



SPECIAL NEEDS • MOVING ON

member to member connection



Breaking through barriers for workers who have children with special needs

N° 42 Summer 2021

The Special Needs Project Celebrates 25 years!

This year we celebrate the 25th anniversary of the *Special Needs Project*. This is covered under Appendix L in our collective agreement. Appendix L was hard fought for and has helped many postal workers who have children with different abilities. Over 1800 members and their families have benefited from this. I do not believe any other union in Canada has such comprehensive benefits as we have.

I believe it was on the bargaining table since 1984. I was part of the Women's Committee that was the mover and shaker in achieving this. It was won in 1991.

To me it is a matter of pride that a postal worker can get help and support through Appendix L. Our union negotiated a fund which is paid for by the employer and managed by the union. It is there if you need it. Use it.

I am now well retired but try to keep up with our union struggle. There are more battles to be won.

In solidarity



Congratulations to the Special Needs Project on its 25th Anniversary!

I am honored to be part of this project and so thankful to all of the members and project staff I've met over the years. You have inspired me with your wisdom and strength, your humor and tears. You've been full of ideas and plans, and open to trying new things. I've learned so much by being part of a project that supports parents in a unique way and is led by an amazing team! Happy 25th!

Special Needs Project Advisor, B.C.





Meeting Members Needs

While we celebrate the 25th Anniversary of our *Special Needs Project* let's remember that the seeds of this project were rooted in an even earlier time.

It began in the early 1980's when CUPW women began to push their union to make childcare a priority. It was at the 1983 Convention that two childcare policies were debated and adopted into our National Constitution:

- Opposition to cutbacks and support for the concept of 24-hour-a-day universal childcare services as a responsibility of government (D-12)
- Opposition to all for-profit childcare centres (D-13)

THE EARLY DAYS

Between 1984 and 1987 we put childcare on the bargaining agenda with Canada Post (CP). In 1987 a comprehensive demand for employer-paid childcare services was tabled. We came out of this with an arbitrated award that included a joint (union and employer) childcare study of all members at Canada Post.

This joint study was undertaken in 1989 and brought to the fore the challenges members face in trying to find suitable childcare they could afford.

In 1991 we negotiated a jointly administered Child Care Fund, but after endless meetings with CP, the union negotiates full control of its administration. Between 1995 and 2000 we established several community-based childcare projects for our members. The Fund works with non-profit community-based childcare programs in different regions of the country to develop services to support CUPW member families and currently supports nine childcare projects.

It was through this first joint study that CUPW became aware of the additional challenges our members face in trying to work and care for their children with disabilities. We knew we needed to better understand these challenges, and in 1996

sponsored a second study, *In Our Way*, to look at workforce barriers faced by parents of children with special needs.

IN OUR WAY: CHILD CARE BARRIERS EXPERIENCED BY PARENTS OF CHILDREN WITH SPECIAL NEEDS

This study provided insight into the additional emotional, financial, and physical challenges our members face when working and raising children with disabilities. **We learned from members that their children with disabilities often face barriers in attending school, childcare programs or play and recreational activities.** We learned that their children often need special transportation to attend programs, and that without additional supports like specialized staff training and equipment that the doors to regular childcare programs remain closed to their children.

We learned about the financial strain these members face because of the additional costs for uninsured expenses related to their child's disability. We also learned that all too often one parent, usually the mother, left the workforce or took part-time work because of the additional needs of their children. This also included members forgoing opportunities for promotion or having to turn down overtime or being unable to attend union meetings/functions.

Using what we learned from members and the recommendations from this study, the CUPW Child Care Fund put in place a pilot, *Special Needs Project*, in the summer of 1996 and we have not looked back. **We are proud that through our *Special Needs Project* we have provided practical supports to over 1,800 postal workers and their families.**

Twenty-five years later and we continue to adapt and respond to the additional childcare needs of postal worker families who are raising children with special needs.

A toast - to another 25 years!



The Pandemic Had Us Climbing The Walls

No one was more surprised than me to learn my daughter Cassandra loved climbing walls. When her respite care giver suggested rock wall climbing as an indoor activity, I was extremely skeptical. I had safety concerns, pandemic concerns, and just plain fear of her falling.

Things I learned:

- Rock Climbing Gyms follow all Covid-19 Pandemic protocols when they are allowed to open
- Sessions are by appointment only
- Rock chalk for hands was mixed with alcohol to make a chalk sanitizer

Things she learned:

- Concepts such as right/left, go/stop, and more that are being experienced kinesthetically as well as verbally
- Hand and foot placement problem solving
- Decision making as she figured out a path and the follow through with the decision
- Focus as she had to continually scan the wall for the next hold
- Increased attention to details and sequential thinking
- Hanging on the wall off the ground she was able to attend to cognitive tasks involving her physical ability and whole body
- Most important... Exercise can be fun!

This activity has its challenges and may not be everyone's cup of tea, however, we found it to be another way to tackle keeping fit during the pandemic and having fun!

**RSMC
Niagara-on-the-Lake, ON**



Hello everyone! The Special Needs Project is 25 years old and I am proud to say that I have been involved for many years! I can see how much good this project does for parents of special needs children. The resources available, the listening skills of the advisors and the financial support that the program provides are essential. Hats off to the parents of these children, but also to the whole Special Needs Project team and the advisors who support everyone! Long live the project!

Special Needs Project Advisor, Quebec



A New Beginning

When I started working as an advisor in 2014, Mario was part of “my” families. At first, talking to him was almost impossible because of his difficult family context, but I finally got to know him in February 2016. I asked him to share his story with the readers. He accepted in the hope that his story might help others.

Five years ago, Mario experienced a very difficult separation. He had to start from scratch and rebuild everything: his life, his credit, his family, his confidence in himself and in others... He faced many challenges, and the system is still often biased against single fathers. He felt he had to prove himself constantly, to be more than perfect, even infallible. He felt like he was constantly starting over: with every new appointment, with every new submission. Even today, his routine regularly includes court visits, service and intervention plans, and many hours of meetings. He has to, with four daughters with special needs to follow up on. That’s a lot of files to manage!

Our first calls were short. I often felt like I was bothering him and I did not feel he was well, even though he told me otherwise. To Mario, I was a stranger, even if I already knew a lot about his family. I was slowly breaking through the wall that separated us. After a few calls, the pressure fell and he confided in me. Trust was growing with every call, as well as his understanding and acceptance of his situation, as he was discovering everything available to help him. Mario and his daughters have grown so much in all areas of their lives since I met them!

Today, Mario is doing very well. His secret? There are no miracles! He chose to hang in there and fight. He found help, rebuilt himself, and changed his lifestyle. He also changes his assignments regularly to attend all his appointments. And his new partner is very involved. By trusting himself more and working with his counselors,



he has proven himself. He has learnt that no one knows his children more than him. He surrounds himself with competent and kind people who support his desire to be a caring father, and who have the development of his children at heart. He participates in meetings, discusses interventions, and incorporates the recommendations he believes will be helpful to his daughters. “I am well surrounded. I have a network that I trust. That makes things easier,” he says.

“The *Special Needs* project helps pay for some of the care,” he adds. “It takes some of the pressure off, not to mention all the help of advisors like Jessica. We spent so much time talking. She listened to me and offered an abundance of resources. We’ve bonded so much that she’s like family, and there’s a lot of her in our success.”

As any advisor would tell you, tools, encouragement, questions and resources can make a difference! Sometimes, having someone to talk to, to reassure you and allow you to see things differently is the push you need to change or not give up.

Don’t be afraid and get informed. For Mario, that’s the most important. “Even if it’s scary at first! Small things can snowball and change everything. Later on, I want to know that I have done and given everything for my daughters, so they have everything they need to continue their journey and do it their own way.”

Every family has its own story, challenges and successes. The situations are different, the children are different. And yet, all calls have something in common: love! The love that drives a parent to seek solutions, better interventions and resources to support their children’s development. This is what I love about my work with the *Special Needs* project. Some parents need someone to talk to, some need resources, some just need financial help. But in all cases, they are open to suggestions, to what we can do for them in addition to financial support. I feel privileged to be, in some way, part of their lives.

The path we follow is not perfect. Neither is life. But isn’t it precisely this imperfection that makes it perfect? :)

**Member in Quebec,
and written by Advisor**



The Special Needs Project is 25! Let's celebrate this milestone!!!

Seven years ago, I joined the project as an advisor and found more than just a job! I'd say it's more like one (great) big family!



- Friendly and professional advisors who care about the families they interact with
- Compassionate managers who unselfishly give their time and listen, ever so willing to provide the best answer possible, be it to members or their reporting advisors
- Amazing families who have much more to discuss besides special needs: shared advice, life stories and inspiration; families I can't wait to talk to and find out how they're doing each time, whose evolution I follow with delight and whose kids I enjoy "watching" grow in every aspect.

THANK YOU:

- To the Project for everything it does!
- To the managers for their incredible work! to my colleagues for everything they share!
- To the members for their openness, their availability and their trust!

Long live the Special Needs Project!

Special Needs Project Advisor, Quebec

My daughter Marisa is doing fine and has started making more friends now that she is in high school. Every day, we notice little glimmers of things improving – her social connections, people she is talking to. She is daily meeting her challenges with our encouragement and the support from Special Needs. Thank you for all your support!

**PO-4
Maple Ridge, BC**

Life can be always full of ups and downs, but nobody likes to live in uncertainty forever.

The coronavirus pandemic is one of those uncertainties which came from nowhere and nobody knows when it will be defeated. As an adult I can somehow accept the fact that it will disappear someday soon, but it is not as easy for my son Arvin, age 15 who has ASD.

The last year was the most challenging year for my son so far. Although me and my wife are doing our best to keep him physically and mentally in good shape, I cannot deny the fact that his overall health is not good.

We appreciate all the support we receive from different sources, including the funding Arvin is getting from the Special Needs Project. It is very much appreciated.

**PO-4
Stittsville, ON**



I have been deeply touched by the stories of the members and how grateful they are for my support and the funding that they receive through the Moving On Project over many years. I am deeply honoured to have been part of this project.

**Ontario
Moving On Project Advisor**



“People were working side by side and yet often didn’t understand each other’s worlds.”

25 Years of Research, Action and Creativity

Reflecting on the Special Needs Project with Jamie Kass (Former Child Care Fund Coordinator), Shellie Bird (Current Child Care Fund Coordinator) and Gail Holdner (Special Needs and Moving On Projects Coordinator)

The Special Needs Project’s 25th Anniversary is a big milestone, and we wanted to do something special. So we invited Jamie, Gail and Shellie to get together (by Zoom, of course), so they could talk about the project’s history and what they think it has achieved—for members and for CUPW.

GAIL: Jamie, you were there at the very beginning. The whole idea for the project came out of the recognition that members had trouble finding child care given their work hours. In 1989 CUPW and Canada Post in bargaining agreed to look at the child care needs of postal workers. Out of the needs assessment, the union became aware of the additional struggles members experienced if they had children with disabilities.

JAMIE: And then the 1996 study [*In Our Way*, conducted by SpecialLink researchers Sharon Hope Irwin and Donna Lero] really explained the impact having a child with a disability had on our members’ work. We heard about stress, lack of specialized

supports and financial pressures. The summer was particularly difficult for postal workers with children, so we did a summer project in 1996. **The focus was on supporting members with funding so they could find appropriate programs. They found it really helped them, and more people got interested.** We put it all together into a full-year, permanent project that fall. We wanted it to feel community-based, so we made its home in Cape Breton. And then we said, okay, it’s about funding, but it’s also about *support*. And that’s where our network of special needs advisors came in.

In the early days we also did a lot of education. The 1996 study showed that people were working side by side and yet often didn’t understand each other’s worlds.

SHELLIE: Education and promotion of the project is still so important. CUPW is developing a network of social stewards and we will be working with them to help us get information about the Special Needs and Moving On projects out to members. We’ve also toured depots and plants across the country and spoken directly to 5,000 members. Sometimes people were angry, because they had a child with special needs and this was the first time they were hearing about the project!



TOP: Shellie Bird, Gail Holdner BOTTOM: Jamie Kass, Lucy Trew (writer)



G: We track where new members have heard about the project and it's word of mouth 98% of the time.

J: **I think we can't understate the importance of the advisors. They've helped to make the project really special. In many ways, they're how we hear about what's going on in the workplace.**

G: The advisors have a fabulous empathy and ability to support members. They help members find community resources and they conduct interviews on our behalf, but they also share members' stories with us. It is important we understand the challenges, and successes, that members experience in their work and home life. **The information we receive from advisors is key to being able to keep the people in mind when we are looking at the paperwork. I don't know if the members understand how valuable their input is.** Not only so we can tweak the project so it better serves them, but also in terms of feeding important information back to the union.

J: During the very stressful period of Postal Transformation the advisors really began to understand the *collision* of work and special needs for the members they spoke to. **Those stories really helped us let the union and the employer know the impact it was having on the workforce.** I think we made such headway with overtime this last round of bargaining because of that.

G: We've also used the interviews with members to ask about health care, and how their benefits were working for them.

J: And this led to some important changes to benefits.

S: And we've heard from members about the difficulty of returning home after a ten-hour day and then having to get on the computer to search for a program or something else their child needs. We've been working on a national database of supports and services across the diversity of disability and across the lifespan with the Canadian Centre for Disabilities and the 211s in different provinces. We're testing an accessible, user-friendly portal with members now, which will also be available to the public. **It's a big project with cutting-edge technology. And it grew out of feedback from our members.**

J: We always wanted this: for what we could do for our members to also have a broader impact. Pushing for better public policy has been our goal through *all* of our child care projects.

G: And just over the past year we've started two other little projects. One about supporting siblings of children with special needs and another to help children transition to adult services, which is always challenging.

J: The Moving On Project, which began in 2005, also really came out of hearing about those challenges from parents: just because their kid reached adulthood didn't mean they stopped having disabilities. And we haven't even talked about *Member to Member Connection!* It started as a little newsletter with want ads and offers. Now it's another way for members to share their stories. And now it's important to see what our members are saying about the pandemic—about what they have lost, and its impact on children with disabilities.

G: COVID is immense and affects everything we do. But it's also very impressive how creative members have been with what they *can* do for their children right now. We're seeing a lot more requests for things that kids can do at home. We know from the advisors that people are struggling to find the resources and services they need during the pandemic. We've adapted with a funding exception that allows more discretionary spending for now. **The members educate us all the time. And we need to be constantly adapting to the information that we're receiving.**

S: **It's symbiotic. The project and what the members are experiencing feeds the union the information that it needs to more effectively represent members.**

J: **You know, postal workers are about action. Research is good, but it's how you use the research that's most important. The Special Needs and Moving On projects were the most important thing I did over my career. They made a real difference. This work affected peoples' lives. It has led us to be able to do the most creative stuff.**



"Our advisor is a wonderful blessing."

Our son, Chad, was diagnosed with global Developmental Delay at the age of three. He was non-verbal and developed seizures in his teens. Since then he's been on medication for epilepsy which is keeping it controlled.

He is attending his last year of high school on-line. We tried our best to help him cope with this pandemic routine. He's undergoing white cataract surgery this December. We're hoping and praying everything will be OK, that his eyesight will improve and there will be no complications after the surgery.

I would like to thank the Moving On Project for the financial help that we've been getting. It's helping a lot of families. I would like to mention too our advisor Susan B. She's a wonderful blessing. The information, knowledge, time...thank you so much. It's wonderful to know someone will be listening and advising you even if it's only twice a year. It's great!

**Stay safe everyone,
PO-5
Ottawa, Ontario**



Then and Now

I would like to thank

everyone involved in the *Special Needs Project.*

Madison has been with you for many years and has greatly benefited through your support. Sylvie, who has been our advisor will be sadly missed. She always set my mind at ease and gave me the confidence I sometimes needed. She is truly a credit to your program.

Madison turns 18 in May and has many new adventures ahead of her. We can't wait to see how she blossoms. Once again, thank-you from our family to yours.

**Letter Carrier
Cornwall, ON.**



It has been a honor and a privilege to have been part of the *Special Needs Project* as an advisor for many years. Through-out the years I have connected with many members. For some members I've been their advisor from the start of their involvement with *Special Needs Project* to the time their child aged out. I think for members the *Special Needs Project* brings a sense of connection to other families that might be facing similar issues. They also enjoy the financial help that allows them more flexibility in the services or equipment they can offer their children. As an advisor I always look forward to checking in with the members and seeing how they are doing and reminding them of any progress I have seen. The Project staff are always friendly and helpful, and it is comforting to the members to know they can call if they need to with any concerns or questions. Twenty-five years is a great milestone. I hope the project will continue for many years to come.



Special Needs Project Advisor, AB

In the Beginning: CUPW's Special Needs Program

CUPW is one of a very few unions that have been able to negotiate a child care fund to assist members in finding and affording quality child care for their children with disabilities. Under the Child Care Fund, CUPW commissioned a needs assessment with SpeciaLink: The National Centre for Early Childhood Inclusion. The study, *In Our Way*, provided the groundwork upon which to build the Special Needs Project.

I, Sharon Hope Irwin, was lucky enough to be the director of SpeciaLink during that period and to have the privilege of helping design and carry out the CUPW Special Needs Project. We ran a test project the summer of 1996. We hoped it would continue the next summer and the one after that, but parents were even bolder in their comments than we were. They asked for a whole school year program too, and CUPW provided that.

It's now been 25 years since the trial program began, and it has grown in size and quality and influence. It now has a "Moving On" section, that includes members' children too old for the Special Needs part. And the program was even part of an influential "report card" (How Does Canada Measure Up?) presented to the United Nations by the Canadian Coalition on the Rights of Children, using stories and other information from the Special Needs Project.

25 years! CUPW and I have moved on — the Special Needs Program went to Baddeck and to Shelley Bird at CUPW, Gail Holdner and staff, while I continue my other work for children with disabilities and their families at Town Daycare Centre in Glace Bay and at SpeciaLink. I am proud to point out that while serving members and their children with disabilities, the CUPW Special Needs Project continues to serve as a model to other unions and a base for change in public policy.

Congratulations on your 25th anniversary!



Walking alongside

We reach John at the family's trailer in Grand Bend, where his family has been staying since late April, during Ontario's latest stay-at-home order for this third wave of the COVID-19 pandemic.

John started with the Special Needs Project in 2003, when his first child, Brandon, needed some extra tutoring in math and language. Brandon, now age 27, is "doing absolutely incredible," John says. "He's a licensed plumber. He wouldn't be if he hadn't developed those math skills."

John's third son, Logan, who has been with the project since 2012, is also thriving: "Even with the lockdown. You'd rather see him at school with his peers, but given the circumstances he's doing really well. And his health is incredible."

Logan was born with a mild form of cerebral palsy and then began to suffer from severe epileptic seizures when he was a little over a year old. Very high doses of anti-epileptic drugs made him lethargic and they weren't doing much to keep his seizures at bay. After a lot of research, John's family found a doctor who

would oversee a completely different treatment: CBD oil. Logan was slowly weaned off his medications and began taking the oil. He has been grand mal seizure-free now for two years. "Once he was off all his medications, it was like meeting our son for the first time," says John. "He's unbelievably active and engaging. He wants to be a part of everything."

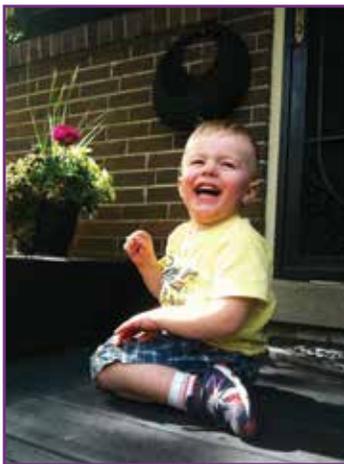
"I hope that other families have an opportunity to be a part of something that I've been a part of for getting close to twenty years. The fact that it's there speaks to the union and how much they do care for members and their families."

But CBD oil is very expensive and isn't covered by Canada Post's drug benefits. John says that without the project's help, their finances would be stretched to the limit.

On the other end of the line is Enna, John's advisor. She sees her role as "walking alongside families who have children with identified special needs" and the project's role as "helping parents and families to reduce some of the emotional, financial and physical stressors that naturally come with supporting children with special needs."

She speaks glowingly of John and his family: "I can really see the progress Logan has made. Though it comes with frustration at times, the amazing thing is how Logan's parents and his brother are all working together to make sure his needs are being met and that he's growing and developing every single day."

"And even though I've never met Enna," John says, "I feel totally at ease with her. I consider her to be a part of our life. She's been there throughout all the milestones. I feel like I can just talk—it's just one of those relationships. And I'm sure you can hear from us talking. I think we're talking like we're friends."



He is a seizure alert dog.



Then
and
Now



My name is Bina and I have a child named Kishan who has ASD. He was diagnosed when he was 4 years old. It was so stressful when we heard first, with lots of therapy suggested by the doctor. It was very expensive and the doctor also suggested various organizations for funding. We tried almost all of them, but it has been such a long time waiting (4 to 5 years or more) so it increased our stress more.

But one day in the workplace we heard about the Special Needs and Moving On Projects. We called them and talked to the staff - it was very friendly and inspired. It gave us new energy to move on. And it's unbelievable but it's true, within a few weeks we started to get financial help with very less paperwork. After this we started various activities for Kishan like swimming, summer camp, gymnastics, respite services, and magic. We also got suggestions for school and his IEP as well.

At the end, me and my family are saying "Thank you from the bottom of our hearts" for helping us over time and making Kishan's future bright.

**PO-4
Brampton, ON**

Happy 25th anniversary to the Special Needs Project! I have been a proud advisor for this program for the past five years. Over time, I have made amazing and invaluable connections with members who face all kinds of trials, large and small. With every interaction, I can see how the program helps them by somewhat alleviating this challenging reality.

Wishing this wonderful project a long life!

**Québec
Special Needs and Moving On Projects Advisor**



**Brandon and his
sister Lizzie.**



Lizzie (21) (autism) lost her big brother Brandon (22) and her protector. Brandon always helped out with his little sissy and never complained. His friends also accepted Lizzie as their friend.

Brandon passed tragically September 27, 2020. He was a lieutenant in the fire service and training officer! He was very dedicated to his employer and hadn't missed a day in the three years he worked for them.

Brandon always looked after Lizzie. They would hang out watching movies, go for a cruise listening to music and singing, swimming and boating together. They were the absolute best brother and sister as well as the best children we could ever ask for.

Now we have to try to live our lives without our son and Lizzie's brother. I don't know how but with the help of family, friends and Moving On, we will take it one day at a time.

Don't take time with family for granted.

***In loving memory,
Brandon MacLeod, 1997 - 2020.***

**Letter Carrier
Stellarton, NS**



Member-to-Member Connection

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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:
**PO Box 237, 65 High Street
Baddeck, NS B0E 1B0**



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