

In May 2016, the federal government announced its long-anticipated review of Canada Post and appointed a 4-person taskforce. The Taskforce was directed to prepare a discussion paper to present to an all-party parliamentary committee. The parliamentary committee held (limited) public consultations and is

set to report to the House of Commons in December 2016.

CUPW worked with members and allies to put forward a vision of how Canada Post could be part of a 21st century economy based upon better public services and greening our infrastructure. It is time for Canada Post to add new services, including bringing back Canada's postal bank and Letter Carrier Alerts to support seniors and others to remain in their homes.

CUPW made detailed presentations to the Taskforce (which you can find at [www.cupw.ca](http://www.cupw.ca)), but many of our recommendations for

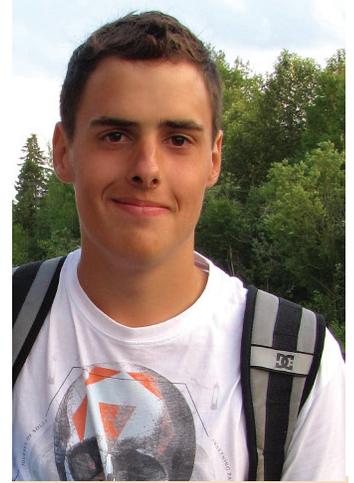
improving and expanding postal service were ignored or dismissed in the final report, where a profit-oriented business perspective, rather than a public service perspective prevailed. We responded to the taskforce report, identifying a number of errors, omissions, misrepresentations and unsupported speculations about the financial health of Canada Post.

The official consultation phase of the review is over but it's never too late to push for better public postal service! Encourage your communities to keep telling the government: **we support expanding postal services and do not want to see any more cuts.**



**Our son was born** after 26 weeks of gestation with many health problems. He needed a respirator for the first three months of his life. He was born in Moncton, NB and the hospital was not equipped for intensive neonatal care. When he was ten days old, hovering between life and death, he had to be transferred from Moncton City Hospital to the IWK in Halifax. He needed an operation to correct a hole in his heart that normally closes on its own when everything goes well with the birth.

Unfortunately, during this operation, a medical error was committed. During the heart surgery our son's recurrent nerve was severed causing paramedian paralysis of his left vocal cord. He spent the first five months of his life in hospital with many ups and downs that continued for the following four years.



**Elliot**



**Elliot**

At three years of age our son was in Georges Dumont Hospital in Moncton, and was later transferred by plane to Ste-Justine Hospital. The doctors believed he was suffering from leukemia. He was very neutropenic and his lymph nodes were very swollen. After a bone and marrow biopsy, we received very good news: there was no cancer. We enjoyed an 8-year period of calm, in spite of a diagnosis of dyslexia and learning difficulties. At 13, he was diagnosed with a stage 4 non-Hodgkins Burkitt's lymphoma cancer. He spent nearly five months in IWK's oncology department. He had to have five extremely strong chemo treatments, as the cancer was very aggressive. It was an extremely difficult period for him and for the whole family.

Our son has been in remission since March 8, 2013. But now we are faced with a new challenge... a diagnosis of a rare immune system illness. We have had to move to Halifax, NS, and he must inject himself with medication at home, possibly for the rest of his life.

**Letter Carrier**  
Mount Uniacke, NS

**In September** we said good-bye to our co-worker Cary who has taken a year's leave of absence. Cary has worked with us for the past ten years and will be missed. The silver lining in this story is Cary's replacement, Dawn MacKinnon. Dawn has an education degree and is very understanding of the challenges children with special needs can face in the school system. Her empathy, thoughtfulness and concern for your well-being will be evident the first time you speak with her. So please call and say hello! We will help you in any way we can.

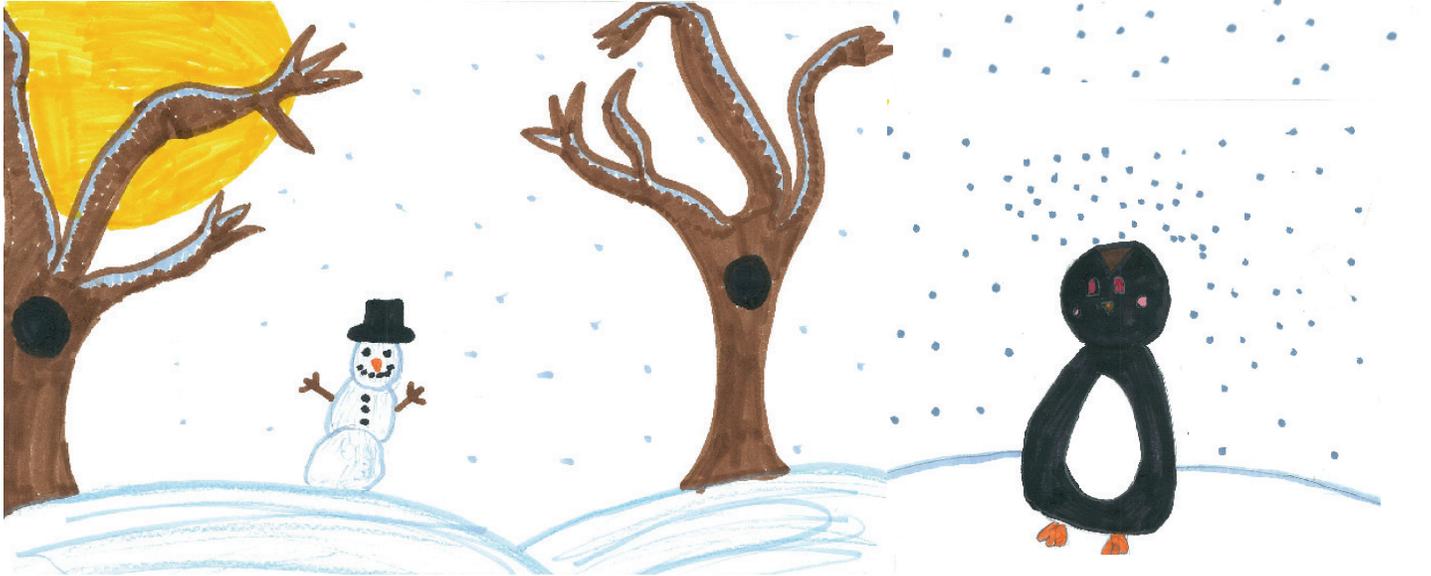
Gail Holdner  
Special Needs and Moving On  
Project Coordinator



**Dawn MacKinnon**



# Season's Greetings from your friends at the Special Needs and Moving On Projects



## Special Needs and Moving On Advisors:

Agnieszka G.	Janet M.	Nancy B.
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Bernadette M.	Judy E.	Roberta M.
Brigitte L.	Karen F.	Sharel S.
Catherine R.	Karen W.	Sheila S.
Charmaine M.	Kathleen B.	Shirley M.
Cherie G.	Lesley-Anne C.	Sue M.
Daniela B.	Lisa V.	Susan B.
Donna M.	Marie-Claude C.	Suzanne C.
Dorothy H.	Marie-Hélène M.	Sylvie G.
Ellen B.	Marie-Josée L.	Tatiana K.
Enna M.	Mélanie C.	Theresa A.
Hélène P.	Nadia J.	Vicki S.

## Family Place:

JoAnna Latulipe-  
Rochon  
Gail Holdner  
Dorothy Keigan  
Dawn  
MacKinnon  
Cary MacDonald

## CUPW:

Dave Bleakney  
Shellie Bird  
Jamie Kass

## UPCE-PSAC:

François Paradis

*May peace, joy  
and prosperity fill  
your home now and  
throughout the new  
year!*

## Quebec

### Coordinators:

Mélanie Bélisle  
Doris Tremblay

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