SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs
N° 37 Winter 2018

I wanted to write to thank the Special Needs Project for all the help they have given my kids and me over the years. My daughter is a visual learner. The public school and high school didn't help with this. She has now gone on to college with art. She is designing and animating 3D computer games. All the support she received helped a lot.

My son is dyslexic and has reading and writing difficulties.

Mom, Clayton and Terra

With the project's help to hire a tutor and the computer training he has greatly improved. The school that he goes to is starting an aviation course to learn about airplanes - to fix them and to fly them. He is so excited to start this next semester. He is a kinaesthetic learner and this will help with a career in the future.

Not all kids learn the same and the education system should help them more in their learning styles. Good thing that the parents and caring helpers are there to support them learning the best way they can. I will be retiring early next year and wanted to say thank you to you all.

MSC
London, Ontario

Clayton and Terra - Then and Now

Special Needs and Moving On On the Road

Gail Holdner, SNP Coordinator and Shellie Bird, CUPW Child Care Coordinator have been on the road to promote the *Special Needs* and *Moving On* projects with members.

Far too many CUPW members don't know about the CUPW Child Care Fund or about these two very important projects. We want to change that!

This tour was inspired by the tour the Quebec Coordinator; Melanie Belisle under took in 2017. Melanie met with over 4,000 members from the Montreal and Quebec regions. She did this by going out to workplaces to meet with you on the work floor.

We used the Quebec tour as the template for our May 2018 tour of the Pacific and Prairie regions. We were able to talk directly to over 2000 members over a six-week period. We then picked it up again in the early fall with a tour of Metro Toronto and Scarborough locals where we talked to about 3,000 members. Through these efforts we have talked directly to 9,000 postal workers about their Child Care Fund and the projects it supports.

We made it a point to, "go out to members" instead of asking them to come to us. We met you in your workplace – postal plants, depots, facilities and retail. We were met with a whole range of emotions – from members being very happy to learn about these projects, to being very angry about not having known about them sooner. Many of you who have used the projects came up to talk to Gail to let her know what the projects have meant to you and to your families. Some spoke up to let other workers know about what being on the project has meant to you. We also heard from members about better ways to promote the Fund and its projects.

We had to put an end to the tour when the CUPW negotiators needed workplace actions and rotating strikes to put pressure on the employer to reach a fairly negotiated contract. Once negotiations have concluded and the dust has settled we will gear-up again and continue to tour other regions across the country.

Stay tuned!

We remember when Jacob was born. Diagnosed with Noonan Syndrome (water on the brain/heart condition/muscular disabilities), we were informed by the doctor that he would never walk, or talk and would die at a young age (before his teenage years). However, Jacob has defied all odds. On May 20, 2018, he turned 21. Currently, he is attending Eastern College in Halifax, NS, studying to be a paralegal with future dreams of moving to Northern Canada to practice law in assisting Native People.

In the meantime, Jacob continues to amaze us with his social skills, sense of humour, wisdom and most importantly, his strong faith in God. This is one time we thank God that the medical experts were wrong!

RSMC
Halifax, NS

Local Connections

"I've done a lot of work in the past few years all over the country and I haven't seen anybody else with a program like this for their workers."

– Catherine Rodgers
Special Needs and *Moving On* advisor
for Newfoundland and Labrador

Advisor

The Weather Network says Atlantic Canada is having "the worst storm in the world" when we reach Catherine in St. John's on a blustery Thursday morning. Luckily, she only has to telecommute to her full-time job with People First of Canada, a national organization based out of Winnipeg representing people with intellectual disabilities.

Catherine has also been the *Special Needs* and *Moving On* advisor for Newfoundland and Labrador since 2015. She says advising has helped her connect to her work more locally: "I've worked nationally for many years. I wanted to get more in tune with what's happening here on the ground with people, to look at more of the programs and options and supports that we might have here in my own province."

When asked how things have evolved over the 30-plus years she's been working in the disability community, Catherine says: "There's been lots of movement but often two steps forward and one step back. When I was first starting, people with disabilities—especially people with intellectual disabilities—weren't even included in school. Now it's different. Kids are included in classrooms. And almost nobody with an intellectual disability or special needs was employed when I started. Federally, I think the Accessible Canada Act is a massive advance for people with disabilities and families who live with disability."

She also sees progress with the members she advises: "I talk to people three times a year, and in one conversation I'll find out a parent is trying to help their child do a certain thing, like maybe get a job or write a resume or something, and then when we next talk sometimes there have been great advances made. And some people are very isolated, so when I hear that someone has made a friend or that things are going well socially it makes me very happy."

Isolation—a problem for many families experiencing disability—can be especially strongly felt in some of Newfoundland and Labrador's more far-flung communities. "It's frustrating," says Catherine. "The family might be in a place with 500 people, so there are no programs, or they'd have to drive three and a half hours, or the speech language therapist only comes once every six months. They don't really get much help."

But together they've found some solutions, many of them online: "One member found a group on Facebook for people like her who are isolated and trying to find supports for their kids. She said it helped a lot just having someone to talk to who knows. And she was able to do video counselling with a professional who would have been an hour or so away by car."

When she's not busy with her work or volunteering, you might find Catherine behind a camera. "I like to take pictures, I'm known as the family photographer," she says. "Two of my frequent photo subjects are the moon and crows. I'm known as the 'crow lady'!"

"Through music he has found a community of peers and mentors."

Building the CUPW-211 Disability Supports Portal

With your help and support!

Since our last update, the CUPW-211 team completed the category mapping work for the CUPW-211 disability supports portal – with your help and support!

This work involved developing categories of disability programs/services and categories of diagnoses. We matched these categories with the terms used to organize the programs and services in the Ontario and Nova Scotia 211 databases. These categories will help members search for information on the CUPW-211 portal.

Our group of members and Advisors in Ontario, Quebec and Nova Scotia provided feedback to help us finalize what will be included in each category, as well as the names and descriptions of the categories. We appreciate your suggestions and ideas for both the program/service categories and the diagnosis categories! THANK YOU!

Now that the 211 terms are mapped to the CUPW categories, our team will be working on the 'front end' and 'back end' of the portal. The 'back end' of the portal includes the technical work of pulling the 211 programs and services into CUPW categories to your location on the portal.

The 'front end' of the portal is the search screen on your phone, mobile device or computer. This is where you will 'search' for the disability support information you need for your child and family.

We will be asking our group of members and Advisors for feedback on the search page – how does it work for you? Is the search page easy to navigate? Can you find the things you are looking for?

We've asked the Canadian Centre on Disability Studies to be involved in further 'testing' of the 'front end' searching and how members feel about the experience of using the portal. For those members in Ontario and Nova Scotia, watch for opportunities to let us know how the portal is working!

Rotating strike 2018 - Toronto local

My sixteen-year-old son, Graeme attended the UBC Summer Music Institute for two weeks in July 2018. This was his fifth summer attending the band camp and the first year he was eligible to volunteer as a junior counselor to help with the younger musicians in Week Two. Graeme has high functioning autism and doesn't always generalize information or experiences well. For Week One, when he was a camper, he stayed at UBC in Place Vanier residence so he would understand what his campers were experiencing when he was a junior counselor for Week Two. He LOVED staying up at UBC and had a great Week One with the senior jazz band. By all accounts he had an excellent Week Two and showed leadership in his counselor role. He also "cut a lot of veggies" for meal prep! It's all about mucking in.

Thank you so much to the project for supporting Graeme's interest and ability in music. Through music he has found a community of peers and mentors where he is accepted and has the opportunity to contribute both in the community and at school. It has also nurtured his love for music that he not only enjoys but it gives him another way to express himself and connect with others.

Letter Carrier
Vancouver, BC

Jimmy and Mom

My son attempted suicide when he was 16. He had gone to the garage to hang himself. His father found him, but by then, my son had gone too long without oxygen and went into a coma for three weeks. He was hospitalized in the University of Laval Hospital in Quebec City for two months, and spent four months in rehabilitation in Jonquière. Like a child again, Jimmy had to learn how to sit, talk, walk, eat and wash.

It was hard for everyone, and very much so for me. I was in mourning for my son and had to accept he was a new person. Jimmy became blind, and had a short memory. Initially, he couldn't remember anything for more than five minutes. He would constantly ask me about what time of day it was. It wasn't easy. He stayed five years at home with me.

Jimmy now lives alone in his own apartment. He gets help and has a multi-service provider coming in two hours a day, five days a week, to make his meals and also do a bit of housework and laundry for him. Jimmy seems very happy. As for me, it will always be hard for me to see him that way.

PO4 Postal Clerk
Dolbeau-Mistassini, QC

MacKenzie has struggled throughout her whole life being different. My husband and I really were those parents that believed to never medicate and this was a phase blah…blah. Come the age of 11, MacKenzie started having such issues that the family couldn't handle it. No one could watch her because of outbursts and her impulsive behavior. She was so extremely hyper that she could not focus at the mere small task of brushing her teeth. It became such a problem that she became aggressive – taking it out on the family, especially her sister. It was time for us to do something.

The pediatrician said it was ADHD but said we better go to a psychiatrist. Well, we went but he didn't know what to think. Then mental health issues started and a new psychologist thought it would be best to hospitalize her. After numerous stays at the local hospital and two summers at the Alberta Children's Hospital, we are still watching her diagnosis change (ADHD, ODD, OCD, Childhood depression and anxiety). Her pills change, MacKenzie changes, and our family struggles. You use what you can of the support available.

I thank this program for the extra help it has given.

Letter carrier
Lethbridge, AB

I'd like to share my story with other parents who are going through challenging times with their children, to let them know they are not alone.

My ten-year-old son Omar has had epilepsy and ADHD with hyperactivity since the age of 7. The road to a specific diagnosis was a long one. But thanks to a lot of patience, love, determination and perseverance, he is making progress at his own rate, little by little.

There have been highs and lows, but, with the help provided by the program, I have been able to give my son a quality of life that I didn't expect him to have before. There is still a long way to go, but we're not giving up!

Thanks to the whole *Special Needs* Project team!

PO-4 Clerk
Pierrefonds, QC

> "A family meal is a great opportunity for communication."

Useful Tips to Help Your Child's Language Development

1. Make communicating an enjoyable experience

Find ways of encouraging your child to talk. Here are a few simple ways, based on everyday situations:

- **Dressing:** the names of articles of clothing, the order in which you put them on, their colours, sizes, textures and other properties.
- **Housecleaning:** Teach them the names of objects used for housecleaning, furniture and other household items, and where each is found in relation to each other (example: The lamp is on the table.). You can also teach what each object is used for by providing a simple definition.

- **Kitchen:** Involve your child in preparing a meal. This will help teach them how steps are sequenced. This can also be an opportunity for them to learn how foods are classified (fruits, vegetables, etc.).
- **Meals:** A family meal is a great opportunity for communication, where everyone has a chance to talk about their day. It's important then to listen to what your child has to say and to encourage them to talk. Be attentive to and interested in what they're saying, and let them finish their message.

- **Telephone:** Letting your child answer the phone will encourage social language development. They will learn how to understand verbal messages without a visual cue and will hone their learning skills.

- **Singing:** Memorizing simple songs and nursery rhymes helps develop auditory memory. This is a crucial skill for future learning.

2. Provide a good example: don't use "baby talk"

Use simple, but adult language. Speak in complete sentences, clearly and enthusiastically.

Reformulate what your child has said, but in a more complete fashion. That way, you provide a simple but slightly more complicated way of expressing what your child usually says. (For example, in reply to "tummyegg," you could say "Oh, you have a tummy ache?") By providing a good example, you draw the child's attention to how the word was mispronounced.

3. Get down at your child's eye level

As much as possible, get down at your child's eye level when speaking to them. Your child will be able to see you better and you'll be able to keep their attention longer.

4. Encourage your child without making them repeat

When a child has trouble with certain words or sounds, it is important to not force them to repeat these just for the sake of practising pronunciation.

Mother: "Yes, an E*L*EPHANT..." Child: "Erephant"

"Language is not an easy tool for children."

Try to understand what your child means, but avoid correcting them every time a word is mispronounced. Instead, say the word again correctly, emphasizing the correct word or sounds that was first mispronounced.

5. Clear up ambiguities as they occur

If you don't understand what you're child is trying to say, don't pretend you've understood, otherwise your child will realize this immediately and end up believing that language is not a tool for communicating. The reverse is also true: make sure your child understands you too as you go.

6. Congratulate every effort

Language is not an easy tool for children. You need to encourage them and not be too demanding.

7. Answer questions

Answer your child's questions. A question is the way they learn. If you're too busy, explain why. Your child will understand.

8. Ask questions

Ask your child to explain their games, what they're doing, and what they're going to do afterwards… Encourage them often to tell you about what they're interested in. Ask questions that require other than a yes or no answer.

9. Let your child cope on their own

Let them answer the questions they are asked. Don't answer for them or finish their sentences. Don't always anticipate their needs or wants. Expect them to ask for or try to say what they want. Set up situations that will force them to speak to get what they want.

For example:

- Serve them a bowl of cereal or ice cream, but without a spoon.
- Put one shoe on, but not the other

10. Have FUN!

Don't forget, any daily activity can provide an excellent opportunity to stimulate your child's language development.

Images from the "Le grand monde du préscolaire" website and the Hanen program. Document adapted by speech therapist Zeina Constatin. Original idea from the Speech Therapy Department of the Des Navigateurs Board of Education.

Rotating Strikes 2018

Channel Port Aux Basques NL

Sunshine Coast local

Season's Greetings from your friends at the Special Needs and Moving On Projects

May peace, joy and prosperity fill your home now and throughout the new year!

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Member-to-Member Connection
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