



member to member connection

Breaking through barriers for workers who have children with special needs
N° 20 Summer 2010



I'm writing this note to thank you for your help. My son, Julien, who is disabled and is dyslexic, will be going to a regular school as of September. He will, of course, still be receiving special training, but just being in contact with typically developing children will be beneficial. Programs such as the Special Needs Project help make our life a little easier and help our children grow in a much more favourable environment.

Letter Carrier
Sainte-Thérèse, QC



Ryan Bail, former participant of the Special Needs Project (1997–1998) had the opportunity to be an Olympic torchbearer in Nelson B.C.

Ryan is now 24 years old and despite his disability, he holds a full time job in Sooke B.C. Congratulations Ryan! Thanks to the Special Needs Project for assisting Ryan to have the confidence to reach his dreams.



Many members are struggling to help their adult son or daughter find support.

Moving On Members Talk

We interviewed 89 members from the Moving On project. Here is what we heard about a range of issues:

RDSP Feedback

The Registered Disability Savings Plan (RDSP) is a new Federal Government program members can access for their adult child.

- 16% applied or were in the process of applying for their adult child.
- 36% planned to apply but hadn't started yet.
- 60% of those who applied said the bank was confused about the process.
- 40% said the process went smoothly but it took a few meetings to set up.
- 25% of those yet to apply said it was a lack of time that had stopped them.

NOTE: Some members didn't apply because they didn't have money to put into it. Don't forget that there is a grant portion for which no contribution is required.

Vitamin Benefit

Vitamin benefits are available to the adult sons and daughters of members who meet the eligibility requirements.

- 73% of the eligible adult children with a disability are covered under their parents plan.
- 32% of those eligible take vitamins related to her/his diagnosis.

Some of these members have applied previously for the vitamin benefit.

"I prefer to purchase them over the counter because it's less hassle", "Have tried several times and been turned down. My daughter takes homeopathic vitamins without a DIN so it is not covered."

Post-secondary education

Many members are struggling to help their adult son or daughter with disabilities find support to be able to continue their education.

- 35% said their son or daughter was in, or planning to attend, post-secondary education.
- 65% of these adult sons and daughters require exceptional education-related services or equipment.
- 40% of those adult son's or daughters in post-secondary school said that the support offered by the school met all of their needs.



"Knowing this program is out there eases the burden just a bit."



My husband and I have two boys, Logan who is ten, and Brandon who is six years old. My husband is a Rural Route driver for Canada Post in Charlottetown, PEI. Brandon is our special needs son. Brandon has gone through a lot the last two years. He went to kindergarten last year and had his own SNA (Special Needs Assistant) teacher who also went to kindergarten with him in the summer. He also had speech and physio support at the hospital. Brandon started grade one in September 2009. He has two EA teachers, his homeroom teacher and a speech pathologist that work with him. We are very thankful for all of them. Brandon has his own grade 1 program adapted to his needs. He has a lot of friends in his class. Logan is in Grade five and helps his brother when needed if he gets upset at school. We are so thankful the Special Needs project has helped us to do things for Brandon that we could not do on our own. Thank you so much. Kim, David, Logan and Brandon.

RSMC

Charlottetown, PEI



Wanted: In Airdrie, AB.

Community programs for children of all ages with developmental disabilities. Looking for groups, programs, events, etc. to teach safety skills, independence, social skills, organization, leadership skills, for special needs children only. Thanks. Please email: conniescomputer@shaw.ca



My daughter's health is starting to decline. She is out of school now. Our costs are \$1000/month on diapers. Truly this has been one of the most expensive years in our family. Without this program and funding we would be at a loss. Every little bit helps. It doesn't reduce the stress in the family but knowing that this program is out there eases the burden just a bit. I have now transferred into retail clerk FT in Orangeville, this has allowed me to be so much closer to home in case of emergency. Thank you.

PO-4

Orangeville, ON

Letter Carrier

Airdrie, AB





"Take a Shop Steward's course. Nothing trains advocates the same way."



It is a scary time for me as my son is entering adulthood. He is transitioning from high school to "something" in the next two years. What that "something" will be is unclear. Daimon has gained minimal independence, as some of his behaviors require constant supervision. As a result he is unsure of himself, always looking to others for confirmation. It leaves me questioning his readiness and how we will cope. This is one of those times when I don't feel in control. Not sure if these are supposed to be happy stories but this is where I am.

PO4
Nelson, BC

It has been a long journey but in February 2009 my daughter Claire was diagnosed with Aspergers Syndrome, a form of autism. It's taken years to have this clarified. Now we have the diagnosis, new therapies and support will open up for her. School is still a problem but Claire is very resilient. All I want to add is that we refused to settle when we had the first diagnosis of ADHD. If you feel your child's diagnosis is incomplete, carry on. Challenge the physician and school system and take a shop steward course. Nothing trains advocates the same way. CUPW has changed our lives for the better and continues to do so everyday. In solidarity,

PO-4
Kelowna, BC

A special thank you

to CUPW for all the help we have received for our daughter. We believe that the Special Needs Project has truly made a difference in member's lives, whether it's the financial help or help with finding resources for our special kids. We are truly blessed to have this much needed help. For those of us who have held non-unionized jobs, you know how lucky we are. Thanks again CUPW, we hope this project keeps going strong for those of us who really need it now and in the future.

PO4
Westhill, ON

I would like to thank

everyone involved with the Special Needs Project. Being part of the project has been a wonderful experience. I will miss speaking to my advisor as she always gave me great information. Thank you again to all the Special Needs Project people behind the scenes. You are all doing a great job! My son will be attending college this fall. He did it! I am a proud mother.

Letter Carrier
Gloucester, ON

"If you don't like being bullied; don't bully people who are different."



We want to thank the Special Needs Project for their assistance. Our son has Asperger's Syndrome, a form of autism, which impacts his social and emotional skills. He has had to deal with many difficult situations as he has difficulty expressing himself. Through additional tutoring for academic reading and writing, Mark is able to express his thoughts more clearly. This year his grade 8 English class had to write an "I Have a Dream" speech. They had to present their speech to their class. His speech was selected by his classmates to be read in front of the entire school. Here is his speech.

Letter Carrier
Pickering, ON

Speaking against autistic bullying

When I was younger, when I was in grade four; people started to notice things about me. People noticed that I started to have a short temper and when things don't work well the first time; I tended to freak out. Sometimes it still happens, but since then I learned to control myself. There are many cases of this in other schools in the Durham Region and all around the world. That is why I stand here today. I have a dream, to explain to you that we, as autistic people, should be treated the same, but instead we are amusement to people who get a joy from our pain. But what people don't think about is that we are the same as everyone else, only with minor differences. I have a dream, that every one who treats us differently learns what we go through and understands what can happen when we are treated differently.

Many people take advantage of autistic people. Non-autistic people do this because they know what causes me, and other autistic people, to react. In doing so we end up feeling like we are separate from the rest of the world. We take things too literal and end up feeling like we were not as smart as everyone else. If the sadness gets too great, we may end up committing suicide. People with autism would do this because we think that no one likes us, we feel that there is nothing left to live for. Sometimes I feel the same way, but when I do; I think. I think of my parents, who always love their child no matter what happens.

Everyone can be equal; no one is perfect, same goes for autistic people. We are the same as everyone else in this room, only with minor differences. We have strengths and weaknesses just like you. In school for example, my strength is Math, but every now and again I need help. The same can be said for many autistic children, teens and adults. Others think that autistic people are nerds because of the amount of knowledge we have. Let me tell you something: Nerds rule the world. They were able to create medicine that can save lives. In a few years Cancer may be curable thanks to nerds. And most of these nerds are like me; they have autism.

If we can teach others about what happens to people with autism, then maybe everyone can live together and treat each other as an equal. I have noticed that there isn't a lot said about autism. There are only a few presentations that talk about it, but most people forget them after an hour. We should find ways of teaching people about autism so the students don't forget what they learned; it should be as if the whole class has what I have. Then teach by example.

I hope that what I have said now will stay with you, so you can think about what we go through in what you call daily life. I have a dream, that we won't get bullied just because we have autism. I have a dream, that people can treat us the same as everyone else. I have a dream that the school board can put into effect; a lesson plan rather than a presentation on autism. So, just remember, if you are about to irritate someone with autism, think about this speech, and remember; if you don't like being bullied; don't bully people who are different, treat them the same.

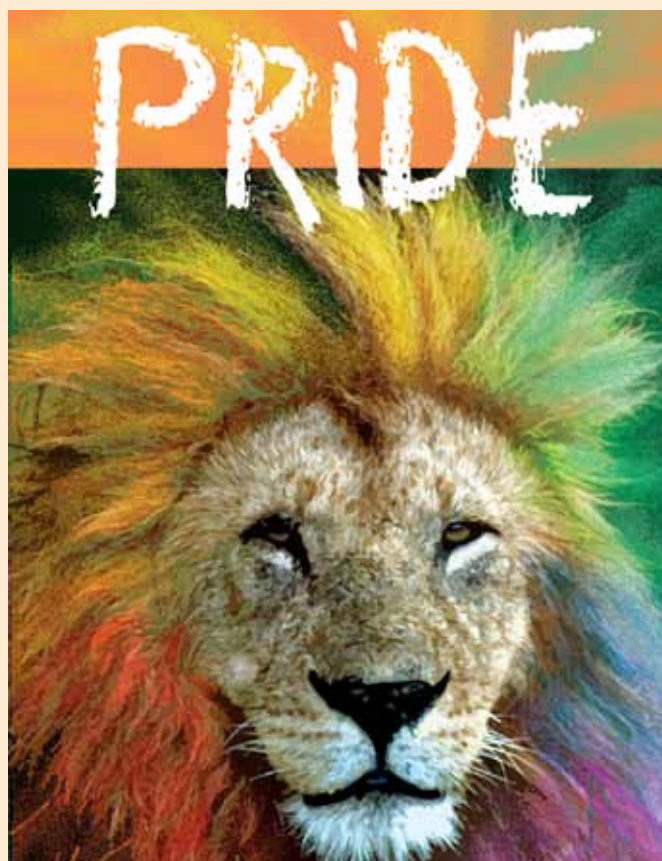


"I tell my girls that my front door and my heart are always open."



A big thank you to the staff at the Special Needs Project and my advisor Enna. My son suffers from mild Cerebral Palsy and must wear leg braces from the knee to toes. This would stop many kids but not Keon. The only time he doesn't wear his braces is when he's on the ice. The skating helps strengthen his leg muscles and balance. Keon is in his second season of hockey skating three times a week. Keon has made a remarkable improvement.

Letter Carrier
Pickering, ON



I am the father of two teenage girls, both special needs. I was a single parent for five years. My daughters and I became very close. Their mother was an alcoholic. During this time my younger daughter wrote me a letter in purple crayon. She told me that she knows that she is different from other girls. She told me that she was a lesbian and loved me. After reading the letter I gave her a hug and told her I loved her and being a lesbian doesn't change anything. About one and a half years later my older daughter wanted to speak to me. She said that she also is a lesbian. Again I said that I love you and it doesn't matter. Since that time many of their friends come to our house to visit and feel safe. To this day we have attended Pride parades, events and concerts. I am straight, no redneck, and feel the world is always changing. I tell my girls that my front door and my heart are always open.

PO4
Hamilton, ON

"He needed our love, guidance and our determination not to give up on him or let him give up on himself."



Michelina is autistic and doing very well in grade 11 at Citadel High School in Halifax. She has learned to play the guitar and has written over ten songs all on her own. She says that she wants to join the Life Teen band and church choir someday because she thinks that God is calling her to do it. She hopes someday to be the church musical director. This year Michelina has joined the school choir. She wants voice lessons and to learn to read and write music.

PO-4
Halifax, NS

Because of your help, my child's school grades have increased by 10% and his self-esteem by just as much. Thank you so much. A grateful father,

Letter Carrier
Blainville, QC



I would like to underline the efforts of my union, CUPW, to ensure that the Moving On program can continue. I know of no other union that cares as much about the disadvantaged in our society. Once again, thank you!!

RSMC
Joliette, QC

With times being tough, the assistance from the Special Needs Project has ensured that I have been able to continue getting the support that has made such a difference in my son's life! Devin has ADHD, Oppositional Defiance Disorder and Learning Disabilities. For a while the school was suspecting Tourette's as well because of his lack of impulse control and blurting out words and comments that were either inappropriate or irrelevant. At first we used the funds mostly for tutoring which helped him to develop some self-esteem. When he didn't feel stupid he didn't act out as much. Now that we have found the right medication and a great skills program Devin (15) is developing real friendships. He has successfully completed two summers of corn detasseling (with assistance from his step brother Daniel) and for one and a half years worked as a chicken catcher at a poultry farm. No longer are there holes being punched in walls. We now have a boy who helps our community with things like neighbourhood Halloween parties for the younger kids. He also helped clear bush and build a bridge over to an island in our marsh. The rough years were well worth working through. We now have the boy that I would catch glimpses of on occasion. He just needed our love, guidance and our determination not to give up on him or let him give up on himself.

Letter Carrier
Harrow, ON



“My daughter has grown up now and is independent. She is my hero!”

Parents Speak

Advisors contacted 393 Special Needs Project (SNP) members and 81 members from Moving On (MO) in Fall 2009. We now have a clearer picture of the member's work and family life. Here is what you told us:

Juggling work and family

- Two thirds of SNP members were exhausted juggling work and home life with over 50% describing how the stress of multiple demands has impacted their health. *“I feel alone compared to families who are raising typical children. I feel like I don't fit in with my friends.”*
- For MO members the lack of time for themselves weighed as heavily as the exhaustion they felt juggling work and home life. *“Supporting and caring for her means it is not easy to get away. Can not just pick up and go - not as much freedom as others with 22 year old children have.”* *“At 58 years old I want to think about myself.”*
- 60% of SNP members and 47% of MO members identified having a child with special needs has helped them prioritize their wants and needs in a positive way. Most members identified that their family has become closer as they learned to value what is important. *“I've learned to deal with my child's needs and I realize that I am happy.”* *“My daughter has grown up and now is independent. She is my hero!”* For others *“24/7 care - supporting our son is very much like having a second job.”*
- Finding money to meet their child's needs was the greatest challenge identified for all members and their partners. However, 46% of all couples said that the challenge made them more creative and assertive and helped them grow personally. *“Each of us has different strengths and weaknesses. We complement each other.”* In the MO project the same percentage also identified that there was no time for them as a couple. *“My daughter is always in the back of my mind. I think of her before anything else. She's it -everyone else comes second.”*

Impact on work

- About a third of SNP members find it difficult to concentrate on their work with their thoughts often at home with only 23% reporting this on MO. However while close to 40% of SNP members report that time at work is actual respite time for them, this was even higher for our members with adult sons and daughters. *“Tired at work- power naps on breaks and lunch.”*
- For 45% of SNP members and 35% of MO members their supervisor's support makes their work life easier. However 21% (and even higher numbers from MO) said the need for accommodation at work to support their child's need has created conflict with management. *Supervisor doesn't understand the demands of being a single dad with a child with many needs”* *“Support has been erratic depending on the supervisor.”*
- 20% of SNP members said taking a real family holiday was near impossible since most of their time is spent taking their child to medical appointments. For parents with adult children this statistic doubled. *“Had to take time off without pay; makes one fear taking time off for any reason”.* *“My wife and I take separate vacations. This works for us.”*



“School is now more tolerable because he enjoys himself in his off time.”



With medication, lots of patience and love, my daughter Nikita is doing much better. Her behaviour has improved. She plays with friends more often. She gets involved with the group, makes an effort and is less aggressive. She's resumed school and sings. She's started seeing her mother more often and is very happy about that. Thank you for your support. I appreciate it a lot.

Letter Carrier
Châteauguay, QC



My son is now 11 yrs old. He has ADHD. He has had a really rough time with friends and school. He is unable to control himself during quiet times at school. He is one of the children always blurting out jokes. He gets himself in trouble with the teacher and very quickly gets labeled as a problem. Since I found out about the program “Special Needs”, I have been able to afford to get my son into something fun that builds his social skills. School is now more tolerable because he enjoys himself in his off time. Thanks for helping our children do some of the fun things in life.

Letter Carrier
London, ON

Check out our website at www.specialneedsproject.ca





“Be a proactive team player, not too aggressive but firm.”

Better advocacy skills

A parent of a child with special needs has to advocate constantly for services and supports. Parents tend to have to speak more and fight more and not let their child's needs fall through the cracks.

80% say the project has helped them become better able to advocate for services for their children.

84% say it helped them advocate for additional support for their child.

79% say it has helped them raise awareness about special needs issues in school, child care and recreation.

72% say it has increased their knowledge about disability organizations locally and nationally.

What they say:

“I don't just hire anybody anymore. I know how to hire qualified people and we can afford to pay for them.”

“We don't always win but are now able to advocate.”
“I've given the school the handouts.”

“I appreciate the information I have received over the past few years. It has opened my eyes.”

Member's advice:

88% of members felt they had the skills and knowledge to comfortably act as an advocate for their child with special needs. When we asked for your advice you were most willing to share what you have learned. Your advice:

Never give up. Be brave. Do your homework.

“If you buy a pair of pants and they don't fit you return them. If services or supports are not right for your child you go back and work things out.”

Knowledge is power. Educate yourself first.

“Know the system and who to contact for answers. Be a proactive team player, not too aggressive but firm. Know your child's needs and that he is entitled to them.”

Believe in your child. Trust your own judgment.

“You have to look at your child and see the human he is without the handicap.”

Build the support system you need.

“Work as a team with your partner. Offer support to your partner to the best of your abilities.” “Stay connected with informed people.” “Talk to people from organizations, board members etc. to get the best angles on how to get the best for your child.” “Do not get discouraged. Ask for help.”

“Be there for your child all the time. Know when to speak and when to keep quiet. Life can only be understood backwards but can only be lived forwards.”

Taken from the Special Needs Project interview June 2009.



"All these activities enable Martine to develop her physical skills and experience real life."



The Special Needs Project has helped alleviate the problems related to my daughter Brittaney's mild to moderate hearing loss in both ears. The project has enabled my family to buy quality hearing aids, get her in guitar lessons, English language syntax lessons, and above all for my daughter to maintain her B+ average in school. She is not shy with friends like before. She takes her hearing problem more seriously than before. She plans to be an audiologist to help people with problems like hers. On behalf of my family I would like to say thank you very much for what you have done.

PO-4

Coquitlam, BC

Preferred time for calls: Evening

Phone: (604) 937-3920

E-mail: tunsuase@hotmail.com



The financial support from the Moving On Project means that we can put our daughter Martine in activities such as alpine skiing, snowshoeing, bowling, dance and the Patro. All these activities enable Martine to develop her physical skills and experience real life. It's very stimulating for her, as well as for us, her parents. Thank you so much for this help.

RSMC

Beauport, QC

The Special Needs Project has helped make schoolwork easy for my two kids (Irfan and Amina). My kids go to the Kumon Learning Centre in Guildford, Surrey. They now get good marks in school. Their teachers at Harold Bishop elementary school are surprised with their marks and school assignments. Their Math and English are very much improved because they have learned the basic skills. Now my kids are able to speak, read and write English fluently. I appreciate the financial help.

PO-4

Surrey, BC

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





Advisors were great supports and often helped by suggesting resources for parents to research.

Inclusion of Children with Disabilities in Recreational Programs

(A research study by Melissa Shapiro with support from Dr. Donna Lero, Family Relations and Applied Nutrition Department, University of Guelph)

Seventeen members of the Special Needs Project in Ontario were recently interviewed as part of a university research study. The objective was to obtain parent's perspectives on the integration of children with special needs in recreational programs.

The study found that although some parents had no problem finding appropriate programs, others identified a number of barriers to their child's participation. They include:

- difficulty finding appropriate programming for their child,
- financial costs of programs,
- difficulty finding programs that their child enjoyed and could stay interested in,
- difficulty balancing school with recreational activities.

Still other factors parents mentioned included behavioral concerns, limits in their child's physical ability to participate, and medication side effects.

The results of the study will be shared with those who offer recreation programs. Parents also offered suggestions for improvements in three categories: changes to staff training, financial matters, and accessibility factors.

Finally, CUPW members were asked about the assistance they received from Special Needs Advisors in finding appropriate programs. Many members said that the Advisors were great supports and often helped by suggesting resources for parents to research. Others suggested that we could improve our Special Needs project by equipping Advisors with even more information on local recreation activities and encourage parent networking for more information and support.

Melissa and Donna both want to thank all CUPW parents who participated in this study.



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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.