



member to member connection

Breaking through barriers for workers who have children with special needs
Nº 26 Summer 2013

Let's rethink child care

Think child care is 'just your problem'? Think again. So many families are struggling to find decent child care and are scrambling to piece together care they can afford. It doesn't have to be this way. **It's time to re-think child care.**

A new campaign on child care is being launched by the labour movement to highlight the difficulties of finding quality child care. Child care is often viewed as an individual problem: "It was your choice to have kids, why should I pay to raise them?" Yet so many parents find the stress of finding, affording, keeping and juggling child care arrangements incredibly stressful. If you have a child with special needs, the challenges are even greater. The lack of quality, affordable child care is really a collective problem.



Through this campaign, we want to create space for people to share their stories, to talk with each other about how hard it is, and to begin to visualize what needs to happen to make things better. We want to make sure your voices and stories are told and children with special needs are recognized.

The campaign will involve Kitchen Table Conversations, small events that encourage sharing stories and experiences relating to child care in Canada. This will help identify what is working well and what needs to change.

This issue highlights stories of our members' struggle to find and afford good care. We hope this will spark you to write your own story.

What you can do

- Check out the campaign website at www.rethinkchildcare.ca;
- Share your own story of child care difficulties;
- Host a kitchen table conversation with a few friends and co-workers;
- Talk to your union local about getting involved.





““He could hear for the first time. Unbelievable.”

“I love you Umaima

but you don't know. When you will know, I don't know.” These are the lines that always came to my mind whenever I think about my little daughter Umaima Khan. I am waiting for the day when she will come from school and share with me all the things happened at school like her other siblings. One time Umaima made a large mess. Whenever I spoke to my older daughter about that she always said “Mummy whenever she makes a mess you say it is a test. What kind of test is it that happens many times every single day?” Now Umaima doesn't make that much mess and I say we passed the test. She is very caring and loving. She tries to solve other people's problems in her own way. It is her first step to her normal life. I remember my bitter culture where I was blamed for having an autistic child. Even my close relatives told me that she was a curse from God for my wrong deeds. Now I am able to tell them that she is a gift from God for my good deeds.

PO-4

Ottawa, ON



In July 2009 my family celebrated the birth of our son, Thomas. Before leaving the hospital they did a hearing test and found something was wrong. Unsure of what the problem was we were referred to an audiologist. The testing was unsuccessful there and we were referred to the Hospital for Sick Children in Toronto. This was on December 23, 2009. We met with Dr. Papsin, an amazing man, who set up all the necessary tests. We found out that Thomas was profoundly deaf in both ears. We were then asked if we would like to be part of the cochlear implant program. Of course we said yes. Who wouldn't want their child to experience what the world sounds like, both good and bad? Thomas was scheduled for surgery on May 10, 2010.

On June 3, 2010 his Cochlear implants were turned on for the first time. Thomas could hear. They gave me a chance to talk first, to be the first voice he would hear. Unfortunately I was too overwhelmed, and all I could do was cry, so his Dad took over and began talking to him. The look on Thomas' face cannot be described in words, but if it could I would say it was a look of total surprise, and question. He could hear for the first time. Unbelievable.

Since then he has excelled in everything and has caught up to and passed every child of his own age and older. He should be about a year behind in speech and listening but is not at all. He turned three in July 2012.

I would like to extend a very grateful thank you to the Special Needs Project for helping us provide Thomas with a preschool that provides audio/verbal therapy everyday that he is there.

RSMC

Brampton, ON



"Our children with special needs teach us more than we teach them."



Our son Lucas was born in May 2001 weighing in at 2.2 lbs and coming 3 months early. Having a brain injury at birth, plus low muscle tone required a lot of determination on Lucas' part to meet his milestones. Walking and talking were quite delayed as well as printing and reading. In 2004 Lucas stopped walking altogether and was in pain a lot. He was then diagnosed with a chronic bone disorder. Now with his medication he is mostly pain free. In 2000 Lucas was diagnosed with a learning disability caused by the brain injury at birth. Thanks to the Special Needs Project he is coming along fine. With a physical and learning disability Lucas' self esteem is low but "the Project" helps fund activities to build his self-confidence. It also helps with tutoring and our trips to Sick Kids. I believe our children with special needs teach us more than we teach them, especially lessons in determination.

Letter Carrier
Orangeville, ON

My son Julien has a moderate intellectual disability and severe dyspraxia. At 11 years old, he's quite the man, weighing about 22 kg and measuring about 1.30 meters tall.

Given his condition, it's hard to find a sport that suits him. Some people have suggested he take up karate. I have to admit I was a little perplexed by their suggestion. When Julien enrolled in karate school, the school director said he had reservations about it, but let Julien try, and now, my son has got his yellow belt. He isn't a master of the sport mind you, but for him, it's quite a feat. Remembering every movement sequence is extremely challenging for him, but he's progressing at his own rate and loves karate. With his trainer's help, he is able to perform routines. Recently, he performed an eight-step routine, which is absolutely fantastic for someone with dyspraxia.

I have to say again that all this would be next to impossible without the help of the Special Needs Project. Thank you from the bottom of my heart!

Letter Carrier
Blainville, QC





"Daycare was hard to find because a lot of people were afraid to take her."

The challenge of finding child care

Nicole, a Rural and Suburban Mail Carrier in Innisfil Ontario, has had trouble finding child care for her four-year old daughter, Sierra, who has special needs. "I had a hard time finding day care because a lot of people were afraid to take her."

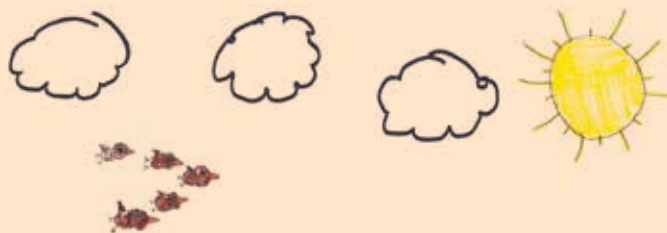
Sierra has severe congenital hydrocephalus*. "When she was born, she wasn't supposed to live," says Nicole. Sierra is not independent and requires constant care. While she can get on her knees and roll on the floor, Sierra cannot walk or speak and her diapers need to be changed regularly. She also has periodic seizures.

The search for child care

"I've had a terrible time finding daycare," says Nicole. Many day care centres weren't sure they could take Sierra given her special needs. Eventually Nicole found a caregiver who was willing to care for Sierra. At the same time, it was understood that when Sierra reached a certain weight, the caregiver would no longer be able to manage physically. However, this arrangement came to an early end due to a combination of factors. Sierra started having regular seizures. She also started using new equipment like seating chairs, and a stander, for which the caregiver lacked the space. Furthermore, the caregiver had no training or education on all these issues and it was too much for her to take on. Nicole was missing a lot of work taking Sierra to medical appointments about the recurring seizures. When her child care arrangement fell through, Nicole had no option but to go on a leave of absence.

Nicole had also tried to get Sierra into a YMCA child care centre. This would have been an ideal setting as the equipment Sierra needs would be there and she would have an aide working directly with her. However, there was no funding for an aide to work one-on-one with Sierra.

In the meantime, Nicole had another child, a son named Tye, who is now 10 months old. She has been at home caring for both Tye and Sierra.



Going to school

This September, Nicole is hoping to return to work because Sierra will start school full-time. "When she goes to school it'll be great," says Nicole. "They'll have all her equipment there and she'll have a wheelchair bus." However, school presents another problem. "Now I need before and after school care," says Nicole. She's trying again to place Sierra with the YMCA. If that doesn't work, the only option is respite care at \$12-18 an hour. "A couple hours before work and after school, that adds up," says Nicole. "How are you going to pay that?"

"I'm just keeping my fingers crossed that come September I can arrange all that," says Nicole.

The financial crunch

Nicole's family is currently living on a single income. "Financially, it's been hard," says Nicole. Equipment costs alone are approximately \$20,000, only partially covered by benefits. "You know, we're not able to do much, we just make it by," she says. "It's been stressful but you just plug through and do it. What can you do right?"

Nicole's mother has suggested finding a new part-time job that would give her more time to care for Sierra. "I've been at the post office 15 years," says Nicole. "I'm just not ready to walk away and do part time, nor do I feel that I should have to. There's got to be something that can be done."

It's definitely time to rethink child care for children with special needs.

** Congenital hydrocephalus is a buildup of excess cerebrospinal fluid in the brain at birth.*

The extra fluid can increase pressure in the baby's brain, causing brain damage and mental and physical problems. This condition is rare.



Advisor Profile

I can't remember exactly when I became an advisor. I've been doing it for quite a number of years.

I heard about the job and thought it was perfect for me, talking on the phone and finding resources. I quickly learned it was so much more. I love the challenge of finding resources or generally helping people. Sometimes it can be as simple as just listening.

I'm a Family Support Worker and a Resource Teacher /Early Interventionist. I have worked with children and families for approximately 35 years. I love my work and I love the simple fact that I can help make a difference in people's lives.

Meeting the families through the project has greatly humbled me and made me appreciate my life more. Being a parent is hard but being a parent of a child with special needs is ten times harder. I'm always continually amazed at the love, dedication and tenacity the parents have for their children. They want to fight for them but sometimes they do not have the tools to do that. This becomes our job. You become like family because you share births, deaths, divorces, marriages, etc. You cry and laugh at life together and learn together.

The thing I like best about being an advisor is the families. You get to meet so many wonderful people. The families have taught me so much about different disabilities and what it truly means to be a survivor. I get so excited when I get to see one of my children in the newsletter. Another thing I like is being able to give support and encouragement. It is satisfactory and rewarding to see the progress, even if it is very small. In some cases it is hard because the child may have come to the level at which they will remain.



I'd like to see the school system change so the children could get the education they deserve. The battles the parents have to go through (waiting list, substandard education, fighting to take their child to appointments etc.) are wrong on so many levels. These families who have so much to deal with should be helped but instead they are sometimes given many more burdens to carry.

I'd like to thank the Project for giving me this unique opportunity and I'd like to thank the families for allowing me into their lives. I am honored to do both.

Nancy Bokma
Toronto, Ontario





"He absolutely loves it at the daycare. He's very excited to go."

Inclusive child care makes a big difference

For Jonathan Cruickshank and his wife, Therese, finding an inclusive, quality child care program for their two-and-a-half-year-old son, Logan, has provided support and peace of mind.

"We've been very lucky," said Cruickshank, whose son went into YMCA Cornerview Child Care in St. Thomas, Ontario, at about age one. "From the very first day they were very, very accommodating. They didn't seem to have any hesitation or reservations about anything."

Logan has spastic hemiparesis cerebral palsy, which affects the right side of his body. He has very little use of his right arm, and cannot walk on his own yet. There are also some speech delays, but his dad says his son is aware and can understand what is said to him.

"He absolutely loves it at the day care," said Cruickshank, who is a letter carrier with Canada Post. "I take him there in the morning on my way to work and he's very excited to go. He sees me getting ready and when I start getting my coat on he knows it's time to go and he gets antsy. My wife [also a letter carrier] can't keep hold of him."

Support on many levels

An occupational therapist and physiotherapist from the Thames Valley Children's Centre in London visit Logan's child care centre as needed to teach the staff how to work with his special needs and help him do appropriate daily exercises according to his development.

There is always a staff person who helps Logan throughout the day. "In the beginning it was just helping to feed him because he couldn't feed himself, and changing him, and playing with him," said Cruickshank.

The staff also make sure to get him active and integrated into the

program with the other children. For example, Logan was not able to crawl at the same time as the others, so a staff person would carry him or hold him to make sure he was part of the day's activities.

Logan sometimes also has severe seizures that require immediate medical attention because they could potentially cause brain damage. There is medication on hand at the centre, and all staff have been trained in how to use it and on the emergency protocol to follow should a seizure occur.

Logan gets along well with the other children at the centre, his dad said, "and they are intrigued by him." When the family brought in a walker to help him have more independence, "all the kids wanted a turn, and the staff let them have one. It gives the children more of an understanding about him."

The parents have two other children, Brandon, 18 and Tristan, 12. Brandon also has special needs. "We might have put him in child care had it been available but it



wasn't necessary at the time because Therese stayed home with him," said Cruickshank.

He added that while it is difficult to speculate what the child care experience would have been for Brandon, his eldest son might have benefitted from being in a social setting at a young age. While socializing with others has been an issue, Cruickshank said this aspect of Brandon's life has continued to improve.

Both Logan and Brandon are part of the Canadian Union of Postal Workers (CUPW) Special Needs Project, which provides support for Brandon's tutoring and Logan's child care program.

As for Logan's situation, his dad said that his condition is not degenerative. "He is healthy and happy. He is a lot of fun. We couldn't ask for anything more."



Special thanks to Moving On advisor Ellen B. for her patience and the support she provides whenever she calls. Today Abbey was admitted to Toronto General Hospital but this will be a short stay for him. His pain is now under control with the medication.

The previous time he was admitted Roberta, the Special Needs Project advisor for his younger brother Kareem, had called. Roberta has been with the family since the beginning of the project and knows Abbey well. She knows that with all his multiple disabilities he is positive. He is a good communicator and is able to help his abled and disabled friends stay out of trouble.

The time Roberta called Abbey was taken to the psychiatric ward where the pain doctor did not believe him until he said he would kill himself. From that day on his medication has been adjusted to a tolerable level.

Letter Carrier
Toronto, Ontario

Laurianne is 21 years old and autistic. Finding respite services is not easy. For one thing, resources are rare, and when they are available, she is very reluctant to use them. But last December, we were finally able to find the ideal spot. It's located in a country house, with a dynamic and caring staff on site. And to Laurianne's great delight, there are animals there too! Thanks to the project, we can provide Laurianne with a weekend full of activities she loves, in a safe and pleasant setting. We use that time to rest up and renew our energy.

Letter Carrier
Longueuil, Quebec



You can now submit your stories and photos to the Member-to-Member Connection newsletter by visiting our website at www.specialneedsproject.ca.

Go to our home page and click on the icon of the newsletter in the top right hand corner.

Share Your Story
For CUPW and UPCE
Members.





"Daniel was isolated with special needs workers at school and in child care."

Much more needed for children with disabilities

If she had it to do all over again, Crystal* says she would have advocated more strongly to get her stepson the kind of support he needed when he was a young child. But Daniel's fetal alcohol syndrome (FSAD) was diagnosed only when he was seven or eight, and it explained why his behaviour was so explosive and unpredictable. Daniel, now 17, also has attention deficit hyperactivity disorder (ADHD). He has two brothers, one 16 (who also has ADHD) and the other eight. Daniel was adopted by Crystal's husband and former wife.

"[Daniel] also has a very sweet and gentle side, and he always feels remorse for what actions have transpired and would cry afterwards," said Crystal, who is a member of the Union of Postal Communications Employees in Winnipeg, as is her husband. The union is a component of the Public Service Alliance of Canada and its members work at Canada Post in administrative, clerical, technical, and professional capacities.

Daniel's adoptive mom stayed home until he was in kindergarten. Then the three parents provided before- and after-school care for him until Grade Two. It was apparent they needed more support, and Daniel was eligible for funding for a resource person at a child care centre. At school, he had already started what would become a constant rotation of teaching assistants. Because of his special needs, there would also be many different before- and after-school resource people and child care centres for Daniel.

Cobbling together care

Crystal remembers Daniel's school (he went to three different ones in total) would frequently call early in the day to say he had to leave because his behaviour had become unmanageable. The three parents had to take days off or Crystal and her husband would off-shift to look after him. Child and Family Services would also provide some respite. Usually, Crystal would take vacation and unpaid leave during the summers to be home with him.

"He was the most challenging child in the school and the teaching assistants bid by seniority, so most did not want to take on that assignment with him," she said. "The school would have to advertise in the paper so he never started a school year on time or at the same time as everyone else, even though they knew he was coming back every year. He also never finished a school year at the same time as anyone else, and was suspended a lot. It is really frustrating because he never felt a sense of accomplishment."

The vast majority of the time Daniel was isolated with special needs workers at school and in child care. Crystal says these workers were not adequately trained to deal with his disabilities and as a result, "he burned them out."

Since around age 13, Daniel has been in a home setting and now lives in a home with someone for 20 hours a day. When he comes to visit his family, he is accompanied by a respite worker paid for out of the Special Needs Project negotiated by the Public Service Alliance of Canada for the UPCE members who have children with disabilities. The family also receives financial support from the project for tutoring Daniel's brother who has ADHD.

The situation has been stressful on everyone, said Crystal, both financially and emotionally.

The family got through Daniel's early years by doing whatever it could and whatever it took to keep things manageable, but it could have used much more support to enable him to develop intellectual and social skills, and be more included with others.

It's definitely time to rethink child care for children with special needs.

** All the names of the people in this story have been changed at their request to preserve their anonymity.*





A huge thank-you to all of you! This is, without a doubt, proof in the pudding that the Special Needs Project money helps.

Since December 24, 2012 (to mid-February) my family has endured a horrific time with our Jennifer as she has spent, on and off, 22 days in the hospital.

Sadly Jennifer's outcome is not the greatest. She has demyelization of the nerves in her brain and seizures. She has had to be heavily medicated for she has also been diagnosed with self-harm and abuse. This is all stemming from her disability – trisomy 12P. There are forty documented cases in the world. She is degenerating.

Also, sadly, our fine Corporation rejected my special leave. So my family has been living on people's good graces, and I am proud to say CUPW Special Needs Project. Thank you for helping us keep a roof over our heads. God bless. Despite the Corporation boating they support good mental health practices look what they do to their own employees....not good."

PO-4
Orangeville, ON



My 23 year old son started with the Special Needs Project when he was eight years old. His elementary school principle told us he was not post secondary material. He is now in his 4th year of college getting a business marketing degree. It has been very difficult but it's paying off for him. My 15 year old son has a similar learning difficulty. He has been with the Project since he was 5 years old. My husband and I are very grateful for all the support the Project has given us. I would like to thank my advisor Donna for all the insight she has given me. I have enjoyed and benefitted from her phone calls and conversations. Thank you also to my past advisor in Calgary, Diana, and all my tutors. I will be retiring in July and leaving the program. Good luck to all the parents and children in this wonderful program. Thank you again.

Letter Carrier
Victoria, BC





"I really think there are still a lot of people that care out there."



My son has ADHD

and has been on a special diet of Isagenix products. These products have both detoxed him on a regular basis and given him an organic whey. Other than this he is not eating any dairy products. As a result he no longer has signs of irritable bowel syndrome and he sleeps better. He has much better concentration now and is only taking a very low dose of Ritalin. He is doing well in school.

You may call for more details of what and how we are doing.

Letter Carrier
London, ON

Personal Days and Special Leave

The following conditions are in place with the Short-Term Disability Program (STDP) for all CUPW members. *Members must use all seven personal days before applying for special leave.

There are two kinds of personal days:

Planned Days: must be pre-approved by CPC and approval can be withheld subject to a time convenient for the employee and the CPC. The purpose for planned personal days is anything that does not fall within the reason outlined below for the use of Urgent Personal Days.

Urgent Personal Days: notice to the CPC should be the first day, before the shift begins or as soon as possible afterwards. If the absence continues to the 2nd day, CPC must be notified of the expected return date.

Purpose of Urgent Personal Days is for the following reasons: illness, emergency, special circumstances, or qualifying for STDP. Urgent Personal Days can be used for any reason you would have applied for Special Leave under the former agreement for example, if you have a specialist appointment for your child, take this leave as an Urgent Personal Day. You must complete the leave of absence forms as soon as possible after the absence begins.

After you have depleted your Personal Days, for any reason, you can apply for Special Leave. The conditions for special leave have not changed from your previous collective agreement.

*Remember to check your own collective agreement for more information or consult your shop steward.

I would like to tell you

about a chef that took the time to send my son a canvas bag and a picture of himself. The show is called "In the Kitchen with Stefano Faita". Karle turned 30 this year and out of all the presents he got this was the best. So I really think there are still a lot of people that care out there. Let's give a hand for this caring person.

P.S. We'll miss you Kathleen J.

RSMC
Johnston, ON



"We see the difference when we feel we are not alone on this journey."



Hi to everyone on the Special Needs Project and members in general. My family and I are grateful for the project and the commitment to support families with children that need extra care and resources to help them fulfill their destiny in life. My family, like others involved in this project, can see the difference when we feel that we are not alone on this journey. For more than 5 years the project has helped support Julian with resources that we couldn't provide on our own. Julian is now 14 years old. He has a lot of challenges to endure but fortunately his parents have been learning the values of patience, love and peace from him. Health and peace!

Letter Carrier
Lethbridge, AB

The Special Needs

Project has educated me both as a mother and an employee. You have to take everything into account when you have a child with special needs. You know your child can succeed at their goals and with the help of this project my child has made me proud! My son has a speech/language, cognitive delay. Assessment after assessment gets very frustrating for child and parent. You, the parent, are expected to provide all the help and tools your child needs, and your child is expected to do his best. My child has gradually improved. I'm very grateful for the support from our union. My son is below grade level average and will continue to be as his schooling progresses but I know I'm doing my best as a parent. I am so honored my union is helping my son be a positive and confident student with his peers. Thank you Special Needs Project.

PO-4
Flatrock, NL



Jessica still has difficulty regulating her behavior. When she loses her belongings or recalls memories of the past (eg. her cousin having to check her assignments), she becomes upset, screams, yells and cries uncontrollably. Recently she has developed seizures and been prescribed Topamax in addition to the antipsychotic drug Risperdale. As a parent my strategy is to deal with her problems but not to get emotionally involved (with these outbursts). I would like to take this opportunity to express my gratitude for the following agencies for their continued resources and support.

1. Community Living Mississauga
(Phone: 905-542-2694)
2. Kerry's Place Autism Services
(GTA - Tel: (416) 537-2000)
3. Peel Behavioural Services
(Phone: 905-712-4124)
4. The Ministry of Community and Social Services
[website – mcss.gov.on.ca
(French and English)]
5. The Mental Services at the Credit Valley Hospital
[877-292-4CVH (4284) or
email: cvhpr@cvh.on.ca;
Multilingual website –
trilliumhealthpartners.ca]

PO-4
Mississauga, ON

Editor's Note: As the member was recommending the above services we took the liberty of including contact information for each one.



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

Member-to-Member Connection is the newsletter of the Special Needs and Moving On projects. It is produced by the Canadian Union of Postal Workers and the Union of Postal Communications Employees—Public Service Alliance of Canada.

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