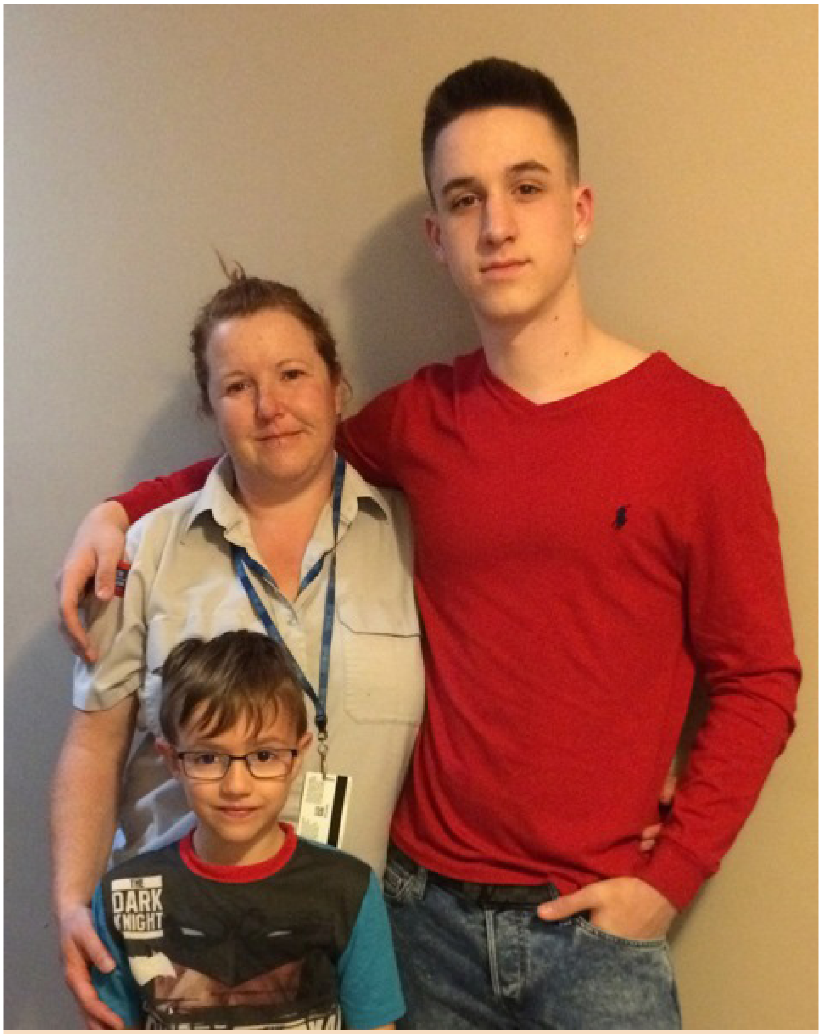
SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs

N° 34 Summer 2017

I have been involved in the Special Needs Project for about ten years now. My oldest son (now 16) was having troubles in school and was disruptive in class. He had been placed on a moderate behavior intervention program. All of this was putting so much stress on our family. With the help of the Special Needs Project we were able to use holistic medicine as it was not completely covered under our health plans. Finally, four years later we decided to listen to the doctors and we put Kayde on ADHD medication. Although it helped greatly, we still have many challenges. Kayde has started at a new school because he does not fit into the factory style school system we have.



Danielle with Kayde (right) and Sheldon.

The Special Needs Project has helped in so many ways over the years. The most important is when I had Kayde's brother, Sheldon. My advisor was interested in family dynamics. I was concerned that Sheldon was not progressing at the "normal" rate and I had spoken to his pediatrician about this but got nowhere. My advisor expressed the same concerns I had. With her support and guidance was I able to get Sheldon the early intervention we needed. We are now able to help guide both our children as they grow and are more hopeful for what the future holds.

Thank you to the Special Needs Project and to my advisor. Words cannot express how thankful I am.

Letter Carrier
Surry, BC

"The Support Navigator will be available to all members in both projects."

Canadian Centre on Disability Studies Program Evaluation Update – Special Needs and Moving On Projects

By the time you read this issue, members in both projects will have completed the evaluation questionnaire with their advisors.

The CCDS Project Team is currently analyzing the questionnaire data and preparing to conduct in-depth interviews with union representatives, project staff, advisors, and a Family Place representative.

The CCDS Project Team will analyze the data from the SNP and MO questionnaires, the interviews and additional project data to identify project strengths, areas for improvement, and a vision to better meet the needs of members who have sons and daughters with special needs and disabilities.

In October 2017 the CCDS Project Team will prepare a final report for the union. We look forward to sharing a summary of the key findings both online and through this newsletter.

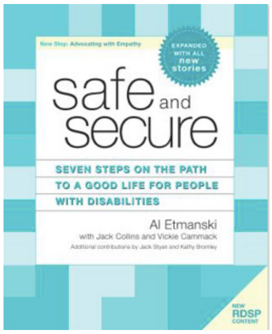
CUPW and the CCDS Project Team appreciate all of the members, advisors and project staff in your individual and collective effort in working with us to learn how – together – we can make these projects better for everyone!

Disability Support Information Update

We are continuing our work to address members' needs for more information about disability supports through a Support Navigator and an online database of disability supports.

We have posted the position for a Support Navigator to join the Special Needs and Moving On project staff at Family Place. The Support Navigator will be available to all members in both projects to assist in finding the disability support information you need.

Check Out These Disability Supports


New Step: Advocating with Empathy

EXPANDED WITH ALL new stories

safe and secure

SEVEN STEPS ON THE PATH TO A GOOD LIFE FOR PEOPLE WITH DISABILITIES

Al Etmanski

with Jack Collins and Vickie Cammack

Additional contributions by Jack Styan and Kathy Bromley

NEW RDSP CONTENT

"Safe and Secure" presents a seven-step process that families can follow to create a safe, secure, and pleasant future for their daughters and sons with disabilities. (Note: English only.)

Download the free e-book at: safeandsecureplanning.com

"Jooay" is a free app that connects children and youth with disabilities to leisure activities: arts, camps, sports, others. Jooay is a growing community Canada wide, and available on the App Store and soon on Google Play. More info at: jooay.com

Note: The Jooay app is available in French. The language of application depends on the user's phone settings. The website is currently only in English.

Jacob

Editor's Note: One of Jacob's poems, *The Spirit Within*, was published in the last edition (#33) of the *Member to Member Connection* newsletter. His dad sent us this update:

Jacob's story will be covered by the IWK (NS children's hospital) Annual Telethon this coming June 2017. He was approached by IWK/CTV News to share his story related to Autism/OCD. Also, Jacob was asked to be an "Ambassador" for the IWK Telethon.

Jacob is planning a "Walk" to promote awareness of "OCD". The slogan for this walk is "Shining a Light on OCD". He plans on visiting selected 'lighthouses' across Atlantic Canada giving educational talks on OCD and its affect on young adults.

RSMC
Halifax, NS

CHILD CARE CONNECTIONS SERVICES DE GARDE PLUS

Update on CUPW Mini Hub

We are in the second phase of our "Mini Hub Child Care Project". In phase one we did background research to find a good model of child care to meet the needs of "harder to serve" members. By this we mean members who live and work in rural and remote areas, or need extended hours or part-time and occasional care.

We found a model from France, the micro-crèche or what we have come to call the "mini hub". The mini-hub will be made up of at least one small child care centre that offers flexible enrolment options, and is connected with other services, including information and referral services, family resource, and licensed family child care.

Through our initial phase the British Columbia Lower Mainland BC was identified as a priority for this project. We are working with the Vancouver, Royal City, and Fraser Valley West locals and have conducted a member needs assessment. We will be meeting with the three locals and the research consultants in May to talk about the results of the assessment and to plan our next steps in this exciting project.

My son Justin has visual problems as well as Aspergers and high anxiety. Taking a bus was always a stressful adventure for him as he could not read the bus information on the front of the bus and always worried about getting lost. Because of this he would not leave the house unless I took him to his appointments or activities. This caused extra stress in my life.

The Moving On Project approved funding for transportation to get him to his appointments and activities. With this funding and a smart phone he now uses public transit and no longer feels anxious about going out.

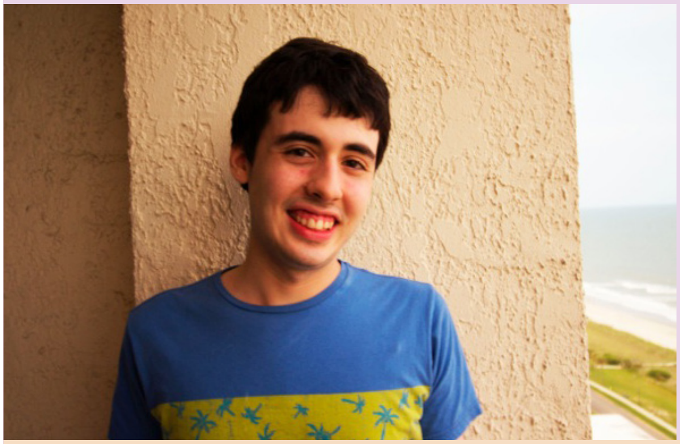
When I asked him why he no longer feels anxious, he said that knowing the cab fare was available if he got lost took away the anxiety of getting lost. Also, the smart phone tells where to catch the bus and where to get off the bus.

Thanks to the funding from the Moving On Project Justin has become more independent and has relieved a great amount of stress from our lives.

Letter Carrier
Waterloo, ON

Justin

Our son is autistic and is now 25 years old. Looking back I can see it has been a long and difficult journey to raise him. I remember the many visits to doctors to determine the correct medication for his behavorial challenges. The result, after many, many tries, is that he is a much calmer and happier person. The road ahead also has challenges. We are still looking for an occupation that could make him feel like he contributes to society.

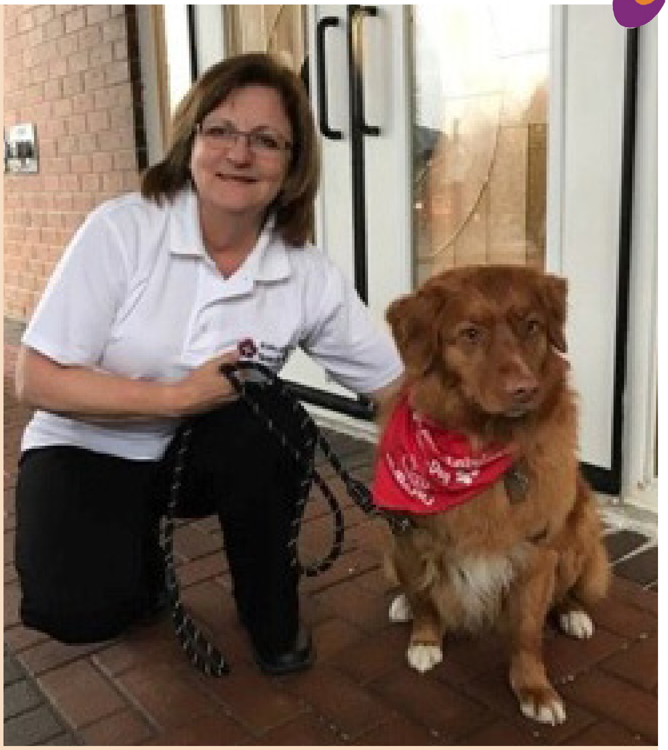


Sergio

In the meantime, he is in a day program where he gets training so he can eventually work in a café environment. For the families just starting out, be courageous and know that all the effort we invest in helping our daughters and sons is worth it. Please remember, even if progress comes slowly, it eventually arrives.

Letter Carrier
Maple, ON

Advisor - Sylvie Giroux



Sylvie and Champ.

"Inclusion is in my veins!" jokes Sylvie Giroux.

Sylvie started with the Special Needs Project over 15 years ago, advising members in the Ottawa and surrounding 613 area. Sylvie also works full-time facilitating inclusion for children with special needs in licensed childcare.

Sylvie and her husband Norm (a CUPW member) have also experienced the Special Needs Project from the other side. At age seven, their daughter Elyse was diagnosed with attention deficit. "She was starting to struggle at school, and we needed some help," Sylvie says. "I knew how the project worked, and so we were able to flag the problem right away, get the needed resources into place, and prevent damage to her self-esteem."

The project helped Sylvie and Norm pay for the math and reading tutoring that Elyse needed. Elyse was able to take the strategies she learned from her tutor and apply them in the classroom setting. By the time she started high school, she no longer needed extra help. Elyse is now at university completing a degree in communications and public relations while working part-time as a communications consultant. "She really learned how to advocate for herself," says Sylvie.

Sylvie took a break from the Project a few years ago to train Champ, her Nova Scotia Duck Tolling Retriever puppy, to become a therapy dog. She knew the training would mean a huge time commitment, so something had to go. "I wouldn't have been able to do the Project justice so I took a step back, but I missed it SO much," Sylvie says.

When Sylvie found out last year that the Special Needs Project was looking for an advisor in her region, she felt the timing was perfect, with Elyse doing so well and Champ now fully trained and accepted into St. John Ambulance's Therapy Dog Program. "And I was very fortunate to link up again with some of the same members that I had in my caseload before," she says.

Sylvie believes that the key to being a good advisor is supporting and listening—having a discussion that leads somewhere. "Maybe the solutions aren't there yet, but after some discussion there comes a moment of possibility. Just that basic piece of being very empathetic—that's the key."

If Sylvie could change one thing for families she'd eliminate wait times. Most parents experience long lapses between seeing there is a need, identifying that need and learning how it can be addressed, and then having to wait for the solution. "Often parents say, 'I need a break and it's now. I can't wait five weeks.' If I could wave a magic wand I would create that flow so they could have it right away."

Meanwhile, Sylvie continues to work hard, and she and Champ volunteer at a local retirement home every week. Her ultimate goal is for Champ to work with children who are on the autism spectrum. "I think we're going to achieve it," she says. "It's going really well."

"Shelden is a pleasure and is loved by all."

Shelden moved in 2011 from a Treatment Center Home, where he spent five years, to a residential home in Whitby governed by Christian Horizons. It is a beautiful home and there are only three male adults, including Shelden, living there. He loves it and is obviously less stressed.

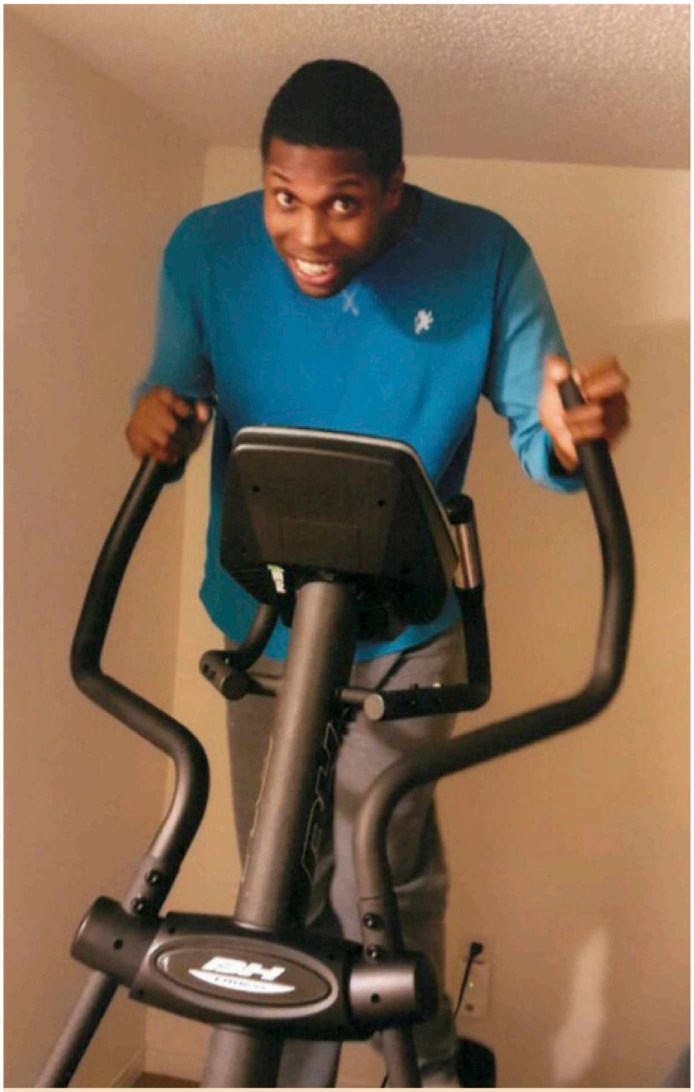
I still continue to fight and advocate on his behalf. Staff either don't care or do not have proper training to work with adults with special needs. He continues to come home every other weekend. Recently the staff said the 35 minute drive to and from Whitby is too long for them. I called managers and supervisors and ranted and threatened to go higher as this is something they have been doing for years. It was a 45 minute drive from the Treatment Center Home and those staff did it willingly.

Shelden is doing well academically. He is using his words and doing more reading. I am so thankful for our health plan as his speech therapy is covered at $500 per year under both his father's and my health plan. His father is also a postal worker but he's not involved with Sheldon and I've had to chase him for the money which Great West sent him. I no longer chase him and pay the rest from my own money. I use the Moving On Project funding for other activities within the community. The final challenge I face now is waiting for the Passport Program so that his workers can do more with Shelden within the community. I have been on the waiting list for three years.

Overall I am happy. Shelden is happy. He loves being at home with his siblings especially for birthday parties and BBQ'S. As you can see by the picture, we have an elliptical in the basement, which he loves. Of course being 6'5", he has to bend a bit. Shelden also loves going to the Raptors game with his worker. This is a favorite sport of his as he is enrolled in special needs basketball. Shelden is a pleasure and a very loving and affectionate young man who is loved by all.

Thank you Moving on Project for your support. Thank you, Ellen, for always showing concern and offering suggestions for us as a family. Blessings to all.

PO4
Scarborough, ON



Shelden

> "Children are presents, and sometimes very special ones."
>
> **PO4**
> Toronto, ON

"CUPW supports the campaign for a national disability insurance program."

A new national disability advocacy organization, Every Canadian Counts Coalition (ECC), has set-up in Canada and is seeking to build a broad coalition of individuals, unions, disability and service organizations. The ECC is calling on Canadian governments to work together to ensure essential disability supports are available to all Canadians living with chronic, long-term disabilities.

Far too many individuals living with long-term disabilities and their families cannot find the supports and services they need. No matter what province or territory, those living with disabilities face similar challenges when it comes to accessing disability services and supports.

The ECC coalition wants to work with others to push governments to undertake fundamental system changes through the introduction of a National Disability Program modeled on the Australian, National Disability Insurance Scheme. ECC wants to move beyond piecemeal solutions and advance a national disability program.

The Australian, National Disability Insurance Scheme (NDIS) is a new way of providing supports to those living with disabilities, their families and care providers. The NDIS provides Australians, under the age of 65 with a permanent and significant disability, with the supports they need to live an ordinary life. NDIS's approach is to invest in individuals over their lifetime. Supporting an individual's needs early on should improve the outcomes later in life.

The ECC wants to advance this vision here in Canada. They want all Canadians to feel included regardless of their abilities or needs. Everyone should be able to participate in Canada's social, economic, cultural, and political spheres as much as possible.

CUPW met with the ECC and committed to submit a resolution to the next Canadian Labour Congress (CLC) Convention as a way to bring more unions into this important coalition.

CUPW wants the CLC to work with its affiliates and other national disability organizations to support the ECC campaign to win a national disability insurance program.

When Jean-David was about three years old, I took him to play at the park in front of the house. The children who were playing there pushed him away, said nasty and hurtful things to him and made fun of him because of his language problem. I started to take him to the park less often and, when I did take him, I would wait until there were as few children as possible. This did not help as he hardly socialized with anybody. His entrance into daycare was very painful. It took time for him to adapt to this new reality.

PO4
Montreal, QC

Introducing A New Way to Enjoy Member to Member Connection

The CUPW's *Member to Member Connection* newsletter is getting an exciting new online look.

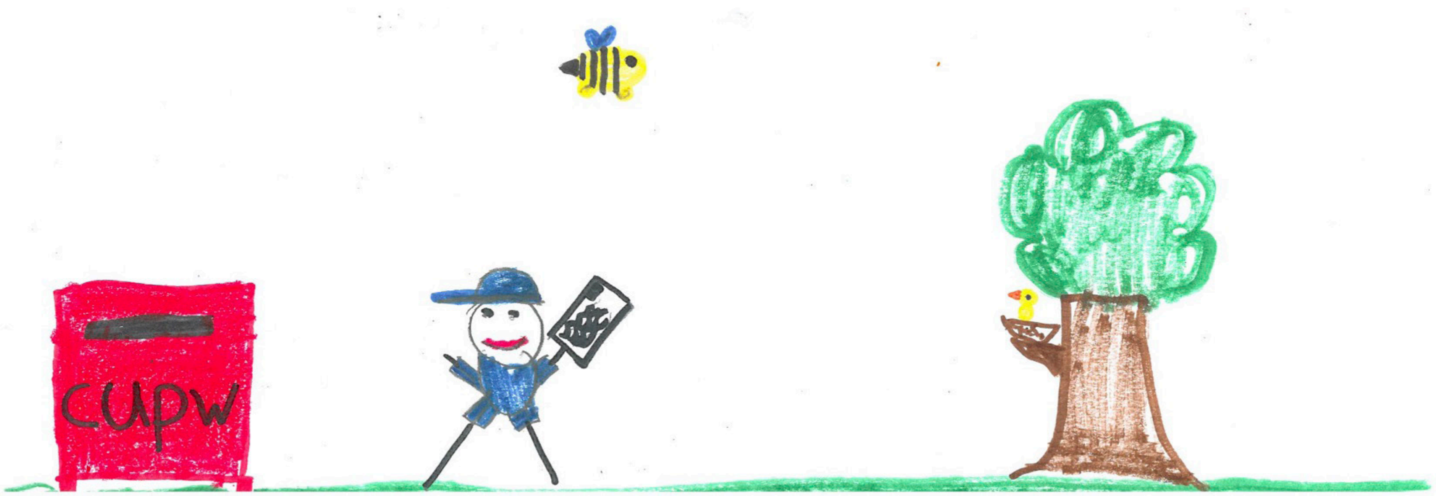
Every family has their own inspiring story. For the last several years, I have had the privilege of working with Gail Holdner of the Special Needs and Moving On Projects to help bring these stories to you in the *Member to Member Connection* newsletter. Informative, engaging, and inspiring, these stories are important not simply to those directly involved, but to every person who shares their experiences, whether parent, child, or friend.

That's why we are introducing a new digital home for the *Member to Member Connection* newsletter.

The new digital edition of the newsletter gives you the same great stories you're used to in a unique way that delights as well as entertains. Available on any device from desktop computer to smartphone, you'll be able to read the latest issue, browse past editions, view photo galleries and share individual stories.

I hope this revamped online edition not only continues the conversation sparked by the families featured in each issue, but also helps to build the community that surrounds the Special Needs and Moving On projects. Look for it online soon. Welcome to the next *Connection*.

Web Designer



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.

Phone: **1.800.840.5465**
Fax: **1.902.295.2296**
E-mail: **info@specialneedsproject.ca**
Website: **www.specialneedsproject.ca**

Please send letters by e-mail or to:
P.O. Box 237,
Baddeck, NS B0E 1B0

The Child Care Fund is administered by the Canadian Union of Postal Workers and financed by the Canada Post Corporation.

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