SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs
N° 45 Winter 2022

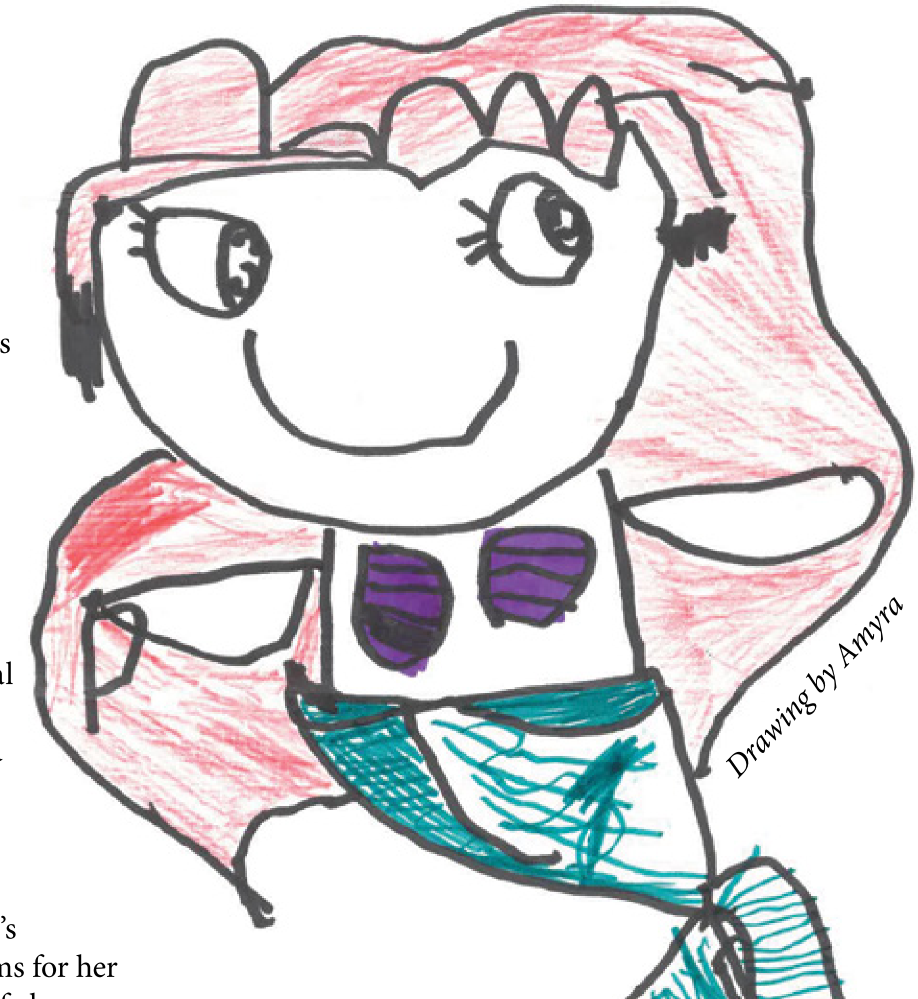
We are very thankful to the *Special Needs Project.* It has been a great support for my daughter's growth. She was three years old when she was diagnosed with severe autism spectrum disorder and a severe speech and communication disability. This diagnosis came with so many things which we never knew or noticed before.

My grandma died the same day Amyra was diagnosed. It was a difficult day. I didn't know how to react to the news of Amyra's diagnosis. It was a shock for me as a mother. It was very painful to write my daughter's name on the medical forms where they asked the name of the person with the disability. I was crying a lot that day. I will never forget it.

But I'm blessed with this beautiful girl. She's so loving, gentle, and adorable. She is good at learning. With the project's help we were able to find special programs for her and special trainers. The first two days of class were difficult for her but now she loves to learn swimming from her special coach and trainers. She started saying "swimming lessons" at the pool. She is always excited every week for her class. She loves water, swimming, colouring, sports, and learning new things.

Thanks very, very much for helping Amyra and contributing to our family's positive growth.

PO 4
Edmonton, AB



Drawing by Amyra

Amyra

"I really did feel like some of the stress was being lifted."

Balancing Work and Family

The Canadian Council on Rehabilitation and Work (CCRW) promotes and supports equitable employment of persons with disabilities.

In 2017, CCRW participated as a member of the Civil Society at the United Nations Convention on the Rights for Persons with Disabilities Committee with a focus on employment. From this CCRW convened a group of like-minded organizations and held its first, Disability and Work in Canada Conference.

The Disability and Work in Canada Conference happens annually in late November. The Conference brings together stakeholders from business, government, and disability communities to discuss progress on employment and disability. The Conference also showcases the voices of persons with disabilities about their experience with finding and keeping employment.

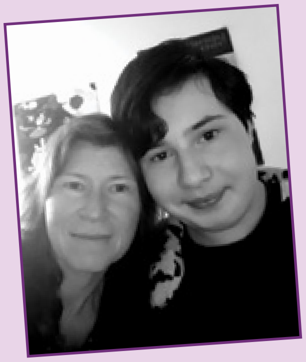
The *Special Needs Project* wanted governments, businesses, and the disability community to learn about the challenges working parents face in trying to balance work and raising children with disabilities.

The Conference organizers thought this was a very important issue for conference participants to learn about. This past November CUPW *Special Needs Project* took part on a panel to explain the projects and to have conference attendees hear from a CUPW member who has a child on the *Special Needs Project*. Below are the comments made by postal worker, Jennifer Hutcheson, to this Conference.

Hello, my name is Jennifer. I have been a part of the Canadian Union of Postal Workers for seventeen years. When my youngest son Ethan was in kindergarten, he was diagnosed with autism spectrum disorder. When I heard the doctor say, "your son is definitely on the spectrum", I was in shock and scared of what the future may hold for my son.

I was a single parent at the time and living paycheck to paycheck. One day at work I was talking to my co-worker about the weekend we had. I had signed Ethan up for group swim lessons a few weeks earlier and that weekend he decided to get out of the pool and bolt around the pool deck. Finally, when a lifeguard caught up to him his instructor came over and said that Ethan will have to leave the group lessons and that maybe one-on-one lessons would be better for him. I tried to get my money back and they said no. My co-worker asked me if I had ever heard about the *Special Needs Project*. I replied "no". She then stated that it is through our union and she gets funding for her son through the project. She then went over to our union board and got a pamphlet for me.

I contacted the *Special Needs* and *Moving On Project* and asked for more info. It was extremely simple to sign up and send in a copy of Ethan's diagnoses. Once I began receiving funding, I was able to increase Ethan's speech therapy to weekly sessions. I was able to get a tutor that comes to our house, I was able to finally sign him up in summer camps with a support worker there for him. I really did feel like some of the stress was being lifted. Unfortunately, the stress just turned into a different stress, from work.



As a parent there are many responsibilities that come with having a child - many appointments, or sick days. At that time, I didn't have a support network for Ethan. I was still figuring everything out, at least a routine for us. I had many babysitters quit on the spot because they were just not trained. I was missing a lot of work and started to get 24hr notice of interviews due to my attendance. Management had absolutely no understanding or compassion that I was raising a child with a disability. I actually had a supervisor say, "can't you just get your neighbor to watch him". The ignorance was appalling. It takes time to create a support network. I had a supervisor yelling at me one day because I had to sit down on the job, while I was having a very bad insulin reaction. She questioned why I was sitting down, and I told her. Then she began yelling at me over and over again that it's my responsibility to take care of myself and get back to work. I was under so much stress.

Now having the funding through the *Special Needs* and *Moving On Project* I was slowly building a team - Ethan's Teachers Assistants at his schools, his tutor Duncan who has been coming to our house for 8 years now, coworkers, and our advisor from the *Special Needs Project* giving us resources and an ear for me to talk things through. At the beginning it was a huge struggle with management trying to get time off work. Now, all I have to do is tell them that I need to be off on certain dates. This ease came from our union fighting for its members and the *Special Needs* and *Moving on Project*. I can honestly say Ethan wouldn't be where he is today without it. He will be graduating from grade 12 with honors this year AND he is now enrolled for September 2023 in post-secondary education at Camosun College Interurban campus. They say it takes a community to raise a child. I like saying it takes a team to raise our children.

Thank you!

Special Needs Parenting: Tips for Holiday Stress Reduction

1. **Whatever you may be celebrating this holiday season (Christmas, Chanukah, Kwanzaa, etc.), lower your expectations**. This concept includes letting go of the pursuit of the latest "must-have" gadget or toy.
2. **Pause for a moment and reflect on what the season means for you and your family.** Light a candle and ponder the blessings and positive imprints that have manifested for your family this year. Meditate/pray/reflect/write/generate a positive intention for your wishes for the new year.
3. **Create/continue one or two rituals that are meaningful for your family, support your spirituality, and which are easy to implement.** If candles are dangerous for your special needs child, perhaps a flashlight or battery-operated lantern/candelabra/menorah may be a center point.
4. **Be OK with bowing out of festivities that may "dysregulate" your child.** Keep routine as much of your child's (and family's) schedule—consistent bedtimes, nap times, feeding schedule, etc.—as you do throughout the year.
5. **Have outlets for excess energy.** Does your child need a space to move his/her body without being scolded for scratching someone's delicate furniture? Seek out indoor play spaces when inclement weather announces itself.
6. **Avoid red food dye and additives which are pandemic to holiday treats (i.e., frosting on holiday cookies and goodies).** Studies indicate that food additives have the potential to contribute to hyperactivity in many children, especially those with pre-existing neurodevelopmental challenges. Try to focus on healthy snacks.
7. **Be OK with saying "no" to anything that does not contribute to your own or your child's well-being.** This may include holiday events/obligations that you (and/or your child) do not enjoy, or any event that depletes versus restores/fills your life energy (or your child's).
8. **Sleep.** For adults, five uninterrupted hours (at minimum) of sleep is essential for a restorative sleep cycle. For children, the need for sleep is even greater. Make sure you do not sacrifice your child's bed time and/or nap time in lieu of other obligations.
9. **Take some time just for you as a parent.** Allow grandparents or other support networks to provide care for your children so that you can indulge in some much-needed rest and restoration.

> "She takes the time to listen to me, advise me, and more."

The bathroom break that changed my life

I was washing my hands when I noticed a poster for the *Special Needs Project*. A few words caught my eye: "Autism Spectrum Disorder, ADHD, Dyspraxia." I was familiar with these three terms because I had been dealing with them for two years. I asked my coworkers about the *Special Needs Project*, but no one seemed to know about it. So I called the number on the poster, and talked to Mélanie, the coordinator for Quebec. She explained it to me and a few weeks later, I was accepted.

My boy and I had been going to weekly speech therapy appointments for two years. It was private care and I had to pay for everything, receiving only $460 a year from insurance. My daughter's private evaluation cost $1,800.

When the *Special Needs Project* came into our lives about six months ago, I received financial assistance to adapt my household to my children's needs. I also receive support from a wonderful advisor who helps me find additional resources. She takes the time to listen to me, advise me, and more.

The journey of parents of children with special needs is unique and challenging, but the support of our community helps us navigate it. Tell everyone about the *Special Needs Project*! It is very helpful.

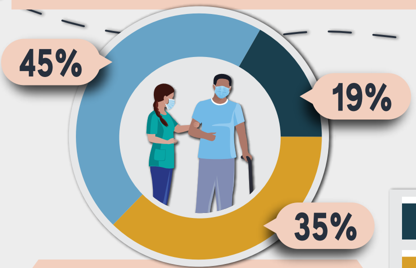
RSMC
Chambly, Quebec

"77% of participants did not receive therapies or services they needed."

How are Canadians with long-term conditions and disabilities impacted by the COVID-19 pandemic?

From June 23 to July 6, 2020, Statistics Canada collected information via a crowdsource questionnaire on the experiences of Canadians aged 15 and over with long-term conditions and disabilities during the COVID-19 pandemic.[1]

Self-reported general health status[2]



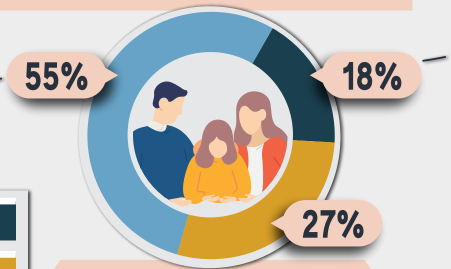
Almost half (48%) of participants reported **their general health** is worse than it was **prior to the start of the pandemic.**

Excellent or very good

Good

Fair or poor

Self-reported mental health status



Over half (57%) of participants reported **their mental health** is worse than it was **prior to the start of the pandemic.**

77% of participants **needed but did not receive** one or more therapies or services **for their condition.**

8% of participants were unable to get COVID-19 related testing or medical attention **due to their condition.**

Women were more likely than men to report **difficulty** meeting their financial obligations or essential needs.[3]

60%

56%

54%

Among those experiencing a monthly household income decrease, **over half** reported difficulty in meeting their food and grocery needs.

38% reported an impact in their ability to meet their personal protective equipment needs.

Notes: 1. Included in this analysis are participants who reported: a difficulty and self-identified as a person with a disability; no specific difficulty but identified as a person with a disability; a difficulty but did not identify as a person with a disability.
2. The percentages do not sum to 100% due to rounding.
3. Includes participants who reported a "major" or "moderate" impact on their ability to meet their financial obligations or essential needs.

Source: Impacts of COVID-19 on Canadians – Living with Long-term Conditions and Disabilities.

Catalogue number: 11-627-M
ISBN: 978-0-660-36110-9

Statistics Canada Statistique Canada
www.statcan.gc.ca
Canada

"It will be my great pleasure to research the information, resources and support you need."

I'd like to take this opportunity to welcome and introduce you to our newest staff member, Isabelle Tanner. Isabelle is taking on the new role as Support Navigator with the *Special Needs* and *Moving On Projects*, which are administered by Breton Ability Centre.

Isabelle will work under the direction of the Project Coordinator. Isabelle will help postal workers find the support, assistance and information needed for their child or adult child with special needs or disabilities. Isabelle will be using the CUPW *disability-supports.ca* portal linked with 211. 211 is a comprehensive source of information about resources and services across Canada.

As Isabelle is bi-lingual, she will provide this support in both official languages.

Isabelle comes to us with an extensive background in Administration from the University of Toronto. After many years of living in Ontario, Isabelle returned to her roots in Cape Breton, Nova Scotia in 2019. She now lives happily in the rural setting of St. Ann's Bay and is surrounded by the natural beauty of the area, friends and community, and her two Great Pyrenees dogs, Myra and Ben.

Dorothy Keigan
Coordinator of Member Support

Dear members of CUPW/UPCE-PSAC,

I am very much looking forward to interacting with you in the very near future! Our disability supports portal, in conjunction with 211s across the country, is in the very final stages of development now and we hope to be able to launch in December or early in January. At that point the website portal will be available to you, and I will be available to assist you in navigating the site and finding disability support resources for you should you need it.

During the last *Special Needs* and *Moving On* projects interviews members were asked what resources they thought their child/adult child needed. I will be contacting those members who identified that they would like some support finding resources. As there are hundreds of requests, and I have just gained access to this information, please know that I am working to follow up on every one of them and will be in touch with you.

I am sharing a few resources in this newsletter that I hope some will find helpful. In the future we will post new resources on our website (*specialneedsproject.ca*) as well as through social media. We are working on those details now.

In my role as Support Navigator, I will be available 3 days a week – in general that will be on Mondays, Wednesdays and Fridays from 9 am-5 pm AST – and I can be reached by phone at 902-295-1645 or by email at *supportnavigator@specialneedsproject.ca*

Please feel free to contact me directly if you wish. It will be my great pleasure to research the resources, support and information you and your child are looking for and provide the referrals you need.

With kindest regards,

Isabelle Tanner
CUPW-UPCE Support Navigator
Special Needs* and *Moving On Projects

Books and magazines of interest for parents, educators and children with special needs.

The Boy Who Lost His Attention by DPA Weston | The FriesenPress Bookstore: Once there was a boy who lost his attention... until he discovered his superpowers. Based on a true story, this book highlights how an attention deficit diagnosis can explain children's behaviour in school and at home and the struggle and frustration that follows for children, their parents, and their teachers. This book shares strategies on how to deal with an attention deficit diagnosis and how to manage the resultant behaviour. The book also recognizes a common family arrangement where children are parented by families who live separately but parent together. The book, The Boy Who Lost His Attention, shows how all people can overcome a learning challenge through persistence, resilience, and a growth mindset.

Speechless Dream by Chandra Lebenhagen | The FriesenPress Bookstore: Anantha is a non-speaking autistic boy, but that does not mean he has no voice. Through poetry and non-fiction prose, this book shares Anantha's poignant interpretation of the harmful effects of therapeutic and educational practices that aimed to remediate his autistic self into something more "normal." Interwoven into his narrative are the stories of the people whose lives intersected because of Anantha's dream to receive an education.

CAREGIVER SUPPORT IN NOVA SCOTIA

Caregiver Benefits

Did you know that Nova Scotia is the only province that provides Caregiver Benefits?

Caregivers of low income adults with a high level of disability or impairment are eligible to receive $400 a month if both the care recipient and the caregiver meet the criteria to qualify for the program. For more information on the Caregiver Program go to Caregiver Benefit | *novascotia.ca* or call 1-800-225-7225.

Facility Based Respite Care

The Nova Scotia Department of Health and Wellness supports caregivers who need respite for a scheduled amount of time (up to a total of 60 days within a calendar year) by providing space and services in licensed long-term care facilities for their loved ones who need personal care. A Care Coordinator will assess the applicant's care needs and eligibility. Once the applicant is confirmed eligible for the service, the Care Coordinator will arrange for a respite bed for the applicant on a first-come, first served basis. Respite bed service is usually preplanned and scheduled; however, there are emergency services available for those unexpected and temporary events. There is also an option available for children. There is a standard charge for a licensed respite bed, however people in need can apply to receive a reduced rate by completing an application form and undergoing an income assessment. For more information on Facility Based Respite Care go to Facility Based Respite Care | *novascotia.ca* or call 1-800-225-7225.

PREPARING YOUR ASD CHILD FOR VACCINATION

Do you have a child with ASD? Vaccinations can be overwhelming and can cause stress for individuals on the Autism Spectrum. These social stories can help prepare you or someone you care for before a vaccination appointment.

https://autismcanada.org/resources/covid-vaccine/

> "I felt empathy, kindness and a deep desire to help me in my distress."

Seven years ago, I turned to the *Special Needs Project* for help. As a mother of four, I had seen it all before, but I did not know what to do with the deteriorating psychological state of my oldest son, then nine years old. The bullying he had been experiencing at school for several months was affecting him so much that his grades were falling and I no longer recognized him.

Do you know what the parents of a child in such a situation keep hearing? "Don't worry. A nine-year-old cannot think of suicide."

Jean-François, an advisor for the *Special Needs Project*, was the first person who really listened to me. I remember our first phone interview. He was a bit apologetic about the paperwork. Then he took the time to listen to me. I felt empathy, kindness and a deep desire to help me in my distress.

He spent seven years with us. He was there to help me when our third child was diagnosed with autism spectrum disorder. He was there to remind me to take care of myself and my relationship. My partner used to say "It's your other Jeff" when he answered the phone, because that's his name too. Having an advisor just a phone call away for seven years has been a real blessing.

Our last call was a few weeks ago. It was so nice to meet you, and we will miss you. Take care of yourself and your little family – as you have so often advised me.

PO-4
Lévis, Quebec

Mom and family in the early years.

Mom and family today.

CATCH UP PAYMENTS FOR SPECIAL EDUCATION (ONTARIO)

If you live in Ontario, you can get financial support to help with the costs of your child's tutoring, supplies or equipment during the 2022–23 school year. Eligible applicants will receive a one-time payment of:

- $200 for each student between kindergarten and Grade 12, up to age 18
- $250 for each student with special education needs between kindergarten and Grade 12, up to age 21

The deadline to apply is **March 31, 2023, at 11:59 p.m. EST.**

You are eligible to apply if you live in Ontario and are a:

- parent or guardian to a student from kindergarten to Grade 12
- secondary school student who is 18 years of age
- parent or guardian to a student from kindergarten up to age 21 with special education needs

For more information and to apply go to:
https://www.ontario.ca/page/catch-up-payments

"There was no one place to find disability supports and services across the range of disabilities or across the life span."

DISABILITY-SUPPORTS.ca

It has been a long-time in the making, but we have finally launched the CUPW *disability-supports.ca* portal for testing! We encourage you to check it out – if you haven't already.

WHY IT CAME TO BE

Members expressed real frustration about how difficult it can be to try to find desperately needed programs, services and supports online. In the words of one member, "it was like trying to drink from a fire hose". So, the CUPW Child Care Fund and the *Special Needs Project* got to work on finding a solution.

HOW IT CAME TO BE

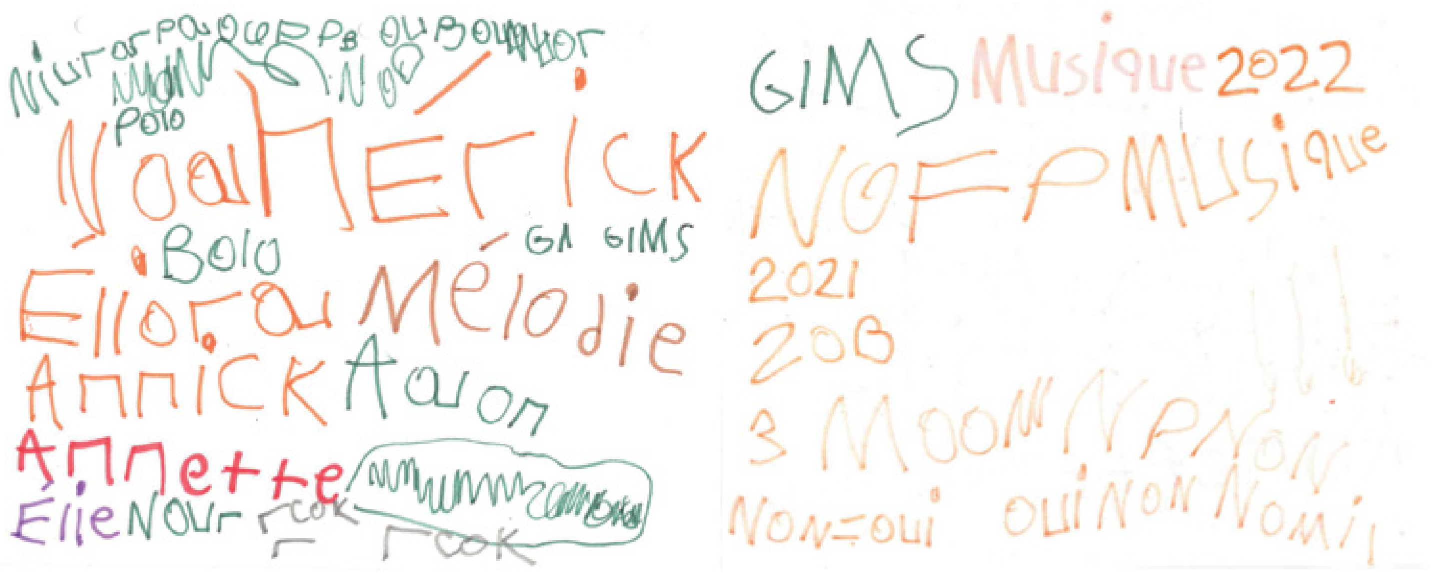
Following an extensive investigative phase that looked at what databases of disability supports existed across the country, we learned that there were a multitude of sites specific to disabilities, client groups or program and service areas. But there was no one place to find disability supports and services across the range of disabilities or across the life span – from infants to seniors.

We did learn that there is a network of 211 community information services across the country that have standards based information (common terms for indexing program records) and regular record maintenance.

And so, our journey began in earnest when CUPW partnered with 211 services in Ontario, Nova Scotia, and BC to develop a CUPW disability portal that would access 211 information and display it in a user friendly, easy to navigate format. While we started small with just the three 211s we have now included 211s across the country, outside of Quebec. Once Quebec 211 is ready to take part they will be added.

The final version of the portal should be available late December or early in the new year. It will be available to all postal workers and the public.

Here is a small drawing from Nour with the names of classmates.
Letter carrier – St-Amable, Quebec



THE BENEFITS OF PETS FOR CHILDREN WITH ASD

Owning and interacting with a pet can have many benefits for the individual diagnosed with ASD. Some of these include:

- provides companionship and friendship
- reduces loneliness
- fosters compassion
- alleviates anxiety
- builds confidence as an animal is nonverbal and non-judgmental
- teaches responsibility

A 2013 study at the University of Missouri lead by Gretchen Carlisle, a research fellow at the Research Center for Human-Animal Interaction (ReCHAI) in the MU College of Veterinary Medicine, involved 70 parents of children with autism and their interaction with dogs. Carlisle reported that nearly two-thirds of the parents in the study owned dogs, and of those parents, 94 percent reported their children with autism were bonded to their dogs. Even in families without dogs, 70 percent of parents said their children with autism liked dogs.[1]

Research continues to be published every year on the benefits of animal assisted intervention and autism. While a pet may not be a good fit for every family, some exposure to animals may be beneficial for a child's development and well-being.[2]

For a first-hand description of how a young adult with Autism grew to enjoy having cats around, read *The Comfort of Pets*, Michael Tanzer's charming account in the November issue of Autism Canada's Sharing the Spectrum newsletter at *https://autismcanada.org/sts-11-15-2022/*

My son has been attending Kumon with the help of the *Special Needs Project*. I can see him improving in math, grammar, and literacy.

Thanks to the project my son can also possibly purchase a new computer so he can further update his skills.

As a union member, I would like to say "thank you" for all the support provided.

Thank you.

Letter carrier
East York , ON

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1 Pet Dog Ownership Decisions for Parents of Children With Autism Spectrum Disorder - Journal of Pediatric Nursing: Nursing Care of Children and Families

2 How Animals Benefit Individuals with Autism - Autism Awareness

The Canadian Mental Health Association

Founded in 1918, the Canadian Mental Health Association (CMHA) is the most established, most extensive community mental health organization in Canada.

We are a federated charity, which means we are a collective of organizations bound together by a brand and mission. Together, we identify and respond to Canada's most pressing mental health priorities. At the national level, we push for nationwide system and policy change. At the community level, millions of people in Canada rely on CMHA's extensive grassroots presence.

Act for Mental Health is an advocacy campaign led by the Canadian Mental Health Association (CMHA) that rallies Canadians to press our leaders for universal mental health care. A growing number of Canadian organizations stand together in asking for the same thing: to make mental health and substance use health care available to everyone under public health insurance. For people in Canada, **Act for Mental Health** is a chance to stand up, be counted, and use our voices to press our leaders for universal mental health care. Care that serves and supports every single one of us. Care that enables us all to thrive. Act for Mental Health is a campaign, a rallying cry, a movement for mental health care that is truly universal. ***Take action.***

The Act for Mental Health campaign is supported by a coalition of Canadian organizations and calls for the promised Canada Mental Health Transfer in the next federal budget as a first step towards true and universal public mental health care.

Canadians are encouraged to **Act for Mental Health** by visiting *www.actformentalhealth.ca* and getting involved. Together we will press the government to provide all Canadians with access to universal mental health care.

We are going to the Emergency Department for #MentalHealth care because there's nowhere else to turn. Canada needs #universal mental health care because mental health care is health care.

Let's not pretend it's not.

Season's Greetings

from your friends at the *Special Needs* and *Moving On* projects.

Happy Holidays! Best wishes for a wonderful holiday season and a new year filled with peace and happiness.

Special Needs and _Moving On_ Advisors:

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Angelia B.
Anne G.
Brigitte L.
Catherine L.
Catherine D.
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Dorothy H.
Ellen B.
Enna M.
Fréderique F.
Gail B.
Janet M.
Janice S.
Jean-François F.
Jessica C.
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Karen W.
Laura G.
Lesa M.
Lesley-Anne C.
Lisa V.
Marie-Hélène M.
Marie-Josée L.
Mélanie C.
Melissa M.
Roberta M.
Rhonda A.
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Claudia Labonté

Member-to-Member Connection

is the newsletter of the *Special Needs* and *Moving On Projects*. It is produced by the Canadian Union of Postal Workers and the Union of Postal Communications Employees-Public Service Alliance of Canada.

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