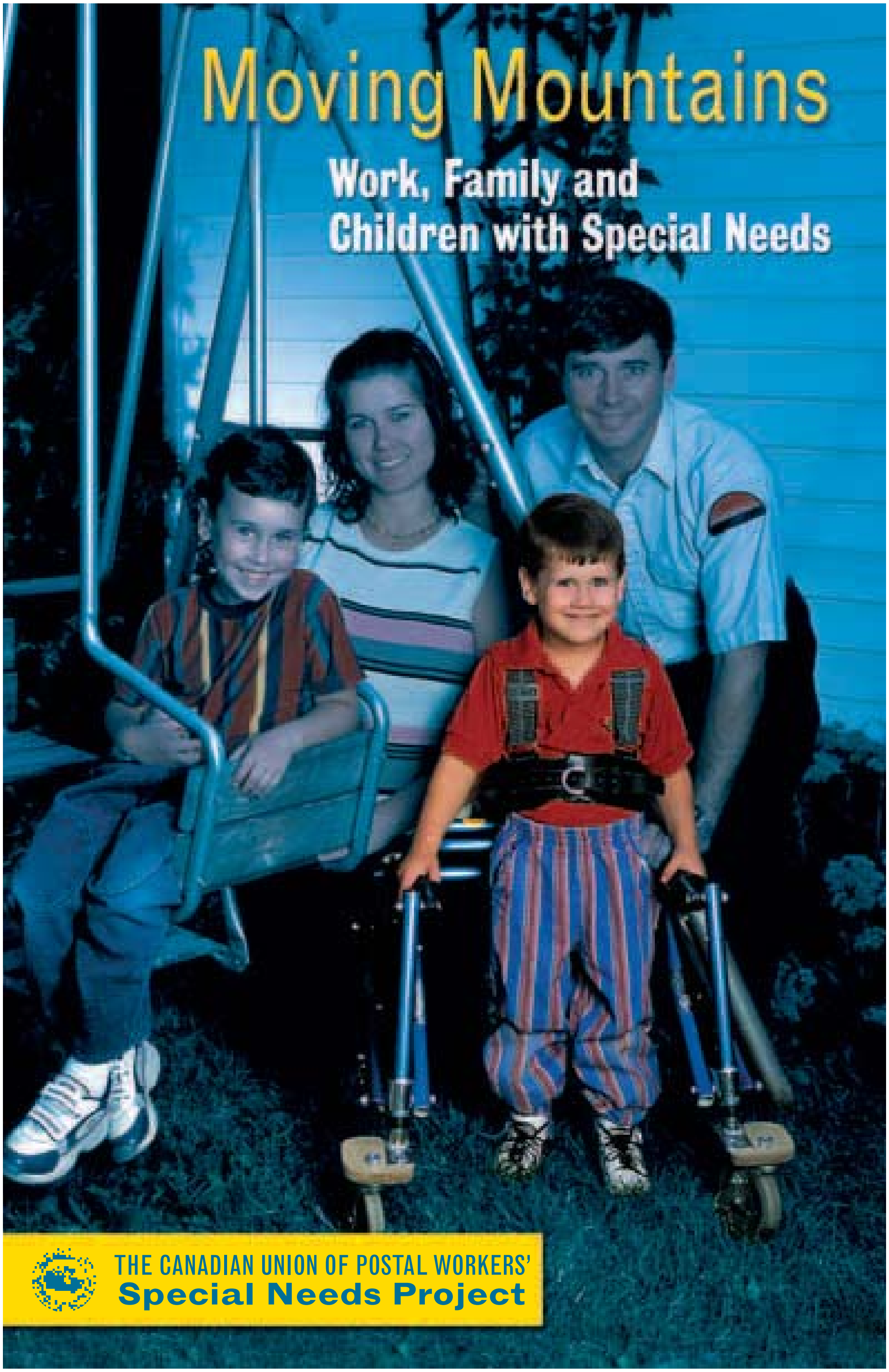
Moving Mountains

Work, Family and Children with Special Needs



THE CANADIAN UNION OF POSTAL WORKERS'
Special Needs Project

ISBN 0-9731900-0-0

PUBLISHED BY: The Canadian Union of Postal Workers, November 2002
TEXT: Bozica Costigliola
TRANSLATION: France Boissonneault and the CUPW Translation Dept.
DESIGN: Joss Maclennan Design CEP 91/CLC
COVER PHOTO: Philippe Landreville Photographe Inc.
INSIDE PHOTOS: Provided by CUPW and UPCE-PSAC members

ON THE COVER: Letter carrier René LePage and Louise Gélinas, from Orléans, Ont., have two boys: Eric, 5 *(right)*, and Daniel, 6. The CUPW Special Needs Project has helped the family deal with the financial stress of having a child with disabilities. Eric has cerebral palsy, asthma and allergies.
See page 25 for their full story.

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Yvonne Gendre, Calgary letter carrier *(centre)*, shown with her family. They are Michael MacBeth, 15 *(left)*; Dad, Clint Sheffield *(in tree with Eric Sheffield, 5)*; Brittany Sheffield, 8 *(with Mom)*; and Jonathan MacBeth, 17 *(right)*. Eric and Brittany have learning disabilities.

FOREWORD

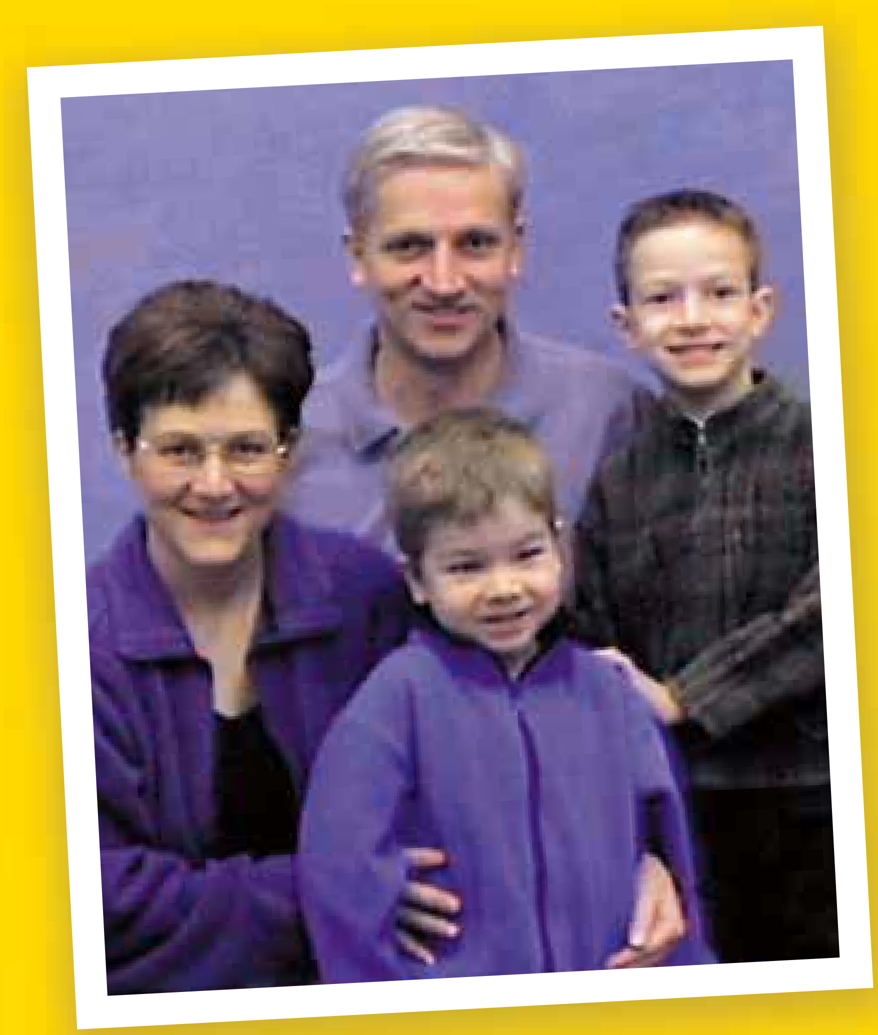
This book is dedicated to the members of the Canadian Union of Postal Workers who have children with special needs. Many parents of children with disabilities have difficulty talking about their family lives. But these members were willing to tell their stories, enabling our union to gain a new understanding of the interconnection between work and family, and to put in place the Special Needs Project in 1996.

Through the advocacy efforts of this group of parents, increasing numbers of their co-workers now have some insight into the financial and emotional stresses that go along with having a child with special needs. The parents have also been key to our ability to put this and other work and family issues on the employer's agenda. We'll continue to press the case with the employer and with governments that workers' lives don't begin and end at work. Support for working families is a shared responsibility. And those whose circumstances are the most difficult require additional assistance.

The Special Needs Project has been a collective endeavour. Our thanks go out to the many community organizations and individuals – too many to name – who were instrumental in helping us develop the project and make it what it is today.

Our union has certainly learned a great deal about disability issues from this project. We've also been deeply moved by the courage, determination and compassion of our members and their families. It is our hope that other unions, community organizations, disability groups, employers and governments will be just as inspired by these stories as we were, and use them to find ways to build a more caring and inclusive society.

– Denis Lemelin
2nd National Vice-President
Canadian Union of Postal Workers



Regina, Sask., mail handler, Maurel Erick, with wife Laura, and sons Luke *(centre)*, and John, 9, who has higher functioning autism.

PREFACE

"...welcome to Holland."

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability – to help people who have not shared the experience to imagine how it feels. It's like this…

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You learn some handy Italian phrases. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland??" you say. "What do you mean Holland?? I signed up for Italy! All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. So you must go out and buy new guide books. And you must learn a whole new language. And you meet a whole new group of people you would never have met in Italy.

> *I am often asked to describe the experience of raising a child with a disability – to help people who have not shared the experience to imagine how it feels.*

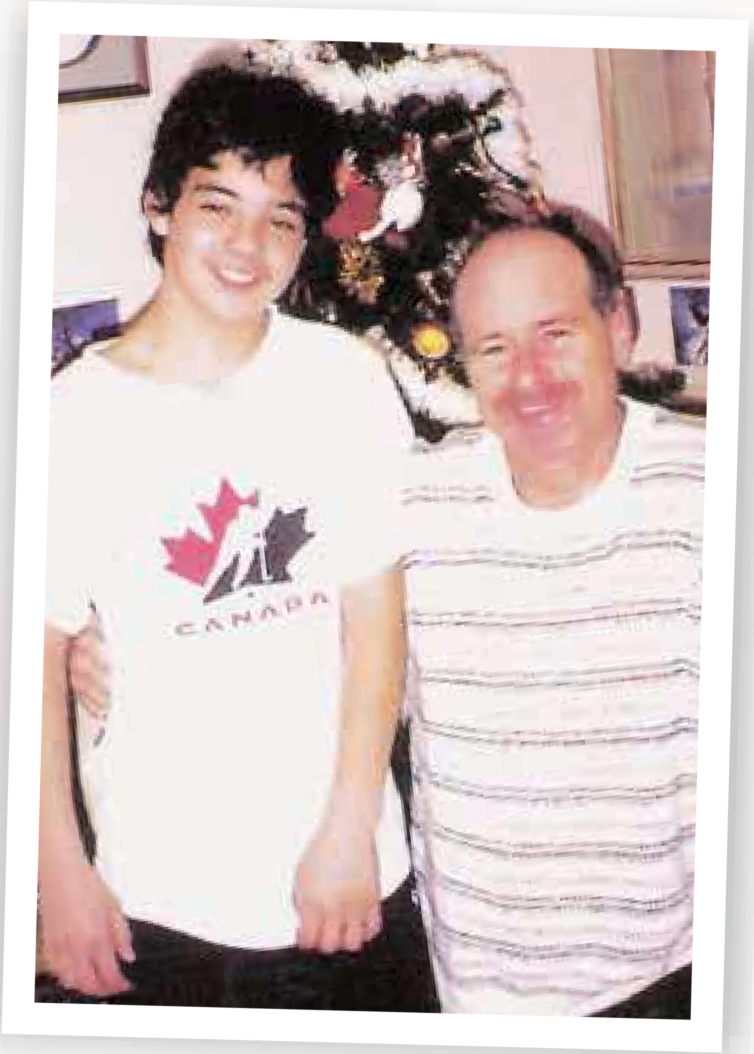
The important thing is that they haven't taken you to a horrible, disgusting, filthy place. It's just a different place. It's slower-paced than Italy, less flashy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that loss will never, ever go away because it is a very significant loss.

But, if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Permission to reprint granted. Originally from Our Lives, Our Voices: Families Talk About Lives Worth Living *(2nd Edition), published by the Canadian Association for Community Living.*

Five-year-old Ashley Hagerman *(right)* gets a hug from her sister, Stephanie, 8. Their dad, Mike, is a postal driver. The Special Needs Project helps the Hagerman family with expenses arising from Ashley's autism.



Gabriel Buchin, 14, with his dad, Howard, a letter carrier. Gabriel plays hockey at summer hockey camp and in hockey league. The sport not only keeps him active, but is recommended to help him develop his social skills, which are severely affected by his special needs: Tourette Syndrome, Non-Verbal Learning Disability/Asperger Syndrome and Attention Deficit Hyperactivity Disorder.

Life is an ongoing struggle for Tina Klinoski, a lone mother who works as a mail sorter in Toronto. Her daughter, Theresa, 6 *(on Mom's lap)*, has multiple special needs, including kidney problems, chronic urinary tract infections and a seizure disorder. Tina also has another daughter, Christina *(standing)*, 12.

1

Step by step to a difference

One mother's story:

The Special Needs Project is a one-of-a-kind program sponsored by the Canadian Union of Postal Workers (CUPW) to help reduce the financial, emotional and physical stresses on the families of members who have children with special needs. This is one member's story of how she came to use the project, and how it works.

Can the union help?

Tina Klinoski didn't know what to do. The lone mother was constantly late for her shift as a mail sorter in Toronto. Sometimes, she couldn't get to work at all. The reason? Someone had to be home when the nurse came to give Tina's daughter, Theresa, her daily intravenous injection for kidney problems. The procedure took four hours. There were also times when Tina would be called away from work. Theresa, then 4½, was being rushed to the hospital because her kidneys were failing.

"I was scared I'd get fired, so I went to the union," Tina says.

Tina was really on her own. She'd been widowed when Theresa was 3½ months old. Her parents lived far away in Italy. She also had an older daughter to take care of, Christina. She couldn't afford to lose her job.

She hoped the Canadian Union of Postal Workers would go to bat for her, and it did – but in a way she hadn't expected. "The union rep told me about the Special Needs Project to help families like mine," she says. "So I picked up the phone and called, and explained the situation."

The interview

Parents dial a toll-free number (1-800-840-LINK) and reach coordinator Gail Holdner at Family Place Resource Centre in Baddeck, N.S. Family Place does the day-to-day administration of the program for the union. Holdner does an interview to determine whether the family is eligible for Special Needs Project funding. Members can call Family Place five days a week and reach someone who's knowledgeable about the project and willing to listen.

Tina answered questions about Theresa's diagnosis (she has multiple special needs), and the impact it was having on the family. Her needs clearly fell within the project's funding criteria, intended to help with expenses directly related to a child's special needs, including:

- Child care or respite fees.
- Recreation programs or camps related to a child's special needs.
- Training for a child care worker, such as how to do catheterization or tube feeding, so that a child with special needs can attend a program.
- A support worker to be with a child during a program and provide the needed specialized care.
- Specialized transportation and/or transportation to such things as therapies and doctor's appointments.
- Uninsured medical expenses, equipment and supplies.

Getting things underway

The next step: Tina was sent an information package and assigned a Special Needs Advisor. The advisor then called to do an in-depth interview with Tina about her situation, assisted her with filling out the project forms, helped identify additional available services and resources, and talked about what might be most helpful to her and her family.

"I completed the forms with the required documents from the doctor and the advisor called me to review everything," says Tina. "Then it was approved and they sent me the cheque. The project money covers most of the cost of a health care aide to be home for the injections while I'm at work. With the help of the project I've also put Theresa in programs for her fine motor skills and her speech because she also has a seizure disorder."

CUPW families of school age children with special needs can get up to $100 a month from September to June for their extra expenses. In July and August, when children are out of school and child care costs rise, they can receive up to $200 each month. Families with preschoolers who are in child care for at least 25 hours a week can get up to $200 a month year round. Families can be part of the project until their child with special needs turns 19.

Letter carrier John Adeshigbin's son, Abbey, is blind and paralyzed on the left side of his body. His brother, Lanre, has sickle cell anemia, a red blood cell disorder that can cause pain, increased infections, damage to vital parts of the body, and anemia. Abbey *(in wheelchair)* and Lanre *(left)*, are shown at a younger age. They are now 17 and 15, respectively.

Accountability

Tina and other families receive project money in three installments, to cover expenses for three periods: September to January, February to June, and July to August.

The funding for the Special Needs Project comes out of the Child Care Fund the union negotiated with Canada Post. Accountability guidelines for all Child Care Fund projects are set out in the CUPW collective agreement.

Tina gets a form at the beginning of each period to invoice the project for her best guess of how much she will have to spend. She also has to fill out a statement for the actual expenses she incurred during the previous period. In the unlikely event that there's money left over, it gets rolled over into the next period.

CUPW is keenly aware that families of children with special needs have to fill out endless forms and tell their story repeatedly during their children's lifetime, as they apply for different types of assistance and deal with doctors and other professionals. So the union has tried to strike a balance, and keep the "red tape" to a minimum. Some people still don't like the forms; but others don't mind them.

Tina doesn't find the forms a pain to fill out. There's a space for people to write about how they're doing, and these stories are sometimes included in the project's newsletter, *Member-to-Member Connection*. "I enjoy it because I write a little newsletter," says Tina, "It's my release and it relieves my tension for a few days."

Personal support

The CUPW Special Needs Project is about a lot more than funding. It's also about providing resources and personal support for parents.

"The last time Pam [the Special Needs Advisor] called, she told me about some programs at Sick Children's Hospital that I wasn't aware of, and believe me, I'm there a lot," Tina says. "This was about counseling and support because I'm dealing with my daughter and still dealing with the death of my husband. There's a group there and we can call each other.

It helps because you connect with parents who are going through similar things."

Advisors call parents three times a year. They ask after them and their families, and act as consultants to help the parents develop child care plans and plans for related services. Sometimes they have specific questions to ask that provide the union with statistics on the project's impact, and identify trends. Advisors are also a source of valuable information, helping to link parents to community resources, disability organizations, and provincial and regional government services.

Making a difference

Life is still tough for this lone mother and her two daughters. Tina doesn't have any time for herself, or any contact with friends.

But she says the project has made a difference in the family's life.

When Theresa's health care aide comes during the weekend, Tina devotes her time to older daughter Christina, who otherwise doesn't get a lot of attention.

And Tina says the project has "helped me mentally and physically, just knowing I can go to work and she's okay. It has also built my confidence and my self-esteem a little because it helps me deal with every day stress, helps me be able to focus more."

Who are the children with special needs?

For the CUPW project, "special needs" refers to disabilities, delays, or health disorders that significantly increase the difficulty of getting and keeping adequate child care and/or child care related services.

When Bryce Hart *(on Dad's shoulders)* was diagnosed with Autism Spectrum Disorder, his parents were advised to put him in full-time child care. His dad, Lorne, is a Sydney, N.S., letter carrier. His mom, Raylene *(holding new daughter Bethanny)*, writes that since three-year-old Bryce started full-time child care he "is starting to interact more... and notice the other children. ...Thank-you! With everything feeling like the world was tipping, [the project] has been a ray of hope and help!"

2

A special program for special needs

In 1996, the Canadian Union of Postal Workers sponsored a study on the workforce barriers for parents of children with special needs. This was the first research of its kind in Canada and Québec. And its findings led to another first – a unique union program, believed to be the only one in North America and perhaps the world, that provides support to union members who have children with special needs.

How did it all come about? Why did this union put such a project in place?

Ten years before work on the study began, the union and Canada Post had done a joint survey of the child care needs of postal workers, whose non-traditional shifts make finding quality child care a challenge.

The union heard from members who worked shifts and weekends whose children couldn't be in school or child care during the hours their parents worked. Significantly, it also heard from a group of members who had children with special needs.

> *...a significant number of the spouses of CUPW members who had children with disabilities were either unemployed, underemployed or worked part-time because of the demands of their child's disability or health condition.*

"They said, 'Anything that everyone else is facing applies to us – only triple it,'" says Dr. Sharon Hope Irwin, executive director of SpeciaLink: The National Centre for Child Care Inclusion. Dr. Irwin researched and wrote the CUPW special needs study, *In Our Way*[1], with Dr. Donna S. Lero, a professor at Guelph University's Department of Family Relations and Applied Nutrition.

When CUPW negotiated sole control of its Child Care Fund in 1995, the union's leaders knew they could start to make things happen for their members – especially those whose children had special needs. The union had negotiated this fund after the initial survey of all CUPW members. But until 1995, it was administered jointly by the union and the employer, and both parties had to agree to any proposed initiatives. It was tough to move ahead on anything – until full control of the fund passed to the union.

The union began by asking parents what it was like to try to hold down a job and look after a child with special needs, and what kind of support they felt they needed.

How do you cope?

"We were interested in how parents coped and the things that made it difficult to cope," says Dr. Irwin. "How working families managed to care for children with special needs while staying employed."

"The results of the study really made an impression on the union," says Denis Lemelin, CUPW's 2nd national vice-president. "It really hit us – the personal and financial sacrifices these parents were making for the children they loved so much, the stress they were under, and how hard it was for them to work."

The study found that a significant number of the spouses of CUPW members who had children with disabilities were either unemployed, underemployed or worked part-time because of the demands of their child's disability or health condition.

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[1] The full title of the study is, *In Our Way: Child Care Barriers to Full Workforce Participation Experienced by Parents of Children with Special Needs – and Potential Remedies.*

These families also had additional, and sometimes very high, expenses that other parents did not have. A major obstacle to work and a source of stress was the lack of access to appropriate, affordable licensed child care.

One of the study's 13 recommendations urged the union to set up a pilot program for CUPW parents of children with special needs.

"So we started a pilot – the 1996 Special Needs Summer Project," says CUPW Child Care Coordinator Jamie Kass. "SpeciaLink helped design it and then administered the program that grew out of it for the next six years. The project brought the costs of child care and child care related activities more in line with those of other parents."

Eighteen-year-old Jessica Kan, who has autistic tendencies, poses for the camera. Her dad, Raymond, is a postal clerk.

That summer, 105 members participated. Most used the project to pay for child care, special transportation and recreation programs that included specially trained workers.

The project's impact went far beyond easing the financial burden for the parents. Members reported lower stress levels all round – for them, their spouses, and other children in the family – and an increase in the well-being of their children with special needs. They also reported increased knowledge of programs and services, and a better ability to advocate for their children with special needs. The members said they were very proud of their union for initiating the program.

The Special Needs Project is now a year-round program. There are 440 participating CUPW families with more than 500 children with special needs. Participating members come from 78 locals and all provinces. The Special Needs Project is the union's most important use of its Child Care Fund. It is also the costliest of all the Child Care Fund projects – because it

Scarlett Plein *(left)*, and her sister, Olivia *(far right)*, have juvenile diabetes. The CUPW Special Needs Project allows the 12- and 18-year-old sisters to attend Camp Huronda, which specializes in diabetics. It's "a wonderful experience" says their mom, Kathie, a letter carrier in Kitchener, Ont.

takes more money to provide effective assistance to families who have children with disabilities.

That's just one reason the union believes it's important for Canada Post to be funding such a program. The other is that helping workers balance their work and family lives should be as much of a priority for employers and governments as it is for unions.

"It's part of our responsibility to help our members juggle work and family," says Lemelin. "We keep advocating for governments and employers to live up to their responsibilities and take the lead, but it's clear that hasn't happened yet. In the meantime, we've stepped in to do as much as we can with a limited amount of money."

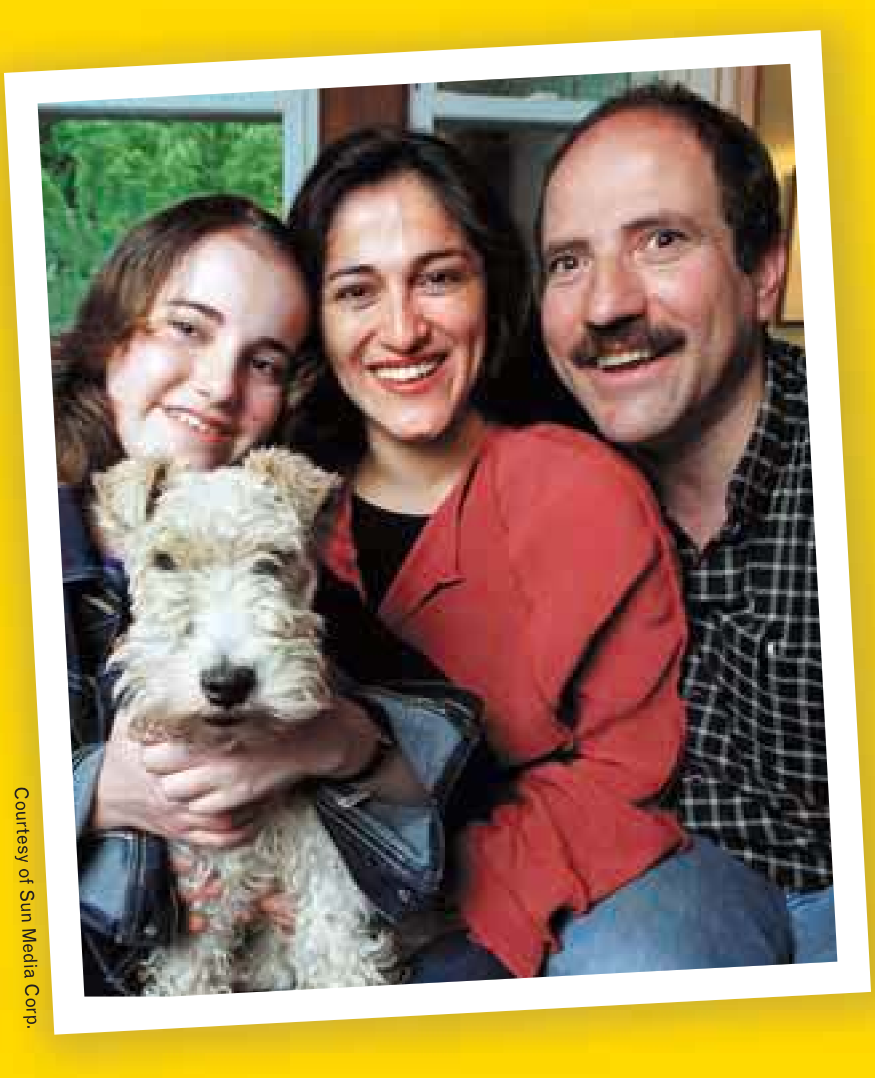
CUPW's Child Care Fund

The Special Needs Project is one of 12 projects funded by the CUPW Child Care Fund. The union negotiated the fund to help CUPW members who have the most trouble finding or affording high quality child care.

The 2000 collective agreement between CUPW and Canada Post stipulates that the employer must put $250,000 into the fund every three months. The fund is capped at $2 million.

It can be used for: projects to provide child care and related services to CUPW families, child care information programs, needs assessments and child care research.

All projects are community-based and non-profit, and accommodate children with special needs. They include child care programs for irregular working hours; supervised child care in members' homes; licensed care in the home of a caregiver; short-term emergency child care; after school and summer care or camps; child care information, referral and resources; and the Special Needs Project.



Courtesy of Sun Media Corp.

Maria-José Bouey *(left)* has had 20 major operations in her 14 years of life, including a kidney transplant. Her dad, Cristian, a Toronto mail service courier, and mom, Marcela, are among the many devoted parents of children with special needs whose lives are filled with constant stresses and challenges – and deep devotion to their children. The family is pictured here with their pet, Lola.

3

What's it like to work and have a child with special needs?

The statistics

The pressures can be brutal. Parents of the seven to 15% of children estimated to have special needs experience added physical, emotional and financial stress. They have fewer work options than others. They get more calls at work from health care professionals, and need to call home or leave work more often to meet their child's needs. And it's hard for parents to find appropriate child care for their child with special needs. That's because their children often require added or specialized care, or because providers and programs are reluctant to take a child with special needs.

CUPW's groundbreaking 1996 study of how parents of children with special needs balance work and family surveyed 151 postal worker and non-postal worker families. Here's what they said:

- 90% of parents surveyed said they were stressed about balancing work and family obligations.
- 88% said they felt tired and overloaded.
- 39% worked reduced hours.
- 26% said they had fewer job choices.
- 46% altered work schedules.
- 68% turned down overtime.
- 27% passed up promotions.
- 64% of two-parent families with one jobless parent said their child's special needs was a major factor in the unemployment.
- 48% took sick leave or vacation for child-related reasons.

The people

"I don't think you can really understand what it's like unless you go through it yourself."

Cristian Bouey

Cristian Bouey delivers mail to large corporations and offices in downtown Toronto. His 14-year-old daughter, Maria-José, has had 20 major operations in her life, including a kidney transplant. She has a rare condition that causes multiple problems in her bladder, intestine and kidneys.

"There are maybe two cases like this in the world," says Cristian. "Sometimes it's emotional and stressful and it's hard on my wife."

Wife Marcela just started working part-time in retail. "That way we're always here," says Cristian. "I work mornings until two in the afternoon. We never left her [Maria-José] alone all her life.

"The project money has helped us in many ways. Maria-José goes through lots of ostomy appliances, mattresses and bed sheets."

The family has also used the project money for respite, and to cover travel costs to doctors and hospitals.

"I am aware it is the only union in the world that is doing this and I love the help," says Cristian.

Christian Isabelle

When Mathieu Isabelle was small his mom, Johanne, stayed home to look after him. The boy often fell ill and sometimes had to go to the hospital three times a week. His Dad, Christian, a letter carrier in Ville d'Anjou, often took time off to be there for his son. Even though Christian's co-workers and supervisors were very understanding, he didn't want to rely on Special Leave (see *Special Leave is a right*) for fear they might think he was exaggerating.

Those were tough times financially for the family.

Mathieu, 15, has a neurological impairment that affects his gross and fine motor skills, a speech impairment and a mild cognitive impairment. Christian and Johanne also have a 12-year-old daughter.

As the boy grew older, Johanne found a part-time job, leaving for work when Christian got off his shift. Many parents of children with special needs work opposite shifts so that one parent can be home with the child all the time.

A CUPW activist told Christian about the Special Needs Project. "I am proud to be a member of a union that does this," he says. The family has used the funds for a modified bicycle to help with Mathieu's balance, and for child care and speech therapy.

Now that Mathieu is older, his parents are very worried about his safety. He has been harassed by other children while riding his bike, so his parents bought him a personal alarm. The alarm is intended for people to take notice, and thus scare away harassers. He also has his dad's cell phone in case he needs to call for help.

Says Christian: "With each age, it's a different stress."

The Isabelle family: letter carrier Christian *(left, standing)*, 12-year-old Vanessa, Johanne Proteau (Mom), and Mathieu, 15, on his bike. Mathieu has a neurological impairment, a speech impairment and a mild cognitive impairment. He's had to go to a special school all his life. The Special Needs Project has helped the family afford Mathieu's bicycle, speech therapy sessions and summer care.

Dalbir Baines

"I don't have lots of time with my wife," says Dalbir Baines. "It is very tiring for both of us. And our youngest ones [they have two boys aged 2 and 4] get frustrated because their sister gets a lot of attention."

Dalbir works nights sorting mail in Richmond, B.C. His wife Prabhleen works in housekeeping in a hotel. Daughter Nadeep is 6 and has autism, communication disorder and a global developmental delay. The family has used the Special Needs Project to help with specialized child care and a behaviour consultant.

"I saw a notice on the bulletin board at work and then I got the number and called. They were very good. They were really following up. The program has helped us a lot."

Mary Hunter

For Saint John coder Mary Hunter, the stress was constant.

"Kyle's always been very sick, hyper, asthmatic," Mary says of her teenaged son. "From Grade One on he always got into trouble. Sometimes I'd get two or three calls a day about him from school."

Things were so bad, says Mary, that "sometimes, it was just a blessing to go into work.

"I heard about the project from one of the girls I work with. She said to me, 'How are you making out?' I broke down – 'I don't know what to do,' I told her."

The family uses the project for tutors and medicine. Kyle's situation has improved dramatically in the past few months, mainly because of better medication dosages, as well as the tutors.

"The tutoring is unbelievable. The tutors get to know Kyle and work with him. They're helping me with times around my shifts, and he's getting more social, more friends. He has got so much self-esteem and motivation… We booked a trip today. Before, we could never take Kyle anywhere."

Letter carrier René LePage and Louise Gélinas, from Orléans, Ont., have two boys: Eric, 5 *(right)*, and Daniel, 6. The CUPW Special Needs Project has helped the family deal with the financial stress of having a child with disabilities. Eric has cerebral palsy, asthma and allergies.

René LePage

When Eric LePage was 13 months old, he came down with a very high fever and a rash. Doctors thought it was just roseola. But after it subsided, "he was a completely different child," says his mom, Louise Gélinas. "He had no muscle tone, his legs were bowed, he couldn't flex his feet, had difficulty with balance, trouble with pronunciation and stuttered a lot."

After extensive testing, Eric was diagnosed with cerebral palsy. The five-year-old is also asthmatic and has allergies. His Brother Daniel, 6, also has severe allergies and problems with his speech. Their dad, René, is a letter carrier in Ottawa.

Eric's diagnosis changed the family's life in many ways – from having to juggle shifts in time for school drop-off and pick-up to the constant battle of getting the appropriate health care and school support. "He's covered all day now [in school]," says Louise, "but I really had to fight for that."

Louise is an indeterminate employee with the federal government. She took five years unpaid care and nurturing leave (a provision in the Public Service Alliance of Canada collective agreement) to look after her children. She went back to work for seven months, then took leave again during the summer for Eric. When she returns to work, she will need a position that is not deadline-dependent and can sustain absences in case of child-related emergencies. Since René's depot is far from their home and he starts work at 6:30 a.m., she'll also need a shift that begins no earlier than 9:30 a.m. and ends at 2:30 p.m.

The Orléans, Ont., family joined the CUPW Special Needs Project three years ago and have used the funds to help pay for special treatments and equipment for Eric's cerebral palsy, and natural products for his allergies. Daniel will also become part of the project soon.

Having a child with a major special need has taken its toll – emotionally as well as financially.

"It's hard," says Louise. "Sometimes, I'm at the end of my rope. I'm tired. When René is playing with the boys, I'm sewing, I'm adapting Eric's clothes. All that time is time spent away from my family."

Louise and René's hearts often ache for their child. "I look at other children and think about how many things my boy has missed," says Louise. "But he's a happy child – always with a smile on his face."

René, Louise and her parents have put a lot of effort into building and modifying the devices that help him exercise his legs and walk. They've built stairs with modified risers, put larger wheels on a walker to enable it to go through rough grass, fitted cross-country skis to another walker, and adjusted Eric's braces so they wouldn't pinch and would lock when they were supposed to. They've even created an ingenious device that gently forces Eric's legs to bend and not swing out when he's walking. They hope to patent the design.

"We're always thinking of how we can help him," says Louise. "Always thinking: 'What else can we do?'"

Special Leave is a right

For some CUPW parents, getting permission to take Special Leave takes "a letter from God," as one member put it. But it shouldn't have to be that way. Special Leave is a negotiated right enabling postal workers to leave work in situations "due to circumstances beyond their control."

Parents of children with special needs use this leave more often because of their children's additional needs. But they feel frustrated at the arbitrary way supervisors grant or withhold leave requests. So sometimes they use unpaid leave (36%), sick leave (40%), or vacation (46%), when they're refused or feel they can't get Special Leave. This means added financial pressures, and reduced time for recuperation and rest for a group of workers already stretched to the limit. It's another example of how parents have to scramble to find solutions when they can't access badly needed supports.

Cristian Bouey was refused full paid leave when his wife was donating a kidney for his daughter Theresa. "They said, 'if you take two weeks, one week should be on you.'"

The union told Cristian to take as much time as he needed and not worry – it would be taken care of.

"When I went back the supervisor said they'd changed their minds," he says. "I could have it all on Special Leave. They tried to take the credit, but I know I have an angel somewhere else."

In an effort to deal with Special Leave problems, the union has intensified its training of shop stewards around the intent of the clause and relevant arbitration cases, as well as provided more information to members and activists about the rights of CUPW members under the Special Leave clause.

There are only three known cases in Atlantic Canada of the syndrome (Smith-Lemli-Opitz) that affects Julie Richard's physical and mental functioning. Here she is shown with her parents, Lynn *(standing left)*, a Union of Postal Communications Employees member in Fredericton, N.B.; and Hervé.

4

Another union signs on

"This is a very special support for working families, and we're proud that we can offer it to our members," says Union of Postal and Communications Employees (UPCE) President, Luc Guèvremont. The members of UPCE, a component of the Public Service Alliance of Canada (PSAC), gained access to the CUPW Child Care Fund and Special Needs Project in 2000.

> " I found out about the Special Needs Project from my union president, who knew I had a child with a disability. I think the project is great. I was one of the first UPCE-PSAC members to get in and I've been able to help new employees get in to also use the program."
>
> – Lynn Richard, UPCE-PSAC, New Brunswick
> (She uses the Special Needs Project funding for child care, respite and an afterschool program for her daughter, Julie, whose body is unable to metabolize cholesterol.)

When PSAC negotiated a child care fund with Canada Post, the union approached CUPW to see about working together. The postal workers' union welcomed the chance to join forces so that more working class families and their children could obtain quality care, and was particularly keen on making the Special Needs Project accessible to UPCE-PSAC members.

UPCE-PSAC represents close to 3,000 members nationally, working in clerical, administrative and professional jobs. Initially, the union negotiated a one-time payment of $200,000 to a child care fund, and additional monies equal to 10% of the quarterly funding received by CUPW each year. CUPW coordinates and administers the Child Care Fund.

Aware of barriers

"The Special Needs Project has made us much more aware of the barriers to work for parents of children who have extra needs," says Guèvremont. "And with all the cutbacks to vital services, it's even harder for parents."

Guèvremont says his union's collective agreement has a clause that provides paid leave for family-related responsibilities. "But even with that, we find that parents of children with special needs still have trouble getting time off to go to all their children's specialist appointments."

> *" The funds allow our son to access programs he wouldn't receive otherwise, since our family is living on one income now. As a result, his developmental and social skills are improving."*
>
> – Survey response by UPCE-PSAC member

He says his union is particularly pleased with the way CUPW conceived and shaped the Special Needs Project. "It's innovative and tries to look at the families individually, so that they can get assistance for the type of child care, programs and other supports that will really help their situation. I hope that other PSAC locals and other unions will look at how they might negotiate such an important support for their members."

Eric Mittelstadt's dad, Ken, works as a purchasing officer in Ottawa and is a member of the Union of Postal and Communications Employees. The union's child care fund is administered by CUPW, thereby giving UPCE-PSAC members access to the Special Needs Project. Eric has Attention Deficit Hyperactivity Disorder/Asperger's Syndrome.

Montréal letter carrier, Claude Gareau, and wife, Jocelyne Brais, with their daughters, Marie-Christine *(left)*, Sophie-Anne and Valérie Annabèle *(on Dad's lap)*. Valérie Annabèle, 6, has epilepsy. Her parents wanted to include her in soccer, a sport her sisters play. So Mom and Dad set up a special program in conjunction with the Pointe-Claire Soccer Association. The program offered children with mild co-ordination and psycho-motor problems, and/or developmental delays a chance to play non-competitive soccer once a week.

5

"It's just awesome!"

Has the Special Needs Project made a difference in the lives of the CUPW and UPCE-PSAC parents who use it? Yes, say an overwhelming majority of participants.

Here are some results from a recent annual evaluation:

Increased well-being

- 89% of parents say the project has made a difference to their stress around child care and related issues for their child with special needs.
- 99% say it's helped reduce financial stress.
- 93% report lower overall family stress.
- 86% say it's made a difference to their overall health and well-being.
- 75% report their spouses have less stress, and better health and well-being.
- 79% say it's made a difference to quality time with the family.
- 81% feel it has improved their morale and effectiveness at work.

> *86% say it's made a difference to their overall health and well-being.*

What they say

" Knowing the benefit the funds have had for my son has helped me as much as it's helped him."

" When you lower the stress of raising a special needs child you reduce the family stress and increase the family well-being."

" Financial help means less stress. Don't know what we'd do without it."

" We have more energy and time for our other child."

" We have more time together [as a couple]."

" Overall this helps to reduce stress. This is a real nice touch that the union didn't have to do but has."

" For CUPW to do this is just awesome!"

Sudbury, Ont., postal clerk Albert Jedrzejek and his wife, Susan, have three children: Sarah, 13, Natasha, 10, and Darnell, 7. Two of the children are part of the Special Needs Project. Sarah has a mild intellectual delay and Natasha has a speech and language delay.

The child's experience

The services and supports parents have paid for with their project funds have had a significant impact on their children's lives.

- 80% of parents report a positive change in their child's language or academic skills.
- 83% say their child's social skills and friendships have improved.
- 90% have seen a change for the better in their child's self-esteem and happiness.
- 79% say their child's physical and recreational skills have improved.
- 82% report their children are more independent and mature.
- 73% say the project has made a difference in their ability to access therapy, services or appropriate equipment for their children.

What they say

"We're so proud of him! He's quite independent now."

"We see a difference in his language skills and he is not as shy as he was. It's so good for him."

"She has a lot more confidence and much greater body strength… now her balance is much better."

"The funds allow our son to receive more therapy than school is able to provide and to maintain his skills over the summer with additional therapies."

*"We see a difference in his language skills
and he is not as shy as he was.
It's so good for him."*

Better advocacy skills

A parent of a child with special needs has to advocate constantly for services and supports. "The parents tend to have to speak more and fight more," says CUPW's Denis Lemelin. "They see how their child's needs just fall through the cracks when there are cutbacks. And they also feel there is silence on their issues."

- 79% say the project has helped them become better able to advocate for services for their children.
- 81% say it has helped them access additional supports for their child.
- 81% say it has helped them raise awareness about special needs issues in school, child care and recreation programs.
- 95% say they are now better able to inform fellow union members about special needs issues.
- 75% have connected with other parents of children with special needs.

What they say

" *I'm fighting all the time for services in schools because of government cutbacks. The government is hindering us in supporting our children.*"

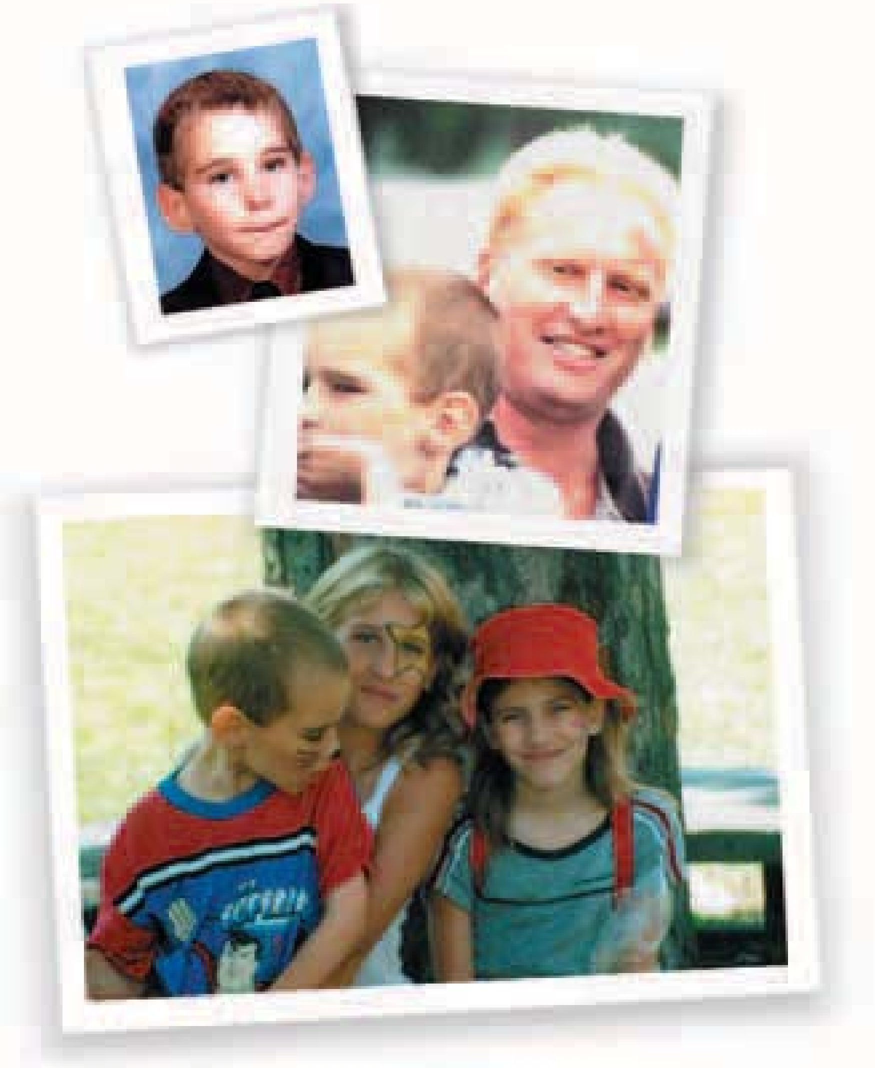
From an advisor:

" *The funding 'sparked' interest in parks and recreation people in Nanaimo. [The parent] was able to start an inclusionary swim program. The money from CUPW was the catalyst.* "

" *A co-worker and I set up a web-site all about autism.* "

" *I formed a support group, which has been very helpful.* "

" *Since I have been with the Special Needs Project I have spoken to other parents at work who have special needs kids with the same issues.*"



CUPW Special Needs Project funds help Jordan Sixsmith's family afford speech therapy and recreation programs like summer camp. Jordan, 9, has cerebral palsy and epilepsy. He is shown *(centre photo)* with his dad, Robert Sixsmith, a letter carrier in Peterborough, Ont., who says he appreciates the Special Needs Program CUPW initiated. Mom, Carol, writes that it has helped the family "live a more normal life, give more attention to [Jordan's] two sisters and reduce stress overall."

(Left:) Elizabeth Holmes, 15, during a specialized therapeutic horseback riding lesson. Elizabeth is blind and developmentally delayed. Brother Jonathan, 17, has Attention Deficit Hyperactivity Disorder (ADHD). The Special Needs Project has helped the family afford important supports for the two children. Elizabeth's mom, Gwen, is president of the Cobourg, Ont., CUPW local and works as a mail sorter. She became an activist because of the union's Special Needs Project and Child Care Fund initiatives.

(Right:) Elizabeth Holmes at her confirmation with her dad, Thomas, and mom, Gwen.

6

Seeing the union through different eyes

Mail sorter Gwen Holmes always thought unions were "just about wages and job protection." The mother of two children with special needs "didn't think of child care as a union-related issue before. I wasn't aware that the union had a totally different side to it."

Holmes was so impressed when she learned her union had negotiated the Child Care Fund and started the Special Needs Project that she became a union activist. She's now president of her CUPW local in Cobourg, and active in the union regionally and nationally.

"It was gratitude," she says about why she got so involved. Gwen and her partner, Thomas, have a 15-year-old daughter, Elizabeth, who is blind and developmentally delayed. Their son Jonathan, 17, has Attention Deficit Hyperactivity Disorder (ADHD). The couple have used the Special Needs Project to help defray the costs of extra expenses for both children for support workers, tutors, specialized summer camps and lessons, and medicine not covered by the benefit plan.

"The biggest benefit of the program is that it has given us the opportunity to do all of these things for Elizabeth. I also became aware of the things that were available to her," she says. "We couldn't do all of these things financially. This has made it easier and given her opportunities regular kids have. There are things that Elizabeth can't do otherwise."

Such as attend a summer drama, music and art camp. To participate in the camp, Elizabeth had to be accompanied by a support worker. Another worker brailled *Where the Wild Things Are*, enabling the girl to narrate the piece while others did the acting.

Union pride

"I talk to parents who are non-union and I brag about our union," says Gwen. "I talk the program up all the time."

Gwen feels she's received a lot back from the energy she's put out for the union.

"I took a lot of union education courses [the Child Care Fund course was one of the first] and became more active," she says. "The union education helped me to be an advocate for my children and an activist.

"I also have better self-esteem now. Even though you love your child, you go through guilty, low self-esteem moments when you have a child who is different. It takes a burden on your spirit. So the union involvement has helped me grow as a person."

Most parents of children with special needs are just as surprised as Gwen was when they learn that the project is union-conceived and union-driven. And 89% say it's enhanced their esteem for the union.

"I was shocked that the union was doing this," says Saint John coder Mary Hunter. "I thought nobody was going to help me."

"I was very impressed and my family was too," says Toronto mail service courier Cristian Bouey. "We find it amazing and touching in our hearts that somebody had the feeling to understand that we deal with a stressful situation."

A needed support

The union views the project as a way to support working parents who are under incredible pressures. Their usual sources for help – governments, schools, community agencies – often prove to be dead ends because of service cutbacks, impossible bureaucracies or a lack of political will.

"The union's goal is to secure the social and economic well-being of the members," says CUPW's Lemelin. "We want CUPW parents to be able to work with peace of mind so they can stay in the workforce. This is an important family support and the right thing to do to express solidarity with our members whose family situations are really challenging."

Gwen Holmes says it isn't easy to work, be a mother to two children with special needs, and a union activist. "You are working tired and living tired," she once told a reporter for the *Toronto Star*.

Gwen is often met with union problems the moment she steps into work, and can find herself dealing with union issues well into the evening. But ultimately, she says, "I juggle all of it because you have to keep fighting and I have to keep advocating for Elizabeth."

The Chew family: Matthew, 13, Jennifer, 9, their dad, Dean, and mom, Yvonne, a letter carrier from Perth, Ont. Matthew has Attention Deficit Hyperactivity Disorder.

Claude Desjardins, a letter carrier from Gatineau, Qué., with his son, Sébastien, 9 *(left)*, and daughter, Stéphanie. The treatment for Sébastien's cancerous brain tumour has left him physically and mentally challenged. Special Needs Project funds have helped the family defray the costs of specialized courses and orthotic devices for the boy.

7

Looking for co-worker support

One of the most important things the union learned from its research was that parents of children with special needs wanted support and understanding from their co-workers. They wanted the union to do more to make their co-workers aware of the challenges they face. Members also said there was a need for supervisor education: an understanding supervisor could make a significant difference in the life of a worker with a child with special needs.

CUPW's strategy has been to integrate issues for families of children with disabilities into all of its work on child care.

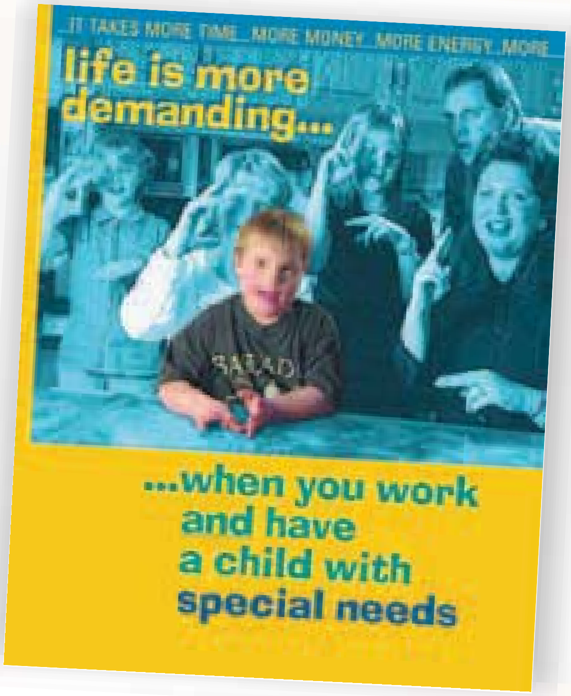
- The union's two Child Care Fund videos, *Juggling With Care* and *The Key to Caring*, include segments about families who have children with special needs. The videos' discussion and resource guides feature sections describing the results of the study and the Special Needs Project. They also go into more detail about the stresses, as well as the workplace problems of a parent with a child with special needs. As CUPW letter carrier Alain Aumond puts it in *Juggling With Care:* "When you have a child with a handicap, it's the entire family that is handicapped. All your life, all the stress, the stress at work, the stress at home…"

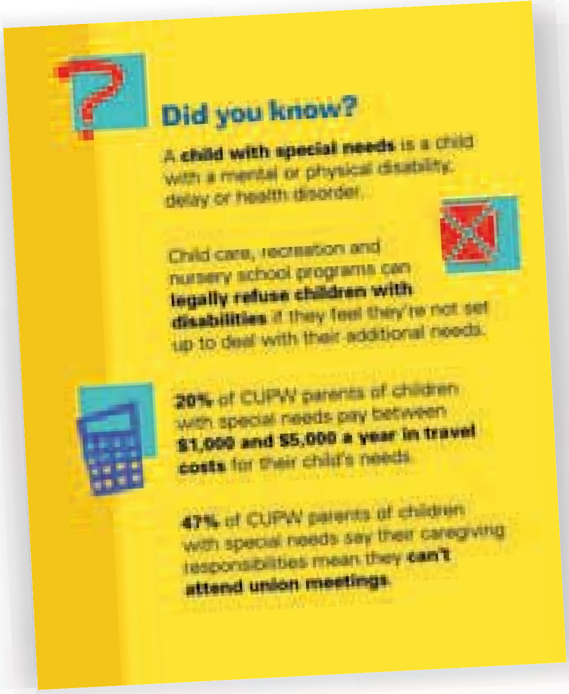
> *" When you have a child with a handicap, it's the entire family that is handicapped. All your life, all the stress, the stress at work, the stress at home... "*

> *" All of these initiatives have helped to raise awareness and understanding among the general membership," says Jamie Kass, CUPW's Child Care Coordinator. "And our members are very interested. We had a huge demand for the quiz and great feedback. But education is a long, ongoing process, so there's definitely still lots more to be done."*

- Special needs issues also figure prominently in the union's five-day residential course on child care, *Child Care Now!* Members who've attended the educational say they've come away with a new level of understanding about the challenges their co-workers have to deal with. Participants consistently report that they've been deeply affected by the special needs component of the educational. The union also offers a three-day regional course on child care.
- In 2000, the union prepared a package of educational material for its locals to use on the shop floor. The package included a quiz on why the life of parents of children with special needs is more demanding, as well as a poster for union bulletin boards.

"All of these initiatives have helped to raise awareness and understanding among the general membership," says Jamie Kass, CUPW's Child Care Coordinator. "And our members are very interested. We had a huge demand for the quiz and great feedback. But education is a long, ongoing process, so there's definitely still lots more to be done."





Did you know?

A **child with special needs** is a child with a mental or physical disability, delay or health disorder.

Child care, recreation and nursery school programs can **legally refuse children with disabilities** if they feel they're not set up to deal with their additional needs.

20% of CUPW parents of children with special needs pay between **$1,000 and $5,000 a year in travel costs** for their child's needs.

47% of CUPW parents of children with special needs say their caregiving responsibilities mean they **can't attend union meetings**.

CUPW put together a package of educational materials to help union members gain an understanding of what it's like to have a child with special needs.

Bernadette MacLellan *(left)*, from Sydney, N.S., has "grown up" with the CUPW families she calls three times a year to find out how they're doing, and to help them identify additional resources and information. She has been a Special Needs Advisor since CUPW started the project in 1996.

Marie-France Haineault *(right)*, from Montréal, has been a Special Needs Advisor for six years. She says she becomes attached to the families she contacts. "You want to know what's going on with them... Sometimes I have an image of the person even though I've never seen them, never met them in person."

8

Making a contribution

Job title: Special Needs Advisor

Description: Conducting telephone interviews and identifying additional services and resources for participants in a union program for families with children with disabilities.

Qualifications: Must be a caring, empathetic person, with experience in the health and social services field. Experience with children with special needs is an asset.

Bernadette MacLellan has all of these qualifications and more. The Sydney mother of three has been a Special Needs Advisor since the project began in 1996, when she was working with SpeciaLink: The National Centre for Child Care Inclusion.

She's one of 40 people across Canada and Québec who call CUPW's Special Needs Project participants three times a year, to assist them in filling out their forms, ask how they're doing and advise on available resources.

She's one of 40 people across Canada and Québec who call CUPW's Special Needs Project participants three times a year, to assist them in filling out their forms, ask how they're doing and advise on available resources.

"I have families all over the country," she says. "I've grown up with them and I feel close to most of them. I always look forward to the interviews and want to know how the last few months went. How did that camp go? How did starting junior high go?"

Advisors are assigned up to 20 families each. They do an initial, in-depth interview with new qualifying families. They ask about the child's special needs, the ages of all children in the family, child care arrangements, the impact of having a child with special needs and the family's coping mechanisms. They help families identify the best use of the funds according to their needs, taking into account other accessible sources of support and funding.

In subsequent calls, they ask how parents used their project funds, and how they intend to use the money for the next period. Sometimes parents need help with the next steps. The advisor tries to provide assistance, suggestions and information about available resources.

There are also pre-determined questions (responses are kept anonymous), to help identify trends in the CUPW families using the project as a group. Members who have children with special needs are like the "canary in the mine" because they often experience program and service changes like health care and education cuts earlier and more intensely than others. Their experiences also provide

Erin Kenny, 7, has cerebral palsy, a medical condition that affects control of the muscles. She lives in Mount Pearl, Nfld. Her dad, Wayne, is a letter carrier.

an important research base for understanding the challenges of parenting a child with special needs.

But equally important, the calls are about providing personal support.

Not just a job

"For some of the more isolated parents, we're the only support," says Toronto advisor Suzanne Chen. "We ask about them, we ask questions about their kids. It's not just, 'How did you spend the money? Okay, I'll talk to you next session.' You think about these kids even when you're not doing the interview. If I know that someone is going for an operation, I'll try to find out how they're doing."

Advisors make their calls during a two-week period. Each call can take between 20 minutes to an hour.

Sometimes, arranging calls can be a challenge. Parents work different shifts and when they're home are often busy looking after their child with special needs.

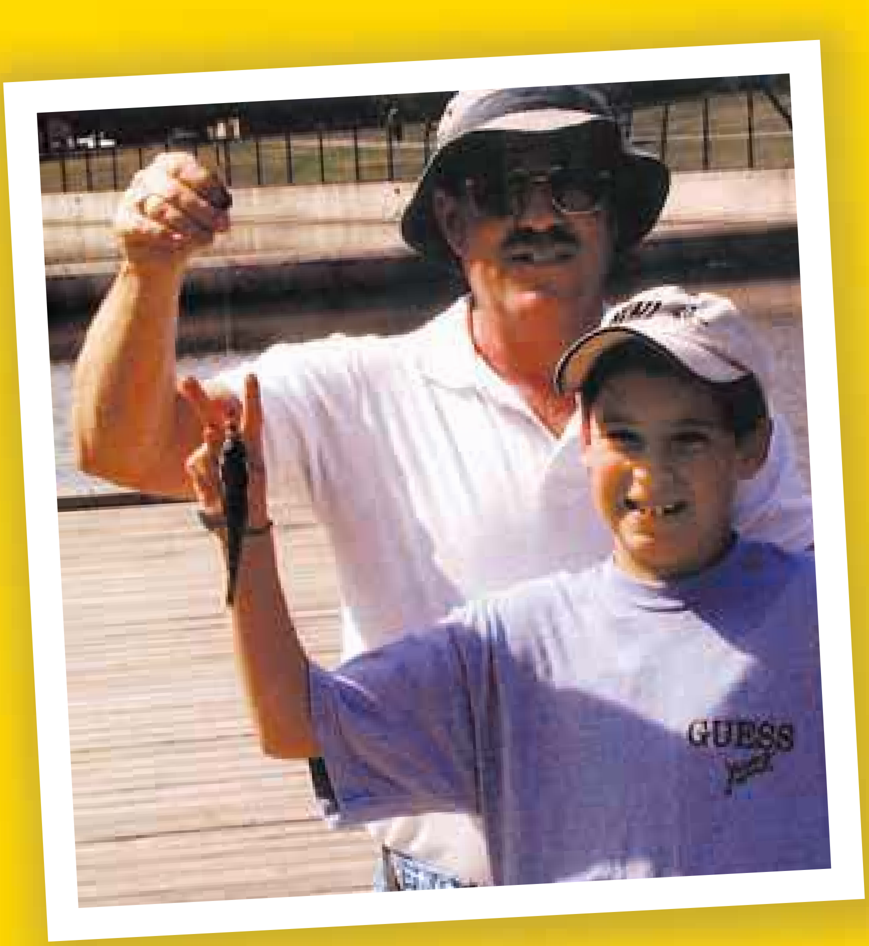
Montréal advisor Marie-France Haineault has a family with two parents who are hearing impaired.

"I am always trying to find a way to do it better," she says. "Sometimes I ask to have an interpreter and we meet. Otherwise, it's over Relais Bell [TTY/TDD], where I'm talking to a person who writes things down and it shows on the phone at the other end. Now, I usually send them the questionnaire by mail and when they have the questions in front of them they can read it at the same time."

Advisors usually hear about the job from other advisors. Before they're accepted, they are interviewed by Special Needs Project Coordinator Gail Holdner, who becomes their project contact person.

"They are incredibly knowledgeable and compassionate," she says. "You can tell they've made a heart-to-heart connection with the members."

Says Marie-France Haineault: "You get attached to the families… Sometimes I find a resource for them and I feel great. My children don't have special needs and I find I'm really lucky. I hope I can do a little bit for these families."



Stephen LaRose has congenital heart disease. He has had two open heart surgeries and will need another one when doctors determine the time is right. His dad, Bill, is a mail service courier. Bill wrote in the Special Needs Project newsletter, *Member-to-Member Connection*: "No one, except those in our situation, will ever really know the daily stress you feel and deal with. The family pulls together and stays strong, the love is much deeper as you know what you could have lost, and life is more precious than ever. We feel blessed to have our son. Even though he has been through so much, he is a very loving and caring person. I guess being through what he has also blessed us to have a healthy daughter, now 6 years old."

9

A strong connection

Johanne Proteau always looks forward to getting *Member-to-Member Connection,* the quarterly newsletter of the Special Needs Project.

"It gives us a feeling of belonging to know that others are experiencing the same things we are," she says. Johanne's partner is a CUPW member. One of the couple's two children has special needs.

The newsletter is one of a number of ongoing supports provided to parents participating in the project. Other supports include the regular calls from advisors, as well as educational and resource materials.

The newsletter is a favourite with participating parents – almost all of them say they read it. It's chock full of information and useful articles – from listings of support and disability groups, and advocacy tips, to how to deal with people who stare at your child or to avoid caregiver burnout.

Letters... we get letters...

Its most popular features are the letters section and the "want ads." Members' letters are usually about how their children are making out and what the project has meant to them. The letters are often very touching.

"Our son Myles is 7 years old," writes Myrna from B.C. *"It's been 4 years I've been waiting for him to talk or even just say yes or no. Finally he did say it. He knows a few words, but cannot talk in sentences… We're so happy to see him saying these words, so to parents, there is always hope for our kids. We thank CUPW and SpeciaLink for the support they have given us."*

The "want ads" are used for requests or offers of specific help. Many times, parents want to get in touch with others whose children have the same special needs, or seek sources of modified equipment and devices to help their children. Sometimes, they or their children will write looking for pen pals.

"My daughter Katelyn is eleven and a half years old," writes one girl's mother from Saskatchewan. *"She has a small stature syndrome and dislocated hips that have not responded to treatment with severe surgeries. She has ADD and is on Ritalin therapy. Katelyn's hips are breaking down and she has to go part time in a wheelchair. She has a wonderful personality and takes things in stride… Katelyn would love to hear from others. She loves to write."*

Says one participating parent: *"My knowledge has really increased through the written material provided by the project. And I really like the newsletter. It's nice to read about other people's experiences and the information provided."*

CUPW/UPCE Special Needs Project

Member-to-Member

CONNECTION

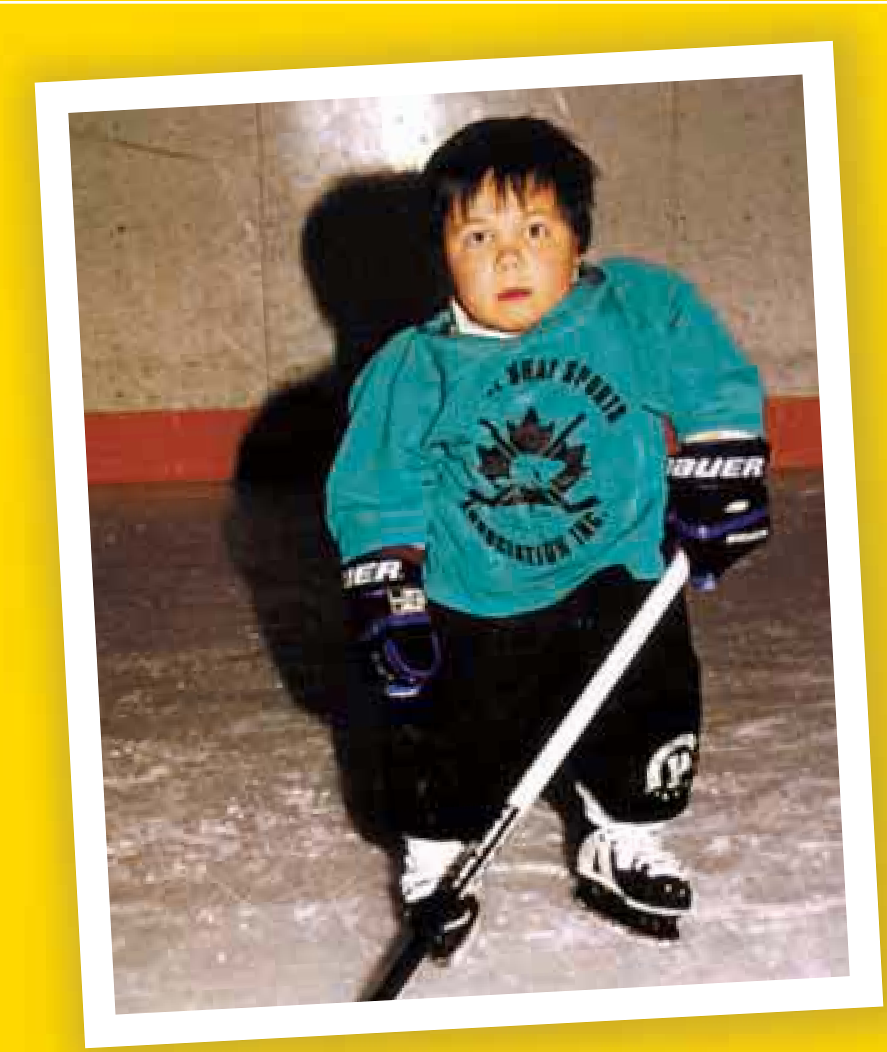
DEALING WITH THOSE STARES

What to do when those questions and stares come your way

The quarterly newsletter of the Special Needs Project is popular with parents. It's one of a number of supports the project provides.

"My brother's autism helped me learn many things," Mark Precilla wrote in the Special Needs Project newsletter, *Member-to-Member Connection*. "Now that I'm older I understand that, even though my brother has a disability, I should always treat him normally, just like any other kid... Through all of these years, I have realized that I really love my brother." Mark's brother, Myles, 10, is pictured with his family *(left)* at age 5. He is held by his mom, Myrna, a postal clerk from Surrey, B.C. Brother Mark is to her left, and his sister, Jennifer, and dad, Jaime, are standing.

(Right:) Myles Precilla at nine years of age.



Collin Halfday, 11, playing hockey. Collin was diagnosed with dwarfism early in life. His mom Judy, a retail clerk, wrote in the Special Needs Project newsletter, *Member-to-Member Connection*, that he will grow into major back problems that could eventually paralyze him. Other areas of concern include hydrocephalus (an abnormal amount of fluid in the brain), swallowing difficulties and limited strength and dexterity. "When you have a child with special needs," wrote Judy, "support is a vital component for both the child and the parent."

10

Head office: Baddeck, Nova Scotia

CUPW originally contracted with Cape Breton's SpeciaLink: The National Centre for Child Care Inclusion, for the day-to-day operation of the Special Needs Project. Executive Director Dr. Sharon Hope Irwin was one of two principal authors of the union's study of working parents of children with special needs. When she decided to put more of her energies into research and development, she helped the union find a new home for the project.

Today, it is administered for the union by Family Place Resource Centre in Sydney, N.S. Family Place is a federally funded, non-profit organization that runs a Community Action Program for children and a Canada Prenatal Nutrition Program in Cape Breton. A coordinator and an office assistant work on the Special Needs Project in an office in Baddeck, about 100 kilometres away.

Karen Morton's son, Calvin Boyd, 8, has a rare and serious genetic condition called Cri-du-chat Syndrome. The condition usually requires ongoing therapeutic, medical and educational support. Karen is a letter carrier in Fort St. John, B.C.

"Kids should have equal access [to services and supports] no matter where they live," says Family Place Executive Director JoAnna LaTulippe Rochon. "Family Place is not any less concerned with kids everywhere else in the country. We always take a broader look."

That's why the Special Needs Project was such a good fit for Family Place, says LaTulippe Rochon, and why its board jumped at the chance to be part of it.

"The CUPW project ties in really well because it is national in scope and we feel more concrete about some of the things it can do and we can do to support families with children with special needs across Canada."

And there's another bonus: "What triples my excitement is that the head office of this project is in Baddeck. It's the only national program coming out of a little community like Baddeck. We are the location of a national program that is unique and we hope we'll be able to celebrate its expansion to other unions."

CUPW Child Care Coordinator Jamie Kass says the union is committed to working with communities. That is a feature of all the projects that are under the Child Care Fund. "We don't want to directly administer everything, and we don't want everything to be centralized at our national office. Community involvement is where it's at for us."

> *"The CUPW project ties in really well because it is national in scope and we feel more concrete about some of the things it can do and we can do to support families with children with special needs across Canada."*

Lisa Poulin *(kneeling)*, at summer camp with friends. She wrote to the Special Needs Project Newsletter, *Member-to-Member Connection*: "My name is Lisa Poulin. I'm 15, turning 16 in November on the 6th... I have diabetes, asthma, arthritis and cystic fibrosis. I'm also in Grade 11, [and] doing excellently and getting great marks... I thought it was great/awesome of you guys [CUPW] to pitch in so I could go to camp. I had a lot of fun, though I wish I could go next year but I'll be too old so instead I'm going to go as a CIT [Counsellor in Training]." Lisa's mom, Mona Poulin, is a postal clerk in Calgary.

The services and supports needed for children with autism, like Aaron Etherington, have always been in short supply. Government cuts to social programs, such as education, have made the situation worse. Aaron's parents, Stephanie and Steve, a letter carrier, are fighting to get appropriate help for their 14-year-old son as he begins high school.

II

The big picture

It's estimated that seven to 15% of children have disabilities, delays or health disorders – such as autism, diabetes, Attention Deficit Hyperactivity Disorder, cerebral palsy, genetic disorders, brain injuries, profound developmental delay and learning disabilities.

While CUPW and UPCE-PSAC parents of children with special needs have access to a program that provides some support, the vast majority of parents in similar circumstances don't have a workplace project they can look to for assistance.

"We believe that government should provide the policies and funding for high quality child care for all children, and innovative programs to help those who have extra needs," says CUPW's Denis Lemelin. "We also believe employers should do their part to help parents with work and family."

" We believe that government should provide the policies and funding for high quality child care for all children, and innovative programs to help those who have extra needs," says CUPW's Denis Lemelin. "We also believe employers should do their part to help parents with work and family."

Lemelin says that governments and employers like to "talk the talk. But our union's child care projects show them how to walk the talk."

The Special Needs Project and other CUPW Child Care Fund initiatives have made a difference to the way the union sees its members. Says CUPW Child Care Coordinator Jamie Kass: "It's broadened our view. Our members can't just park their family lives at the door before they step into work."

Levelling the field

"Many families don't have access to support and programs like [the Special Needs Project] to give them a fair chance," says JoAnna LaTulippe Rochon of Family Place, the organization administering the union's program. "The project provides some equity, a way of levelling the playing field."

Seven-year-old Andrea Rabaza has Bardet-Biedl Syndrome, a complex disorder involving many parts of the body. Her dad, Victor, is a letter carrier.

It also provides ammunition and scope for advocates, she says.

"The usual response… is that government can't do it alone. Well, this project ups the ante. It's a wonderful opportunity to say, 'What can government do to add to what the union is doing? Where is the government's responsibility?' "

A model

The project has already had an impact by serving as a model and base for reliable information about the requirements of families with children with special needs. The research has been used worldwide, and information on the project has appeared in several publications in Canada and the U.S. Researchers, other labour unions, advocacy organizations, policy makers and the Maternal and Child Health Branch of the U.S. Department of Human Services have all expressed interest.

The findings from the special needs study were also used in an influential advocacy "report card" to the United Nations to show that Canada was not fulfilling its obligations to children with disabilities under the *UN Convention on the Rights of the Child*.

The experience of parents in the project also continues to point the way to trends and emerging issues that affect everyone. This is because CUPW members whose children have

" The usual response… is that government can't do it alone. Well, this project ups the ante. It's a wonderful opportunity to say, 'What can government do to add to what the union is doing? Where is the government's responsibility?' "

special needs often use health and social services more frequently and for longer periods of time, and experience changes to services sooner than the general population.

Government services and funding have always been inadequate for children with special needs. Cuts have made things worse, with 26% of parents in the project saying they've had to spend more money and time getting what they need for their children. In one province, parents reported teacher aides have been cut; in another, speech therapy for children over three. The list goes on.

One Ontario parent told the union he's been unable to get appropriate support for his autistic son in high school. He says he feels his only option is to withdraw his teenager from school – and take the school board to court.

Older children

The demands of looking after an older child is another emerging issue. After they reach 19, children are no longer eligible to participate in the Special Needs Project. Most of them are also no longer in school.

"People are angry, and rightly so, about the help they can't get in schools now," says SpeciaLink's Dr. Sharon Hope Irwin. "But just wait until the child is 21. It's shocking to see how few services and programs are available to adults with disabilities.

"We're now hearing more about members living with relatives who need care – adult children with life dependency

It's not likely that the union will give up fighting for the rights of children with special needs until they and their families are guaranteed the dignity, quality of life and economic security they deserve.

issues, and spouses and parents needing home care and elder care. The time is right for another project addressing needs around an ill parent, spouse or dependent adult child."

"I have four years until the money runs out for Elizabeth," says Cobourg local union president Gwen Holmes, whose daughter is blind and developmentally delayed. "What then? Elizabeth is not independent. She always has to have someone with her."

If CUPW has anything to say about it, she always will. The union supports the idea of universal, high quality child care services and other social services as responsibilities of government. It believes one of its roles is to advocate for social change. "The struggle continues" is CUPW's motto. It's not likely that the union will give up fighting for the rights of children with special needs until they and their families are guaranteed the dignity, quality of life and economic security they deserve.

Chris McCarthy, 16, has a developmental disability.
His mom, Bonnie, is a letter carrier.

Fourteen-year-old Anna Suschkov has been part of the Special Needs Project since it began in 1996. Mom Dorothy Miller is a letter carrier in London, Ont. Anna has Attention Deficit Hyperactivity Disorder, gross and fine motor difficulties and learning disabilities.

Contact us

For more information about the CUPW Special Needs Project and the union's Child Care Fund contact:
CUPW Child Care Coordinator,
377 Bank Street, Ottawa, Ontario, K2P 1Y3
(613) 236-7238

To contact the Special Needs Project dial:
1-800-840-LINK *(English)*; 1-888-433-2885 *(French)*
E-mail: cupw-upcespecialneeds@ns.sympatico.ca *(English)*;
sttp-sepcprojetenfants@ns.sympatico.ca *(French)*

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THE CANADIAN UNION OF POSTAL WORKERS'
Special Needs Project

Moving Mountains

Work, Family and Children with Special Needs

In 1996, the Canadian Union of Postal Workers put in place a summer pilot project to support its members who had children with special needs. Today, the Special Needs Project is a year-round program. It is considered a model for ways to reduce the financial, emotional and physical stresses on working parents of children with disabilities. *Moving Mountains* takes an in-depth look at the project and pays tribute to a group of very special, courageous families.

> *" [The project] has helped me mentally and physically, just knowing I can go to work and my daughter's okay... It helps me deal with every day stress, helps me be able to focus more. I think what the union is doing is really good."*
>
> – Tina Klinoski, Toronto mail sorter

THE CANADIAN UNION OF POSTAL WORKERS'
Special Needs Project