CUPW/UPCE-PSAC SPECIAL NEEDS PROJECT

Member–to–Member CONNECTION

Number 11 • SUMMER 2005

Dear Sisters and Brothers,

This summer marks the 10th year of the Special Needs Project. Starting as a summer project with 105 members in 1996, we've grown to a year-round project with over 533 members with 612 children with special needs. From one coordinator and less than five special needs advisors, we've now gone to two full-time and two part-time staff and 43 advisors across the country.

We have accomplished a lot together. Member-to-Member Connection—the project newsletter with your stories, ideas, requests and letters—is now sent out twice a year.

We published Moving Mountains: Work, Family and Children with Special Needs, a book about the project filled with pictures of your children and your stories. We have given out thousands of books to parents, disability and child care organizations, training and support groups, unions, government and employers.

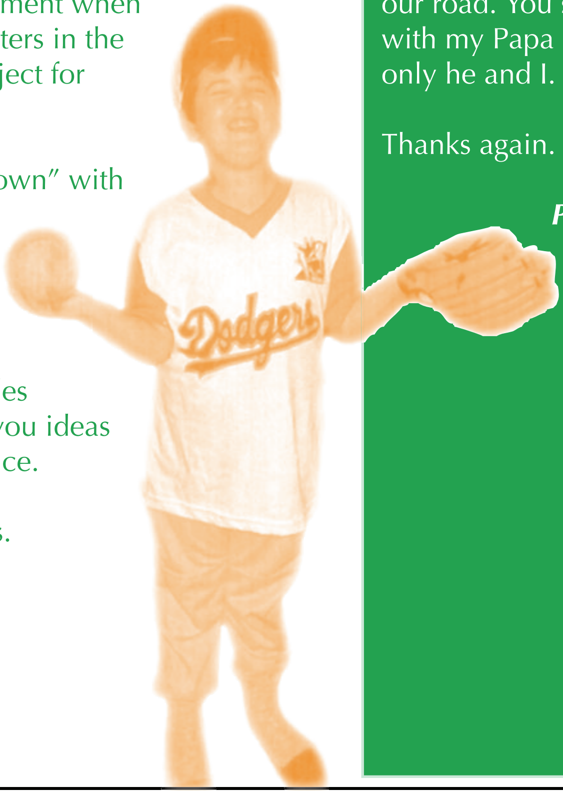
Your feedback from many surveys on issues including special leave, benefits, information needs, advocacy and cuts to educational services and disability programs has helped us immeasurably as we prepared for negotiations, lobbied governments, or let your co-workers know about the additional challenge you face every day. We really saw the benefits of your involvement when Canada Post agreed to include your adult sons and daughters in the Child Care Fund ... and now we have the Moving On Project for support.

During the past 10 years, many of your children have "grown" with the project as they moved from preschool to elementary school, through middle school to high school and beyond to work and further education. You often tell us that it would be helpful to have information about "transition" topics, such as planning, when to start and how to prepare for transition times. This newsletter includes resources, information and tips which we hope will give you ideas to help support your child on their journey to independence.

Thanks for 10 wonderful years. Thanks for sharing with us.

In solidarity,

Denis Lemelin, *2nd National Vice-President, CUPW*



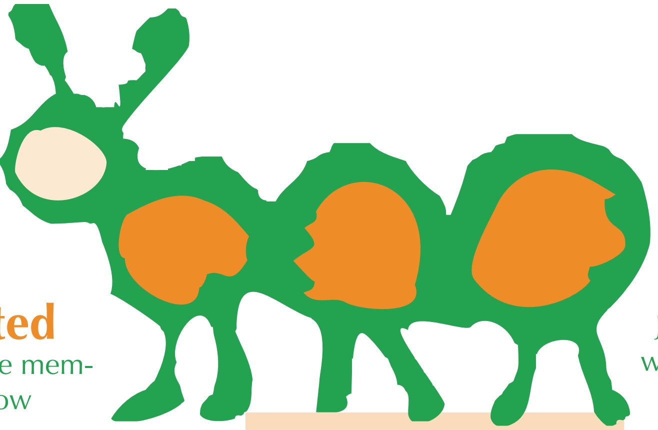
I am sending you a picture of me, Ryan Mogridge, age 7, in my baseball uniform.
I played Challenger Baseball last year and met new friends, even got my first trophy, thanks to you people opening up new doors for me and my Papa.

As I am getting older, I feel for my Papa knowing that he can call, write or even telephone this project, to get new ideas and talk to other members for suggestions.

It helps us as we go along our road. You see, I live with my Papa and there is only he and I.

Thanks again.

P04
Stoney
Creek,
ON



I just wanted to let the members know that the Employer's EAP plan can sometimes be used to help maximize our benefits. I know that, historically, the employer has not always been scrupulous about privacy issues and the EAP, but these problems do not seem to be happening where I am now.

We used the EAP as a springboard into counseling for our child. Because this is employer paid, it means that our Extended Health Benefits won't have to be tapped into until a little later when our child begins an extensive (and expensive) psycho educational assessment.

Postal Clerk
Kelowna, BC

I have finally purchased a booster seat. I still need either a kick sled or a dog sled (to adapt) for exercise and to get Jordan outside during the winter. Call if you have a sled for sale.

Thank you

Letter Carrier
Bobcaygeon, ON

Our son enjoys the lake. Living on the water was a dream for us as a family. We wanted to get away from the pollution and allow our son who has Cerebral Palsy and Autism, to roam freely without the restrictions the city life would have on him. Jordan loves to wander back and forth on our walkway and goes around the house and up and down the steps to the slide. The biggest problem was his fear of the water.

When we moved up into the Kawartha area, we knew something was wrong with our baby. The real problems didn't come out until he was almost a year old. We enlisted the help of doctors and therapists to train him to sit, crawl and walk. It was evident the first time he went to our community beach that there was a problem because of the way he yelled and cried. We didn't know why he was upset as he was then, and continues to be, non-verbal. Any time we went close to the beach or the lake, he would yell so loudly it would echo across the bay and we were unable to stay and allow Jordan's sisters to play or swim. Year after year this continued to be his behavior. No one could explain why or give advice to stop this behavior. Then we joined the small group that Five Counties Children's Center recreation department organized. This was the experimental swim program at the Lindsay pool. Initially Jordan would yell and scream, we would stay as long as everyone could stand it. Eventually Jordan has over the years, overcome his fear and we are able to join the program for the full session (most days) and better yet, this accomplishment has allowed us to go to the beach, pool or lake without worry of Jordan having a negative reaction.

Without the Cerebral Palsy Swim program we would still be unable to enjoy normal family activities. We are not the only ones with this experience and most of the children in the program are using it for therapy and swimming. Some have gone on to accomplish much in swimming lessons and are great swimmers. These programs are a source of help to the families and comfort to the parents. We appreciate and enthusiastically support this program that is continuing to help us and our son Jordan.

Letter Carrier *Bobcaygeon, ON*

Meet our precious son Caleb Phillip Steeves. He is 3 years old and was diagnosed last October with mild Autism. Since birth Caleb has been a very difficult child. He never achieved his milestones on time. We had to attend a variety of therapies that took a lot of patience and understanding. We still need all of his therapies but with everyone on the team we hope and pray that when school starts in 2 years he will be ready. Thanks to CUPW/Special Needs Project. They are part of our team.

Letter Carrier
Moncton, NB

We have a 15 year old son with Asperger's Syndrome and are having difficulty finding a councilor/psychologist/therapist to assist him with life/social skills (i.e. appropriate ways to be assertive, socially acceptable ways of communication, etc). Anything we, as parents say, apparently holds no merit in his mind. We live in Maple Ridge, BC. Has anyone else had success in finding such support?

Postal Clerk
Maple Ridge, BC

Dear Special Needs Project,

The fact that my 2 children need extra help in order to maintain control throughout each week at school greatly increases the daily stress in our family. The money from CUPW Special Needs Project to help our children do well is a blessing. Thank you. Because this funding helps with tutoring and child care it means we can save some money in those basic areas. We can now do something fun as a family together and the kids enjoy this. It's a time for much needed laughter for myself, and my husband, with the kids.

Miscellaneous *London, ON*

"What You Said"

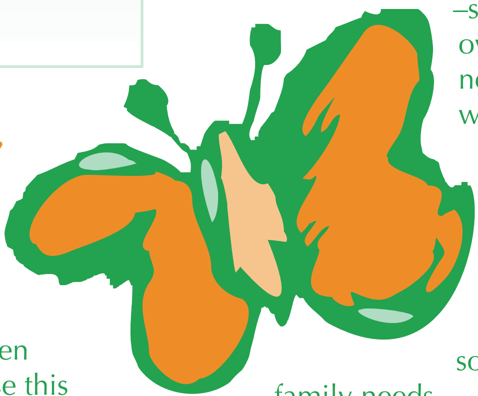
During the Advisor phone interviews, we ask questions to help us find out what else the project can do to support you and your family. Here's what you said in September 2004 about Education Information and Support Groups. You'll find some of the topics you suggested in the articles and resources of this issue of our newsletter. Thanks again for your thoughtful answers to our questions!

Education Information

- More than half of members read the article titled "Your Child and the Education System" and most found it helpful.
- Nearly all members would like more information related to the education system, including advice on advocacy, sources for materials, what has worked for other parents, specific disability information, transitions and options after high school

Support Groups

- About 25% of members are presently participating in a support group, and many found out about this group through the child's support team.
- About 75% of members don't participate in a group right now (40% don't have the time, 25% don't feel the need or aren't interested and 25% can't find an appropriate group).
- Members shared some of their experiences with support groups:



  –some members started their own groups and informal networks when their children were young
  –some members were involved with groups but now use a circle of other parents for support
  –members commented that as their child's needs change, so does the kind of support the family needs.
- Over 60% of members would be willing to offer support to another member of the Special Needs Project, and most would want to connect with other members by telephone. We are working on a way to make this happen. And as we work on developing a website for the projects, we're planning to include on-line member-to-member support.

Forward to the Fut

Children and families experience many transitions as they grow together. Some predictable transitions occur: when children move from child care and preschool programs to elementary school, when they approach adolescence and move to high school, and when children move from adolescence to adulthood, through high school to further education and beyond to work and independence. Other transitions that our children make include moving into new programs, working with new agencies and care providers and making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go of others.

As a parent of a child with special needs, you may be caught up in day to day survival. You may ask, “How can I think about tomorrow when I’m just trying to make it through today?” But when those moments come when you can catch your breath it may be helpful to be aware of those transitions and allow yourself to think forward to the future.

What follows are transition timelines with suggestions that will encourage your child’s independence. Planning and preparing for transition begins today! We hope this timeline will give you ideas to help your child achieve independence as s/he grows

Transition Timeline

Age 0-2

Begin Financial Planning

Set aside money to assist your child when he or she makes the transition to adult living. Have a will written and revise it as necessary.

Encourage Language and Communication

Assist your child in learning some means of communication - the more vocabulary that is understood and expressed the better.

Age 3-5

Involve Your Child in Social Activities

Enroll your child in preschool, cooperative play groups, and/or a child care centre so that the child gets experience socializing with others.

Age 5-6

Seek Inclusion

Consider very carefully what type of schooling your child will receive. Make sure that he or she is included as much as possible in the typical school program. Regular kindergarten in your neighborhood school should be the first option to explore.

Age 6-11

Expect Your Child to Participate

Have your child do regular chores as part of the family’s activities. Involve your child in neighborhood and community activities, including such things as swimming lessons, soccer, dance, martial arts classes and so forth. Invite children to your home and make it a pleasant place for all types of children to visit.

Teach Your Child Life Skills

Assist your child in learning money management and shopping skills. Help your child spend some or all of their allowance. Make your child responsible for good grooming and selection of clothing to wear. Teach your child to make simple meals and wash clothes. Assign regular chores that match and stretch your child’s abilities.

Begin Sex Education

As your child grows and matures, help him or her to understand human reproduction and sexual development as a normal part of growing up.

Make Your Child Aware of Safety Issues

Some children with disabilities are vulnerable to exploitation because they do not have the ability to sense danger or predict consequences. It is important to teach your child how to protect himself or herself from harm. Begin early to teach your child how to avoid dangerous situations, what to do in emergencies, and who to call on for help.

Teach Your Child About His/Her Disability

As soon as your child is ready, provide information about his/her disability. Encourage your child to “take ownership” of the disability and begin to advocate for himself or herself. Include your child in the IEP process as early as possible.

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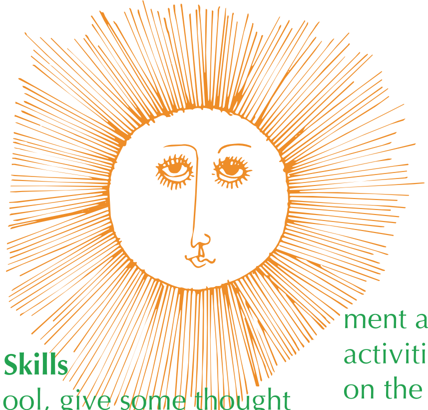


Age 12-14

Functional Skills Vs. Academic Skills

As your child enters middle school, give some thought to how much time in school should be spent on academic skills and how much on functional life skills. Some children will need to have emphasis in their schooling shift to functional skills that prepare them for the adult world.

Encourage Your Child to Work

Have your child do volunteer or paid work in the home, neighborhood or community. Assist your child in developing good work habits.

Age 14-18

Teach Your Child to Use Public Transportation

If your community has public transportation, teach your child to use it. Encourage your child to get to places in the community on his/her own.

Consider the Type of High School Program Your Child Will Pursue

Consider carefully your child's options for high school education. Decide at the outset what type of diploma your child will earn and when he or she is likely to graduate (e.g., at 18 or late). Encourage community based job training and life skills if these are appropriate activities for your child. Involve your child in all decision-making.

Begin Formal Transition Planning at School

Be sure that your child has a Transition IEP that addresses academics, vocation and living skills: whatever your child needs to make a successful transition. Begin to involve adult service agencies if your child will need these kinds of supports either short or long term. Make sure your child's name is on waitlists for services.

Age 18 -21

Encourage Steps Toward Independence

As appropriate, encourage gradual moves toward greater personal independence and self-care. Encourage your child to find a job in the community or to pursue postsecondary education or training. Support your child in establishing an appropriate living arrangement and becoming involved in volunteer and leisure activities in the community. Take on the role of coach on the sidelines and let your child become the decision maker.

Apply for Adult Services

As appropriate, apply for the income and/or employment support programs offered in your jurisdiction. Seek other families and support agencies who can help navigate the application processes. Complete the transfer of medical care to an adult provider. If appropriate, contact the Office of the Public Guardian and Trustee to begin guardianship process before your child turns 18.

Continue Community Learning and Involvement

Attend resource fairs, visit employment providers and post-secondary institutions in your community. Contact the local Community Living Association, Independent Living Centre, support groups and other organizations for resources in the areas of family support, education, employment, rights, participation, advocacy and self-planning. Other adults with disabilities and their families can also be a great resource. Encourage young adult to participate in support groups and/or organizations related to his/her disability.

Adapted from the work of the Adolescent Health Transition Project sponsored by the Children with Special Health Care Needs Program, Washington State Department of Health and the Clinical Training Unit, University of Washington., including "Working Together for Successful Transition", the Washington State Adolescent Transition Resource Notebook.

Transition Stories

Do you have experience with a "transition story"? Here's a chance for you to share your stories of how your son or daughter has successfully transitioned from child care to school, or is transitioning from the adolescent world to adult life including health, postsecondary education, work and independence.

Please share these stories with other members through this newsletter - they just may help to spark ideas for more successful transitions! If you need help please call the Special Needs Project and Moving On Project office - 1 800 840-5465.

Resources

Autism

http://www.autism.net/ - Geneva Centre for Autism provides information and support to enhance the lives of people with autism/P.D.D.

Learning Disabilities

"Teen learning disabilities: help your teen overcome his learning obstacles" by Christine Langlois, Canadian Living On-line: http://www.canadianliving.com/CanadianLiving/client/en/Family/DetailNews.asp?idNews=230162&idSM=311#content (May 19.2005)

Post-secondary information

http://www.neads.ca/ - The National Educational Association of Disabled Students is a consumer organization, with a mandate to encourage the self-empowerment of post-secondary students with disabilities Website has an extensive on-line resource centre.

Equipment

http://www.tetrasociety.org/ - Tetra Society is dedicated to assisting people with disabilities achieve an independent and fulfilling life in the community by creating assistive devices

Transition

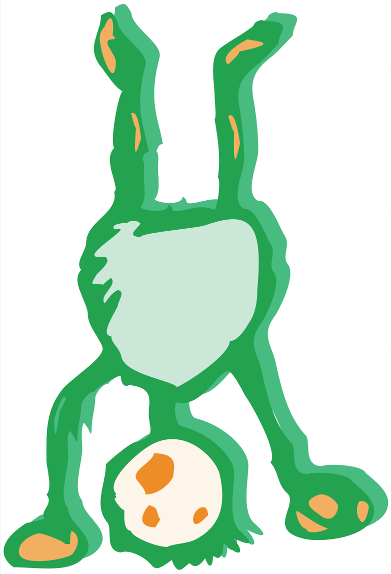
http://depts.washington.edu/healthtr/index.html - Adolescent Health Transition Project: a resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities.

General Resources

http://www.enablelink.org/index.html - EnableLink: " linking people with disabilities to a world of resources".

Sibshops

There is a listing of "registered Sibshops" across the country that provide opportunities for brothers and sisters of children with special needs to meet their peers and discuss their joys and concerns in an atmosphere that emphasizes play, discussion, wellness and camaraderie. To find the list go to : http://www.thearc.org/siblingsupport/sibshops-directory and click on the link for Canada. Contact information for all available Sibshops will be listed there.



I want to thank the Special Needs Project for the financial assistance. It comes in very handy for the special therapies and special services. Gabriel is able to get some special therapies that otherwise we would not be able to afford.

Again, thank you very much for the generosity of the Special Needs Project.

MSC Mail Service
Toronto, ON

Thank you! Jessie is a complicated case. She has never been textbook. Her epilepsy caused paralysis on the left side of her body when she was 2. After, she had to learn to walk again and her behaviour changed dramatically. We have not been able to do normal family things since. Her seizures are in the form of behavioural outbursts. It is very difficult to educate her to handle crowds or any kind of change at all. Thanks to this program I am able to get her the structure she requires, and the respite we require, to make life a little bit easier for our 3 children. Jessie is growing up nicely. At 6, music is her "calming system" and her worker Alicia helps her with basic social skills. Thank you.

Casual PO
Triverton, ON

To parents of Autistic children who are non-verbal: *It is very difficult to explain your child's diagnosis to him/her. On our son's 16th birthday we created a note explaining his situation titled "Who am I?" and read it to him. He agreed to give this to all his teachers during his care conference in school. We would like to share this with all the parents who have a non-verbal child.*

Mr. And Mrs. Jose Carlos R. Paua, Jr.

WHO AM I?

My name is Carlos Angelo Paua and I am Autistic. Most of you have come to know me since last year and maybe each one of you has a tale or two to tell today. I was born with a brain disorder called Autism that makes me different and special from the rest of the general population. Because of this brain disorder, I have difficulty living in your world. Allow me to tell you about myself through my parents who have known me for 16 years.

I find it hard to understand why people behave the way they do. Relating to others is like going to an unknown territory. Because of this difficulty I prefer to be alone. When there are a lot of people doing many things I get restless, anxious and nervous. This sensory overload shuts down my body in the form of a meltdown. This is not an over reaction to stimuli but this is my body attempting to tune out. During this episode, I may hear words from people around me but they are all jumbled. Often times, you will see the warning signs of impending overload or hypersensitivity. This is when I cover my ears, hum or make guttural sounds.

My behaviour is labeled inappropriate, disruptive and a nuisance to others. I urge you to be sensitive to my disability. Leave me alone and soon I will calm down. I may not look you straight in the eye but I can see you well from the corners of my eyes. I need help to respond and connect with other people by way of picture symbols and printed words. I cannot initiate an activity without visual aid or prompting. In order to participate in an activity it is important that the steps involved be described to me in order of occurrence.

I have to be told in advance what is to happen next by way of a social story.
My intelligence is called visual-spatial intelligence. I am good with puzzles, word mazes and constructing something with a plan.

The most important feature of my disability is difficulty in communicating with other people. I cannot express myself in words or gestures. I hear spoken words but I cannot express the way I understand these words. That connection in my brain is missing.

Lastly, I am not flexible to change. I stick to my routine whether it is self-care, nutrition or other activities of daily life. It is hard for me to choose but slowly, with your help, I can now make some choices. These choices do not always conform to our world.

I am forever grateful to everyone who has touched my life and helped me to live in our world and enjoy living in it.

Permanent Full Time
Mississauga, ON

Going to court for justice

How do parents of children with special needs – already stressed to the max – find the strength and energy to take a government or school board to court to get support for their child?

For Susan Clough and others in the CUPW Special Needs Project who've gone the legal route when all else failed, the answer is simple. "This is my child," says Clough, a single mother of two. "I will do whatever I have to in order to make my son's life the best I can and for him to reach his full potential."

Clough, who lives in Barrie, Ontario, has been fighting for justice for the last six years for Jared, 12, who is autistic and non-verbal. Jared's dad is a CUPW member.

She's taken the government to court to get funding to pay for the 24/7 services Jared needs. (She won, but might go back to court because the amount the government gave her is far from what is needed.) She is also pursuing two human rights complaints against the school board for restraining Jared 107 times in two days and suspending him when he reacted aggressively because of the emotional impact of his teacher's death. Ironically, when Jared returned to school, the board implemented everything Clough had previously asked for to keep him in school. Still, she is determined to see the complaints through to the end because she never wants it to happen to anyone else.

Parents who take legal action are aware that their cases could help those in similar situations. "Everything we've done since James's accident has made it easier for others," says Dale Dewart, a mobile letter carrier in Calgary. His partner, Margaret, has taken the lead in the legal fights for their son James, who has attention deficit hyperactivity disorder and was severely brain injured in a bicycle accident years ago while the family was visiting BC. The Dewarts also have a daughter, Kate.

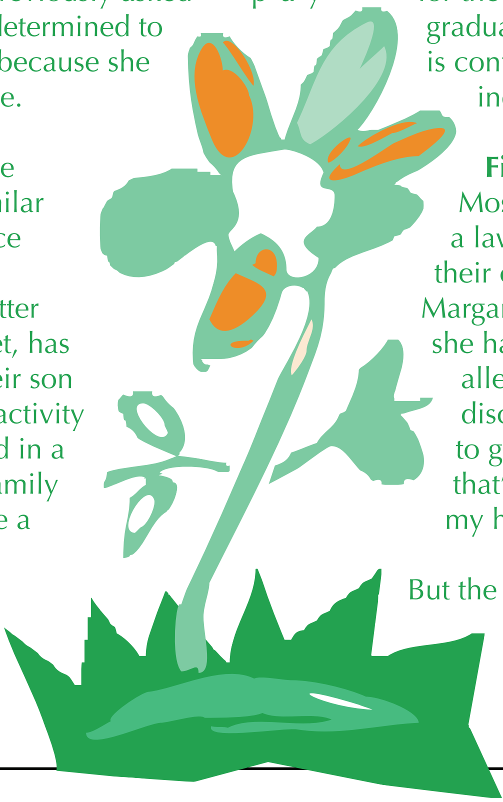
With the help of a lawyer, the Dewarts took Alberta Health to court and won when the government would not cover the cost of the emergency flight back to the province.

As well Margaret, acting on her own, won a minister of learning review (a decision since overturned by the Court of Queen's bench) to get the government to pay most of James's tuition for a school more suited to his needs. "It took 100 per cent of my time and it was very hard," she says.

Dewart has amassed 70 binders that include every conversation or report pertaining to her son's situation. The binders have come in handy: she's been able to decisively counter school board lawyers when they've disputed facts of the case.

Guy Vienneau, a (MAM 11) from Greenfield Park, Quebec, also acted on his son Patrick's behalf in a discrimination case before the Quebec Human Rights Commission. Vienneau's complaint alleged that the school board was discriminating against Patrick, who has dysphasia, because it refused to provide him with a speech therapist and a specialist in orthopedagogy.

Vienneau prepared for the case as if it were a grievance. In the end, the commission ruled in the board's favour. Nevertheless, with help from the CUPW Special Needs Project, the Vienneau family was able to pay for the services Patrick needed. He's now graduated from high school and his father is confident that he will be able to be an independent adult.



Financial and emotional costs

Most parents who are in the courts hire a lawyer at some point, especially if their case becomes overly complicated. Margaret Dewart got legal help after she had to file a human rights case alleging that the school board was discriminating against James. "I started to get legal papers from the board and that's when I thought, 'I'm way over my head.'"

But the legal costs can be huge. "The financial burden that is placed on parents is completely uncalled for," says Stephanie Etherington, who won a three-year battle against the Halton District School Board to get a specific placement for her son Aaron, who has autism. “It appears the school boards have unlimited funds provided by the ministry for legal counsel and a parent who is in a confrontational position must then absorb all the financial costs themselves and that is not fair.”

Stephanie and her partner, Stephen, a letter carrier in Burlington, Ontario, have already spent tens of thousands of dollars on Aaron’s case. After they won, they had to go back to the tribunal because the board failed to implement the decision. The clarification added another $8,000 in legal bills. Etherington feels the ministry of education should put in place a legal fund or provide legal aid to parents in similar situations.

Another obstacle for parents contemplating legal action is the enormous stress that families undergo.

“It sucks you down really bad,” says Margaret Dewart. “With the accident James had to have 99 per cent of our time. People would say to me, ‘I don’t know how you could fight and still look after James 24 hours a day and deal with lawyers and school board officials.’”

In spite of the daunting challenges, all parents interviewed for this article would do it again if they had no other options. “I think it is very important to advocate and never feel you are intimidated or can’t speak up,” said Etherington. “There is no perfection, but when programs are inappropriate and the school board is not willing to negotiate with you, I encourage parents to go to the courts.”

Colin has adjusted well into the middle school and has started Grade 7. There is a resource room for the special needs students to work in. I can’t help but think of one of Colin’s friends in particular as I write this story. Catrionna was immature for her age and this made her a victim for bullying from kindergarten to Grade 5. Her mother would cry at the IEP meetings because of the cruelty her daughter had to endure. It always hurt to know that Colin was being left alone by his homeroom classmates. Colin was moved to Catrionna’s school because his shut down. Finally, Colin would come home and say that he liked school. Grade 6 was positive for both Colin and Catrionna. We are advocates for our children, but we need help with that role. Special needs children have constitutional rights and awareness of those rights should be part of the teaching curriculum from preschool onward.

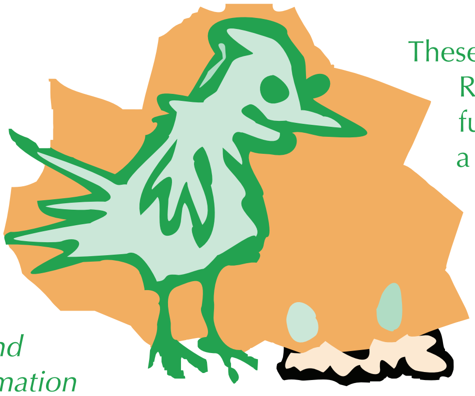
PO4
Kelowna, BC

Advocacy Advice from Parents Who’ve Been There

- Make every effort to negotiate a solution. Only use the courts as a last resort. Legal recourse is time-consuming, stressful and very expensive.
- Always have a witness or an advocate come to meetings with you for moral support and to take notes.
- Use mediation if you are trying to negotiate a resolution.
- Document everything: dates, times, names, things that were agreed upon. Keep copies of everything-minutes, reports, notes.
- Follow up meetings with a letter of thanks that states what was agreed to.
- Find out what your rights are by getting in touch with an organization that specializes in your child’s disability. Seek out support networks, such as your local Association for Community Living, or other parents who have children with disabilities.
- Consult professionals and get their assessment and recommendations for your child so that you can present this information at meetings or hearings.
- Don’t hesitate to seek counseling if the stress is getting to you.

Canadian Human Rights Commission – www.chrc-ccdp.ca
Promotes human rights

Advisor Profile



Each issue of the newsletter will now bring you a profile of an advisor. Advisors are key to both the Special Needs and Moving On Projects. Through telephone contacts advisors provide members with support and resources as well as collect information about issues that impact work and family life, such as health benefits. Advisors do this part time cyclical work in addition to other employment, raising families, attending school and volunteering. We hope you enjoy the Advisor Profile!

This issue our featured advisor is Roberta M., a Special Needs Project Advisor in Ontario.

Roberta has been an Advisor for the Special Needs Project since June 1998. Roberta worked as a day care consultant when she heard about the Project and the need for Advisors in Ontario. After she contacted the Special Needs Project office, Roberta went through an interview and screening process. Soon she became the 'Advisor' to eight member families from Ontario, Manitoba and Quebec. Seven years later Roberta continues with the Project, providing support and resources to eighteen families!

For Roberta, the best part of being an Advisor is the ongoing contact with families. Roberta enjoys the chance to get to know the families and to hear about their child's progress and change. She is delighted when families let her know that a contact she suggested worked out for them!

As an Advisor to families in different parts of Ontario, Roberta learned how varied services are in urban and rural parts of the province. In smaller communities, families may be more isolated and have greater distances to travel for services. Working with members in three provinces, Roberta expanded her knowledge of programs in different parts of the country. The Project "widens the horizons" of Roberta's perspective of Canada.

These days, Roberta works full time as a Program Coordinator for a family home visiting program. This program assists families who have children with special needs. Outside of her busy job, she works on planning for her passion in life: travel. Roberta's passport includes stamps from Hong Kong, Morocco, Thailand and Israel. She also enjoys reading, especially Canadian authors.

Roberta enjoys her work with the Special Needs Project, and appreciates its uniqueness and the support it offers to members. To all the members she phones, Roberta extends her appreciation for their patience and flexibility in arranging those telephone interviews. Roberta also thanks Gail and Dorothy for all of their resourcefulness, hard work and support!

I have never experienced shame and disappointment about my life until my last child was born. Despite all the necessary medical precautions and surgery to ensure we would have no more children, another son was born and he too has sickle cell disease. We now have 4 children, 3 of whom have sickle cell disease.

I never wanted to mention this to the Special Needs project. My advisor Roberta, who has become part of my family, helped me to be able to communicate this. Now I am ready to enroll my youngest son.

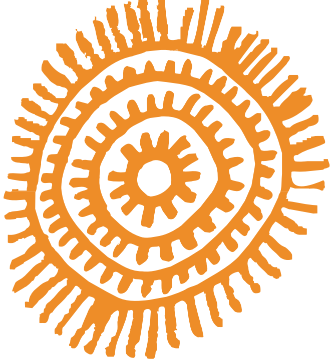
Thank you,
Mail Devivery
Brampton, ON

I'm a letter carrier in Terrace, BC. I have four children ranging in age from 8-16. My two middle boys, Michael and Craig have been diagnosed with ADHD and ADD and have experienced developmental and learning disabilities ranging from mild to severe. This has led to an enormous workload for myself and my husband to deal with school related issues including homework and behavioral difficulties. The support offered by the Special Needs Project will go a long way to lessen the financial strain of tutoring and skill development programs. We sincerely appreciate the support of the CUPW Special Needs Project. Thank you.

Letter Carrier
Terrace, BC

I enjoyed your newsletter and reading about others in this program. It was fun reading what Dennis and I wrote. I hope we helped somebody. I'm hoping to read more about how others keep enough food in the house for 3 meals, 3 snacks and food for highs & lows. I can't seem to ever have enough for my 15-year-old diabetic. He wants to eat all the time.

Mail Clerk
Toronto, ON



I don't normally read the Member-to-Member Connection. I felt like writing in though. We have 3 children, 2 girls, 8 and 10 and a 13-year-old boy with Noonan's Syndrome. You've probably never heard of it. My son has scoliosis; he wore a back brace from 3 years old to 7 years old. He has had a spine fusion and rods. He has asthma due to the amount of operations. He could outgrow that. He has some learning disabilities. He is also very small for his age. The Special Needs Project has been helpful for us. I would be interested in hearing from anyone who has a child with Noonan's Syndrome.

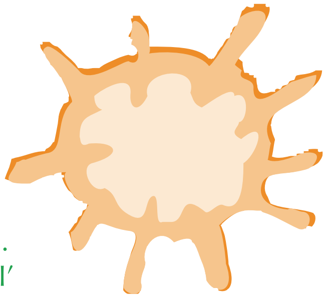
Mail Carrier
Big Lake, BC

We're Moving Forward!

The 'Moving On' Project, for members with adult sons and daughters with disabilities, is up and running. Over 25 members have already phoned the Moving On Project to sign up for the project. During the past months, we have recruited Moving On Advisors across the country and found Advisors experienced with services for adults with disabilities. We now have Advisors ready-to-go in all ten provinces. We're looking forward to members hearing from their Moving On Advisors soon!

What next? We're finalizing all of the administrative details, making sure that the project smoothly supports members and their adult children. We gathered lots of advice from you last year, and we are trying to incorporate as much as possible into the way the project works.

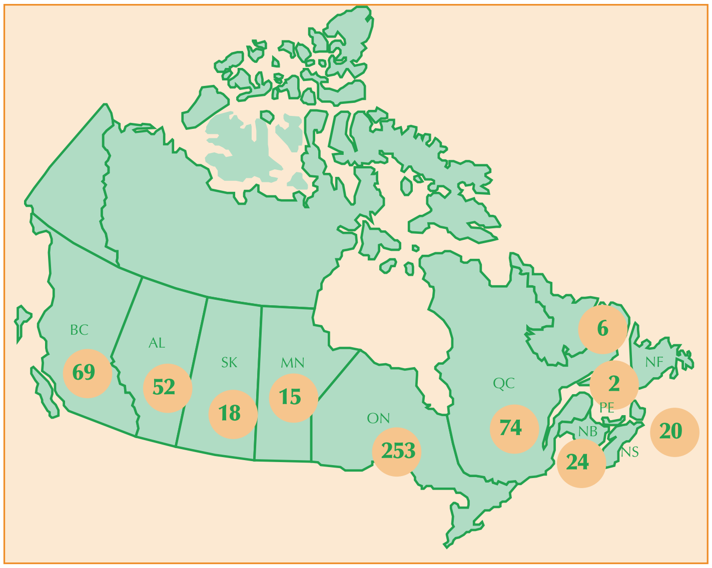
You can expect a letter from the Moving On Project a few months before your child turns 19. If you are interested in being part of the Moving On Project, you need to call the Family Place office to sign up. Please contact the Moving On Project office if you have any questions or concerns. And, if you know a co-worker with an adult son or daughter with a disability, spread the word!



Cody is now 6 years old. He has had bowel problems since he was at least 3 years old. We travel to the USA to see specialists. Cody has been for CAT scans, MRI' many different types of x-rays, many prescriptions and over-the-counter laxatives. The testing in the USA is really helping to find a cure for Cody. The next step for him is a biopsy of the bowel. Cody has had it rough but he is a super trooper. We are very proud of him. He is very brave.

Postal Clerk
Lower Coverdale, NB

The Special Needs Project supports members across all ten Provinces. This map shows the total number of CUPW and UPCE-PSAC members in each province who are participating in the Special Needs Project 2004-2005: 533 members (with 612 children).



We need to change what qualifies as "Special Leave" in our contracts. Example: If we (the employees) have a child enrolled in the UPCE-PSAC Special Needs Project and have to attend a function for this child (example: IPRC, day trip with school or special facility Special Olympics Baseball, Basketball Tournament, etc.), we should be able to access Special Leave. Medical Coverage: If our child is covered under the Special Needs Project, all the child's expenses deemed necessary by a licensed physician (example: speech therapist, chiropractor, etc) should be covered with no maximum. Or, the child's maximum per year should be increased. Now when a child requires Speech Therapy our plan only covers a maximum of $500 per year. At $100 per hour for speech therapy this child is covered for 5 1-hour visits or 10 1/2- hour visits, which is not enough. Therefore I feel this amount should be increased. Please let your Union Representatives know of your concerns if you agree.
Thanks,

PO4 Clerk
Hamilton, ON

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