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3.21

Canada's
Down Syndrome
Magazine

DOLLARS and SENSE:

Why hiring people with
Down syndrome
is good for
business

The Employment Issue

The Sock Baron:

John's Crazy Socks

Success Stories:

Matt MacNeil &
Scott Fattedad





3.21 is a joint publication of
Down Syndrome Resource Foundation

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Canadian Down Syndrome Society | **Société canadienne de la trisomie 21**

Welcome to the inaugural issue of
3.21: Canada's Down Syndrome Magazine!

CDSS and DSRF are joining forces to bring the expertise of Canada's leading Down syndrome professionals and advocates to families across the nation. We trust that 3.21 will quickly become a valuable resource and source of inspiration for people with Down syndrome and all who love and support them.

Our first edition focuses on employment. People with Down syndrome have so much to offer Canadian businesses when given the opportunity – as you'll see from the hard-working and capable individuals spotlighted within these pages.

We'd love your feedback! Drop us a line at 321DSMagazine@gmail.com with your thoughts, story ideas and opinions.

Enjoy 3.21!

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DOLLARS and SENSE:

Why Hiring People with Down Syndrome is Good for Business

by Mark Wafer MSC OMC

A recent poll of 40 Canadian corporate CEOs by Canadian Business SenseAbility shows just how much work we still must do to ensure equality and inclusion for people with disabilities in the workplace.

The survey asked two simple questions: What percentage of Canadians have a disability? And, what do you believe is the average cost of an accommodation or adjustment to ensure your company could hire a disabled worker?

The response was alarming. On average, respondents estimated the percentage of Canadians with a disability at 4-5%, and the cost of accommodation at \$10,000. The reality is quite different indeed, with 24% of Canadians reporting a disability and the average cost of an accommodation being \$500 or less. In fact, only 35% of workers with disabilities require any accommodation at all.

The problem with this sort of mindset is that in thinking the demographic is so small, businesses can afford to ignore it. This is where negative stereotypes take hold.

Over the past 25 years, my wife and I employed over 200 workers with disabilities in every aspect of our Tim Hortons franchise business. We believe there isn't a disability type that we have not employed. Our most senior employee had a disability; she is now a Tim Hortons restaurant owner. In 2017 we sold our business and all 46 workers with disabilities remained with the new owners.

Without question, many of these workers with disabilities were our best employees. This hit home very early in our journey when I hired Clint Sparling to work in the dining room of our first restaurant. Clint, who was 23 at the time, has Down syndrome. He had just graduated from high school and was eager to work.

Clint saw a "help wanted" ad on our door and applied for the dining room attendant's job. As a deaf Canadian, I understood the many barriers the disabled face when it comes to employment. I knew that if Clint simply cold called on businesses, none of them would hire him. Employers back then (and many today) bought into every myth, misperception and stereotype about the disabled. They believed that workers with disabilities worked more slowly, were sick more often, took too much time off, worked in an unsafe manner, lacked motivation, required excessive supervision and had no ability to be innovative. Hence, they saw these potential workers as a liability. This was especially true for companies in competitive markets. They believed their competitiveness would be challenged by hiring workers with disabilities.

Counterintuitively, the exact opposite is true – and Clint proved this from the beginning. Training Clint took a few days longer than training someone without a cognitive disability, and that was okay. We enlisted the help of Community Living Toronto, whose excellent job coaches helped us get Clint ready for the job by teaching him how to take the bus and helping him understand social norms in a busy restaurant with 50-60 employees.

Within weeks I realized Clint was my best employee. He came to work an hour before his shift; he would not take a break and I couldn't convince him to go home at the end of his shift. The job meant that much to him. He wore his uniform with pride and the dining room was spotless.

In fact, I had to make a policy exception for Clint. My employees were required to change into their uniforms

once they got to work so there was no contamination from the subway or buses, but Clint wanted everyone on the bus to know he worked at Tim Hortons. I was happy to make an exception for this! The first year Clint worked with us he took off for his Christmas holidays and had a family photo taken on Christmas Day. When he showed me the photo, there was Clint wearing his Tim Hortons uniform to Christmas dinner. This degree of employee loyalty is unheard of.

As we built our business and added restaurants, we hired employees with different types of intellectual disabilities. Some had Down syndrome, some had autism and others had multiple disabilities. They proved to me that the myths were just that: myths and misperceptions. These workers required no supervision, they were never sick, they didn't take time off, their productivity was the same as or better than workers without disabilities and they worked in a far safer manner.

This led me to believe that there was a business case for being inclusive. Absenteeism, employee turnover and safety concerns are extremely expensive to a business owner. If capacity is built into a company's hiring practices, it seemed clear to me that it would be more profitable.

As a result, in 1996, my wife and I opened our doors to anyone with a disability. We hired workers who could do the job or could be trained to do the job. Over the 25 years we owned the restaurants, we employed more than 200 workers with disabilities. Some faced significant challenges, but all made a contribution to our business – and they all contributed to their own lives by receiving a paycheque and paying taxes and CPP. Truthfully, we would have hired a lot more than 200 workers with disabilities, but our employee turnover was so low that job openings rarely occurred. We all want to contribute and having a disability doesn't change that.

The data compiled over the years is striking. In one study, the absenteeism rate for 46 employees with disabilities was 85% lower than for 200 workers without disabilities. DuPont, an American automotive paint manufacturer, had an 86% lower absenteeism rate for their employees with disabilities. Our safety rating was highest in our sector because workers with disabilities don't take chances and deaf workers are more aware of their surroundings, whereas non-disabled workers take more chances and break safety rules.

Innovation is also increased by including those who have unique problem-solving skills. Clearly, a wheelchair user navigates the world in a different way. That leads to innovative thinking.

Clint's life has been remarkable. He is a trailblazer, setting a path to employment for so many others with Down syndrome. Being successful in full-time, competitively paid employment was an anomaly 25 years ago, whereas today we expect it for our children.

Clint has been interviewed many times for print, radio and TV shows. He had a feature-length documentary made on his life and starred in a CBC News mini documentary, "Return on Disability," which was rewritten into a feature length documentary in 2016. Peter Mansbridge said it was the best documentary he has ever seen.

About five years ago, the federal government's standing committee on intellectually disabled Canadians asked Clint and I to sit before them in Ottawa. I asked Clint if he was up for it, and sure enough, he wanted to do it. We arrived in Ottawa on a freezing December day and after going through multiple security checks we were ushered into a large room with long U-shaped tables. There were 15 members on this committee from three different political parties. We were in the room first, and

I asked Clint if he was still okay with this. He replied that he was fine.

The Members of Parliament entered the room and took a seat. Behind the Chair of the committee was a bank of TV cameras. Each person had a microphone, and Clint and I sat at a small table at the top of the 'U.' As the red lights flickered to life on each camera, the Chair asked for quiet in the room.

Slowly the hubbub died down until there was a moment of silence. At that point, Clint pressed the on switch of his microphone, looked at me and said, "Would now be a good time to ask for a raise?"

It was the first time in years that all three parties were laughing at the same joke.

Yes, it was funny, but more importantly, it showed how Clint had gone from a young man who most likely would have been thrown into a sheltered workshop back in the early 90's to a thriving, confident adult who married his high school sweetheart, bought his own condo and lives life to the fullest – all because he had a real job for real pay.

Just like you and me.



The **SOCK BARON**

by John and Mark Cronin

JOHN'S CRAZY SOCKS:

Blazing a trail for entrepreneurs with Down syndrome

Our story starts in the fall of 2016. The business I (Mark) was working in shut down overnight. I was 58-years-old, wondering what I was going to do for the rest of my life.

Meanwhile, John was in high school, and the rule in our area is that you can stay in the public school system until you graduate, or you turn 21 – whichever comes first. John was 21, so this was going to be his last year of school. Like everybody else at that stage of life, John was trying to figure out what comes next for him.

We looked at a lot of options. John looked at some jobs, he looked at a college, and he looked at some social service programs. But he didn't see anything that he liked. It's a reality faced by many. We call it the 21-Year-Old Cliff. You're taken care of medically, you're educated, and then... nothing. The choices aren't great.

John came to me and said, "I want to go into business with you." He's a natural entrepreneur, and he thought, "If I don't see anything out there that I like, let me go create it." Of course, I was excited. My son came to me and said, "I want to work with

you." He's the youngest of three sons, and he's the only one I can actually work with!

We explored a number of ideas for the business. John's first idea was to open a "fun store" – but neither of us had any idea what a fun store is. He pitched a food truck, but we ran into a problem: we can't cook.

Then, right before Thanksgiving, John had his eureka moment. He wanted to start creating socks. "They're fun, they're creative, and they let me be me."

John had worn crazy socks his whole life. He has a very particular sense of style. He would lay his clothes out the night before school and his brother Jamie would come to me saying, "You can't let him wear that to school." And John would remind him, "You're not the fashion police!"

We figured, if there's something you love, chances are there are going to be other people who love it too; there are going to be other people in your tribe. So, we decided to move forward with socks.

To John's credit, he didn't just come and say, "I want to sell socks." He had the name, and he had drawn out what a website could look like. I suggested we could call it Mark's Serious Socks, but that only ticked him off.

We opened bank accounts, registered with the state of New York, built a website and got some inventory. The only marketing we did was to set up a Facebook page and make some videos, starring John of course. He came up with a slogan: "Socks, socks and more socks."

We opened for business in late 2016, and got a flood of orders right away. Most of them were local, and John had a plan: he wanted to do home deliveries. We got some red boxes and threw in some candy, along with a handwritten thank you card.





We made one of our first deliveries at 10:00 at night. We're lucky we didn't get shot! But in all seriousness, customers loved it. Word began to spread. That first month we shipped 452 orders. We felt awesome.

Right away we began hearing from families who had children with Down syndrome or other differing abilities. They told us John was an inspiration. It was a bit of a mental leap for me to make, because he's just my third son. He's just John. But early on, that was an important connection.

Mission: Happiness

Our mission at John's Crazy Socks is to spread happiness. That mission drives everything we do. With this purpose in mind, we have built a social enterprise.

It's a different type of business model. We have a social mission and we have a business mission, and they're indivisible; they feed off each other. We've built it on four pillars:

1. Make it Personal
2. Socks You Can Love
3. Giving Back
4. Inspiration and Hope

Making it Personal

The personal touch that started with our home deliveries continues to be so important. To this day, every package has John's smiling face on the outside, and when you open it up, you get the socks, you get a note card from John with the story of John's Crazy Socks on the back, two discount cards (one for the customer and one for a friend), and some candy. You also get, on your packing slip, some stickers showing the names and the faces of the sock wrangler – that's what we call our pickers – and the happiness packer who packed that order. When you open it, you're not just getting socks; you're getting a little dose of happiness.

If you post to our Instagram or Facebook page, John responds with a thank you video. It turns out that posting a 5- or 10-second video is a lot easier than John writing notes. When we were receiving 50 orders a day, John would handwrite every note. Someone showed me a thread on Reddit where people were trying to calculate how many hours a day John was having to spend writing all the notes. That's not possible now; he's way too busy!

Socks You Can Love

We have 2,300 different kinds of socks. That makes us the world's largest sock store, in terms of selection. Some of the socks are specially designed by us, but most are purchased from wholesalers.

We have a Sock of the Month Club, and Monday Madness: a grab bag of socks that John picks out. When I ask him what's in it, he says, "It's a surprise! I'm not telling you!"

Giving Back

John is a Special Olympics athlete, so we donate 5% of all profits to Special Olympics. And that's just a start. We've also added products that raise money for charity partners.

The first one was a Down syndrome awareness sock. In January 2017, we discovered that on World Down Syndrome Day, people wear wild or mismatched socks to celebrate. You would think we knew that before starting a sock store owned by a person with Down syndrome, but we didn't! We went looking for a Down syndrome sock that we could sell, and we couldn't find one. So, John said, "I want to create one." And he did. Two dollars from each pair gets donated: one dollar to the National Down Syndrome Society, and another dollar goes to a local group called ACDS.

When we sell this sock – and it's our bestselling sock – people wear it to celebrate. It's raising awareness and it's improving acceptance. We're not going to hide. We're not going to be ashamed. We're going to wear this, and we're going to make sure everybody knows: I have Down syndrome, or I have a son with Down syndrome, or a friend or a family member, and we want to sing that out. That's true about the Down syndrome socks, and it's also true about our autism socks, our Williams syndrome socks, and others.

Inspiration and Hope

Inspiration and Hope is our most important pillar. We want to show the world what people with differing abilities can do.

We have different metrics than other businesses, because we have different goals. We are trying to come up with a happiness index; if we're in the business of spreading happiness, can we measure that? But here are some of our current metrics:

- **How many jobs have we created?** 39! 23 of those jobs are held by people with differing abilities. We give people meaningful work. We get to see miracles everyday, simply by giving people jobs with meaning and purpose.

- **Awareness.** The videos we make – to call them low-fi is to overstate them. But they've been seen over four million times. A video about us on The Mighty has over 20 million views. The BBC put one out over a year ago; last I looked it had 44 million views.
- **Giving Back.** To date, we've raised over \$270,000 for our charity partners.
- **Making Customers Happy.** We have over 20,000 online reviews; 96% of them are 5-star reviews. One third of our orders are repeat customers.



“Follow your dreams, follow your heart, and show what you can do.”

-John Cronin

I don't like talking about money, but it helps us demonstrate that this is not just a nice story about a cute kid and an incredibly good-looking father.

That first month when we shipped 452 orders, we had \$13,200 in revenue. Our first full year, 2017, we shipped 42,710 orders, for \$1.7 million in revenue. Last year we shipped 144,000 orders and had \$5.5 million in revenue.

When we say that, people pay attention. And we want them to know we're able to do that because of the workforce we have. In a day and age where there is a growing labor shortage, we have an awesome workforce. It's because we tap into people with differing abilities.

When we talk about “socks you can love,” it comes back to that social enterprise model. We have to be a great e-commerce business. We are competing with Amazon and Target and Walmart and all the others. We can never say, “Well, you have to understand: look who we hire.” It's the exact opposite. We need to show we'll go toe to toe. In fact, we do better shipping than Amazon. If an order comes in, it goes out by 3:00 that day. Our accuracy rate is high; our return rate is very low. And that's part of the message: look what people can do. Plus, Jeff Bezos is

not putting a thank you note and candy in his packages!

We have people with differing abilities working side by side with neurotypicals. Everybody earns that job. You have to pass a sock wrangler test, which is really complicated. Here's what it is: you come out and meet with John and me, because we want you to know what the business is about, and we want to make sure that you want to be there; it's not just mom and dad or your job coach who want you there.

Then you go and learn the job from a current sock wrangler, who teaches you how to pull the orders. We've simplified the system; it's an address system and it tells you: “Go to Aisle A, Rack 2.” You can take as long as you'd like to learn. We don't pay you until you pass the test. Some people are good to go after an hour. Some people, it takes them weeks. They learn at their own pace, but they have to pass that test. And once they do, they are given a meaningful job that matches their ability, and the support they need to succeed.

You can say that our business model is a morally good thing to do, and I'm not going to argue that. It may make you feel better going to church or synagogue or the mosque on the weekend, but that's not what it's about. It's simply good business. It gives us a competitive advantage. And we want other people to go and copy that.

Every time John stands in front of an audience and tells our story, it changes people's minds a little bit. We're doing everything we can to move from just raising awareness to acceptance, so that when you see people with different abilities contributing to the community, it's just normal. Of course John runs his own business. Of course our colleagues are doing the jobs they do, and doing them well. Why wouldn't they?

This article was transcribed from a presentation by John and Mark Cronin at the Down Syndrome Resource Foundation in March 2019, as part of a USG-funded speaker program.



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Becoming Part of the Voice Revolution:

Project Understood, a New Opportunity for People with Down Syndrome



Imagine a young adult starting their day in 2032. They wake up to an alarm playing the latest hit they requested the night before, are greeted by their friendly robot in the kitchen with suggestions on what to have for breakfast to fuel their morning, and a handy voice reminder to take their medication. Another chimes in, advising them of what is on their agenda, offering suggestions on what to wear based on the local weather and the day's activities. They leave for work in their driverless car with a bag packed with everything they need while away from the house for the day. The door locks, heat turns down, lights turn off behind them. And this was all made possible with voice technology.

Now imagine this voice-first future not working for people with Down syndrome. The reality is that some of

the people who could benefit from this technology the most might be left out.

According to Google, the current error rate for people with Down syndrome is on average 30 percent. But there is work being done to improve this. A few years ago Google launched a program called Project Euphonia to make voice technology more accessible for individuals with non-standard speech. One challenge for Google has been recruiting enough people to participate in the data collection process. The Canadian Down Syndrome Society (CDSS) saw this as a great opportunity to collaborate and reach individuals within the Down syndrome community. Between Google's technological expertise and CDSS' connections, the partnership works to further Project Euphonia's research. CDSS wants to

ensure that individuals with Down syndrome are being well represented in the future of voice technology, and so Project Understood was created.

"For most people, voice technology simply makes life a little easier. For people with Down syndrome, it has the potential for creating greater independence. From daily reminders to keeping in contact with loved ones and accessing directions, voice technology can help facilitate infinite access to tools and learnings that could lead to enriched lives," says Laura LaChance, Interim Executive Director with CDSS.

Project Understood aims to collect voice data from adults with Down syndrome in order to improve its voice recognition models. "With the help of CDSS we were able to sample a small group to test whether there were enough patterns in the speech of people with Down syndrome for our algorithm to learn and adapt," says Julie Cattiau, Product Manager at Google. "It's exciting to see the success of that test and move into the next phase of collecting voice samples that represent the vocal diversity of the community. The more people who participate, the more likely Google will be able to eventually improve speech recognition for everyone."

"This project has really struck a chord with the Canadian Down syndrome community," says Glen Hoos, Director of Communications for the Down Syndrome Resource Foundation. "As we've shared Project Understood with our families, there has been a great deal of enthusiasm for it. It's easy to see how the technology can be leveraged to create greater independence for many people with Down syndrome, if it can be successfully adapted to diverse patterns of speech."

So now it is up to the Down syndrome community to take action. Machines learn through data. The more data they get, the more accurate they are.

How to Get Involved:

- ▶ Are you an adult with Down syndrome who speaks English? Visit ProjectUnderstood.ca to sign up to participate right away!
- ▶ Do you know a person with Down syndrome who is over 18 and speaks English? Text or email them the link to ProjectUnderstood.ca.
- ▶ Are you part of a social media group with followers who have Down syndrome or are connected to the Down syndrome community? Visit the ProjectUnderstood.ca website to share videos and the project.

It is up to the Down syndrome community to make this project happen! Learn more about the project goals, Google financial incentives, and what's involved at ProjectUnderstood.ca.

PROJECT
**UNDER
STOOD**.ca



I'm teaching Google. You can too.

The Canadian Down Syndrome Society is partnering with Google to help make voice technology work better for people who need it the most. By sharing voice samples, adults from the Down syndrome community are teaching Google's technology to better understand them. But we need more voices.

If you have Down syndrome or know someone who does, visit ProjectUnderstood.ca to donate your voice.

PROJECT
UNDERSTOOD

Jessie
CDSS Advocate



Employment

SUCCESS STORIES

Individuals with Down Syndrome Thriving in Work and Life



Scott Fattedad

Scott Fattedad is something of a celebrity in his small town of Tsawwassen. Wherever he goes, he's sure to bump into any number of friendly faces very pleased to see him – most of them belonging to customers he's cheerfully served at one of his three jobs.

Scott's primary job is at Thrifty Foods, where he's been a popular team member for 16 years. "My main duties are front end customer service, such as packing groceries for customers," he explains. "I empty the recycle bins, take returns to the back, and put new bags in the bins. I also work in produce, usually bagging vegetables and putting them out."

After completing school, Scott took a job preparation course at Kwantlen College, and they arranged various work experiences for him. Towards the end of this program, Scott had set his heart on working at Thrifty's, and Kwantlen made the introduction. It's been a great fit for both employer and employee.

Scott's mother Mary Lynn wholeheartedly endorses this approach to transitioning from school into employment. She suggests that parents enroll their son or daughter in a program that provides training, job experience, and assistance in deciding what they wish to do. "Some of the programs also provide a job coach for awhile, which can be very helpful for both the employee and the employer," she notes.

Scott agrees. "You need to get training on the job and take some training first, but don't be scared to take your resume to places you would like to work. Always make sure you are clean and dressed appropriately when job seeking – and SMILE!"

Starting a new job has its challenges for all of us. Scott recalls his biggest hurdle being learning all the safety rules and procedures for his job, but says he knows most things now. That's due in no small part to Thrifty's positive, proactive approach. "We all learn differently," emphasizes Scott's manager, Laurie Jaggard. "We train, communicate, and coach" – just as you would do for any new employee.

Mary Lynn remembers a couple of challenges in particular. "Scott worked from 10-2 with only a 15-minute break, but he wanted to eat some lunch. This made him late getting back to the floor. I discussed allowing him



extra time to eat and just having him stay longer at the end of his shift, and the manager agreed. He also used to get more hours, but the store cut back. We were able to help Scott successfully advocate for a few more hours on another day."

Any accommodations that Thrifty's has made have been well worth it. Laurie says that Scott brings an invaluable positivity to the work environment, which rubs off on other team members. "I love everything I do – especially being friendly with all the customers and my co-workers," says Scott. "And I like earning my own money!"

"He loves going to work and it gets him moving and out of the house... he might just sit and play video games otherwise!" says Mary Lynn. "Also, the extra money enables him to purchase things he wants and pay his own way. Because he lives at home and pays less rent than he would otherwise, he has been able to save for holiday trips and recreational programs."

Just as valuable as the money is the impact on Scott's personal well-being. "I think having a job, even a few hours per week, really helps a person feel valued and helps their self-esteem immensely," says Mary Lynn. "Plus, they often become great ambassadors for others with Down syndrome or other developmental disabilities."

Scott's advice for individuals with Down syndrome just starting out on their employment journey? "Just keep on trying and don't be afraid to ask for help."

As for his employer, Thrifty's is quick to endorse inclusive hiring practices. Asked why they chose to employ an individual with Down syndrome, Laurie answers without hesitation: "The better question is, why would you not?"





Matthew MacNeil

Those who know Matthew MacNeil use words like “friendly, reliable, helpful” and “responsible” to describe him. All those words also describe the beginnings of a great resume, as well as a model employee. But the road to inclusive, paid employment was a lot of work for Matt, and for his family. Matt’s mother, Carolijn, attributes volunteer experience as the key component to developing Matt’s resume and finding a job. She has some great advice for seeking volunteer work: “Find things that you are passionate about and start there. This experience pads your resume, and the more experience you can add, the better.” Matt’s family also prepared him for the interview process with mock interviews, and talked a lot about the key attributes employers look for in an employee. They encouraged Matt to never sit idle at work, to be helpful and always find something to do.

Not only has Matt’s volunteerism done great things for his resume, it has also led to many more accomplishments, including receiving the prestigious Citizen of the Year award in 2017 from his town of Tillsonburg, Ontario. The night Matt accepted his award, he was described as much more than a community leader; he was described

as a community *builder*. His volunteer experience has included helping at summer camps, advocating for accessible transportation, youth programs and recreational inclusiveness, and sharing his stories about advocacy and volunteering through many public appearances and speeches.

Matt has now been working with the Sobeys Tillsonburg team for twelve years. His day-to-day duties include cleaning, bagging groceries, and carrying groceries to vehicles for customers who need extra assistance.

Matt’s feelings about work are much the same as they are about volunteering. He says that “it makes you feel good to do things to help in your community.” His supervisors agree with Matt about the importance of adding to the community. When asked why they would choose to hire someone with Down syndrome, they said, “Extending fair opportunity towards individuals regardless of personal circumstance is something that all people, not just employers, should seek to promote. Allowing individuals to contribute to a company where and how they can only reinforces the opportunity for success – both for the employer and for the individual.”

Matt also likes to think of his job as inspiring to others. “It shows that I am valuable, that I can work. It shows that anyone else can work as well,” says Matt. “It has really changed my life, to show that people with a disability can work just like everyone else.” Matt’s supervisors see Matt like any other employee in most ways. “Each person you hire is unique; someone with Down syndrome is not outside this truth. Training and integration have to mirror other employees... with a more tailored approach. Understanding your role in a company is critical for fulfilling your employer’s expectations. This starts from the ground up, so by Matt having an extra solid foundation to stand on, it gives him something he can fall back on when faced with new challenges.”

When asked recognizing the benefits of hiring someone with Down syndrome, Wendy of Sobeys Tillsonburg said, “It sends a positive message to customers, and to other employees, that the company supports people... and seeks to help individuals build and cultivate success.” When leveraging this unique benefit, they also recognize that “it can be very effective at promoting the opportunity to quell misunderstandings toward individuals who break the mold. If customers can see your company as

an entity that embraces all facets of contribution, that is immensely beneficial and a huge win for everyone.”

Like his employer, Matt’s family has also given him the tools to be successful. Matt is very independent. He checks his schedule, and does everything he needs to do to get to work and be a reliable employee.

Matt has recently made a decision to increase his number of paid work hours by seeking a second job. They have been there. Matt and his family know that it is hard work to find a job. Their advice is simple: “It takes some pounding of the pavement and building relationships, but in the end it is all worth it. Keep trying and do not give up!”



Matt has served as chair of CDSS’s VATTA group - Voices Around the Table for Advocacy, for ten years. He is a familiar face across Canada these days, as he has played a key role in the development of CDSS’s 2019 national awareness campaign ‘Project Understood.’ This last fall he travelled to California to meet with representatives from Google AI to talk about ways that voice technology could better serve people with Down syndrome. The story on page 14 describes this project in more detail and how others with Down syndrome can become involved.

Aging with Down Syndrome:

One family's story



Many people with Down syndrome are enjoying longer lives with post-secondary education, strong employment, healthy recreational activities and meaningful relationships. According to Liza Kiegler, Administration & Resource Coordinator for the Canadian Down Syndrome Society (CDSS), one in every five phone calls the CDSS receives about resources are people looking for advice and information specifically about aging. “As with anyone aging, resources are needed that support and navigate this new life stage and the unique planning it requires, and with the median lifespan for people with Down syndrome now being older, it is essential.”

Dr. Elizabeth Head of ICI MIND, the University of California's Centre for Aging and Dementia Research, explains that resources about aging are important to people who have Down syndrome “to read and understand what may come as they get older, and also to see how other people with Down syndrome cope with challenges and yet enjoy life through the stories and information.” She adds, “The more information you have, the more you feel in control of your situation, and that provides a level of comfort that is invaluable.”

The importance of planning is key, agrees Lori Pollett, who spoke at the 2019 Canadian Down Syndrome Conference in Victoria, BC. Lori's sister Susan had Down syndrome, and Lori and her family were forced to manage Susan's aging process at the same time as their mother's health deteriorated. Their mother Rosemarie was always the primary caregiver to Susan, and the challenges this dynamic brought as they both aged kept the support planning in constant flux. As Lori managed the group and situations, she offers heartfelt and valuable advice for others.

Lori says resources about aging that are specific to Down syndrome are “a necessary goal, because the number of people living longer with Down syndrome has increased enormously, the system can't bear the need, and this is compromising people with Down syndrome and their support persons, like aging parents.” As much as possible should be planned in advance; Lori adds, “although we never formally labelled ours a ‘plan’ until later, we were always doing just that: planning.”

Lori feels that involving and sharing resources with siblings of people with Down syndrome is key, because sometimes they have not been involved in the early

years. As Lori's parents aged and recognized a decline in their own health, conversations began with their other children about desired roles to help support Susan.

As a group, Lori and family identified what was important to the process and also what was important to Susan by asking her. Roles included guardianship, long term care planning, direct care, the quality of Susan's life, her social life, and employment. As her activities and needs expanded, so did her support circle. A monthly meeting was set up with all family members and key support people, as well as Susan. They had an agenda and a facilitator. Anyone who was unable to attend the meeting in person was set up to join via video conference. The group all agreed to take on one activity each per month, to keep from getting overwhelmed. They also set up an electronic joint calendar with meetings and appointments. At the beginning of each month, a reminder was sent out to the group to indicate what they could support if more help was needed.

Susan's support circle committed to “laughter, fun and love” above all else when they were together.

Beyond all the planning, Susan's support circle committed to “laughter, fun and love” when they were together. They did something social at each meeting. The group paid close attention to what made her smile, cues to what made her anxious, and addressed these non-verbal signs in their planning for support.

“Be brave, give grace, stay curious.” Lori offers this advice to anyone moving through this stage of life with a loved one. Staying curious helped the group feel secure in the fact that they were making the best decisions for Susan in her final years. Some things that were interesting to her in the past did not interest her anymore, and her support group made a point – even when she was non-verbal – to query her. Susan's face would light up when something she was still interested in was shown

to her – a magazine, a book, things she liked and still enjoyed. What represented her previously did not always represent her now, and visual clues when the gift of words were not present helped the group understand what was important to Susan, and what made her feel safe, valued, loved and remembered.

Lori says that knowing the group was working towards what their sister wanted gave them a sense of calm and helped decrease anxiety. They were able to come together not only during urgent times, but at planned times with Susan as the common connection, to enjoy each other as a family.

But moments were not always calm. During one trip to urgent care with Susan, Lori recalls feeling “bombarded, without information close at hand; I was overwhelmed and feeling as though I had let Susie down.” After this experience, a notebook was left with Susan at all times for easy access to her personal and medical information, and an updated electronic copy was sent to others in the group.

Preparedness is important, as Lori can attest. “Being prepared and knowing your role can help you find joy in the journey.” Being prepared also helped Susan’s parents as they aged, as Lori explains. “Our parents lived in a more peaceful state knowing that we had a living plan that could be adjusted along the way.”

“Feeling overwhelmed can be paralyzing,” says Lori. “Be emotionally honest with yourself; you have a big responsibility and it will be scary at times.” This applies especially to people who do not have an expanded support circle, or difficulty maintaining one. There are groups to help in these cases; one that we recommend is **p4p Planning Network**, an Ontario-based non-profit group with free resources to help empower individuals and families and secure futures.

Upon Susan’s death in 2018, Lori’s family decided the most important thing to do was to share her story in order to help others who will deal with aging and disabilities. We hope that Susan’s story and the resources mentioned help others to navigate the future with planning and positivity.

RECOMMENDED READING ON THIS TOPIC

- *A Guide to Good Health*
- *Mental Wellness for Adults with Down syndrome*

both by Dr. Dennis MacGuire

Today & Tomorrow: A Guide to Aging with Down Syndrome

Download in **French** and **English**



“Be brave,
give grace,
stay curious.”



DSRF CORNER

DSRF COMES TO THE OKANAGAN

This fall, DSRF took its first steps in serving the wider BC Down syndrome community when we welcomed back to our team speech therapist Jillian Baldwin, who recently relocated to Kelowna. Jillian hosted our first Down syndrome workshop in Kelowna on Sept. 25, presenting "Profiles of Learning and Development in Down Syndrome" to a full house.

In the coming months, Jillian will lead more workshops in the region, and will begin offering speech therapy services. This is the first time DSRF has offered services outside the Greater Vancouver area. We are currently conducting an in-depth review of our service delivery model as we seek to make our unique programs and expertise available to families in other parts of BC and across Canada.

OH BEHAVE! DSRF INTRODUCES BEHAVIOUR AND MENTAL WELLNESS SERVICES

Through our years of providing speech therapy, occupational therapy, one to one reading instruction and other programs, we've noticed a common thread underlying the difficulties that many students face in these areas: behaviour. Many young people with Down syndrome exhibit mild-to-moderate behaviour problems that negatively impact the child and/or their family's life. These issues may hinder the individual's ability to fully participate in school, therapy and other settings, thereby delaying skill acquisition and development.

Over the past several years, Susan Fawcett, DSRF's Director of Therapy, Behaviour and Family Support, has been working towards

her doctorate in positive behaviour support. Now, our students and families are reaping the benefits of Susan's hard work, as individuals with Down syndrome can receive positive behaviour support right here at DSRF.

By collaborating with others on DSRF's professional staff team, Susan's expertise is impacting students in all our therapy streams, whether or not they receive formal behaviour services. Susan regularly consults with DSRF's other therapists and teachers, giving them strategies to address behavioural issues that are preventing students from getting the most out of their sessions.

In addition, Susan has also introduced a new Mental Wellness service for individuals with Down syndrome and their families. Much like behaviour issues, mental health problems compound many of the challenges faced by people with developmental disabilities, and addressing these matters will help our students unleash their full potential.

BLACK BELT COLLECTS KLUKAS AWARD EN ROUTE TO INTERNATIONAL TAEKWONDO GAMES

Darryl Andaya is no stranger to extraordinary accomplishments. Through nine years of intense dedication and hard work, he earned his black belt in taekwondo. His excellence in the martial arts has propelled him all the way to New Zealand, where Darryl represented Canada last month at the International Special Needs Taekwondo Games. There, he made history as one of the first Special Needs Taekwondo World Champions, winning two gold medals, one silver, and one bronze.

Those are not Darryl's only accolades of late. Before jetting off to the Games, Darryl added another prize to his growing trophy shelf: the 2019 George Klukas Achievement Award.

Presented annually to a student of the Down Syndrome Resource Foundation by DSRF Board member George Klukas in recognition of significant improvement and success over the past year, the prestigious Klukas Award celebrates the achievements of an older teen or young adult with Down syndrome.

Darryl, 19, has completed years of speech therapy at DSRF, as well as participating in the popular Music in Motion program. Through his work at DSRF, Darryl has begun to speak more and become better able to vocalize his thoughts. He has become more confident and



increasingly independent, making his own decisions and learning how to use the transit system.

Darryl's growing communication abilities, social skills, decision making, and athleticism have helped him in his transition to adulthood and in his development as a martial artist. From an early age, his perseverance and strong spirit have been clear, and have enabled him to achieve things that other people never thought he could do.

In addition to competing, Darryl also teaches taekwondo to young children, including children with disabilities. He is loved everywhere he goes, whether at school, at work, at the playground, or at the taekwondo studio. Darryl never loses his drive and determination to master new skills. That makes him a very worthy recipient of the 2019 George Klukas Achievement Award. Congratulations, Darryl!



Down Syndrome Resource Foundation

Together. Hand in Hand.

FRIENDS OF DSRF

Coast Capital has donated \$5,000 towards DSRF's Money Math & Budgeting program, which helps adults with Down syndrome develop math and money skills crucial to independent living.

The Ames Family Foundation has invested \$25,000 towards the development of a Reading Assessment Online Student Portal, which will track individual student progress, assign skill-specific strategies individualized to the learner, and keep teachers working in partnership to maximize student progress.

RBC Future Launch has generously invested \$20,000 in DSRF's transitional programs for young adults with Down syndrome, including Reading and Communications Plus, Social Communication and Navigation, and Money Math & Budgeting.

The John Hardie Mitchell Family Foundation has donated \$2,000 in support of DSRF's educational programs for individuals with Down syndrome.

UPCOMING AT DSRF

- Christmas Breakfast
Hyatt Regency Vancouver - December 13, 2019
- DSRF's 25th Anniversary - March 13, 2020
- World Down Syndrome Day - March 21, 2020
- Up the Down Market Toronto
Arcadian Court, Toronto - April 23, 2020
- BMO Vancouver Marathon #RUN4HOPE
Vancouver, BC - May 3, 2020
- Run Up for Down Syndrome
Swangard Stadium, Burnaby - June 7, 2020

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CDSS SPOTLIGHT

NOVEMBER'S CANADIAN DOWN SYNDROME WEEK A HUGE SUCCESS

In addition to the CDSS launch of *Project Understood* on November 4, other events were organized across Canada to celebrate Down syndrome in Canada. There were Go21 awareness and fundraising community events, school presentations, engaging photo exhibits, blue and yellow light shows, and interactive social media 'takeover' programs. Thanks to all who helped others to #SeeTheAbility!

BLOG NEWS!

Awareness leader Paul Sawka's latest blog is about support workers. He writes about what his support people help him with and offers helpful advice on how "everyone can support people with Down syndrome, even if they are not a support worker by doing some simple things." Link to Paul's blogs [here](#).

SCREEN TIME WELL SPENT: MOVIES WHERE ACTORS WITH DOWN SYNDROME TAKE THE LEAD

At the Toronto European Film Festival, which ran November 7 – 21, CDSS co-presented *Dafne*, a touching Italian-based movie about a spirited young woman who has Down syndrome. When Dafne's mother



suddenly dies, she has to help her father manage his life and grief, as well as her own. Watch the trailer [here](#).

Did you take in *The Peanut Butter Falcon*? We can't wait for awards season to find out what it might be up for! You can now rent or buy this fantastic film on Amazon.

One movie that comes highly recommended is *Kairos*, an inspirational story about a young man with Down syndrome, whose dream is to become a professional boxer. To watch the trailer visit [this YouTube link](#).

A THANK YOU TO CDSS'S OFFICE VOLUNTEERS



CDSS has two groups of volunteers who work every week to help mail tax receipts to donors and put together resource packages to send out to expectant parents, educators, medical professionals and families. CDSS recently hosted a thank you event to thank this group for the hundreds of hours they dedicate to CDSS. Over the course of the year, Sheldon from Columbia Day College in Calgary and Kelly, Leigh, Roger and Sharon from Calgary Community Day Services help ensure that more than 16,000 pieces of mail are sent from the CDSS offices!

Thursday, December 5 is International Day of Volunteers! Don't forget to thank those volunteers in your life on this special day.

UNIVERSITY OF BRITISH COLUMBIA STUDY

UBC is conducting a study to measure what it means to be an adult, and are particularly interested in the meaning of adulthood for people with Down syndrome. UBC is looking for parents or caregivers of individuals with Down syndrome, as well as their adult children with Down syndrome, to participate.

The questionnaire for parents/caregivers takes approximately 10 minutes. After completing the questionnaire, parents/caregivers are asked to pass on a separate questionnaire to their children with Down syndrome. The second questionnaire for adults with

Down syndrome will take 30-60 minutes to complete. If both parent/caregiver and child complete the survey, a gift certificate will be sent from the research group as a thank you.

If you are interested in participating in the study please visit [this link](#).



MARCH 21 IS WORLD DOWN SYNDROME DAY!

Mark your calendars for Saturday, March 21 2020. Down Syndrome International has unveiled their 2020 message for World Down Syndrome Day: 'We Decide'. You can learn more about this initiative and the many ways that you can become involved as a group or individual at [this link](#).

Order your CDSS SWAG items NOW to ensure delivery before March 21! Some of our items ship internationally and take 30 days to deliver. Stay tuned to CDSS social media feeds to find out how you can become involved on March 21, 2020.

GO21 EVENTS POPULAR IN ONTARIO THIS PAST FALL



Fall 2019 was a busy season with five Go21 events all in Ontario. Down Syndrome Niagara, Down Syndrome Association National Capital Region, Down Syndrome Guelph, Down Syndrome Association of Hamilton and Waterloo Regional Down Syndrome Society held successful Go21 events that helped bring their communities together and fundraise for their own local programs and services while raising awareness for Down syndrome. The events raised over \$165,000, with more than 90% of those funds staying within their local communities to support programs like literacy, employment and awareness.

Some of the events were filled with entertainment, bouncy castles, face painting, raffles, photo booths and some yummy food, but most of all, a time to connect with other community members and spend time building awareness.

See our ad on page 13 and email go21@CDSS.ca to discuss Go21 opportunities for your community!



PRENATAL: UNVEILING A NEW RESOURCE FOR EXPECTANT PARENTS

Undergoing prenatal screening and diagnostic testing for Down syndrome is a very personal decision. CDSS is developing a resource for expectant parents who are considering undergoing prenatal screening, or who have recently learned of the possibility of their child having Down syndrome, and are seeking more information to learn about Down syndrome.



The pamphlet will be a free, downloadable resource on the CDSS website, and shared on social media, and available this December in English and in French in early 2020.

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UPend
expectations

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quality of life

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