



member to member connection

Breaking through barriers for workers who have children with special needs

N° 38 Summer 2019

To the people at the Special Needs

Project: Thank you for the continuing work you do to help all of us members who have children with special needs. I am continually in awe of the amazing support we get from all the people in our lives. The saying “It takes a village to raise a child” has never been more apparent than now. Thank you for inadvertently being part of mine. Your resources are much appreciated. Many, many thanks,

Letter carrier

Maple Ridge, BC

By: *Jordon - Age 5*
and *Hazel - Age 10*



Evan



Ava

Our son Lucas was born premature at 28 weeks coming into the world at 2.2 pounds. A brain injury occurred at his birth as well. We worked really hard to get Lucas to meet his milestones. Lucas was developing quite well but when he turned 4 he couldn't walk anymore. Lucas was diagnosed with CRMO Chronic Recurring Multifocal Osteomyelitis (quite a mouthful). This condition is fairly rare and there is no known reason why this illness happens. Fast forward – Lucas will be 18 in May. He suffers with joint pain everyday and takes medication to help him cope. Lucas walks with a noticeable limp but is now almost 6'2" tall and very handsome and kind. We are blessed.

When you have a child with special needs the parents can work together or not. In our case we have survived as a family unit but I know that many families cannot stay together. It has not been easy but all the sacrifices have been absolutely worth it and we could not have been more thankful for the Special Needs Project and Janet our advisor. To the younger families out there, remember to take one step at a time and advocate, advocate, advocate for the children.

Letter carrier

Orangeville, ON



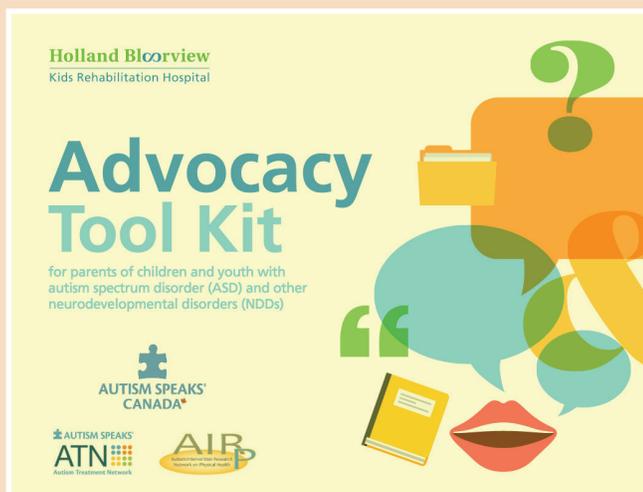
"Sometimes I want to shed my parental responsibilities."

Canadian Advocacy Tool Kit for parents, by parents of children with ASD and NDDs

Holland Bloorview Kids Rehabilitation Hospital has launched the Advocacy Tool Kit for parents of children and youth with autism spectrum disorder (ASD) and other neurodevelopmental disorders (NDDs). The tool kit was developed by the autism research centre (ARC) at Holland Bloorview and parent advisors, and is funded by Autism Speaks Canada. It aims to provide Canadian parents with basic knowledge of advocacy and negotiation skills along with useful and practical tools.

The Advocacy Tool Kit aims to demonstrate how to apply advocacy skills to different situations throughout early childhood and adolescence through useful tips, links to additional information, list of local resources by provinces across Canada, and many other interactive features. It includes sections on self-advocacy, advocacy within the family unit, advocacy in the community, school advocacy, and advocacy in health care.

We encourage all families to view and download the Advocacy Tool Kit. <http://hollandbloorview.ca/Assets/Research/ARC/AdvocacyToolKit-July24-LINKED-LOCKED.pdf>



It is difficult letting go of an adult child with special needs. My son is 25 years old. Allowing him to make choices that I don't necessarily agree with, or approve of, is difficult, especially when I witness it on a day-to-day basis.

Sometimes (often) I want to shed my parental responsibilities. It is at these times that I feel the most guilt in my support for my son. I am thankful for the support that my advisor provides and welcome the resources offered.

The funding gives me the opportunity to have others guide my son, plus space and time to reflect on my guidance to my son, myself and my family.

Letter carrier
Victoria, BC

Highlights of one-person-one-fare policy decision

On January 10, 2008, the Canadian Transportation Agency ordered Air Canada, Air Canada Jazz and WestJet to adopt a One-Person-One-Fare Policy for persons with severe disabilities on flights within Canada. The airlines were given up to one year to implement the Policy, which does not apply to domestic segments of transborder and international trips.

The Decision means that, for domestic services, these carriers may not charge more than one fare for persons with disabilities who:

- are accompanied by an attendant for their personal care or safety in flight, as required by the carriers' domestic tariffs; or
- require additional seating for themselves, including those determined to be functionally disabled by obesity.

The Decision does not apply to:

- persons with disabilities or others who prefer to travel with a companion for personal reasons;
- persons with disabilities who require a personal care attendant at destination, but not in-flight; and
- persons who are obese but not disabled as a result of their obesity.



How parents and guardians can prevent bullying

A PROBLEM YOUTH CAN'T ALWAYS SOLVE ON THEIR OWN

Bullying is a power struggle that is difficult to resolve without the help of an adult. In most cases, it requires only a few minutes of intervention to stop, especially if adults act immediately and in a consistent manner. If you are present when bullying occurs, talk to those who are being aggressive. Explain the hurt they are causing and have them make amends to those who were harmed. This can break the cycle.

DID YOU KNOW...

Set the example

Always consider how you treat others and how you allow others to treat you. As a role model, your actions and reactions can influence how youth relate to each other.



IF A YOUNG PERSON TELLS YOU SOMEONE IS BEING BULLIED

Listen - and take it seriously even if it seems trivial, such as name-calling. Youth usually go to adults with these problems only as a last resort. In a very small number of cases, bullying behaviour is a chronic problem requiring the involvement of families and the assistance of a health professional.

WHAT ELSE CAN YOU DO?

Parents and guardians:

- Talk, talk, talk. Don't wait for your child to come to you, bring up the conversation about bullying if you suspect or see/hear something.
- Talk to the adults who were in charge when the bullying occurred to find ways to remedy the problem and prevent future situations.
- If presented with the opportunity, confront the child, teen or group guilty of bullying and explain to them the hurt they cause.
- Stop any bullying behaviour at home, because consistency matters.

Adults responsible for young people (such as teachers, principals, coaches and other leaders)

- Be aware of the social interactions in your group of children - separate youth who tend to have negative interactions with others.
- Place left-out youth in groups where they will be accepted - try to avoid situations that will victimize at-risk youth (for example, don't have peers pick group partners or teams).
- Support other adults who work directly with youth to end bullying - by enforcing the separation of disruptive teens, increasing supervision in bullying hotspots and placing vulnerable youth in positive groups.

DID YOU KNOW...

Anti-bullying policies

Leaders of organizations responsible for young people can create anti-bullying policies that clearly set the limits on acceptable behaviour. Include meaningful consequences in the policy to help teach aggressive youth healthier ways of interacting. Allow time for the policy to be reviewed and agreed upon by everyone (including teens), and ensure the policy is consistently and universally applied by all involved.

Taken from the Government of Canada website:
English: <https://www.canada.ca/en/public-health/services/bullying.html>



Bullying (ages 4 to 11)

When the cycle starts

The cycle of bullying often begins between the ages of four and 11 when children are forming their own social identities at school and through other activities. No matter when it starts, it's important to remember that *bullying is not a normal part of growing up*. It needs to be dealt with directly by adults who are willing to recognize there is a problem and take whatever steps must be taken to stop it.

THE DIFFERENT KINDS OF BULLYING

Physical

- Hitting
- Kicking
- Punching
- Pushing/Shoving
- Stealing

Psychological - Verbal

- Insults
- Name-calling
- Threats
- Comments about how someone looks or talks
- Comments about someone's ethnicity (culture, colour, religion)

Psychological - Social

- Gossiping
- Rumours
- Ignoring
- Not including someone in group activities

RESULTS

- Can hurt a child's body, damage belongings (clothes, toys, etc) or make a child feel badly about himself or herself.
- Can make a child feel badly about himself or herself.
- Can make a child feel alone and not part of the group.



HOW TO HELP

If a child comes to you for help with a bullying situation, he or she may need reassurance as well as practical advice. Use your judgment about the circumstances and get as many details as you can. Here are some things you can say:

If the child is being bullied

- "Stay calm, try to show you won't get upset. Anger can make things worse."
- "As soon as you get bullied, find an adult you trust and tell the adult what happened. It is your right to be safe."
- "If you are afraid to tell an adult, ask a friend to go with you."
- "Stay close to friends or children you know will stick up for you."
- "Stay away from places you know bullying happens."
- "If bullying continues, walk away and join other children or ask someone for help."

If the child sees someone else being bullied

- "Speak out, you can help by telling the bully to stop - nobody deserves to be bullied."
- "If you are afraid to speak out alone, ask a friend or many friends to do it with you."
- "Comfort the person who was hurt, tell them they don't deserve what happened."
- "If you are afraid or telling them doesn't work, find an adult you trust to help you."
- "Help children who are bullied. Invite them to participate in your school activities - this will help them not feel like they are alone."

Assurances you can give children:

- "Despite how it seems, it is not a hopeless situation. Something will be done to stop the bullying, I will help you."
- "There is always someone who you can talk to about bullying, whether it's me or another adult/teacher at school."
- "Remember, if you walk away and get help, you are part of the solution. If you stay and watch, you are part of the problem."



Bullying (ages 12 to 17)

A CHANGING SPECTRUM

As children get older, the type and range of bullying behaviour increases. While physical, psychological and social bullying happen among children as young as four, other bullying behaviour emerges as children move toward adolescence. For example, *sexual harassment and dating aggression* typically begin in middle school. *No matter what form it takes, bullying is not a normal part of growing up.*

DID YOU KNOW...

Some common forms of bullying in adolescents and teens:

Dating aggression, which includes physical or verbal actions including grabbing, pushing, punching, spreading rumours and name-calling.

Sexual harassment, which occurs when a person or group hurts another person by taunting or discussing sensitive sexual issues, creating sexual rumours or messages, making homophobic comments, rating sexual body parts or name-calling, telling sexual jokes, and initiating unwanted sexual touching.

Ethnoculturally based bullying, which includes any physical or verbal behaviour used to hurt another person because of his or her ethnicity (culture, colour, religion).

ADVICE FOR TEENS

Although situations concerning bullying often differ and vary depending on the incident, some common guidelines for teens to follow are:

- *Ignore the bully* - Bullies look for big reactions, so ignore threats, walk away and go to a place of safety.
- *Stand up for yourself* - Challenge the bully to stop in a loud and firm voice, and walk away (run if needed). Bullies keep attacking if you do what they say and tend to pick on those who do not stand up for themselves.
- *Don't bully back* - Physically fighting back satisfies the bully and is dangerous because you could get hurt or end up in trouble.
- *Tell an adult* - Anyone being bullied or who sees someone being bullied has to tell an adult. Principals, teachers, parents and lunchroom monitors can all help. *It's not tattling, ratting or snitching*: calling out a bully isn't telling on someone for something small - bullying is wrong and it helps everyone if it is stopped.



I have two children with special needs. One has severe ADHD with severe impulsiveness and major oppositional disorder and learning difficulties, including dyslexia and dysorthographia. The other has also been diagnosed with dyslexia and dysorthographia, and has been given access to technological assistance in school since the Christmas break.

My two children have had a tutor since the start of their schooling. My 11-year old daughter, in Grade 6, still writes based on sounds. My son only learned to count to 20 in Grade 2, and had even repeated Grade 1. Therefore, I have experienced

the whole range of issues associated with homework and learning, in addition to behavioural issues.

The program allows me to have someone to listen and provide support in finding organizations that can help, in addition to providing financial assistance that helps alleviate some of the costs associated with the many specialist reports required.

Thank you for being there.

Postal clerk PO-4

Les Cèdres, (Québec)



“We spend a lot of time talking about what families rights are to special education related support.”

A natural fit

“I think it’s amazing that postal workers have this benefit and that the union has made it a priority to support their members in that way—to understand the importance of family and how much of a difference it makes to people to have that extra bit of support for their family needs.”

Janet Marlin has been a Special Needs Project advisor in the Greater Toronto Area region “for so long that I don’t actually know exactly how long it’s been!” she says. We figure it’s been at least 15 years, since her own kids were small enough that she had to worry about how to keep them quiet during her advisory calls. And long enough that some of the families she talks to have kids that have now aged out of the project.

“Some were on my list right from day one until the time they went on to the Moving On project,” says Janet. “It’s funny, you talk to people for years and years not having any idea what they look like, but you get to know them, you hear all about their lives, and you feel like you really do know them. That to me is the really rewarding part.”

Advising parents of children with special needs is a natural fit for Janet. After getting her master’s degree in developmental psychology, she worked in children’s mental health. “And then after I had my kids I realized that all my work took place when kids are out of school, on evenings and weekends, and so I was never going to see my own kids,” she says. It made sense to take a year to go back to school

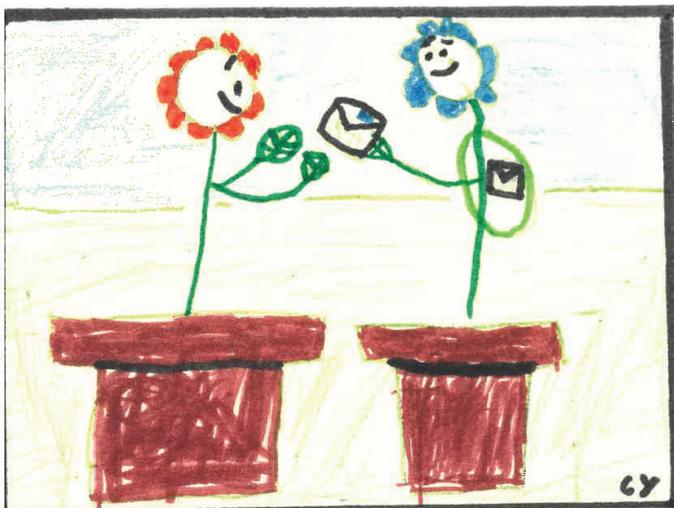


to become a teacher, so Janet could work on the same schedule that her kids were on.

Janet’s experience as a full-time elementary school teacher can be a big help to the families she advises. “Lots of parents have to deal with the school board,” she says. “To be kind of inside of it, I think, can be helpful to families. It’s all acronyms and processes that, when you’re on the outside looking in, are very complicated to understand. And so we spend a lot of time talking about IEPs [Individual Education Plans] and what they can and can’t do, and what families’ rights are in terms of getting special education support.”

But being a teacher—or a student—in Ontario these days can feel a bit uncertain. On the day we talked to her, several of Janet’s teaching colleagues had just been laid off. Families of children with special needs are understandably extra concerned about the future. The province has already cut autism funding, and education cuts have only just got started. Janet and the families she advises will have a better idea of how special education will be affected come September.

Meanwhile, Janet is looking forward to the summer as a time to regroup. She plans to spend time with her family, keep up her yoga practice, do some gardening and play tennis.



← Christopher - Age 11



Jack.org 101

1/7 youth in Canada report having suicidal thoughts. This year, 150,000 of these young people will act on these thoughts by attempting suicide. For hundreds of them, the attempt will prove fatal. This is the leading health-related cause of death for young people in Canada.

Enter *Jack.org*, Canada's only charity training and empowering young people to revolutionize mental health.

Through *Jack Talks*, *Jack Chapters*, and *Jack Summits* young leaders identify and dismantle barriers to positive mental health in their communities. Jack.org is working towards a Canada where all young people understand how to take care of their own mental health and look out for each other. A Canada without shame, and where all those who need support, get the help they deserve. With thousands of young leaders across every province and territory in Canada, we're only just getting started.

By: Christopher - Age 10



Jack.org Programs

Jack Talks - Professionally trained and certified youth speakers using the power of personal stories to inspire, engage, educate, and equip young people to take care of themselves and their peers and take action in their local communities.

Jack Chapters - Trained youth-led groups working year round to identify and dismantle barriers to positive mental health in their communities.

Jack Summits - Youth-led conferences around Canada designed to connect young mental health advocates and build their leadership and advocacy skills so they can implement real strategies for change.

Regional Summits - Jack Summits at a local level, led by community leaders who serve the youth population, and guided by Jack.org staff.

Network Reps - 12 young leaders chosen to represent every province in Canada. Throughout the year, our Network Reps lend their voices to program design and speak on behalf of the network in national media and events around the world.

Our work in progress:

Improving your access to information about disability supports



Support Navigator



Disability Supports Portal

During the spring interviews, Advisors asked members about the kinds of disability supports and services their children need and use.

We thank you for sharing your support needs with us! We will be preparing a summary of your information needs for our new staff member, the Support Navigator. We hope to have the Support Navigator hired by the end of the year.

The Support Navigator will be available by phone to help members find information about disability programs and services.....and use the CUPW_211 disability supports portal!

The portal will provide direct access to provincial disability program and service information. We plan to have the portal launched by the end of the year, too!

"It gets a little bit better everyday!"

My daughter Marisa has grown in leaps and bounds. We took her off medication because we saw it affected her with mood swings and loss of appetite. I was thankful when a friend recommended fish oils and the pediatrician backed up the necessity of her taking them. We have definitely seen an improvement. We have seen her appetite increase and social relationships begin to flourish.

It gets a little bit better everyday! We celebrate the help from the Special Needs Project. Thank you!

PO-4 Postal Clerk

Maple Ridge, BC



Marisa



By: Jordan - Age 5 and Hazel - Age 10

Digital Newsletters

If you want to read or share a digital version of the newsletter you can find it at the address below. To view past copies of the newsletter click the "Downloads" button on the top right corner of the page. Enjoy!

<https://membertomemberconnections.com>

<http://echangesentrenous.com>

Member-to-Member Connection

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