SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs

Nº 23 WInter 2011

The Special Needs/ Moving On Projects are very significant, not only to the members and their children, but to the larger community as a whole. These projects open a curtain for the unfortunates to become fortunate; they help unthinkable problems become thinkable. They help the children to pursue their god-gifted talents, whether it is in academics, or in sports. They help alleviate the stresses involved - such as financial stress, family breakdowns, and work absenteeism. And they unite families with a common understanding that they are not alone. Together we have moved mountains. My daughter has become a top student, an active sports participant and a confident person. We keep our fingers crossed she will be entering university next year. With full honesty, we could not have achieved my daughter's dreams without the help of the Special Needs/Moving On Projects. It's much appreciated.

PO-4
Surrey, BC

Zachary

I would like to thank the Special Needs Project. I have two children. One has an attention deficit disorder and the other had surgery for a brain tumour. The fund helps us pay for tutoring, sports activities for the oldest, as well as for travelling costs for the many therapy appointments and sports activities for the youngest.

Anthony is 12 yrs old.

Zachary is five years old.

Thank you very much.

Letter Carrier
Saint Constant, QC

"My friend says he's never had that much money in his own account."

Are you crazy???

That's what my friend had just said. We'd been having an animated discussion for at least 15 minutes and he kept saying "Are you crazy?" or "I don't believe you!" I have to say that my friend is a day labourer getting minimum wage and the father of five children. I don't know how he manages, but he does. He doesn't count his time and always agrees to work overtime. Needless to say, his budget is tight, and my friend has a disabled child, like me, but still has time to volunteer or keep up with current affairs. He has people to feed, and is always working, so when I learn that such or such service is available, I make a point of telling him about it. This is what I did when the Registered Disability Savings Plan became available. When I told him that the federal government would give $1,000.00 to my disabled son each and every year, and that all I had to do was to open a registered disability savings plan account, he said "I don't believe you!" And when I added that I had deposited $500.00 in this account and that the federal government had tripled this by depositing $1,500.00 in my son's account, he called me crazy!!!

The next day, my friend called his bank and asked to have papers drawn up so his son could also have a registered disability savings plan account. He didn't think he'd be able to deposit money in the account, but he wanted to take advantage of the $1,000.00 every year… Nevertheless, my friend has managed to put $500.00 per year in his son's account, which is now at more $6,000.00 (in only two years).

My friend says that he's never had that much money in his own account. He thought that, during his entire life, his son would never have any other income than social assistance, but now he knows that after he dies, his son will have more than $100,000.00, perhaps even $200,000.00 (if he finds a better job) in savings, i.e. financial security and a better quality of life for his son's future… what more could he ask for?

So, to you, who are reading this, if you have not yet opened a registered disability savings plan account for your child, I'm tempted to say "Are you crazy?"

RSMC
Joliette, QC

This program is giving my son so much extra support that I could not afford alone. He is learning so much. His independence and social skills have improved. I use the money for programs for him and respite for me. This helps my family's life to be so much easier. Thank you Moving On Project!

PO-4
Oliver, BC

> "iBioMed is an app which is an organizer and social network for health."

I detoxed my son last year through a naturopath. It ended up being an initial $1000 for all the hair follicle, blood tests and removing lead and other metals that came up during the tests, vitamins, probiotics and iron. He was on 90 mg of Ritalin at the time and he went to 45 mg after the detoxing and his grades went up to B's from C's and B's. This year as last year I took him off Ritalin for the summer and let him eat anything and removed it all for school. We started a different way this year.

I looked into a product that was 100% organic, costing $300/month. It's a breakfast and lunch shake that my son can take at school along with snacks and a few 100% natural real food pills per day and 8 glasses of water. Every 14 days Jayden does a cleanse. He is not hungry – it's a drink plus water and 6 snacks through his day. Jayden's grades went from B's to A's 2 weeks after starting this regime so I gave him less Ritalin. Jayden is on 35 mgs Ritalin now, 10 mgs less than last year, and only needs this amount to concentrate. Only 2 years ago he was on 90mgs of Ritalin and I still needed to increase it. Now I am sure he is going to go even lower, or at least not increase, the dosage as he gets bigger (he is 5'7" now). He is 25 pounds heavier than last year and has grown in his chest. His ADHD symptoms have almost gone.

I am amazed at how lean, fit and healthy my son is. He does his homework all on his own now too. This product continually cleans his body out and provides the best form of nutrition needed daily for his brain and organs to function well. I tried it first to see how it could improve my health. I had been on heart burn and reflux meds for 8 years, used my asthma meds twice a day for the last 1½ years and my fingers were burning in the fingertips of my left hand. I was told I was pre diabetic - not a healthy letter carrier. After being on this for a few weeks I didn't need any of the meds and all the symptoms had gone. I am now full of energy and can remember names and information.

Letter Carrier
London, ON

Mathew

I wanted to touch on the "Importance of Keeping a Medical Journal". There is an app called, iBioMed for all of you out there that have a iPhone, iPad or iPod. iBioMed is an organizer and social network for health. Any person living with a complex health condition will benefit. Best of all it's free! I came across it a few months back and I've got to tell you it's a great feeling to know my son's many doctors, supplements, past surgeries, progress, etc. is all in the one place. Check it out!

Note: Google iBioMed.com to get the app.

Letter Carrier
Toronto, ON

Check out our website at www.specialneedsproject.ca

"He did not come into the world with a book of instructions."

Advisor knows from experience where parents are coming from

For Advisor Kathleen Jordan, sharing experiences and storytelling are key to the strong relationships she's developed with families in the Moving On Project.

"These things establish trust and without trust my information and advice has no handles," says Jordan, an advisor for 15 Ontario families involved in the project. *"As an advisor I'm not using any professional status. I'm just using my role as a parent, social activist and informed taxpayer."*

Jordan can relate in a personal way to parents in the Moving On project. Her middle son, Christopher, 37, was born with multiple disabilities.

"I got involved [in special needs issues] when my son was born. He did not come into the world with a book of instructions and he crossed all the boundaries."

From the get-go, Jordan read everything she could about Christopher's disabilities and joined many organizations that provided support to people with special needs, eventually sitting on many of their boards.

"I discovered that many of the needs of parents who had children with disabilities crossed categories. They were based on the availability or non-availability of resources and the function or lack of function of our children. There was transportation, criteria for services, conflicts because of lack of time, other family responsibilities, energy." As well, she points out, children with disabilities *"don't get cured at age 18 or between Monday morning and Friday night when services are available."*

In the late 1990s, Jordan founded Lifetime Networks Ottawa, an organization modeled on Planned Lifetime Advocacy Networks (PLAN). Both are dedicated to helping families with lifetime planning for their relative with special needs.

Interdependent living

Christopher lives in an Ottawa condominium with his mother and father, but would like to live on his own with friends. The ideal would be a home designed architecturally with him in mind. Christopher would share his home with a couple of "supportive roommates" who would be specifically recruited for this opportunity and have different skills and interests compatible with his. Additionally, the personal support he now receives from seven associates would continue in his new household. Jordan calls this new and innovative approach to living in community "interdependent living".

Jordan has been an advisor with the Moving On Project since it began in 2005. She says it's "*phenomenal*" that the union developed this project *"to make life easier and better for everybody. It has a focus on keeping parents at work, and therefore provides support for them in order to keep them functioning at work and that's great."*

This former teacher and high school principal, mother of three adults and advocate for people with special needs has never had a lot of "me" time. In the next phase of her life she'd like to once again take up activities she used to enjoy, such as golf, bridge and chess.

And near the top of her bucket list is learning how to rollerblade. *"My kids say they'll teach me."*

“Signing your donor card can save 12 lives.”

As the leaves start to drop and summer becomes fall, Herbert my ever faithful dialysis machine accompanies me. Soon after I wrote the last time (Member-to-Member #22 Summer 2011) my cousin/donor was hit by a car. Now we eagerly await his full recovery to follow through with my transplant. Test after test each milestone is being hit on his part as he chugs along like a champ. I on the other hand seem less strong but find my support in my blog, friends, family and distant followers, like CUPW members.

It never ceases to amaze me how much of a reach I am getting with all of your help to bring awareness about organ donation. Week after week I get messages of new people who now have signed their donor card because now they are aware. “Knowledge is Power”, and it cannot be more right. Changing the world takes one person, but if they don’t know what change they want to make or what changes are needed nothing would happen.

With this update I want to give you more power.

- More then 36000 people are waiting for a kidney transplant in Canada.
- The wait list for a kidney transplant begins at 7-9 years minimum for the most common blood type. Age, gender, health etc is never a factor.
- We have 2 kidneys in our body and can live with one.
- On average an organ lasts 15 years post transplant.
- Signing your donor card can save 12 lives.
- I am awaiting my second kidney transplant.
- I signed my donor card.

Thank you for your ever so strong ongoing support! It means the world!

Toronto, ON

"You have to choose your battles."

Is the education system working for your children? This is what you told us

In June 2011, 351 members of the Special Needs Project were asked to update us on how the education system was working for their children.

Need for improvement:

Half of the members experienced cutbacks in educational services for their child since he/she started school. Twenty-five percent of members said the areas of greatest concern were cutbacks in relation to availability of school based therapies and resource teachers, and the hours of educational assistants.

Taking action:

Sixty-six percent of the members who experienced cutbacks took action in relation to the cutbacks:

- 48% provided more information to the school board
- 77% provided more information to their child's teacher, assistant or principal
- 44% hired a tutor or provided considerably more assistance with homework

"Requested a meeting with the school because the plan isn't working. It's very hard for him to be in a big group and the new lady in charge doesn't understand his needs. He hasn't been in school for 3 weeks. The trust has disappeared."

"He now has less supervision at lunchtime. I explained about his stress about the impact and damage to his self esteem if he's bullied at lunch."

"Services such as scribes and dictation have been cut. Worked with school on alternatives. I hired a tutor with the help of the SNP, and we agreed on more accommodations for him around testing (given more time to complete tests).

Of the members who didn't take any action regarding cutbacks 36% thought it would be a waste of time and 34% didn't have time to deal with this.

"There are so many other problems at school with him – you have to choose your battles."

Some improvements and satisfaction:

Three quarters of members were satisfied with their child's program or placement. Those who weren't happy identified a lack of support as part of the problem.

Half the members felt the education system had improved for their child. Most improvements were related to new programs or technological support, and a better fit of teacher or aide with the child.

“Our stories matter.”

I would like to take this opportunity to introduce myself. I was most fortunate to be elected as CUPW’s new National 2nd Vice President at the recent National Convention on October 2011. I will replace the wonderful Sister Lynn Bue who, as I have publicly stated, is truly irreplaceable.

Sister Bue was passionate about the Special Needs Project because she knew first-hand what it was like to be a working parent and care for children with special needs. And so do I.

As a mother of two wonderful children who required intensive medical interventions during their school-aged years I know how difficult it was to find support. My experience tells me that through supportive networks we, the parents of children with special needs, gain much strength, wisdom and inspiration. Our stories matter.

I feel so fortunate that my new role allows me to be part of the Special Needs and Moving On projects. The Member-to-Member Connection newsletter is a sparkling jewel where these important stories can be shared and we can support one another. By supporting children with special needs and their families, we are making the world a much better place

I share Sister Bue’s commitment to continue the delivery of resources and services that will make a difference to the lives of CUPW families who have children with special needs. I am equally committed to actively pressure governments and employers to provide all necessary support for working families who are struggling to balance work and family life.

Most importantly, I am looking so forward to hearing more of your stories.

Cindi Foreman
2nd National Vice President

My son Julien is moderately mentally challenged and has severe dyslexia. Thanks to your assistance, he has been able to attend summer day camps in Blainville, where he was assisted by skilled special education students. Any help that can be provided to our sisters and brothers on the North Shore is much appreciated. Thanks so much to the Special Needs program for making things a bit easier.

Letter Carrier
Blainville, QC

> "I had a responsibility to break the silence."

Rolling around in my head

What follows in an excerpt from the blog of Dave Hingsburger. Dave has worked in the field of disability since graduating from university over 30 years ago. He became disabled a few years ago and now uses a wheelchair when out in the world. He is Director of Clinical and Educational Services at Vita Community Living Services in Toronto. To read the full version of Dave's October 30th blog below please check: http://davehingsburger.blogspot.com - english only

A few days ago, in the comment section (of my blog), Julia asked a question. She had been on public transit, a large woman had been sitting nearby taking up nearly two seats. When she got off, an older man sat down, calling her a 'fat pig' and suggested that if he had his way he'd send her to a boot camp (though the word could have been translated to mean 'concentration camp') Julia spoke up, out of real anger for what he had said, and told him that he wasn't so good looking either. There followed a war of words. Julia asked me how to best deal with these situations. I'm not sure I know the best solutions and it's taken me days and days to formulate an answer of any kind.

Dear Julia,

First off, thank you for trying to do anything at all! I am always impressed when someone, in a world that prefers to greet cruelty with silent acceptance, has the courage to go against the grain and rise in protest.

It took me a long time to reach where you are now. It took me a long time to realize that I had a responsibility to break silence. I had to learn to speak, out of protest, not anger. Like you, I began by using the fuel that anger gave me, to ignite my courage, and like you I always left the situation wondering how to have done it differently, said it differently, reacted more carefully. When I discovered the difference between protest and anger, I got a little better at it. I follow these three rules.

1. Never respond to insult with insult. To talk about his looks after he commented about her looks leaves a kind of agreement that looks are fair game for judgment and comment on another. The issue isn't the old guy's looks, it's his behaviour and it's his assumption that all around agree. Those to me are the issues at the core of what needs to be addressed.

2. Speak about 'self' in 'I statements', not about 'them' in 'you statements'. The temptation is to go on attack. People leave these situations saying things like 'and out of the blue she attacked him' - you become the story, the issue is forgotten.

3. Speak as much, if not more, to others around rather than to the person specifically. You've got to bet that there are others who agree with you but are afraid, for many reasons, to speak up. Engage them, make their silence an agreement with you rather than an accord with the bully.

So, some responses that might have been useful in a situation like this:

Look around at others and say some things like:

I don't know about the rest of you, but I like the fact that others are different.

Look who thinks we are all bigots.

All I know is that I could never behave so hatefully to another.

My mother brought me up to behave with kindness, I guess this is why.

Or, if addressing him directly, and these need to be used more cautiously assessing your own personal danger. Call me a coward but I'd never use these when alone with the person in a closed environment:

Don't assume that I agree with you–I like differences in people.

"I don't like hearing hateful talk about others, I believe in kindness."

"Whoa, what happened to civility?"

So those are some ideas. I found that I was bothered as much by the assumption that I'm part of a mob who find hateful remarks acceptable as I was about the hateful remark itself. I didn't like the absolute trust that bullies have in the complicity of others, me included. I didn't like being made meek in the face of another's outrageous courage. Those are what I felt I had the power to respond to.

The other thing that I realized is that kindness is seen as synonymous with passivity - it's not - kindness is powerful, is motivating, is revolutionary. The power of kindness is the ability it gives the speaker to speak from a different point of view. Love may not rage as much as hate does - but love is an unstoppable force, if only because of the constancy of the fuel supply. So, I believe that acts of public kindness go beyond picking up a lost teddy for a crying child - I think acts of public kindness are most powerfully done in a voice raised in protest at the treatment of another.

I believe Julia, you acted on an impulse to love and care for another, in the face of a brutal attack. Your action, even if you might want to do it differently, made a difference. Trust that.

I would like to thank the Special Needs Project. Thanks to the financial assistance it provides, my son Frederick has, for several years, been able to take part in the activities he enjoys, such as special soccer, recreational activities offered by the South Shore Parents Association on Saturdays, including outings, crafts, cooking, etc.

Special thanks to my counsellor, Tatiana, who at each interview gives me all the information needed to help my son and I reach some of our objectives.

PO-4
Longueuil, QC

Gabriel is in therapy sessions at school. This is a big challenge for Gabriel, a 15 year old autistic boy who has started to communicate through the computer and is now learning the PIC system (picture language) because he is nonverbal. Thanks to the Special Needs and Moving On Projects my son will have his own computer at home and a tutor who will come after school to help him to learn to communicate with others for the first time in his life. Thank you for helping my son integrate into the "normal" society by being able to speak to others and have others understand him.

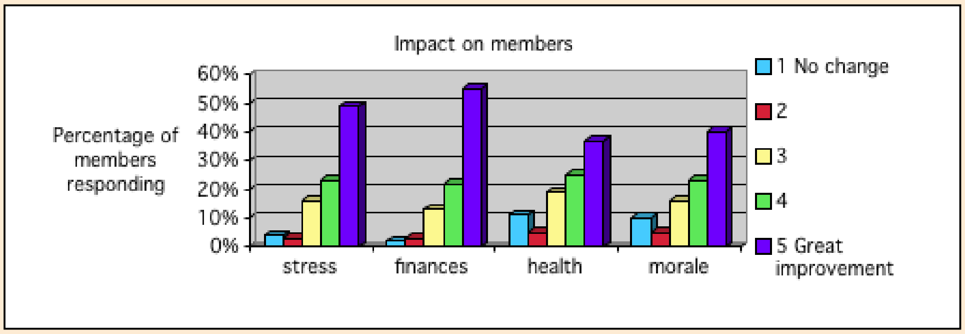
Letter Carrier
Brampton, ON

What you told us

In the spring of 2011 we asked 368 Special Needs Project (SNP) members and 80 Moving On (MO) members to reflect on their entire time participating in either of the projects and to tell us how we're doing. You also shared the impact the projects have had on yourselves, your children and families. Here are the results. This will help us continue to support our members and families.

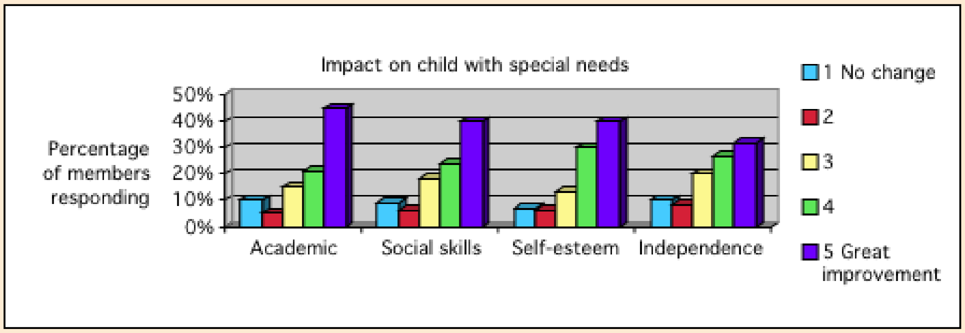
Administration:
Most members felt that the projects were very helpful and provided information and cheques in a timely fashion. The one thing members said would have been more helpful was additional funding.

SN and MO projects impact on the members:



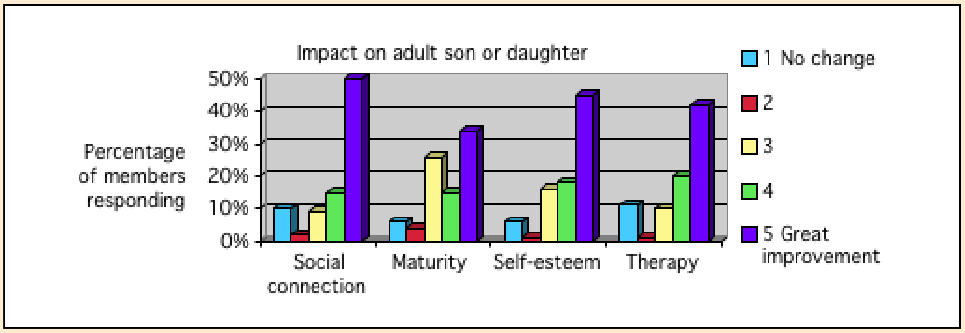
The projects were a significant help in reducing members' personal stress as well as financial concerns. Members also felt the project played a part in improving their health and their morale and effectiveness as a worker. For 52% of members the project, and specifically the Member-to-Member newsletter, helped improve the members' attitude towards the union.

SNP impact on child with special needs:



The SN project played a significant role in improving their child's social skills, self-esteem and academic skills by enabling them to access services or resources not previously available to their child. Almost half the members felt it contributed significantly in improving their child's communication skills, fine and gross motor skills and access to therapy or related services.

MO impact on adult son or daughter with a disability:

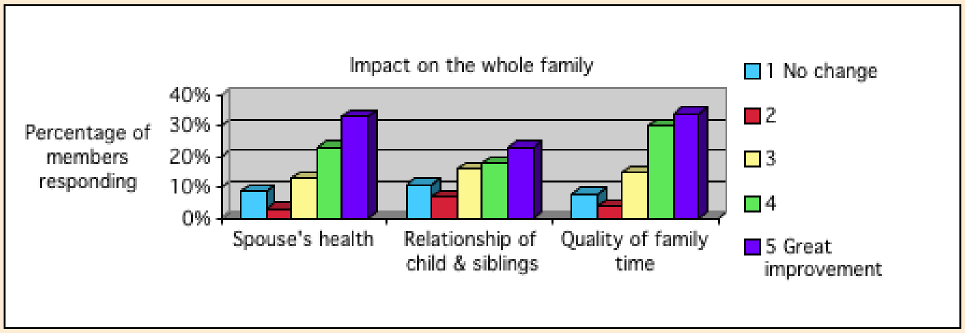


Members felt the most significant contribution the MO project made was the increased opportunities for social connections for their adult daughter or son. For 45% of members the project helped to access work or day programs required. Twenty-eight percent of members found the project contributed to their son or daughter's ability to advocate for themselves.

Advisor support helps to alleviate tension.

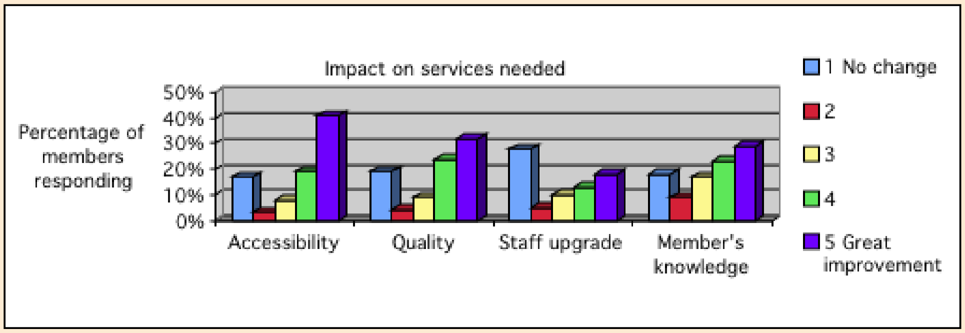
SN and MO projects impact on the whole family:

Members felt the projects' support had a great impact on improving the health of family members. Members have told us the opportunity to speak with an advisor and the financial support provided helps to alleviate the tension and assists them in accessing more support for their child's/adult child's needs. It can also free up their own funds to access additional programs for the other siblings in the family.



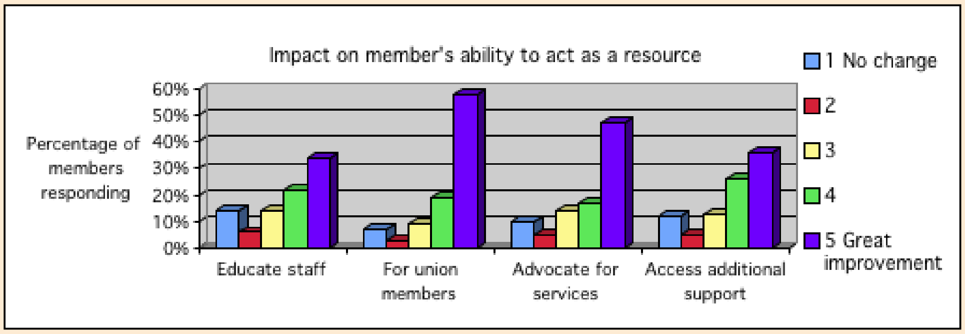
SN and MO projects impact on services available (community facilities):

The projects helped educate most members about available resources and allowed them to access new or better quality services for their child. Close to half the members felt that project support had a moderate to significant influence on improving their child's/adult son or daughter's relationship with their peers.



SN and MO projects impact on member's ability to act as an advocate and source of information:

Close to 60% of members felt they were better able to inform their co-workers about special needs issues as a result of being in the project. Many members felt the project increased their ability to educate staff in school or programs their child/adult child was attending about special needs issues. They also felt it contributed to their ability to access additional supports and to advocate for what was needed. Twenty percent more MO members than SNP members felt the project helped them be better able to advocate for services.



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

Special Needs and Moving On Advisors:
Bernadette M.
Shirley M.
Donna M.
Marie-Josée L.
Roberta M.
Suzanne C.
Pam M.
Arlie R.
Anne G.
Sylvie G.
Pat M.
Angelia B.
Ellen B.
Sheila S.
Lesley-Anne C.
Nancy B.
Agnieszka G.
Sue M.
Sharel S.
Enna M.
Kathleen B.
Cherie G.
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Donald G.
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Normand R.
Cora B.
Genevieve P.
Theresa A.
Trina S.
Jean C.
Marie Hélène M.
Tatiana K.
Lisa V.
Nadia J.

Family Place:
JoAnna LaTulippe-Rochon
Gail Holdner
Dorothy Keigan
Cary MacDonald

CUPW:
Lynn Bue
Cindi Foreman
Jamie Kass
Doris Tremblay

UPCE-PSAC:
Patty Ducharme

Wishing you every happiness now and throughout the coming year!

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

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.