SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs

Nº 18 Summer 2009

Finally, something positive! The financial assistance you give me has helped me improve Jean-François' health, and we even went on a short trip. He's finally able to leave the house for a bit, which is something he hadn't done in at least eight years. I was very happy to receive information on the Registered Disability Savings Plan (RDSP). I'll now be able to secure his future for when we're no longer around. That was my biggest concern. Thank you very much.

CS, Letter carrier
Rouyn, Norands, QC

I just wanted to let people know that I am truly grateful for the Special Needs Project. My son has had trouble with reading since grade 1. Unfortunately nothing was resolved until he was diagnosed with ADHD and CAPS (Central auditory processing disorder). Around the same time that we found this out I ran into a co-worker I hadn't seen for some time. We got talking about our kids and she told me about this great program. Since then we applied for assistance and then enrolled my son in Sylvan Learning for reading. He has been there now for about 4 years. Since he has been going there his reading level has greatly improved. Sylvan really does work. If it were not for the Special Needs Project we could not afford to send him there. Thank you again.

MMC, Letter Carrier
London, ON

The reason for this letter is to give a special thanks to the children that my son Keegan goes to school with. He was diagnosed with CP at 14 months. His classmates have always treated Keegan as an equal and constantly encourage him and help him with his difficulties because of his disability.

Each time I observe him with his friends I see the same things over and over. He is very lucky to have such a wonderful bunch of classmates and I just want to acknowledge this.

Thank you.

D.O., Letter Carrier
Kingsville, ON

> "They helped me understand that Karle would need something different than just mom."

Karle and teacher.

We all wonder what is going to happen when our kids transition from school to adult life. When my child was 6 years old I started asking our government what will I do? I got involved with DSLG (Developmental Services of Leeds and Grenville) and the transition was very good. They helped me understand that Karle would need something different than just Mom. Please get involved with an agency like this. It will really help you have peace of mind and they do a lot of good things for the kids.

RSMC
Prescott, ON

I would like to thank the Special Needs Project so much for their continued support of my family. I am a single mom of 4 special needs kids. The financial help from this project allows them to do things they normally couldn't because of the load I carry. The staff is so wonderful, helpful and caring I just really want to say Thanks!

PO-1
Winnipeg, MB

Michelina received an acoustic guitar for Christmas and has learned to play all by herself with no training or guidance from anyone. The guitar came with some guitar chord charts. She can switch from one chord to another without any hesitation and she has the ability to know what chords fit with the words that she is singing. Michelina would like to join the church band some day. Right now she can play and sing about 20 religious songs. Michelina believes that she is being called by God to play and sing in the church Life Teen band.

PO-4
Halifax, NS

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.

> "It gives me peace of mind to know that when I'm gone they won't be living in poverty."

RDSP first deadline a "scramble"

In the rush to meet the March 2, 2009 deadline for allowing people with disabilities to open and contribute to the new Registered Disability Savings Plan (RDSP), banks were flying by the seat of their pants trying to determine appropriate processes and policies, says Toronto Moving On Advisor Susan Beayni.

The RDSP allows tax-free investment for people with disabilities coupled by federal grant and bond contributions to assist families in saving for the future. The plan is a long-term savings strategy (there are penalties for withdrawing the money if 10 years have not elapsed since the last federal contribution).

Beayni says many kinks still need to be ironed out, but is glad the government went ahead with it and didn't wait, even though it led to scrambling and confusion.

"As soon as I gave information to families on the project about the RDSP, it changed," she says. "This was very frustrating for them." Issues around when legal guardianship is required (obtaining one is a complex and long process), whether there can be two holders of the accounts, and whether an account needs to be opened with the bank that holds your RDSP were also handled differently, not just by different banks, but different branches of the same bank, says Beayni.

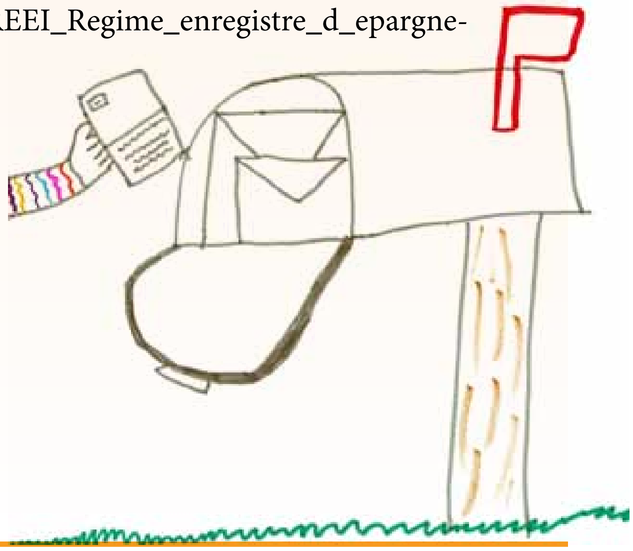
Beayni is very positive about the plan itself and its potential for helping those with disabilities fight poverty. She and her husband opened an RDSP for their daughter, Rebecca, who has a developmental disability and cerebral palsy. "It allows us to save for Rebecca so that she will have enough money for quality of life—for example, an accessible van to get around in, a piece of equipment that is not covered that she could get…or just that she has enough money so she doesn't have to live under the poverty level."

This sentiment is echoed by Debbie Wilson, a Special Needs Advisor who lives in Coquitlam and has two grown children, Brent and Roxanne, with developmental disabilities. Opening the RDSPs was a snap for Wilson—"It took at most 20 minutes for the two children". The plan means her two children will be able to "lead a fulfilling life. It gives them an opportunity to do things their other friends who have jobs might be able to do, such as take a vacation. It gives me peace of mind to know that when I'm gone they won't be living in poverty and they will have opportunities to do some fun things in their life."

Both Wilson and Beayni see the RDSP as fulfilling another important function—helping siblings who do not have disabilities and whose responsibilities related to their sisters and brothers with special needs will increase as parents age and die. "Our other son will not have to be concerned financially about Brent and Roxanne," says Wilson.

Anyone who qualifies for the Disability Tax Credit can open an RDSP.

For more information:
Planned Lifetime Advocacy Network (PLAN) for RDSP:
English only: www.rdsp.com
Le Curateur public du Québec pour le Régime enregistré d'épargne-invalidité (REEI) (uniquement en français) :
http://agora.qc.ca/thematiques/inaptitude.nsf/Dossiers/REEI_Regime_enregistre_d_epargne-invalidite



“Good communication is key.”

Guide for Successful Transitions: Your Feedback

What has worked for you?

The Special Needs Project End of Summer interview 2008 was about helpful strategies for transitions for your children. Over 415 members talked to their advisors and this is what we heard.

Transition to Early Learning or Child Care

71% of members (298) had used an early learning and child care program with a caregiver other than the child’s parent or sibling.

Good communication with the early child care educators was top of the list. *“Be clear about your expectations.” “Good communication is key.”*

Two strategies with the greatest positive impact were:

- Arranging for an initial meeting with child care program staff to discuss the centre’s ability to meet the needs of the child, and parent’s expectations.
- Recruiting / training support workers (tutors, in home support workers, attendant care, etc)

“Having the appropriate staff makes all the difference.”

Others recommended bringing a health care professional or support person knowledgeable about their child’s disability to speak to child care staff.

Transition to Kindergarten or Primary School (K–8)

86% of members (360) identified that their child had entered kindergarten or primary school.

Creating good communication with the school was the focus of three of the top five strategies members used. *“Communication with teachers (is important). Parents are experts and should stand their ground.” “Daily communication seen as the most vital link.” “Getting to know staff before school begins gives a head start in building a good communicative relationship.”*

Selecting a neighbourhood school and arranging for their child to visit ahead of time was also useful.

The strategies members identified as having the most positive impact were:

- Setting up a form or regular communication with my child’s homeroom teacher (daily agenda, emails, weekly summaries, etc.)
- Having someone, (child care staff, nurse, therapist) accompany the child to school at the beginning to ensure that school staff are aware of the child’s needs.
- Building peer awareness by having someone such as a health care professional or a disability expert (i.e. the Canadian National Institute for the Blind) make a presentation to the teacher and class about the child’s special needs. In some cases the child talked to the class her/himself.

"Parents are experts and should stand their ground."

Transition to High School

51% of members (211) identified that their child had entered high school.

By this time in their child's life, members often spoke about tailoring their strategy to their individual child's need. However good communication with teachers remained key. Other suggestions included:

- Shadowing an older child for a day.
- Contract signed between the student and teacher regarding appropriate behaviour.
- Child was part of the process of visiting potential schools and had a say in decisions made.

Members were fairly evenly split as to which of the 15 strategies listed in the interview had the most positive impact on this transition. Many identified the suggestion they offered had the most impact (see three suggestions above). In addition, members agreed that holding planning (transitional) meeting(s) with school professionals prior to start of new school year was a great help.

Planning for leaving High School

11% of members (44) identified that they were currently planning for when their child leaves high school or moves into adult services. These members had children between the ages of 14 and 19. The children's needs range from learning disabilities to severe physical and mental disabilities.

"It's too early" and *"I'm not ready to deal with this yet"* were the two main reasons we heard from members who had not yet planned for the end of high school transition.

"Dad is more bogged down with his son's current situation than he has time and energy to spend on the next transition."

"I don't know where to start – I can't imagine her not at home."

Brainstorming with their child to identify what her/his wishes and desires were for the future was identified as a key strategy even though most members were still in the planning process.

Our son constantly surprises us with how well he is doing so we are reluctant to start planning until he is a bit older so as not to over or under estimate his ability."

"N. is currently in a coop program which is giving him some good direction for the future as he explores his interests and natural aptitude."

Check out our website at www.specialneedsproject.ca

Special Needs & Moving On

Projects of CUPW/UPCE-PSAC

Breaking through barriers for workers who have children with special needs

> "I have been able to make headway on building Dawson his own community."

My name is Jeanette, I married a wonderful man named Brian last summer. Brian had 2 kids, Sana and Dawson, and I had 2 kids, Terrence and Tristan. All of our children live with us so it makes a full house. Our son Dawson was born with a chromosome abnormality. In my quest for information and help I came across the Special Needs Project at one of our union meetings. I made the call and found that there was help for our family not only for medical expenses but they had information too. I have been able to make headway on building Dawson his own community and been able to find out about other programs that are available for him. The Special Needs Project was the first step in my search and they continue to help and support my family. I couldn't have done any of this without your help. In preparing Dawson for the future the Special Needs Project will be a big part of out plan. Thank you so very much.

RSMC
Golden, BC

TIP

A good resource for help in Bruce County, Ontario is 'Keystone'. They will help in the school system as well as at home. I find it exciting that there is finally an organization that will branch out to both aspects of our children's life.

Keystone: Phone: (519) 371-4773
1-800-567-2384
www.bgcskids.org

A child, youth, and family service agency that provides free information, counselling, and extra support for families throughout Grey and Bruce Counties.

PO-4
Tiverton, ON

Amina and Irfan

The Special Needs Project has been very helpful to my family. It has enabled me to purchase prescription medications for my son and my daughter. It enabled me to hire private tutor for my 2 children to learn Math and English. The private tutor enabled my kids to improve their learning skills. Now my son and my daughter, who have attention deficit disorder, are able to read, speak and write English fluently. The private tutor enabled my kids to participate in the class with other students equally and normally. The CUPW Special Needs Project is helping the development of my children.

PO-4
Surrey, BC

"It's good to know there is someone who understands what we struggle with everyday."

We have twins who have been diagnosed with autism and developmental delay. At first it was hard until we started therapy. The Special Needs Project has been very supportive. They have helped our kids get the therapy they need in order to socialize more and develop skills. We are so thankful to the project. It's good to know there is someone who understands what we struggle with everyday and can answer questions about our children's needs. Thank you.

Letter Carrier
Coquitlam, BC

My daughter Davis was diagnosed with quadriplegia. When she entered grade one we were told that she would not print. I noticed that she had the physical strength to print; her brain was just patterned differently. We put her in a school called Arrowsmith, part time every second Saturday. We had 20 minutes of homework each day. She is now in grade two and she is printing at grade expectations, more importantly, with little effort.

Letter Carrier
Pickering, ON

Music therapy has proven to be something that Jacob (age 5) truly enjoys. He especially enjoys being sung to. Because the Special Needs Project funding is helping cover the costs of his ABA (applied behavior analysis) therapy we have been able to buy him different instruments – bongo drums, a harmonica, tambourine and various shakers.

Jacob has limited language (under 10 words) so I love when he hums on the harmonica and realizes he can make beautiful sound. Recently when handed one of these cheesy sing along microphones he started to sing (or make noise). But hey he loves it and whatever makes my guy happy!

Sometimes Jacob and his sister Hannah Rose (3) and I will pick an instrument and have a little musical parade around the house – always a laugh! Thanks so much for this special funding!

Customer Service Analyst
Hanwell, NB

“Transition - it’s really a strategy of little steps.”

Strategies for Transitions: report from what we heard

In November 2008, seventy-eight members participating in the Moving On project shared their experiences with their adult sons and daughters transitioning from school to adult life. We heard comments: *“It’s really a strategy of little steps”* and *“It doesn’t matter how soon you plan if the services don’t exist, it just doesn’t matter.”* While another member said, *“our transition was smooth and we were prepared”*. Following is some information from our members that might help others to smooth the transition for their children.

When did you begin planning?	% of members	Was this soon enough?
Started graduation year	9%	33% of these said no
One year before graduation	26%	7% of these said no
Two years before graduation	15%	13% of these said no
Three years before grad	8%	Yes
Did not plan ahead	22%	66% of these said no

Some members said that it was difficult to plan because the adult son or daughter kept changing his/her mind or was uncertain as to what s/he wanted to do.

Strategies that work

Members identifed strategies and plans that helped the transition from school or child services. The most common ones were eligibility for the Disability Income or the Disability Tax Credit and finding a new doctor/ medical support. However, the two strategies that got top marks for making a positive impact were:

- Working with son or daughter’s support team to identify areas of concern
- Brainstorming with my son or daughter to identify what her/his wishes and desires were for the future

How is it going?

Close to twenty percent were early in the transition to adult services. For the members whose adult son or daughter had been under the auspices of adult services for a while 4% had not found any supports; one-quarter had some supports but they were not sufficient to child’s needs; close; about one-third had a support system in place that was filling all the child’s needs; and finally 6% said they do not need much in the way of support.

When asked to rate their son or daughter’s experience with this transition 65% of members felt that it was a neutral to a very positive experience. Seventeen percent felt is was somewhat negative and 10% of members felt it was a very negative experience.

“The biggest challenge at this time is getting health concerns around her feet taken care of. She is learning some of the medical self-care right now. We should have started this years ago. Hindsight is a wonderful thing.”

“Once our daughter got used to the separation she has done very well.”

> "She listened and gave me the support I needed to deal with the situation."

Advisors weigh in

Our Advisors who did the interviews also reflected on what they heard.

Members identified that the caregiver's health and ability to continue providing support were major concerns for many families.

Parents report a constant worry about the long term care of their child when they are no longer able to be there. Some members were discouraged by the lack of options, cost or long waiting lists when looking for supported living arrangements.

The lack of a social network and work/volunteer experience contributed to members concerns about their adult daughter or son's future. Advisors noted many members who have done incredible work to find or create opportunities for their adult child.

We can certainly learn from each other.

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.

Suzanne has been my advisor for many uncountable years. She has become a part of our family. She is very knowledgeable and resourceful. She has educated me on things that I did not even know existed like the Disability Tax Credit and the Registered Disability Savings Plan and so many more.

Even though I have not met her nor seen a photo of her, she has touched our lives in so many ways. My older son has moved to the Moving On Project and it never fails that she asks about him as well as my other children who are not with the project. There were times when I felt she was overwhelmed with my problems, because God knows I have been through so much, but nevertheless she listened and gave me the support I needed to deal with the situation.

I am grateful for her support and words of encouragement.

PO4
Ajax, ON

I wish to express my sincere thanks to everyone involved with the Special Needs Project for the support and funding that has helped so much over the years.

As a single mother who has worked full time and raised a son who is deaf and has ADHD, this project has been a benefit to both of us. My son excels in sports, especially baseball and having an interpreter at most of the games gives him that extra confidence.

Thanks again.

Letter Carrier
Richmond, BC

> "The young intern said she learned a lot spending time with Laurianne."

Our daughter Laurianne is a 16-year old autistic teenager. Ever since she started going to school, she's been the only girl in her class (this handicap is more prevalent among boys). However, this past January, a special education intern was assigned to her class. Because she is younger than the teachers, Laurianne quickly accepted her. She would say she was her friend.

At the end of the school year, Laurianne was very sad to leave her friend. Because she no longer wants to go to day camps, we decided to get her involved in activities. To help her open up to others and have confidence in people other than our family, we asked the young intern if she'd be willing to do some activities with Laurianne.

And so we killed two birds with one stone! Laurianne learned to have confidence in someone outside our family. The young intern said she learned a lot spending time with Laurianne. It's one thing within the school environment, but it's very different outside that environment. She gained confidence and was able to put what she'd learned into practice.

The Special Needs Program helped make Laurianne's wish come true – having a friend of her own.

Letter Carrier
Montreal

I am sending a newspaper clipping to share the story of my son's success. (Article headline: "Uplifting spirit – Legally blind John Tee not only wrestles for Notre Dame, he's darned good at it.") We are really thankful that we have this project. It really helped a lot of families that have children with disabilities. Since this is the last year for my son in this project I would like to extend our gratefulness to all of the people who created it. We really appreciated all the support, especially financially, it is a very big help.

PO-4
Vancouver, BC

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

"Society needs (children with special needs) as part of the fabric of a whole spectrum of people."

Supporting families from the very beginning

When it comes to Special Needs Advisors, Shirley McGuire is an original. Her first connection with CUPW was interviewing parents for the 1996 study, In Our Way, which looked at the workplace barriers for families who have children with special needs. The study gave birth to the Special Needs Project, and soon thereafter Shirley became an advisor.

"I thought the study was interesting but also thought it was just going to end up gathering dust somewhere," she says. "Instead it turned into a project that was forward looking and innovative."

Thirteen years later, Shirley has developed strong connections with many of the parents she calls three times a year to help with project forms, suggest resources, and touch base with.

"I talk with some of the parents from the time their children are very little. I get a sense of the children, their siblings and their parents, and grow up with them. It's neat. And then [when they become too old for the project] they're gone and it's almost like a sadness….I had one mum who I talked with as part of the study, and her son just aged out last year so I talked to her for almost 13 years."

Shirley was also part of the CUPW think tank of parents and advisors who began the discussions around developing a project for postal worker families with adult sons and daughters with disabilities—the Moving On Project that exists today.

She has been interested in disability issues as far back as she can remember, and has worked in the field since 1976. The mother of two grown children, she is now semi-retired, having worked for the Saskatchewan Association for Community Living for 14 years as a respite coordinator and a family network coordinator. She now does some contract work for a number of disability organizations.

Shirley is passionate about valuing children with disabilities. Once a year, she co-ordinates a grief workshop for families whose children with special needs have died. "Sometimes people forget how much value the children have given to their families and the impact they have made on their families' lives. They also forget they are part of society and society needs them as part of the fabric of a whole spectrum of people."

Take a moment to tell us about your advisor!

The next issue of Member-to-Member Connection will showcase the advisors. Please help make this a special issue by writing a letter about your advisor. There was a guide to help you write your story in the last package you received from the project.

> "The union actively works to represent our interests in every area of work life."

Dear Sisters and Brothers,

Welcome to the next edition of Member to Member Connection. Again, your stories of resilience, problem solving and generosity inspire us and your stories of challenges and heartaches connect us.

Our economy is in deep trouble and we need to take stock. Many industries like the auto sector are threatened and workers are being laid off or forced to take reduced hours. Pensions and benefits are being eroded and workers are feeling under more stress at work and at home. If your family hasn't been directly affected, you likely know families that have been affected. And many of our members are feeling rising pressure as the Corporation goes through many changes. If you have a child with special needs this can mean increased anxiety about your job and the work demands.

Canada Post has recognized the value of our work on child care, and in particular our Special Needs and Moving On projects. The support we provide to reduce the financial pressure and improve the family's health and overall well being impacts on our members' ability to sustain and engage in their work. In the future we will want to expand our Child Care Fund and our Special Needs and Moving On projects.

The union actively works to represent our interests in every area of work life. We need collective agreements that protect our job security, wages and working conditions. But this alone is not enough.

Although we must fight for decent jobs that can sustain a family, there is no guarantee of future jobs with benefits for our children with special needs. To protect our children and the children of other families without our projects, we must fight for broader social policy programs. That will be good for all our children and our communities.

In solidarity,
Lynn Bue

Registered Disability Savings Bond (RDSP) TIPS

- If an eligible individual has an income under $21,816 but there is no funding to contribute to an RDSP Grant on his or her behalf he/she can still benefit by applying for the RDSP Bond (no matching funding needed) which will provide $1,000 a year for 20 years.
- The only requirement by a bank for opening an RDSP should be to create a "profile". This is different than an account. You are not obligated to open any additional accounts, apply for credit cards or transfer any accounts or money from another bank to the one processing the RDSP.

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.