

ENGAGING LEARNERS:
LESSONS LEARNED
FROM A YEAR OF
TELESERVICE

Community
Q&A: GOALS

Supporting
Students
in the
Classroom

Augmentative
and Alternative
Communication

SECOND
LANGUAGE
LEARNING

Back to School,
Back to Life

Plus: STARTING A LIFE PLAN - An interview with Eric Goll



We want to start off by wishing you all a Happy New Year! Because when you think about it, in our North American society, September is even more of a 'new year' than the traditional January 1st we typically circle in red. After the lazy, hazy days of summer, it is now time to get back to routines, to reality, and to goal-setting. As Ren, pictured on the cover, shares inside these pages, realistic goals and planning with the support of others "helps secure a happy, successful future."

If we learned anything in the last year and a half, it's that a happy, successful future starts with being kind to ourselves and to others. Keep that in mind when looking ahead at what this fall brings your way as you get back to routines, work, and school.

This issue of 3.21 has 40 pages of advice, ideas, support, and stories from those who have either been there, or are on the same road as you in planning for the future. We hope this issue brings a smile to your face, and also a generates a handy list of resources to help you achieve your 'new year' goals.

We would love to hear from you! Drop us a line at 321Magazine@gmail.com with your thoughts, story ideas, and opinions.

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ENGAGING LEARNERS

Lessons Learned and Reaffirmed from a Year of Teleservice

By Danielle McKinney, B.Ed

Making the switch to online learning for students with Down syndrome was daunting! Where should we start? What new tech do we have to learn about? How do we prepare?

As therapists and teachers, we all had a collection of go-to lessons and no-fail games and activities that we could pull from at a moment's notice. Visual supports were printed, laminated and Velcro-ed. We could control the environment to reduce distractions. We knew how our students learned best in the clinic setting. And then, suddenly, we were faced with SO MANY unknowns.

What we did know was that the principles we believe essential for optimal learner engagement would hold true, even in an online setting. Things were going to look different, and we would have to make some changes, but following those guiding principles was a start!

An Individualized Approach

For students with Down syndrome, focused and individualized planning is essential. We worried that teleservice would not work for all our students. What we learned was that we COULD support our students via teleservice, but what that looked like would differ from student to student.

We found that some students thrived in a direct instruction model. They were engaged, excited, and learning! Other students benefitted from a more indirect service delivery model. We continued to have weekly sessions, but instead of leading much of the session, we supported families in carrying out learning and therapy activities with their child. Still other families opted for a consultative approach. Based on what they told us, we made suggestions and provided materials for them to use with their child, and followed up with routine check-ins to answer questions, problem-solve and provide direction. The way we deliver services to meet the needs of all our students is one thing we will bring back to in-person teaching and therapy.

Setting Up for Success

The way we set up the learning environment and activities affects engagement. Providing structure and routines can take away some of the barriers to learning that students may experience and set them up for success.

Teaching online convinced us that if it was possible to manage two environments - the student's space at home and the virtual learning space created



over Zoom - it was definitely something we could be sure to do when we got back to in-person learning. In the virtual learning space, consideration of how many things the student needed to attend to was key. It was often tempting to use all the fun, motivating features that this new form of teaching provided; however, the student already had to get used to this new mode of delivery, learning in a different environment, and being supported by a parent or caregiver. So, it was beneficial to introduce one or two new things each session, and re-use activities with which the student was already familiar. It was also beneficial to use familiar materials with multiple uses, so that there was only one change to learn for each activity.

As for the content of the lesson, targeting or focusing on one piece of information at a time was also beneficial. Considering the demands of the task is just as important for in-person learning, and having this highlighted through our experiences with teleservice served as a good reminder.

Accessibility

As with other things, communication looked different. How information was presented during teleservice sessions could be a challenge. This can also be true during in-person lessons, though often not as obvious. Visuals were much more in the hands of the teacher, with the need for screen sharing and multiple files to be open, meaning they were not always accessible to the student. This was a good reminder that, even in-person, we need to be aware of where we place our visuals, what size visuals we use, and what symbols or pictures we put on those visuals so that they are accessible to the student.

Sound quality and positioning could be problematic over Zoom. The need to use short, direct instructions, be animated, enhance non-verbal cues, speak slowly, and emphasize key words was even more important in this environment. For our AAC users, having greenscreen backgrounds of their AAC system for modeling and making sure their device volume was loud enough for us to hear were key considerations.

Providing appropriate ways to respond is always important, and teleservice meant that we had to get creative with this. Without careful planning, we were left with verbal communication as the default; the ability to provide physical prompts or allow students to respond by pointing or picking up objects was taken away. Having caregivers support or asking a yes or no question to confirm their response when we could not see what they were pointing to on the screen was useful. Using distinguishing features like colours, numbers or highlighting pictures as part of the activity provided a way for students to respond when they couldn't point or verbalize their response accurately. We were reminded that, in any setting, we must make interactions as easy to access and engage in as possible.

Motivation

For any student – and especially for students with Down syndrome – motivation is key. Motivation is influenced by

many things, but a few of the factors we have seen at play include providing the student with choice, predictability, confidence, purpose, enjoyment, and social interactions.

Giving students choice allows them to be in control of some part of the experience. This was more difficult online, because activities often required materials to be sent ahead of time or prepped by the caregiver. Finding ways to provide choice in online sessions reinforced the notion that providing even small choices can be very powerful. Choice of which colour marker was used to annotate on screen, the order in which we did the activities, or what activity the student would like for a break were some of the go-to ways that small choices were offered throughout the session.

Nothing was predictable when teleservice began, but we could incorporate aspects of the in-person sessions with which they were familiar to help them make the transition. As with any unfamiliar situation, visuals were a helpful support in online sessions. A visual schedule presented at the beginning of the session let the student know what to expect and offered a chance for us to provide them with choices.

This also increased their confidence. They knew they had seen these activities before and how to perform them, so they could be successful.

While the purpose of the learning activity was one factor that did not change from in-person to online, the activities may have looked a little different, so it was often necessary to thoroughly explain what to expect within this new context.

Finally, teleservice re-affirmed the importance of enjoyment in learning. Passively staring at a screen was difficult and it was often possible to watch the student's attention fade before our eyes! Surprises, attention getters, and brain breaks were even more necessary with teleservice. The need for new learning materials, strategies, and delivery methods brought out the creativity in all of us, and the response from our students inspired us to continue to think outside the box, switch things up, and make learning activities fresh and fun. We were reminded that enthusiasm is contagious!

The online learning environment created opportunities for social interactions that were not always present in the clinic setting. Parents, siblings and even pets joined in on sessions, allowing for more varied communication and encouraging us to include other participants in our in-person sessions more often.



Personalization

Some things were much easier to do online! Images, GIFs, and videos are great tools for learning new vocabulary and enhancing comprehension, so they are sure to make more frequent appearances in our in-person sessions going forward. Incorporating interests was so easy to do ‘big’ online. Green screen backgrounds, PowerPoints with favourite characters and online games had such an impact in many learning activities, and made choosing a preferred activity for a break or end of session reward so simple. Customizing learning materials for each student by changing the colours, themes or characters used was also easier. Observing the success of using these strategies reinforced the value in using them in-person, even if it was a little harder!

Flexibility

The unfamiliar territory that was teleservice meant that as much as we tried to establish the perfect conditions for learning, we also had to be prepared to pivot. Having readily available back-up activities allowed us to follow the student’s lead, to switch things up when necessary, and to realize and adjust when our plans were not being executed, well, as planned! This is as important in-person as it was online. It is sometimes easier to try to convince the student to continue with the plan when we are in-person, but I think it is wise to take guidance from our experience this past year and recognize that what we had planned may not be the best plan for the moment.

A Team Effort

Another unexpected bonus of this year of teleservice was that we got to see our students’ support teams in action! The benefits that come from working with a collaborative team were highlighted as we got the opportunity to work more closely with teachers, education assistants and parents.

As we move away from teleservice for the majority of our students, we will continue to connect through occasional Zoom sessions with school teams, using recorded sessions or activities as examples and providing coaching to team members and families.

Always Learning

One final and important takeaway from this experience is a reminder that we are all learners. We were reminded that it can be uncomfortable to be in a place of uncertainty, as was felt at the start of this endeavour. But lessons were learned, opportunities arose, skills developed, and we all came out on the other side better for being a part of it.



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iPad, uPad, We All Pad!

The Value of Educational and Communication Technologies

By Liv Meriano, M.Sc. RSLP

When asked what I thought of my sister's disability, five-year-old me paused, shrugged, and then I turned to the reporter and said, "She's a little different, but she just needs a little help sometimes."

My older sister Navia was born with cerebral palsy and was nonverbal. Being so close in age, we developed our own language of eye gaze, choice making, and head tilts that signaled "yes" or "no." This slowly developed into speech-generating switches and then an assistive technology device mounted on her wheelchair. She learned how to request what outfit she wanted to wear and what Friday night take-out she wanted, and was able to share all the excitement of our family vacations with her classmates. As we got older, she certainly learned how to flirt with handsome doctors and order herself a beer!

My sister was the first experience I had with someone using assistive technology, and the power it gives a person to have a voice – not only to advocate their wants and needs, but more importantly, to socially connect with others and participate in society. It allowed my sister to reveal her colourful personality, exercise her independence, and, equally as important, reveal her competence to others who would otherwise underestimate her.

People with developmental disabilities like Down syndrome often have communication challenges too. Being strong visual learners, they can benefit from technological intervention to help their speech, language, social development, and education.

What is AAC?

AAC stands for Augmentative and Alternative Communication. It captures all the things that support communication when someone cannot always rely on their natural speech or language skills to express themselves. The goal of AAC is to enhance the communication of individuals with complex communication needs.

If we think about it, we use forms of AAC all the time – we may not realize how much we

communicate without speaking, whether it is giving a thumbs up to a friend from across the room or pointing to a picture on the menu to signal to a waiter we want that delicious looking meal that is too difficult to pronounce!

The term AAC encompasses all forms of non-verbal communication, including unaided forms such as facial expressions, gestures, vocalizations, body language, and signs, as well as low-tech tools such as picture symbols, communication boards, or writing with a pen and paper. During the pandemic, in particular, we've all discovered the value of high-tech communications devices like mobile phones and tablets. Many individuals with Down syndrome will utilize more than one of these aides over the course of their lifetime.

Why Would Someone Need a Communications Device?

People with Down syndrome can have difficulty being understood for many different reasons. Difficulties could be related to speech; that is, the sounds someone makes using their mouth. AAC is often considered when speech intelligibility is an issue. 'Intelligibility' is a word often used when talking about AAC, but it has nothing to do with

intelligence. Intelligibility simply means how well someone can be understood. So, if someone gets across their message clearly, their intelligibility is high. If it is difficult to understand them, we would say they have reduced or lower intelligibility. Intelligibly is usually moderately to severally reduced in people with Down syndrome.

Receptive language is often better than expressive language in individuals with Down syndrome. That is, people with Down syndrome often understand a LOT more than they can express. People with Down syndrome are strong visual learners, so visual technology can help them better communicate with others. Regardless how someone communicates, no one should be denied access to communication!

Strategies for Implementing Technology

Here are some tips that are intended for individuals who are still learning to use their communications or educational technology:

1. Always Have It Available

Where do you keep your device? If the individual is using the device to communicate, it is important to give them access

As parents, we knew that some kids with Down syndrome need extra help to communicate. So we started learning ASL together as a family when Isaac was a baby. Later, when our first SLP showed us a few PECS icons, we used ASL to teach them to Isaac.

Our second SLP made us a communication book, which was divided into categories (colours, shapes, food, toys, etc.). Isaac's preschool got a copy, too, and his EA worked hard with Isaac and the book.

Before beginning kindergarten, the SLP told me that we should start using an AAC device. The AAC device has been a great tool. Isaac quickly realized that he can have a voice now.

Now with the help of our wonderful SLP Liv, Isaac can tell us (and his peers) his choices and feelings, and make decisions for himself. It's also great for learning concepts and for reading, because as he learns the icons, he learns the corresponding words, too.

- Pamela Carvajal, Isaac's mom



Christian, who is seven years old and has Down syndrome, lives in Ontario with his parents and his sister Lucy. He has been in speech therapy since he was ten months old and has a current vocabulary of about ten words that anyone can understand, and about 25 that his family can understand. He has yet to be fully diagnosed for his speech due to his young age. Christian uses many gestures and signs to communicate – something that is strongly encouraged by his family and peers. He also makes up his own signs, which helps him to communicate his emotions and needs.

Christian started using an app from AssistiveWare on his iPad during the summer of 2020, to help him communicate both in and outside of the home. He was introduced to it through the AAC program at his local children's treatment centre, where his mom advocated for additional assistance, after Christian was being discharged from the speech program at age five with no speech. Since he has started using Proloquo2Go, his parents have "noticed that he has gotten better at communicating more proactively."

Christian's mom Paula strongly encourages parents to ask about what supports are available for their children to help with communication skills in general, and specifically about AAC. As a family, they found that "if you don't ask, no one will tell you about communication programs and where to find help. Ask your doctor, your specialists, your school, and other families who have been in your shoes." Christian's family is grateful that they asked early for referrals, and they believe that support early on will lead to better communication skills for him, and improved support in school. Asking what supports are available locally should be an ongoing task. This fall, for instance, Paula adds that, "Christian will be attending a program through our school board that actually focuses on communication, which will in turn help him to become accustomed to using the device as a main source of communication."

Christian also returns to school this September with his device supporting him. Paula expects this

to go well, as he sees his peers on devices, and realizes the benefits of his growing communication skills. His mom hopes that Christian's improved communication will be healthy for both his learning, and for his self-esteem. "Christian is an intelligent kid, but his speech limits what he can relay back to his teachers about what he has learned. Just because he is not saying what he's learned doesn't mean he isn't learning it. The device will allow him to communicate his learnings more easily and accurately."

At home, his family "would love to one day have a conversation with Christian about his day, about what he did and how everything went." And they don't care how that comes out, whether it is through traditional speech, sign, gestures, or on a device. They have gotten past the common worry about electronic supports becoming a crutch. "You can't think of it that way. This is an opportunity to support him NOW."



to it all the time. That means that it is out, charged, within reach, or always in the same place.

2. Model, Model, Model

As we know, people learn to talk by hearing those around them speak. The same goes for those who use a device to communicate. They need to see what it looks like to use technology when communicating with others. There is sometimes a misconception that tech is “magic,” and a student should be able to use it fluently right away – but that is far from the truth. Individuals need to be taught how to use their systems. We cannot expect them to learn to use AAC without being shown how to use it.

3. Find Opportunities to Use it in Your Day

Once you feel comfortable modeling the technology, find natural opportunities to use it in your daily routine. The individual will learn their system faster, the more you build in opportunities for them to use it. And what better way to build in natural opportunities than at home? Think about all the different words you could model! The more opportunities they get to practice, the more likely they will generalize their language skills with different activities and people.



TECHNOLOGY MYTHS AND REALITIES

There are many myths about communication and educational technologies, which can impact the willingness of a family to pursue it for their loved one. Thankfully, due to research, we now know more about the positive outcomes of technology for individuals with complex communication needs. Below are the most common myths we come across:

AAC hinders or stops further speech development - Myth!

Fact: AAC does not stop the development of speech or someone’s motivation to use their speech. In fact, it may enhance the development of natural speech and language when intervention is multimodal and incorporates forms of AAC.

AAC is a “last resort” in speech-language intervention - Myth!

Fact: AAC can play many roles in communication development. Research has shown it to have better outcomes in encouraging more spoken output, expressive, and receptive language and decrease frustration and challenging behaviors when introduced early on. There have also been studies that show significant benefits in socialization, independence, and self-esteem.

AAC is only for children who are nonverbal - Myth!

Fact: AAC is for any person, regardless of age, who does not have reliable communication 100% of the time. Meaning, anyone whose natural speech or language skills do not meet their needs to participate in all aspects of their life could be a good candidate for AAC.

If your loved one does not have effective communication, consider referring to an SLP for a consultation. They will do an assessment of your loved one’s speech and language abilities and recommend what system best fits their needs.

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The Wonder of Words:

Second Language Learning for Individuals with Down Syndrome

By Adelle Purdham

Before I had kids, as a young and eager French immersion teacher starting out, I used to believe that the French immersion program and second language learning was for everyone—with the exception being, perhaps, if the child had some sort of language delay. Several of my colleagues believed that a child requiring additional support shouldn't be receiving instruction in a second language. I hadn't considered second language learning as a privilege, but looking back now I see that's what it was: a privilege only afforded to certain children.

Enter Elyse. Becoming the parent of a child who would experience language delays forced me to challenge my own assumptions. From the time I received her prenatal diagnosis, I thought—and if I'm being honest, worried—about what Down syndrome would mean for her future education. Would she go to the same school as her big sister? Was a French immersion program feasible for a child with Down syndrome? Did learning a second language make sense for a child with cognitive, developmental, and communication delays?

My own experiences with second language learning and the benefits of bilingualism up to that point had been extensive. After going through a French immersion program as a child, I was able to study French in university, live and work in a French community, meet a French boyfriend, secure a job, be interviewed by CBC Radio in French, and engage in meaningful conversations when encountering French speakers around the world. As a new parent, I understood intuitively I wanted these experiences and opportunities to be available to my own children.

The benefits of second language learning are well documented and supported by research. Learning a second language helps to develop problem-solving skills, critical-thinking and listening skills, as well as improving memory, concentration, and our ability to multitask. Children who are proficient in other languages show signs of enhanced creativity, mental flexibility, and academic achievement. But perhaps most importantly, learning a second language helps children develop positive attitudes, empathy, and understanding for other cultures, and fosters cultural sensitivity and tolerance. Second language learning helps children develop a curiosity about the world and become global citizens.

In knowing the benefits of bilingualism, I balanced my desire for Elyse to be able to learn a second language with my fear that I may be wasting years of her education by not focusing on her first language, where I saw areas of concern. Thankfully I remembered that, years before, I'd completed a research project where I asked that exact question: does learning a second language create a deficit in one's first language? The answer was a resounding no.

But what about for kids with Down syndrome? As renowned researcher Dr. Sue Buckley reported more than twenty years ago, "There is no evidence of a detrimental effect of bilingualism for children with Down syndrome or that learning two languages has any negative effects on the development of the child's first language." Dr. Buckley was clear on one matter,

Bonjour!

Привет!

Hi!

Hej!

今日は!

Hola!



“ LANGUAGE LEARNING IN ONE LANGUAGE DOES NOT TAKE AWAY FROM LANGUAGE LEARNING IN ANOTHER LANGUAGE; IT ADDS TO AND EXPANDS OUR COGNITIVE CAPACITIES.”

though: “No matter what language of instruction you are using, early reading is a key tool in speech and language development.”

Language learning in one language does not take away from language learning in another language; it adds to and expands our cognitive capacities. The learning strategies Elyse would encounter in French, say in decoding while reading, would be the same strategies she would use in English. She would learn to think in French, and the skills she developed in French school would serve her well in English. What did it matter if Elyse was learning concepts in French or English, once she’s acquired the language? The question was, would she acquire the language?

Children who learn another language before the age of five use the same part of their brain to acquire a second language that they use to learn their mother tongue. I couldn’t think of a good reason why Elyse shouldn’t learn French. Why shouldn’t she have the privilege of learning a second language? The same privilege that I had, that her dad and extended family had, and that her sisters would have? I had to acknowledge that perhaps it was only preconceived notions—my own, and societal—that might hold her back.

We decided to go for it.

A year before Elyse was eligible to be registered for school, I met with our local French immersion school. I had one simple question. “What supports are available in the French immersion program for a child with Down syndrome?” I met with the school’s resource teacher whose job it is to ensure each student has the supports they need.

“That’s a good question,” the resource teacher said, as in, who knows? That was not the answer I was looking for. I came to understand that perhaps the idea of French immersion programs being “elite” or for a certain type of learner still held some ground and that there remains work to be done and stereotypes to be broken down. Perhaps certain school boards, like me before I did my research, had yet to get the message that second language learning is for everyone.

I turned to the French First language boards. I reasoned that if Elyse was placed in a French First language school where she would learn exclusively in French, there would be no alternative but for her to learn French. When a family speaks more than one language in the home, a family member with Down syndrome learns those languages. And guess what? That’s exactly what happened with Elyse at school.

Second language learning requires an investment of time. Initially, it takes time for a child to develop the vocabulary and grammatical awareness of a second language, and this may be at the expense of learning other skills typical of that age group for a period. For example, English spelling may lag. But that gap all but disappears before high school. As parents, it’s important to be patient—a child’s first language won’t suffer in the long term. The earlier and the more exposure to the second language the child is given, the better, especially if the goal is to achieve some level of mastery and reap the benefits of bilingualism.

While expert consensus is that the ability to acquire a second language becomes more difficult after the age of eight or nine years old for the majority of us, and an individual becomes less likely to acquire the language proficiency of a native speaker after childhood, it is never too late to learn a new language.

Elyse entered French First language school at three years old and receives 100% support from an educational assistant. Five years later, as an eight-year-old, she reads short books in French confidently. Her comprehension and receptive language in French is fluid, while her expressive capabilities remain a challenge in French and English. The concepts she learns in French hold the same meaning as if they were taught in English. As a native English speaker, Elyse is working towards becoming a bilingual French speaker. Her ability to tell a joke in any language still holds.

While the gift of being able

to speak two languages is nice, the possible health benefits are even nicer. As I alluded to earlier, there may be life-long health benefits for second language learners, especially for individuals with Down syndrome who have a higher incidence of developing Alzheimer’s dementia. Alzheimer’s is a progressive disease that begins with mild memory loss and can seriously affect a person’s ability to carry out daily activities. As the most common type of dementia, Alzheimer’s involves parts of the brain that control thought, memory, and language.

Second language learning helps with the brain’s plasticity, which researchers are confirming can help to stave off Alzheimer’s. One study reported that being able



to speak two languages could delay Alzheimer's by as much as 4.5 years.

By the age of 40, most people with Down syndrome have beta amyloid plaques, which is one of the hallmarks of Alzheimer's disease. A staggering estimated 50% of people with Down syndrome will develop dementia due to Alzheimer's. By comparison, 11% of the general population will experience Alzheimer's dementia. A 2018 research team lead by Natalie Phillips at Concordia University reported that bilingualism, or proficiency in two languages, creates changes in brain structure that are linked with resilience against Alzheimer's disease and for delaying or preventing the mild cognitive impairment that often precedes Alzheimer's. Bilingualism may also contribute to the development of certain brain areas that control executive function and attention tasks, which are areas of need for many learners with Down syndrome.

While many of the numerable benefits of second language learning remain unseen, the greatest joy for me as a parent has been watching my girls use

their second language to connect with French speakers on our travels. Elyse befriended a little boy from France while playing at the pool; they splashed and laughed together at a resort we stayed at in Thailand. The little boy asked for Elyse every time he saw me and passed along sweets to give to his new friend. I like to think kids speak a universal language—the language of the heart—and that perhaps those two would have become friends no matter what languages they spoke aloud, but when it comes to making new friends, comprehending, and speaking their language certainly doesn't hurt. Language is an essential form of connection.

Through language we connect with others, but there is also the reward of learning a second language for the exquisiteness of its expressions: the simple beauty of the language itself—a beauty that should be made accessible to all. As Charlemagne put it, "To have another language is to possess a second soul."

While an appreciation for language comes with time, Elyse has shown me that individuals with Down syndrome are more than capable of learning a second language and are ready to do so with joie de vivre.





*"I just had to reach out to say thank you for existing! Wow. What an important resource. I am inspired by **The LowDOWN Podcast**, which has been saving my life over here in relative isolation. I love this podcast so much."*
- LowDOWN Listener



The LowDOWN Season 4: Coming Sept 1

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STARTING A LIFE PLAN: AN INTERVIEW WITH ERIC GOLL OF EMPOWERING ABILITY



Eric Goll, Founder of Empowering Ability and author of *The Ultimate Guide to Independence*, is a family member and a family coach. Eric played a key role in helping his sister Sarah move out of their parents' home and into a home of her own over the last seven years. Eric has coached over 350 families to support their loved one with a developmental disability to gain more independence. Eric focuses his support upon finding employment, increasing overall capability, building relationships, and creating individualized homes.

3.21 Magazine spoke with Eric about his work and about the family journey he took together with his sister Sarah in her increased independence.

3.21: TELL US WHY YOU USE THE TERM "ORDINARY" IN DESCRIBING THE PROGRAM YOU OFFER.

Eric: I avoid the term 'special.' I find that once a person is put on a 'special needs' path by the medical and school systems, they are then treated as 'special' in other parts of their life, which results in them often being removed from all the good, 'ordinary' things that we typically experience within our communities. To me, 'special' things are the opposite of 'ordinary' things, and so 'ordinary' to me is the ultimate goal.

3.21: HOW DID YOUR PERSONAL EXPERIENCE WITH HAVING A SIBLING WITH A DEVELOPMENTAL DISABILITY MORPH INTO TODAY'S EMPOWERING ABILITY?

Eric: It found me and I found it. Over the course of my journey with Sarah in helping to increase her independence, I met other families who were on the same path. Working with them and understanding their struggles inspired me to become a family coach.



Sarah and Eric as children

3.21: HOW LONG AGO WAS IT THAT YOU TOOK THE FIRST STEP TOWARDS CREATING SARAH'S MORE INDEPENDENT LIFE WITH HER?

It began with a call from my mom in 2015, reaching out for our family to help support her. After that call, it took a full year to even begin to see a plan take shape. But we kept working, and in 2018 Sarah moved in with me. Sarah grew tremendously during those two years, and made a believer of herself and my parents that she was capable of having a home of her own. As of this Fall Sarah has been living on her own, with some supports, for a full year. She is truly building her own ordinary life.

3.21: WHAT WAS THE BIGGEST BARRIER FOR YOU TO STARTING THE PROCESS WITH SARAH IN CREATING HER OWN ORDINARY LIFE?

The biggest barrier in the beginning was shared by us all. It was our belief, and Sarah's belief (based on our actions and treatment of her) that she was not capable of a more independent life.

ADVICE FROM ERIC FOR FAMILIES ON STARTING CONVERSATIONS ABOUT THE FUTURE:

- ✓ Recognize that life experiences for those with intellectual disabilities are often quite limited when compared to neurotypical life experiences. You have to keep that in mind and be respectful of that. Sarah would often answer "I don't know" to my many questions. I found it frustrating, but then realized that she actually didn't know. Because of a lack of life experiences, she really didn't have perspective on certain topics.
- ✓ I find it helpful to use others as examples. If you can point to an individual who moved out and now lives independently (whether they have or don't have an intellectual disability is beside the point, you simply need a person who once lived at home and now lives independently to illustrate the scenario). This makes it easier to talk about the plan that person needed to get there, and find similarities.
- ✓ Start the conversation casually. It does not have to be an official 'family meeting,' or planned in any way. Work conversations into everyday life to get someone thinking about more independence and how to get there. For instance, "Do you think so-and-so is happy living in their new apartment?" or, "Can you imagine yourself one day living in an apartment of your own?" or, "What do you think you would need help with if you lived on your own like so-and-so?"
- ✓ Families have watched videos on my website together with their loved one, and that has helped to start conversations too. This one is a great start: <https://www.empoweringability.org/1-thing-learned/>
- ✓ Sometimes it will be a "no" at the beginning of these conversations. But as you and your circle of supporters start to build upon the plan and your loved one sees and hears that this really is something that is going to take shape, they will start to become more engaged and positive about it, and participate. With greater frequency of conversation about independence, fears start to diminish and ideas start to get shared. Then families and those with the disability can start to work towards common goals.
- ✓ By involving more people in the plan and conversations, you get more ideas. Often those ideas come with support from that person because of their excitement about 'their' idea. As a collective group, you are able to think bigger and develop a more complete 'ordinary' plan. Generally, there is more buy in and success.

3.21: HOW DID YOU OVERCOME THAT BARRIER? HOW DID SARAH OVERCOME THE PREVIOUS LOW EXPECTATIONS THAT WERE PLACED UPON HER?

Eric: There was a perception that Sarah was being 'lazy,' that she wasn't keen on striving towards her own independence. But she was not lazy. The fact was that she had learned over time to become helpless. So much was done for Sarah that she had even started to believe herself that she was incapable. Once our family changed our attitudes and processes Sarah did too. This was accomplished through the right level of challenges, with the right level of supports.

3.21: HOW IMPORTANT ARE CONVERSATIONS WITH YOUR LOVED ONE WITH A DEVELOPMENTAL DISABILITY IN PROGRESSING FORWARD AND GROWING?

Eric: That is not an easy one to answer. It is tricky to talk about the future with those who have developmental disabilities. The future is often an abstract concept. It can also feel very overwhelming to talk about a future where parents are not a part of that future, and that can naturally create worry and fear. There sometimes is the added perception of "oh, so you are kicking me out..." so, I often advise people to be very careful in their approach. Each parent and sibling knows their loved one best, and will know the best approach for them.



Sarah and Eric as adults

3.21: HOW MANY PEOPLE HAVE YOU WORKED WITH WHO HAVE DOWN SYNDROME?

Eric: Lots. My courses are very popular with families who support someone with Down syndrome. I don't track figures but would guess more than 50 families I have supported include someone with Down syndrome. The course, membership, videos and podcasts are all developed for families. There are others that are developed specifically for supports. All are designed in a step-by-step, action-oriented way, so people can move through the steps together.

3.21: TELL US THE BIGGEST SUCCESS STORY YOU HAVE EXPERIENCED OR SEEN.

Eric: Success stories are all relative. I could not pinpoint just one because they are all so unique to the individual and to the individual family. There are a lot of little steps along the way and each one is a success for that person. Of course, when someone moves out on their own that is a huge success, and very celebrated, but to someone else a huge success may be taking the bus independently, or managing their own supports that is their biggest success, or finding a job.

3.21: IS IT EVER TOO LATE IN LIFE TO START WORKING TOWARDS A MORE INDEPENDENT LIFE? OR TOO EARLY?

Eric: It is never too late or too early. It goes back to 'the ordinary,' and to setting expectations at any age. The average age of those I work with is about 18 – 45 years. I have recently launched The Independence Coaching Program. Families can first access the Free Growing Independence Workshop available through this link: <https://www.empoweringability.org/independence-workshop>. After the free workshop, if families want to go deeper they can with the Independence Coaching Program. This program is more applicable to younger families. It consists of self-guided video lessons and three group coaching sessions, one each month for three months. The program has a rolling registration, which families also find helpful in planning schedules.

ERIC, DESCRIBING SARAH AND THEIR JOURNEY TO INCREASED INDEPENDENCE:

My sister Sarah is in her early 30's. She has been living on her own for almost a year. She loves the freedom she now has to make her own decisions, and loves having control of her own space, which she shares with her much-loved cat, Annie. Our family has watched Sarah's capabilities grow immensely, with a sustainable support system. When I zoom out to see the 'big picture,' it is going extremely well. Day to day has its challenges, and Covid has exacerbated some of those challenges, but when we look back upon where Sarah was five years ago, the growth for us all has been remarkable. I'm sure she would agree.



Sarah and her cat, Annie

JOSH & KAREN MACDONALD, ON JOSH'S 'ORDINARY' LIFE:

Together with his family, Josh MacDonald first completed The Life Plan Coaching Program through Empowering Ability to initially build a plan, then joined The Empowering Ability Club to implement their plan with ongoing support. Here is a little bit from Josh and Karen MacDonald, on Josh's 'ordinary' life:

Josh: My name is Joshua MacDonald. I live with my sister and my parents. In ten years, I think I will be living in my own home. I will be independent and have my own job. I will be hard-working and travelling the world. Right now I do my own washing and dressing. I make myself meals with food in our fridge. I vacuum, I empty the dishwasher, and I help with the laundry. I have a music teacher that I enjoy writing songs with. My resume is complete and I have been waiting for quarantine to lift so I can look for work. I am learning to take the bus by myself and my father is teaching me how to cook.

Karen: Our son Joshua is 25 years old and his sister Cassandra is 21. Joshua graduated from high school at the age of 21. At the time, there were not a lot of options for further education or developing work skills. Joshua was bored at home. We needed to talk to him about what he wanted his future to look like, what his dreams were, and what his goals were.

We heard of Eric Goll's program Empowering Ability Club or 'EA Club,' through the Down Syndrome Association of Toronto (DSAT). We signed up a year ago and just registered again for year two. My husband, Tim and I both work, so we do not have a lot of free time. Month after month, and year after year would go by and no plans were being made for Joshua's future.

The EA Club program was exactly what we needed. We have our Zoom classes, and we spend about three to five hours each week helping Joshua plan his future. We are working on building a support circle right now with Eric's help. Joshua is living his awesome ordinary life!



SUPPORTING STUDENTS WITH DOWN SYNDROME IN THE CLASSROOM: AN OT PERSPECTIVE

By Hina Mahmood, M.OT and Arianna Coles, M.OT



The beginning of the school year can be an exciting yet stressful process at the best of times. While teachers and school staff are working to prepare lesson plans and organize the classroom, parents are rushing to purchase supplies and get kids back into a routine. Meanwhile, students with Down syndrome may be experiencing their own sense of excitement, anticipation, and anxiety.

The uncertainty of the COVID-19 pandemic has disrupted the school routine and impeded the learning process for many students. As we gradually return to a sense of normalcy, it is vital to maximize every opportunity to increase success in the classroom, and occupational therapy can provide the framework to do just that.

Occupational therapy is a client-centered, holistic health discipline that empowers and enables individuals of all ages and abilities to live functional and independent lives doing the things that are most meaningful to them. OT's can help individuals increase independence in the areas of 1) self-care (feeding, grooming, toileting, sleep), 2) productivity (school, work, volunteering) and 3) leisure (hobbies, exercise, social participation).

Occupational therapists can use a variety of approaches to help clients become more independent. According to the Person-Environment-Occupation framework, to achieve optimal performance in any given task, there must be a suitable interaction between three components: 1) the person 2) the environment and 3) the occupation or task. As OTs, we often use the PEO model not only to assess and create learning goals, but to problem solve when challenges arise. The PEO model can serve as a good visual reminder that if all three components are in balance, the opportunity for learning and progress are increased.

On the following pages, we break down the PEO in relation to how we support our clients with Down syndrome.

PERSON

This domain can include self-concept, health, cultural background, and cognition

★ Medical Factors

From frequent coughs and colds to more chronic conditions such as obstructive sleep apnea and stomach issues, individuals with Down syndrome must contend with multiple medical challenges throughout their lives. These health conditions can impact day-to-day functioning, resulting in difficulties with behaviour including the abilities to listen and focus, follow directions, and self-regulate. When our students are having a typically difficult day in the classroom, we must take into consideration how they are feeling on that day. Did they have a poor sleep the night before? Are they just getting over a stomach bug? Often, there may be another reason why they are struggling in the classroom.

★ Physical Factors

We must also consider the physical characteristics of Down syndrome. Low tone, hypermobility, and decreased strength and endurance can make learning even the most basic skill a challenge. As OTs we take these factors into consideration when creating an intervention plan or providing strategies. Many times, our students might have difficulties with completing schoolwork because they fatigue more quickly than their typically developing peers.

★ Cognition

Another key component when considering the person is cognition. We know that individuals with Down syndrome have certain challenges with learning, but they also have many strengths. Understanding the full scope of how they take in, process, and use information can be extremely valuable in assisting with learning and development. Are we using enough visuals? Are we providing them with too much verbal input?

OCCUPATION

This domain includes the task, how it is structured, and the steps required to complete it successfully

First, ask yourself what are the **steps of a task** and how many are required?

- ★ Depending on the student, being provided with too many steps can be overwhelming and difficult to process.
- ★ Task analysis involves breaking down the steps of a task, identifying where the student is having difficulties and beginning your support there. The goal will be to go from maximal support fading into minimal support/independence.

Next, we need to consider the **subskills** required to complete a particular task.

- ★ E.g. You are asking your student to clean up their desk and change their shoes to go outside for recess. Factors to consider include:
 - Can your student effectively process multistep verbal instructions?
 - Does your student know how to take off/put on their shoes?
 - Does your student know to untie/tie their shoes?

Finally, think about **how a task is structured**.

- ★ Is it broken down into manageable pieces where each step is clearly laid out, or are the expectations unclear?
- ★ Students with Down syndrome are strong visual learners. Using visuals to lay out the sequence for a task can support successful task completion.
- ★ Providing your student with the **just-right-challenge** means you are meeting your student where they are at, adapting an activity to where they are still being challenged, but not too much that it seems unachievable and can lead to frustration.

OPTIMAL PERFORMANCE



ENVIRONMENT

This domain includes the physical, cultural, socio-economic, and institutional environment

What is occurring in your student's immediate environment also impacts their levels of anxiety and their performance. Aspects of the environment to consider include:

★ Classroom

- Is there a lot of noise or activity?
- Are the lights too bright or too dim?
- Are there many visual distractions around the classroom? (i.e. bright colours, cluttered desk space, decorations)

★ Supports – Equipment

- Is your student set up with supportive seating? (i.e. feet flat on the floor, hips and knees at 90 degrees, table or desk at an appropriate height, back support)
- Are your student's sensory needs being met? (e.g. providing a wiggly cushion to allow your student to move and stay regulated)

★ Supports – People

- Are teachers and/or other students aware of your student's needs/how best to support their learning?
- Is there additional support in the classroom if needed?

As occupational therapists we encourage parents, caregivers, teachers, and school support staff to also use the PEO framework to help assess and problem solve challenging situations for your loved ones and students with Down syndrome at home and in the classroom. Examining the interaction between each of these components can help provide a holistic understanding of your student's learning needs, and ultimately provide tools that can help to set them up for success!

For more information please contact DSRF OTs Hina Mahmood, M.OT (hina@dsrf.org) and Arianna Coles, M.OT (arianna@dsrf.org)



Hi, I'm Julia from Timmins, Ontario! One goal that I have set is to independently take the bus to work. Another goal is to learn how to prepare meals independently, including planning meals and grocery shopping.

In order to reach my three main goals of taking the bus to work, meal prep and grocery shopping, my plan is to be part of a program called Respite Care. Now that the restrictions are lifting, I will be able to start my Respite Care Program. Respite Care is where I get a worker to help me with my goals that I want to reach for my independence in my dream of living on my own.

I would also like to do my own laundry, housecleaning, and improve my money skills. I am working on all these skills in my home, so I can become more independent.



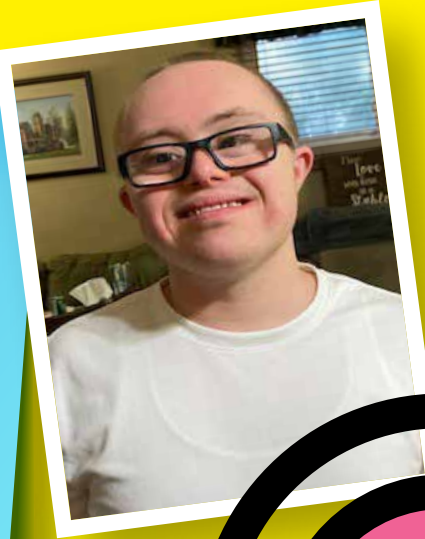
Hi! This is Ren, and I am writing to you from Kitchener, Ontario. With COVID restrictions lifting, I plan to visit my brother in Montreal soon, and also to return to my job at Dairy Queen by the fall. Over the next year or so, professionally, I'd like to be working full time, and to continue with my volunteer job. Personally, I'm really looking forward to maintaining friendships in person.

Right now, I am continuing my weight loss and health journey. At the start of 2021, I began a meal program called Noom. It helps me make healthy food choices, and keeps me motivated. Every day, I try to include some form of movement, by going on the treadmill, walking outside with my parents, but mostly swimming in the backyard. I have lost over 30 pounds and would like to reach 75 pounds. My Fitbit helps me stay on track too. I'm very proud of where I am with this goal, and being proud is motivating.

I am working hard to prove my independence. Ultimately, I want to move out of my mom and dad's, but still visit once a week to have a meal, and do my laundry at their place. I want to have my own apartment, or live with a friend. I also want to get my license. My ultimate dream is to someday own a red Mustang convertible, to publish my own book, and work in an office with my best friend, Shannon.

My plan is still a work in progress right now, but I am saving every penny I earn for my future. My parents work to put systems in place to support me in my independence, and they have lots of chats with other parents and friends to help secure a happy, successful future.

My name is Joshua and I will be turning 25 years old this August. My goal is to find a job this year. I plan to hand out my resume to companies looking to hire me. I also want to learn how to salsa dance! I plan to take lessons in order to learn it.



GOALS Q&A

This is Eric from Coquitlam, British Columbia. My goal is to return to speedskating and curling with Special Olympics. A few years ago, I won one gold medal and three bronze. I hope to get back to the British Columbia or Canada Games and win more medals!

I would like to do weightlifting by myself at a gym. I had a membership before Covid, and I would like to get back to it. I lift 5-10 pound weights currently.

Training helps me to reach my goals. I do skate training from September to March every Sunday morning. I time myself to see if I'm getting faster. My weightlifting helps me get faster on the ice too.



Matt here from Tillsonburg, Ontario! My current goal does not have a timeline set to it, but it is a big goal and an important goal. I am becoming more active. I am focusing on distance running, cycling and swimming as I would love to run a Triathlon. Setting this goal by myself shows what being truly independent is all about. I ask for advice from friends, family and professionals I know if I need it.



DSRF's
BIG BOCC
ThrowDown!

September 11, 2021
North Vancouver
Bocce Pits

[DSRF.org/Bocce](https://www.dsr.org/Bocce)



*Celebrating our return
to in-person events!*

CDSS SPOTLIGHT

Canadian Down Syndrome Week Will Take Place from October 24 - 31, 2021!



Join your fellow Canadians and the world in celebrating Down syndrome this October! As announced on our social media wires in July, The Canadian Down Syndrome Society is adjusting Canadian Down Syndrome Week to align with many other celebrations held during Down Syndrome Awareness Month. Oct 24 – 31 will be Canada's week to shine!

Start planning now to host an awareness and fundraising community event, a class or school presentation, blue and yellow light shows, and get active on social. Let's all get involved to promote awareness, advocacy and teach others to #SeeTheAbility! #CDSW2021

If you need help with your plans or materials for your awareness work, or are a Canadian group and would like messaging from CDSS to share news of the date change with your members, **reach out to us here!**

Slip Into Some New #CDSW Socks!

Celebrate Canadian Down Syndrome Week in style! We've unveiled our official NEW Canadian Down syndrome socks to help spread awareness and cheer this October, and to help raise valuable funds for our programs and resources!

Deadline to order to ensure delivery by the start of #CDSW within Canada is Friday, October 1. To order, visit www.FridaySocks.com. Don't delay, quantities are limited! See our ad on page 15 for all the details.

#CDSW Webinar Speaker Series Focusing on Mental Health

#CDSW week is not just about celebrating, it is about our mission to support the Down syndrome community across Canada. During CDSW we will host three new webinars, to be held the evenings of Tuesday Oct. 26, Wednesday Oct. 27, and Thursday Oct. 28, all with a focus on mental health and wellbeing.

For now, mark your calendars! Further details and a registration link will be shared in October on social media.



October is Disability Employment Awareness Month! #DEAM

Thinking about finding work, discovering what kind of work interests you, or preparing for the interview and hiring process this fall or winter? Don't forget about CDSS's employment resources. Find links to employment agencies, information on life skill programs, volunteer websites, tips about job applications, resumes, cover letters, interviews and practicing common interview questions.

Download them here:
<https://cdss.ca/resources/employment/>

Giving Tuesday is Tuesday, November 30th

Watch for our #GivingTuesday campaign. On November 30 we kick off the holiday season on this International Day of Giving!

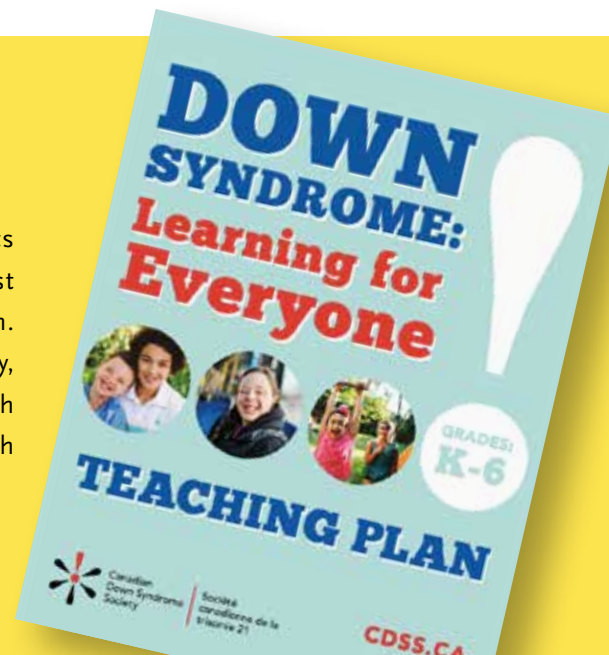


A NOTE OF THANKS
Thanks to all our supporters who are raising funds for CDSS through Fundraise My Way, our DIY event platform. We've had golf tournaments, marathons, small business ventures, gaming events and even beard shaving events! It's been a great summer of fun DIY events, and to date you've raised over \$23,000. Feedback from users so far is that the platform is "SO easy to use", and "I set up my event and had a donation within the first 30 minutes!" Let's keep it going Canada - we are here to support any idea you may want to turn into some goodness!
Contact Events@CDSS.ca today!



FREE, Easy to Download & Share - Back to School Resources Supporting Students, Teachers and Parents

Visit the CDSS Educator Hub for resources to help educate students and staff, raise awareness and celebrate Down syndrome, and most importantly, to support a learner with Down syndrome in the classroom. Links and downloads can be circulated digitally to promote inclusivity, used to train administrative staff, and to help welcome a student with Down syndrome. Access all of our free resources **here** in both French and English.



New Website!

We can't WAIT to share this with you all!
The new **CDSS.ca** site is fresh, easy to navigate, and better suited to use on mobile devices.
Coming to a screen near you this fall!



Canadian
Down Syndrome
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FIND US / TAG US

@CdnDownSyndrome on all our platforms



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DSRF CORNER

Coming to You Live and In-Person!

With COVID restrictions lifting, DSRF is ready to roll with our first in-person event since 2019! DSRF's Big Bocce ThrowDown will hit the pits on September 11 in North Vancouver.

Join us as we soak up the last of the summer sun, crank up the tunes, crack open a beverage and unleash our competitive side - all in support of people with Down syndrome. In between games, enjoy a delicious lunch, a ticketed bar, a selection of valuable silent auction prizes, 50/50 draw, great music, and awesome people.

Bocce teams consist of 4 players. Register a full team, or sign up as an individual and we will place you on a squad.

Visit [DSRF.org/Bocce](https://www.dsrf.org/Bocce) to enter your team. See you in the pits!

And speaking of events, here's some breaking news: DSRF's legendary Up the Down Market Dinners returns this fall to Vancouver, Toronto, and Montreal. Due to the fourth wave of COVID-19, the events will once again be presented in a virtual format.

Make a real investment in people with Down syndrome through an unreal stock game. Learn more and reserve your virtual table today at [DSRF.org/UDMD](https://www.dsrf.org/UDMD).



Running Apart... Together

For the second consecutive year, hundreds of people throughout the Lower Mainland connected virtually in early June to Run Apart for Down Syndrome.

After blowing away expectations by raising over \$200,000 in 2020, the COVID-19 version of DSRF's most popular annual event did even better this year, topping \$223,000 raised in support of the Down Syndrome Resource Foundation's educational programs and therapy services for individuals with Down syndrome.

Runners were inspired by Special Guest Race Ambassador Chris Nikic, the world's first Ironman with Down syndrome. Chris, who just happened to be competing in the Ironman World Championship in Hawaii as Run Apart was taking place, encouraged participants to empower people with Down syndrome to overcome obstacles and achieve their dreams, just as he has.

"Anyone who wants to accomplish something great, you just have to be willing to be consistent for a couple of years and you can do amazing things," Chris says. "The easiest thing to do is quit. The hardest thing to do is just keep improving every day. I used my dream to keep me going. If you want to do something big, then start by writing down a BIG dream and look at it every day. Never take your eye off your dream."

Together, we did something very big indeed at Run Apart for Down Syndrome. Thank you to all who participated and supported our efforts!



Ready, Set... G.R.O.W.

Every person with Down syndrome dreams of potential joys and accomplishments throughout their lifetime. Every person who loves someone with Down syndrome sees their potential to have a fulfilling adulthood.

G.R.O.W. (Gaining Relationships and Occupational Wins) is DSRF's newest small group program for adults with Down syndrome. G.R.O.W. focuses on two pillars of a rewarding, independent adulthood: meaningful relationships and gainful employment. It is a celebration of the small joys in life, from sharing laughs with friends, conquering the nerves of a job interview, and flirting with your crush. At the same time, G.R.O.W. prepares you for life's monumental moments by helping you discover how your strengths can contribute to your community, and exploring the ideas of finding intimacy and love.

Learn more about G.R.O.W. and other DSRF group programs at [DSRF.org/GroupPrograms](https://www.dsrf.org/GroupPrograms).



FRIENDS OF DSRF

The Ames Family Foundation has generously donated \$10,000 in support of DSRF's educational programs and therapy services for people with Down syndrome. The Foundation has been a faithful supporter of the Down Syndrome Resource Foundation for many years. We are so grateful for their gift.

The Kiwanis Club of Vancouver generously donated \$2,209 in support of DSRF's Summer School for teenagers and young adults with Down syndrome. Our popular summer program returned to its traditional in-person format this summer. In addition to working daily on reading and math skills, students took part in a variety of fun activities including improv, Hatha yoga, Bollywood dance, and much more. Thank you to Kiwanis for their support!

Pacific Blue Cross has generously donated \$3,000 in support of DSRF's educational programs and therapy services. We appreciate their investment in students with Down syndrome.

The John Hardie Michell Family Foundation has provided a generous grant of \$2,000 in support of DSRF's educational programs for children and young adults with Down syndrome. We are deeply grateful for the Foundation's long-term support.

DSRF would like to thank all the participants who helped make the 2021 Run Apart for Down Syndrome such a success. In particular, thank you to our top three fundraisers: Geoff Gates, Bill and Trudene Longman, and George Klukas. A massive thank you as well to the Macquarie Foundation, which generously matched the \$35,000 raised by Geoff Gates.

UPCOMING AT DSRF

DSRF's Big Bocce ThrowDown – September 11, 2021

Up the Down Market Vancouver – TBA

Up the Down Market Toronto – TBA

Action 21 Montreal – November 18, 2021

FIND US / TAG US

@DSRFCanada on all our platforms





Canadian
Down Syndrome
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CALLING ALL POST-SECONDARY STUDENTS!

**Become an
Ambassador for the...**

Canadian Down Syndrome Society!



Feel good by doing something good!

Ambassadors fundraise and advocate for inclusive education for all students, including those with Down syndrome.

How we help you!

Volunteering helps to achieve your educational and professional goals.

JOIN THE TEAM!

Register your school fundraising event at CDSS.ca and click on EVENTS



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