



# Family Pulse

*Where exceptional families thrive.*

Issue 121  
May 2020

## Inside this issue:

A message from Sue Simpson	2
How Living with Exceptionality has Helped Prepare Me	3-4
Steph's Corner	5
SEAC Updates & Survey	6
What's Happening at WRFN	7
Information, Resources, & Opportunities	8-9

## What's in this issue?

### What's Happening In This Issue

As the world continues to deal with the COVID-19 pandemic crisis, there is a glimmer of good news as the number of cases in the Waterloo Region begin to stabilize and the region's hospitals have not been overwhelmed. Social distancing and stay at home measures appear to be working! While it's been difficult for everyone, especially families with children with or without exceptionalities, it's important to remember that our collective efforts are having the intended affect and that we're all in this together.

In this month's issue you'll find some entries from two staff members, both with exceptionalities, one on COVID-19 and on how to navigate uncertainty and a biographical sketch of our admin helper, Steph! There's an important survey on the impact of COVID-19 on families and lots of other useful links and information.



Waterloo Region Family Network - WRFN



@FamilyNetworkWR

## Support WRFN Today

<https://www.canadahelps.org/en/charities/waterloo-region-family-network/>

Waterloo Region Family Network  
[www.wrfn.info](http://www.wrfn.info)  
[info@wrfn.info](mailto:info@wrfn.info)

## A Message from Sue Simpson

Dear WRFN Families and Self-Advocates,

At WRFN we are passionate about supporting your well-being – connecting you to resources and information. We are committed to helping exceptional families – like yours – and individuals thrive, even under the most challenging of circumstances.

The past several weeks has brought about feelings of uncertainty and anxiety. So too will a transition into the phase of re-opening businesses, services, public spaces and, at some point, schools.

You're not alone. You are important to us and we are still here to support you through virtual programs and services available through phone or email.

I would like to take this opportunity to thank Social Venture Partners Waterloo Region, United Way Waterloo Region Communities and the Astley Family Foundation for their very generous recent support of WRFN through the COVID-19 Community Response Fund. Through this support, we will ensure that you continue to feel connected, heard and understood during these unique times and as we all move forward.

Please don't hesitate to reach out if you or anyone you know needs help.

We're in this together!

Stay safe and keep well,

Sue

**What is social distancing?**

Social distancing means avoiding close contact with others to prevent the spread of COVID-19 and can include:

-  Avoiding non-essential trips in the community
-  Limiting, postponing or cancelling gatherings
-  Working from home, where possible
-  Conducting meetings virtually
-  Keeping kids away from group settings
-  Avoiding visits to long-term care homes and other care settings

**Keep a distance of 2 metres from others when going for walks or shopping for groceries.**

 Region of Waterloo  
PUBLIC HEALTH AND  
EMERGENCY SERVICES

[regionofwaterloo.ca/COVID19](https://regionofwaterloo.ca/COVID19)

## How living with exceptionality has helped prepare me for the COVID-19 Crisis

By Cristina Stanger, WRFN Self-Advocacy Liaison

*-- My heart goes out to those whose lives have already been touched by COVID-19, to those who are at high risk of infection and complications, and to those who are dealing with other hardships/tragedies that are compounded by this challenging social environment. And my deepest thanks to the frontline workers, on whom we all depend. --*

While I may appear composed from the outside looking in, my 'sky' is so often falling because I find different aspects of the world around me confusing due to my exceptionalities. But given these unprecedented times of medical threats and rapid societal changes brought about by the coronavirus, I have noticed that I've been uncharacteristically calm throughout all this upheaval. And I thought, "Well, this is strange." And then I got to wondering about why that might be?

A stay-at-home order inherently allows me to bypass many aspects of everyday life that typically overwhelm me. However, I don't feel this accounts for my clarity of mind. Then I thought, "Is it possible that my life experiences, as an exceptional individual, have helped prepare me to navigate these current events?" My intuition is telling me 'yes,' both in terms of weathering the emotional storm and also in finding healthy coping strategies. By no means am I saying that I am handling this perfectly, but I thought it might be valuable to highlight some of the advantages my experience with exceptionality has afforded me in the context of the COVID-19 pandemic. And in doing so, my hope is that you will be reminded of your own wealth of experience, your own strength, and your own resilience in the face of adversity.

### **Some ways of feeling...**

Firstly, there is grief. Particularly, the type of grief sparked when reality doesn't match what you envisioned for yourself or your family. And this is paralleled by what we face today - celebrations postponed, unstable employment, education disrupted. These are examples of how our hopes and expectations for the future have been undermined by COVID-19. I have given myself permission to grieve. In acknowledging my grief, I can move through it, in my own unique, non-linear way, as I have done before.

Secondly, there is the anxiety that comes with uncertainty, with which I am well acquainted. I am sure that many of you reading this now have also had periods of time when you wondered, "What will my future hold?" When you asked, "How much longer can I go on like this?" I am asking myself similar questions again now. And I can employ the same techniques to navigate this uncertainty, such as: (1) identify my feelings and use them as a cue about what I might need, (2) stay present, as I cannot experience anxiety in the now, and (3) seek out support.

## How living with exceptionality has helped prepare me for the COVID-19 (continued)

Thirdly, there is a familiarity with internal existential conflict. I had a three-year period in my life when I was working very hard to overcome obstacles, yet it felt like I was never getting anywhere, and I wondered what my purpose was. Progress was slow and hard to measure. However, during this time I did learn things, such as: (1) a sense of who I am as a person, rather than valuing myself based on my productivity ('being' rather than 'doing') (2) a more forgiving and flexible perception of the passage of time (I will get there when I get there) and (3) the benefit of forming a routine to guide myself through unstructured time (pets are immensely helpful in this regard). While it may feel as if I am currently stuck in limbo, I remind myself that I still have value, I still matter.

### Some ways of coping...

I also understand the need to be gentle with myself. I try to focus on what I can control and take things one step at a time. There are good and bad days when living with exceptionality. So too have I had good and bad days during this pandemic. Identifying which kind of day I am having is key to weathering this storm. Hard days warrant more self-compassion. Good days allow me to take small steps forward.

Adaptations are something that those with exceptionality work with on a daily basis. I have had to find different ways of doing things that other people might take for granted. So, I am able to view COVID-19 shutdown as an opportunity to use my creative problem solving. Knowing my strengths and weaknesses also comes into play, and I can work within my support circle (while socially distancing) to divide and conquer challenges.

A strategy of gratitude is relatively new to me, but I have found it incredibly grounding. Thinking about what I am grateful for helps actively shift my inner focus from what is negative to what is positive. And whether I am dealing with exceptionality or COVID-19, a lens of positivity can work wonders in finding the courage to carry on.

Finally, there is power in acknowledging the journey. The future may be uncertain but taking pause to honour the struggles I have already weathered, can be helpful. I do not feel that I am strong in spite of my exceptionalities, but rather I am stronger because of them. My hope is the same will be said for the COVID-19 pandemic, both on an individual level, and for society as a whole. Please try to give yourself credit for navigating these unforeseen challenges; let's become stronger because of them.

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If you or your family members would like to discuss this, or any other topic, please reach out to Cristina through the Ask A Self-Advocate program (AASA) via our [Online Booking Request Form](#). As with all WRFN programming, the AASA program is provided at no charge.

## Steph's Corner—All About Me

By: Steph Prysnuik

My name is Steph Prysnuik and I just turned 30 years old. I live with a roommate in an apartment building behind KW Habilitation. My Supported Independent Living (SIL) worker and facilitator support me in living as independently as I can. I have an amazing family and Dream Team (Circle of Support) that help me do lots of things and to have a full life.

I like to be busy. During the week, I do lots of activities. Some of the things that I do are music at KW Habilitation, LEG Up classes, Praise Band, Crescendo Choir, Fitness and Boxing, Adult Education, Sports for Special Athletes Bowling and yoga. I really like to hang out with my friends too.

I enjoy taking photographs wherever I go. I have made some of my photographs into notecards. I hope that my notecards make people smile. Researching topics on the internet and keeping connected with everyone by text, email and Facebook are things that I like to do too.

I also like to volunteer in the community and help others. I volunteer at our church, Knox Waterloo, in the nursery and with the Logos program. I also love working and volunteering at WRFN. I have been helping Sue since WRFN first started many years ago. I, typically, work at WRFN on Thursdays in the office. I do filing, put activities on a calendar, labelling, photocopying, count and staple workshop packages and look things up on the computer. It's fun working with Sue and the rest of the staff. They are encouraging, helpful and positive, which helps me to feel good about myself and to do a good job. I miss being in the office these days and look forward to returning. I love Thursdays and I am so thankful to be part of the WRFN team.

Check out Steph's picks for fun activities for kids:

[Photography for Kids](#)

[The Educators](#)

[Activity Village](#)

## SEAC Updates

### Waterloo Regional District School Board Update

Details about future meetings are being determined.

### Waterloo Catholic District School Board Special Education Advisory Committee Update

*Submitted by Sue Simpson and Karen Kovats*

The May SEAC meeting has been postponed until later in the month when the committee will meet virtually.

For news, updates and tips on learning at home, please visit [www.wrdsb.ca](http://www.wrdsb.ca) and [www.wcdsb.ca](http://www.wcdsb.ca)

## Survey Opportunity

### For your participation: Family survey on the impact of COVID-19

Waterloo Region Family Network is committed to doing everything we can to protect the health and safety of people with developmental disabilities and those who support them during the COVID-19 pandemic.

We have been asked by a partnership of Ontario's developmental service agencies called the Sector Pandemic Plan Initiative for assistance in understanding needs, advocating for resources and creating strategies to best manage the impact of the COVID-19 pandemic on people with developmental disabilities and those who support them. We are asking for your participation in a survey to learn:

- The needs of families during this time
- The impact of COVID-19 on the person(s) with developmental disability you support
- The impact of COVID-19 on you as someone who provides support
- What resources, if any, have you found helpful?
- What supports are needed to maintain health and safety (for example, access to behaviour services by phone or facetime), or technology (for example, to use in submitting for Passport reimbursements).

Your participation in this survey is voluntary. **All responses are anonymous and confidential.** The working group will gather the confidential responses and create a list of priorities. This can then be used to help with advocacy and the creation of resources to support families and people with developmental disabilities during times like these.

The survey can be completed in about 10 minutes. You can go back and edit your responses as long as you have the survey open. Once you click the 'Done' button and submit the survey, you will not be able to edit your responses.

Please click on the following link to complete the survey:  
<https://www.surveymonkey.ca/r/TDSAFamCareCOVID>

The survey will remain open with no defined deadline, to allow families to provide their input as they find the time to do it. The working group will be continuously looking at the input they've received and will start prioritizing items. So please make an effort to complete the survey in the next 2 weeks, if possible.

Thank you for sharing your valuable input!



## What's Happening at WRFN...

**As is the case with all non-essential businesses and organizations, due to the COVID-19 virus, all in-person programs and gatherings are cancelled until the health authorities deem it safe to begin again.**

**We will be listing online and virtual resources that we think will be helpful as you navigate social distancing. Also keep an eye on our Facebook Page and our Twitter account (@FamilyNetworkWR) for more!**

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**Ask A Self-Advocate**—Do you need to look at a challenge you are facing with a new perspective? Would you like to bounce ideas off someone who's been there? Cristina was diagnosed with exceptionalities as an adult, and is passionate about sharing her lived

experience. Speak with Cristina to discuss your own questions and concerns to gain new insights and ideas. This program is currently available through phone, email or virtual connection to individuals with disabilities, families, or service providers. For more information on Ask A Self-Advocate please contact Cristina

Stanger at [Cristina.Stanger@wrfn.info](mailto:Cristina.Stanger@wrfn.info).

To request a booking please complete the request form available on our website.

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**WRFN's Family Resource Coach**

During this current COVID-19 health crisis and ensuing quarantine, personal support has become paramount for many families. Erin Sutherland, our Family Resource Coach, is available by phone or email to lend a helping hand and personal guidance to families and to connect you to updated information, resources, and virtual opportunities. We encourage you to reach out. Call Erin at 519-886-9150 ext. 4 or email her at [Erin.Sutherland@wrfn.info](mailto:Erin.Sutherland@wrfn.info)

We provide support in all life stages - NO diagnosis is needed.

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**School Issues Support Group**

This peer-led group provides support, advice and a safe environment for parents who have questions or concerns about school issues affecting their children with special needs. This group is currently meeting virtually. If you're interested in participating, please contact Sue Simpson at 519-886-9150 ext 1 or [sue.simpson@wrfn.info](mailto:sue.simpson@wrfn.info)

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**Coffee Club**

Hi Coffee Clubbers,

I miss you so much! Please contact me to tell me how it's going at 519-500-7153 or [carmen.sutherland@wrfn.info](mailto:carmen.sutherland@wrfn.info). If you have Facebook, you can friend me and we can chat. Tell me how you've been keeping busy, what you've been eating (LOL!). If you were thinking of joining Coffee Club and haven't yet, please still reach out, I want to meet you. We are currently meeting through Zoom.

## Information, Resources & Opportunities

**Kerry's Place Autism Services** has a list of resources for families with exceptional children to help deal with the current COVID-19 crisis. They can be found here: <https://www.kerrysplace.org/covid-19-resources/>

**Recreational Respite** has been working hard as a team to find a way that continues to promote inclusion, encourage community participation and nurture social connectivity. We understand how imperative it is to stay connected. So, we are bringing you a very unique interactive opportunity, that proves innovative and offers experiential outcomes in 1:1, mini or small group virtual settings. That's right, these programs are now available online! They can be found on their website here: <https://recrespite.com/virtual-services/>

**Foundations in Fetal Alcohol Spectrum Disorders (FASD)** is a basic training course intended for everyone that will come into contact with individuals with FASD including all sectors of work, families, individuals with FASD, spouses, and the general public. This foundational level training program provides the perspective of individuals who have FASD, is evidence-based, employs a culturally sensitive approach, and is presented in a way that is responsive to the learners needs. This online basic training course will take on average two hours to complete. Level 1 training will provide knowledge and understanding of:

- an overview of FASD assessment and diagnosis in Canada
- an introduction to FASD interventions and promising approaches
- the effects of prenatal alcohol exposure on the fetus
- the impact of alcohol on brain development
- issues related to stigma and FASD
- strategies for prevention and support
- barriers to prevention and support
- the signs and symptoms of FASD across the lifespan

A certificate will be provided to each participant upon completion: <https://estore.canfasd.ca/foundations-in-fasd>

**KidsAbility** is offering a list of resources for parents for therapy, education, community, as well as fun activities. They can be found on [their website here](#).

**Transition to Adulthood Clinic (for KidsAbility clients 15+)** Have you started to think about your life after high school? Do you have questions about services for adults with disabilities in the community? Would you like to find out about resources that are available to help you with your transition planning?

The Transition to Adulthood Clinic is an opportunity to meet with the Transitions Lead who will help to guide you in the right direction with planning for your future. During Covid-19 isolation, all appointments will be occurring through Zoom. Once KidsAbility Centres have opened up again there will be the option to meet with the Transitions Lead either face to face or through Zoom.

For more information or to schedule an appointment, contact your KidsAbility therapist or call Intake at 1-888-372-2259, Ext 1214

**Sunbeam Centre's Brightside ABA Services** specialize in supporting clients that are 9 years of age and up to support skill development in key areas such as social skills, communication skills, emotional regulation skills, building independence in activities of daily living, and to reduce challenging behaviours. Their fee for service website is now live and can be found here: <https://brightsideabaservices.com/>



## Information, Resources & Opportunities



**Family Compass Waterloo Region** is a central website to guide families to services for children, youth, and families in our community.

The website offers the option to find information about general services for children and youth as well as specialized services that can help to address developmental concerns. It also offers a link to resources designed for parents through the Parenting Now website.

During the COVID-19 crisis, many community organizations and initiatives are providing various services and supports for children, youth, adults, and families. Follow the COVID-19 response link on the Family Compass website to find information and resources that are available during this time.

Click on their logo above to go to their website.

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**Wilfrid Laurier University's School of Social Work** has cancelled all in-person workshops and courses for the spring and summer due to COVID-19. They have added additional sections to courses currently online in cognitive behavioural therapy and addictions. More information can be found on their website:

[WLU - School of Social Work.](#)

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**The Centre for ADHD Awareness, Canada (CADDAC)** is offering a webinar on Remote Learning for children with ADHD. Currently the event is sold out but you're still able to sign up to receive a recording of the webinar here: <https://caddac.ca/adhd/events/webinar-remote-learning/>

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**Early Literacy Alliance of Waterloo Region** is offering a webinar on May 5, 2020 at 2:00pm on Supporting the Professionals who are Supporting Parents during the Pandemic & Beyond with Parenting Author Ann Douglas. Find more information and register here: <https://www.crowdcast.io/e/ann-douglas-presents/register>

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**The University of Waterloo** will be hosting free, weekly community talks on COVID-19 topics. Each Wednesday, for the next six weeks, Waterloo researchers will share information and answer your questions. Community talks will be held online using a video link that will be provided before the talk. More information and registration can be found here:

<https://uwaterloo.ca/community/>