

Finding a Village: Establishing a Global Community

Disability and Climate Change

The Value of

A Response to the

Canada Disability

Vulnerable

People:

Benefit

Fighting for Home:
An Interview with
Lauren Simpson

I Don't Do Disability and Other Lies I've Told Myself

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Resource Foundation

In this issue of (5.71



Life with a disability is a life of advocacy.

We wish it wasn't so. We wish our society universally recognized the inherent value of every person, and afforded every individual equal opportunity, support, and dignity, regardless of ability (or race, religion, gender, sexual orientation, age, and any other factor that is used by some to discriminate on an individual or systemic basis).

As far as we've come – and make no mistake, we have come far - we still have to fight to make our voices heard and advocate for our needs and rights when it comes to the issues that matter to us.

In this issue, we meet people in our Canadian Down syndrome community who are doing just that: self-advocates, parents, and allies working on important issues like inclusive housing, racial justice, the Canada Disability Benefit, ableism, and climate change. We hope these stories will inspire you to keep fighting the good fight.

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4 Fighting for Home:
An Interview with Lauren Simpson

8 I Don't Do Disability and Other Lies I've Told Myself

12 Finding a Village:
Moses Latigo Odida on Establishing a Global Community

16 Advocating at the Intersection of Disability + Climate Change

22 The Value of Vulnerable People A Response to the Canada Disability Benefit

26 Self-Advocate Q&A

32 CDSS Spotlight

34 DSRF Corner

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Fighting for Home:

An Interview with Lauren Simpson

Lauren Simpson has taken a leading role in the fight for an affordable, inclusive housing project in Surrey, BC. Lauren is an alumnus of the Down Syndrome Resource Foundation, having taken many programs through the years, including Speaking Out: Advocacy + Climate Change. 3.21 Magazine recently sat down with Lauren to hear about her inspiring advocacy work.

3.21: Tell us about yourself.

Lauren Simpson: I am Lauren Simpson and I'm 28. I live with my family in South Surrey, BC: my mom and dad and Jax. Jax is my dog. I like to go out for coffee and go to restaurants. I listen to music and spend time with my family. I love Special Olympics. In the spring and summer, I will be participating in running and softball.

3.21: You are a housing activist, a public speaker, and a disability advocate. Why is it important to you as a woman with Down syndrome to advocate for yourself?

LS: It is important to me. I like to stand up for myself and make my voice heard, and for other people in my community to have choices in their life.

3.21: As a member of UNITI's Community Development Committee & Self-Advocates of Semiahmoo, you have been advocating for several years for the Harmony housing project. Can you describe this project for us?

LS: Harmony is a 91-unit affordable, inclusive, accessible, six-storey rental apartment building. It will be built by UNITI, a non-profit organization.

3.21: Why is the Harmony project so important to you personally?

LS: I want everyone to have the place they deserve; to be safe and happy, and to live where they grew up. I want to live there myself.

3.21: It has been a long journey to see Harmony become a reality. What are some of the things you have done to advocate for it?

LS: I spoke at the public hearings, and I had a phone meeting with the Mayor at that time. We delivered flyers to neighbours. I did interviews and conferences. We did a documentary called *Lauren's Story*.

3.21: What obstacles have you faced along the way?

LS: In 2021, the Mayor at that time and four members of city council said no. The neighbours also said no because they won't get any sunlight.

3.21: How did you feel when the City of Surrey rejected plans for the Harmony development?

LS: I was really disappointed and angry. I cried. Everyone was heartbroken.

3.21: The story didn't end there, fortunately. How did you regroup and continue to push for what you needed?

LS: We never gave up. We made *Lauren's Story*, which we showed at the Inclusion BC Conference in 2022. We wrote letters and spoke at housing conferences and gave interviews. We put pressure on the city council.





3.21: Where does the Harmony project stand today?

LS: Harmony was finally approved by city council, and we are breaking ground in 2024. We will start our public fundraising campaign soon. It is called the Leadership Committee Campaign for Harmony. Hopefully the building will be ready to move in by 2027.

3.21: What have you learned through this whole process?

LS: I learned a lot. I learned to speak up and talk to people about what I believe in. I can talk to the local government, and they will listen to me. We are a good team at UNITI.

3.21: You've earned some wonderful honours for your work, including, most recently, the Surrey Board of Trade's

2024 Women in Business Social Trailblazer award. What other awards have you received, and how does this recognition make you feel?

LS: In 2023, I received the YWCA Women of Distinction Community Champion award. I also received the Down Syndrome Resource Foundation's George Klukas Achievement Award in 2020. I feel happy and honoured.

3.21: What other causes are important to you, that you would

like to advocate for in the future?

LS: I want to keep working on affordable housing. We have a lot of work to do. I also advocate for single moms, families, and seniors.

3.21: What would be your advice for other people with Down syndrome who feel like their voices are not being heard?

LS: Don't be afraid to use your voice. Be part of a team. Never give up.

UNITI is a partnership of three affiliated societies that have provided important community services for decades. Semiahmoo House Society provides quality services and

supports to people with disabilities and their families in Surrey and White Rock. Peninsula Estates Housing Society provides affordable and inclusive housing that reflects the diversity of our community. The Semiahmoo Foundation ensures that UNITI has the recognition, relationships and resources to support an inclusive community. UNITI promotes inclusion and creates models that will influence societal change. To learn more about UNITI and follow the progress of the Harmony project, visit https://uniti4all.com.







One parent's pathway to confronting her own ableism and becoming an advocate for individuals with Down syndrome

By Adelle Purdham

What does it mean to DO disability?

In high school, I was a competitive gymnast who volunteered in her spare time. I raked leaves for the elderly and visited a woman with Alzheimer's Disease. I walked dogs in shelters, and collected canned goods for those experiencing poverty. I sold lollipops to raise money for organizations that combatted child slavery, and I taught children with difficult home lives how to read.

I loved working with children, and I knew, one day, I would become a classroom teacher. I also harboured a strong desire to write. In a journal entry from my early twenties I scrawled the words, "I want to write a book — I just don't know about what?"

One day, as a teenager cutting across the grass field of my high school, I grappled with the realization that I had volunteered with every group, it would seem, except those with cognitive and physical disabilities — a population I had been actively avoiding. I perceived disability as a weakness.

Standing on that grassy field, with the flush of shame threatening, I comforted myself: It's okay, I thought, I just don't do disability. With that one tidy thought, I dismissed

an entire segment of the population. I reinforced the idea that to be disabled was a "bad" thing, and I distanced myself from that way of being in the world. If I couldn't relate to disability, then disability wouldn't happen to me or those I loved. I dismissed the idea that I had ever been disabled — as a dependent infant or when I was sick in bed — or that I may ever become disabled and dependent again, such as many of us do at the end of our lives — and during. In my quest to be a do-gooder, I lost the human thread. I wouldn't come to see, until much later, how we are interwoven and interconnected; how each thread is a unique part of the quilted whole of "us."

At twenty-eight years old, now a classroom teacher, disability entered my life in a meaningful way with the birth of my second daughter, Elyse, who has Down syndrome. With her arrival, the old stories I had told myself about "good" and "bad" ways of being could no longer hold, and my world view began to shift. The process of dismantling my own ableism — the belief that an abled body is better — had begun.

In Elyse's pregnancy, I allowed a worry to slip in that filled me with guilt: what if I didn't love her the same as I loved my first daughter? I didn't have to wait long for that particular fear to dissipate. The heft of each of my daughters' small bodies inside my abdomen weighed the same in my mama heart. My feelings toward Elyse were fierce love, and once she arrived, I wanted the whole world to understand that love — and feel the same way. I no longer inhabited a world that was "them" and "me." It was just "us."

However, Down syndrome was a topic I then knew little about. I turned to books, and registered for conferences where I could learn. I encountered wonderful resources on the Canadian Down Syndrome Society and Down Syndrome Resource Foundation's websites. I became involved with my local Down syndrome associations; first serving on the board in Hamilton, and later Halton region. I began to meet many individuals with Down syndrome and their families.





When she was an infant, I wrote my first article about Elyse and our family, a story about unconditional love that was published by our local newspaper. In my search for information about Down syndrome, I visited a nearby national book chain. I was dismayed to find there weren't any books written by a mother to a daughter with Down syndrome — there weren't any books about Down syndrome period. And this was during October, Down syndrome awareness month in the U.S., followed by Canadian Down Syndrome Week.

"No books" would not do. I needed the stories of fellow moms, and to familiarize myself with Down syndrome, but most importantly, I needed to know that someone else cared. The missing books spoke volumes about those who remain invisible in society.

I spoke to management, and they agreed to order several books into the store. I imagined another mother like me who might walk in, looking for resources, and not feel so alone. I believe this is how advocacy can begin for any one of us: small steps, seeking out information, asking for representation, sharing our stories, being or making the changes we want to see to create positive social movement and improvements in the right direction.

A turning point in my advocacy journey came in 2014 when Elyse was two years old and I attended The World

Down Syndrome Congress (WDSC) in Chennai, India. The WDSC is an international Congress that occurs every 3 - 4 years funded by Down Syndrome International. I thought I was attending the conference to bring back cutting-edge research that would help families and individuals with Down syndrome in my local association. I somehow didn't anticipate learning from a person with Down syndrome speaking up for themselves.

Among a throng of volunteers in brightly coloured saris, I met Susette from South Africa, mom to self-advocate Sheri Brynard, who ushered me into the room where Sheri's presentation was about to begin. Behind the podium, Sheri, a petite blond with glasses, spoke about her life as a woman with Down syndrome. She didn't shy away from recounting the difficulties and obstacles she encountered to become the world's first qualified teacher with Down syndrome. For her perseverance in the face of incredible barriers, Sheri was awarded South Africa's Woman of the Year.

But it was Sheri's pleas for the dignity of her own life that grabbed at my heart and have stayed with me long past the conference.

"People like me," she said, "are aborted. We deserve to live!" Her words shook the core of my understanding like thunder. The audience was electrified into silence by her powerful speech; every person in that room awestruck.

I came back from that congress knowing that the greatest teaching about Down syndrome would come from



individuals with Down syndrome themselves. In the many experiences I've had since, this has proven to be true.

At a local Down syndrome association picnic, I became friends with special Olympics athlete Emily Boycott, and, after realizing we shared common interests such as gymnastics and writing, we became fast friends and were soon presenting in schools together. Even though I've since moved towns, Emily and I remain friends nine years later, and recently gave a keynote address as copresenters at the Celebrate Down Syndrome Expo, an event connecting businesses and the Down syndrome community.

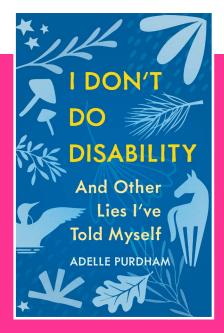
When Elyse was a baby, I read every disability-related parent memoir I could get my hands on: George Estreich's Shape of the Eye, Martha Becks' Expecting Adam, and later Heather Avis's The Lucky Few. These stories helped immensely, but none of them were written by a young Canadian mom who had a daughter with Down syndrome. The question I needed answered, what I was searching for when I read those books was: what is the value of my daughter's life? I needed to know so that I could shoot the naysayers down — it's true —but I also needed to know for myself.

I want to write a book — I just don't know about what? Now I knew. I wanted to write a memoir about my experiences parenting Elyse as a way to advocate for her and other individuals with Down syndrome.

I continued to write articles for newspapers, blog posts, then magazines. The process took me five years, but in the hours between diaper changes, naps, preschool and eventually kindergarten, I wrote four drafts and finally had a complete memoir. That first book, my journey as a mother, remains unpublished — but I didn't give up on my advocacy plans or my desire to reach a wider audience to share our love. I went back to school to complete my Master of Fine Arts (MFA) in Creative Nonfiction writing, and I leaned in to becoming a full-time writer. During my MFA, I continued to think and write about the immense value of my daughter's life, but I also asked a second question that addressed my own feelings of invisibility: and what is my value as her mother?

The process to publication took me eleven years — the length of Elyse's life — but I finally wrote the book that I needed all those years ago.

My memoir-in-essays, I Don't Do Disability And Other Lies I've Told Myself (Dundurn Press) focuses on disability parenting, being a woman, and becoming a writer. The book is about a mother confronting her own ableism and making herself — and her daughter — seen; the true narratives push back against stereotypes and showcase the idea of "us," and our interconnectedness. My greatest hope is that you will find yourself in my words; that you will feel like these are "our" stories. That you will know that you are seen. I see you. And I care. You are not alone.



Told Myself will be available wherever books are sold by its launch date of November 5th, 2024 — but pre-orders are available now. Don't be alarmed, as I once was, if you walk into a bookstore or library and I Don't Do Disability isn't on the shelf yet; do consider requesting a few copies. Our stories matter.

What does it mean to DO disability? You'll have to read my book to find out.

10

FINDING AVILLAGE:

Moses Latigo Odida on Establishing a Global Community

By Sarah Caraher

Moses Latigo Odida is a filmmaker based in London, Ontario and father of Selah, a four-year-old girl with Down syndrome. His mini-documentary series Down: Canada's Black Caregivers, which was created as part of the Telus Fund Stories for Caregivers program, shares the experiences of Black caregivers across Canada. Canadian Down Syndrome Society sat down with Moses to discuss the power of representation, the unique challenges faced by Black caregivers, and his advice on approaching advocacy.

SARAH CARAHER OF CDSS: Tell me a little bit about Down. What sparked the need to create this project?

MOSES LATIGO ODIDA: When I first learned about the opportunity to produce *Down*, I realized two things. Number one, I immediately had this imposter syndrome. I thought, "I'm not qualified enough." The second observation was I saw a gap in the moving stories that had already been told - they weren't representative of



my full self. I'm a Black man. I was born and raised in Uganda and so for me, one fundamental way that I view the world is through the lens of race because I know that's an inescapable experience for racialized communities.

At that time, my daughter was three years old. I was trying to imagine what raising her as a Black father would be and I imagined that on the one hand, there would be all these resources. But they would be missing that integral component of who I am as a person, as a Black man. I wanted to integrate Black experiences into the existing stories to try to illuminate the public consciousness and contribute to lessening that gap.

SARAH: After noticing that imposter syndrome, but feeling the need for these stories to be told, was there a moment of, "if not me, then who?"

MOSES: Exactly. When I first held my daughter in my arms, it was one of the most significant moments in my entire life. I remember committing to her that I would do anything and everything that I could to help create the sort of world that I want her to live in. A world where she's not an afterthought, but one in which she's assumed to be as fully human and as fully deserving as anyone else. What really pushed me to help overcome that imposter syndrome was my responsibility to not just my daughter, but to the world.

SARAH: I think a lot of caregivers can relate to that responsibility being a driving force for advocacy, but we also see many caregivers who struggle with burnout. How do you prevent that responsibility from becoming detrimental to your own health?

MOSES: As a Black man, talking about race, and as someone that's living with clinical depression, talking about this stuff is never easy. It's that tension of wanting to just detach and escape from the world, juxtaposed against my responsibility to advocate. It's something I'm still navigating every single moment. I'm beginning to accept that the tension will always be there, so the challenge then, is how I live through that reality.

For me, the first part is why advocacy. My conviction is that if we as a society want to achieve whatever idealistic goals we have, what will help us to get there is truth-telling. Without coming to terms with what is true, there's no justice. Unfortunately, that truth-telling often points me to spotlight some of the most controversial phenomena in life like systemic racism and all manner of oppression. But I'm convinced that unless we come to terms with those things, then we have no clue what we want to ameliorate.

A lot of the stuff that I talk about can be very triggering. The implications are real. The picture that I paint for the world to see with a view to acting to reverse the dynamics of such a world tends to be dark and ugly and dehumanizing. And that impresses on my mind; it's a constant reminder that this is the world that we're living in. At the same time though, when I observe connections between something I advocated for and a positive response to it, it's encouraging. It reassures me that there are so many people that are willing and ready and interested in joining efforts.

SARAH: Do you feel that in order for us to make meaningful progress with disability advocacy, it has to happen collaboratively?

MOSES: 100%. For me as an African, I grew up in a context in which the approach to life is such that I see my own humanity tied to that of others around me. That's what on the African continent, we refer to as Ubuntu, this organizing principle that, "I am because we are." Our conception of progress or health or thriving is a collective one.

If any of us want to prosper, we have to understand those aspirations in the context of the wider community, because a human being by definition belongs. You belong to a group that's larger than you, whether it's your family or your community. So our approach to advocating for the members in our community that live with different exceptionalities has to be collaborative.

SARAH: Why are projects like *Down* significant to Black caregivers and also to the broader disability community?

MOSES: I wanted other Black caregivers to know that they're not alone. There is this subconscious underlying sense that, "there's no one like me." I was also speaking for myself that I wanted to find a village. My Blackness has caused me to be isolated because I don't see people like me very often in different spaces. My wife is white,



and the resources that we've seen, the default has been mostly white experiences. How do I place my full self as a Black man in that? So I was both communicating to the wider Black caregiver community and to myself that there are more of us than perhaps we expect. I began to discover quickly that our stories are so similar.

To the larger non-Black caregiver community, my hope is that *Down* is an intimate invitation into our private lives, to see the stories that we share, to see the tears that we shed and why, to see also the beauty of the lives that we live. Through this series, my hope is that people will be able to see the beauty of our precious loved ones, so that they view them as fully human and deserving of every treatment as a human being. Ultimately, I want all of this to equip people to be better informed advocates.

SARAH: You've touched on Black caregivers feeling isolated from the broader Black and disabled communities. Why do you think that is?

MOSES: When I say the Black community, I hope that folks know that it's not a monolithic entity. There are so

many Black people whose life experiences I cannot relate to by virtue of the fact that they might have been born and raised here in Canada, or in the Caribbean, and I wasn't. But there are certainly also fundamental ways in which we share deep kinship. Within this diverse Black community, I've heard several stories from different parts of the world that the way that Black people, in certain segments of our communities, view disability and mental illness, is not very helpful. For instance, I grew up in Uganda where there's really no pre-existing language or framework for understanding or for talking about disability or mental illness. The fact that that's absent is in itself a hint at the perceptions that we have. At best, someone with a disability is quietly forgotten, isolated from the community. Or worse, there's this assumption that disability is a result of a curse from God.

Within the Black community, these things serve to isolate, or to force Black caregivers into thinking that they did something wrong. There's usually this blame game that one must have done something to warrant the disability, which means that when the loved one

is born, they are already viewed as less than human or as deficient. I still have some of my own well-meaning family members from Uganda who, whenever they check in, remind me that they're praying for my daughter to be healed. I trust that intent is good because they care. But the impact and the implication is absolutely dehumanizing. Those sorts of experiences contribute to why some Black caregivers might feel isolated from contributing and participating fully in the community.

Dealing with that particular phenomenon through an episode in the series, I felt it was kind of risky. Because I'm effectively speaking directly to people like me, to family members, to friends, to people that I know, that we need to talk about this and this is not right. Through the series, you will see that there are some other Black caregivers who have voiced a certain version of that phenomenon as well.

SARAH: What would be your advice for individuals and organizations who want to better support Black caregivers and the Black disability community?

MOSES: I should note that my own stab at this answer is my own as an individual and it does not end at all at having listened to what I share. We all come into any situation with an assumption about how the world operates that is typically informed by our upbringing. The first thing that I would encourage anyone to do is to understand where you're coming from and what your pre-existing assumptions are, and then assume those to be your own. This is not to say that they're wrong. But assume that there is something different and that difference is not deficiency.

Once you have that self-awareness, come with a curious mind. Expect to be confronted with a different set of realities. And it can be scary, it can be a way of perceiving the world that's completely different from what you're used to. And that is absolutely okay. It would be a weird world if we were all robotically similar, but the world is so beautiful in its diversity.

For me, the change is more attitudinal. Otherwise we could do the basic work of checking the boxes, you could say, "I had a seminar or I watched this video, or I hired this EDID person." But that means absolutely nothing if you still assume the world to operate the way that you always have.

In addition to that, come with humility. Because on the other side of humility is what many of us in racialized communities continually struggle against, white supremacy. White supremacy, for me, in its most simplistic form, is that you're assuming whiteness and what is familiar to whiteness to be the overall standard for all of humanity. That doesn't make sense, right?

The shortest distance between strangers is a story. So I would encourage anyone to find stories of people who are not like you. Because that will serve to establish a proximity which is necessary for you to understand them, to know how much closer they are to you as a human being than you might have previously assumed.

The good thing is that there are series like *Down* which help to highlight these stories. I encourage folks to look at the TELUS Stories for Caregivers. You'll find not just *Down*, but several others which over the years have illuminated the Canadian audience to the phenomenon of caregiving.

THEY CAN BE FOUND AT TELUSFUND.CA UNDER FUNDED PROJECTS, STORIES FOR CAREGIVERS.

15

Advocating at the Intersection of

Disability + Climate Change

By Glen Hoos, Director of Communications + Sustainability, Down Syndrome Resource Foundation

As an avid weather watcher, I saw the 2021 BC Heat Dome coming.

Not in the macro sense, mind you. The extreme nature of this event, which saw temperatures approaching 50°C in Lytton, BC – annihilating Canada's all-time temperature record – shocked even the most seasoned climate analysts. It wasn't supposed to be able to happen; at least, not this soon. And yet it did.

A week before it hit, forecasts were calling for temperatures pushing into the mid-40's in the Lower Mainland, and there was one thing I knew for certain: my family would not be able to hack it.

Leaving aside my own distaste for heat and humidity, there was the matter of my daughter Becca. 16-years-old at the time, Becca has both Down syndrome and autism – and adamant requirements for her personal environment.

Becca hates fans, and she hates opening her window at night-time, no matter how hot her room gets. Not that cracking a window would be of too much use with overnight lows around 30°C, but for Becca it wouldn't even be an option.

She also hates drinking water. She simply won't do it.

People with Down syndrome are more vulnerable than most to heat exhaustion and heat stroke. What's more, this particular person with Down syndrome has a high propensity for keeping her family up all night long when she can't sleep, which, in a home lacking air conditioning, was virtually assured.

So we fled.

Five days before it struck, I booked a room at the hotel up the road for what were expected to be the three hottest nights of the heatwave. Just as thermometers began nudging 40°C, we ensconced ourselves in our blessedly cool room, curtains drawn and air conditioning blasting. We planned not to emerge for 72 hours.

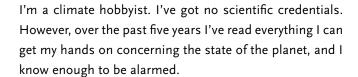
The next morning, however, I needed something from my car, so I took the elevator down to the lobby. I could hardly comprehend what I saw there. At a time of day when people typically check *out* of a hotel, it seemed the entire town was trying to check *in*. The lobby was jam packed with masked families (this being the height of COVID times), and they all had the same horror story of a miserable night in a stifling home. The hotel was not able to accommodate them all.

As I passed through the crowd and then the doors that led to the parking lot, the heat hit me like a wall. Just walking through it was physically oppressive, as if the air itself had obtained weight. It was 10 am, and 43°C.

The hotel room did its job. We hunkered down for three days – not happy, exactly; our family finds travel challenging at the best of times. But at least we were safe and cool.







When I share my concerns with my longsuffering wife, she sighs and says, "Don't we have enough problems already?" She's not wrong. Along with Becca, we also have a teenage son who has multiple developmental disabilities, and my wife herself is in poor health. We're not short on challenges; it's hard enough just to get through today.

As most who are reading this can likely attest, life with disability is a life of endless advocacy. We advocate for services. We advocate for income support. We advocate for inclusion. We advocate for respect. It's exhausting, and the last thing we need is another cause to fight for.



Nevertheless, I now also choose to advocate for the needs and rights of people with Down syndrome and other disabilities amidst the defining collective challenge of our generation: the climate crisis. It's a problem that none of us can afford to ignore – *especially* those of us with disabilities or disabled loved ones.

The crossovers between disability justice and climate justice are abundant. "Disabled people are at the frontlines of the climate crisis and often have unique barriers to responding when wildfires, flooding, heat domes and other emergency climate events happen," write Rowan Burdge, Jen Kostuchuk, and Ismail Askin in a recent op-Ed for The Tyeeⁱ. "Research has shown that in emergency contexts, disabled people are significantly more likely to suffer morbidity and mortality."

People with disabilities face greater risk from the weather-based emergencies that are becoming increasingly common across Canada and around the world. Such events have physical, social, economic, and emotional components which are magnified for those with disabilities like Down syndrome. According to a 2023 report by Vancouver Coastal Health, "climate change exacerbates existing health inequities" – including those experienced by people with long-term and permanent disabilities. And as my experience with Becca indicates, measures that are commonly advised in such situations may not be feasible for these individuals, for a variety of reasons.

Beyond the impact of extreme weather emergencies, in the coming years, our society will be transformed through a combination of climate mitigation and adaptation efforts. The energy transition is underway, and it will impact every part of our lives – changing how we live and move and eat. It is essential that the needs of people with disabilities be centred through these shifts, to ensure that such changes benefit all members of the community, beginning with the most vulnerable.

In 2023, the BC Climate Emergency Campaign issued a briefing and policy backgrounder with comprehensive recommendations for A Just Transition in BC. The aim of these proposals is to ensure that no one is left behind in the transition to a sustainable, clean, secure, and fair economy – in particular, Indigenous communities, resource-dependent communities and fossil fuel workers, and vulnerable groups such as people with disabilities.

As it turns out, there is significant overlap between the needs of the Down syndrome/disability community, and the urgently needed climate solutions that will contribute



to a better world for all. Below are a number of climate advocacy opportunities that should be of particular interest to people with Down syndrome and their families.

1. Inclusive Emergency Planning

Historically, emergency planning has focused on what works for the majority of people, without regard for the unique needs of those with disabilities and exceptional circumstances. Families like mine may need extra time to prepare, making early warning systems critical. These systems must be accessible for those with intellectual disabilities and hearing or vision impairment. Provision needs to be made for those without access to personal vehicles, which are often central to evacuation plans. Public shelters and emergency facilities must also be fully accessible.

Special attention should be given to those who live in supported housing situations such as home shares and staffed residences. Those who are entrusted with caring for people with Down syndrome and other disabilities must be equipped with emergency plans and supplies in case they find themselves supporting someone through a weather-based emergency.

2. The Right to Cooling

During the heat dome of June 2021, 619 people died in BC. The majority of those who lost their lives were elderly people, disabled people, and low-income people, most of whom were in homes without adequate cooling systems such as air conditioners or fansiii.

Now more than ever, access to cooling is a human right. With the heightened susceptibility of people with Down syndrome to heat-related illness, it is essential to ensure that the homes of our loved ones are equipped with cooling devices.

Fortunately, there is a wonderful piece of technology that meets this need while also reducing the carbon emissions that cause climate change: the heat pump. Contrary to its name, heat pumps do double duty, both heating and cooling homes with incredible efficiency and a fraction of the environmental impact. Government rebates are available for retrofitting homes, which is a great option for individual households. On a wider scale, we need to advocate for government-sponsored heat pump installation in all homes for those with disabilities and other low-income folks.



3. Improved Public Transit

Many people with Down syndrome rely heavily on public transit to navigate their communities, and would benefit greatly from a better, more robust public transportation system. At the same time, public transit is a critical component of climate mitigation efforts. Sustainability requires not just a shift from gas-powered to electric vehicles, but also a transition towards vastly more efficient community transportation systems. Investing in the expansion and greening of public transit is a win for both the disability community and the climate.

4. Green Jobs for All

The green energy transition will be a massive job creator, generating good jobs in clean energy and ecological restoration. In BC (as well as nationally), there is a movement for the creation of a Youth Climate Corps that would offer two years of guaranteed employment and training to young adults to work on climate mitigation and adaptation projects in their communities. Many of these jobs could be appropriate for people with Down syndrome, providing an opportunity for them to contribute meaningfully to their communities while gaining valuable work experience. We should be advocating for inclusive hiring practices that allow every person to lend their skills to the cause.

5. Income Support

Canada is knee-deep in a cost-of-living crisis that is disproportionately impacting people with disabilities. Current rates of disability assistance are well below the poverty line in all provinces. The unfolding climate emergency will bring additional financial pressures to individuals and households; it is expected to be a leading driver of inflation in the coming years.

The Down syndrome community has been active in advocating for the Canada Disability Benefit. We need to continue to insist that the federal government swiftly implement an adequate CDB, while also advocating for improved supports at the provincial level.

Social justice is inherently intersectional, and there is

much work to be done at the intersection of disability and climate. By centering the needs of those with Down syndrome and other disabilities, listening to their perspectives, utilizing their unique skills, and learning from their resilience, we can build a better world for all of us.

Glen Hoos is the Director of Communications + Sustainability for the Down Syndrome Resource Foundation and a member of the BC Climate Emergency Campaign. Interested in joining with others who are advocating for disability justice within the climate crisis? Please reach out to Glen at glen@dsrf.org.

CLIMATE + DISABILITY RESOURCES

- Stay Cool: Tips for Facing a Heatwave (PSA video produced by adults with Down syndrome)
- Staying Safe During a Heatwave: Tips for People with Down Syndrome and Their Caregivers
- "A Dad's Fight for Climate and his Child with Down Syndrome" (CBC Radio program What on Earth)
- Climate Change: A Plain Language Guide
- Disability and Climate Change: Plain Language Version



- ¹ Burdge, Rowan, Jen Kostuchuk and Ismail Askin, "Why We Need Social Justice in the Just Transition." The Tyee, Apr 13, 2023.
- ¹¹ Protecting Population Health in a Climate Emergency. Report of the Vancouver Coastal Health Chief Medical Health Officer, 2023.
- "Burdge et al, with data from https://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/coroners-service/death-review-panel/extreme_heat_death_review_panel_report.pdf







Down Syndrome MALK

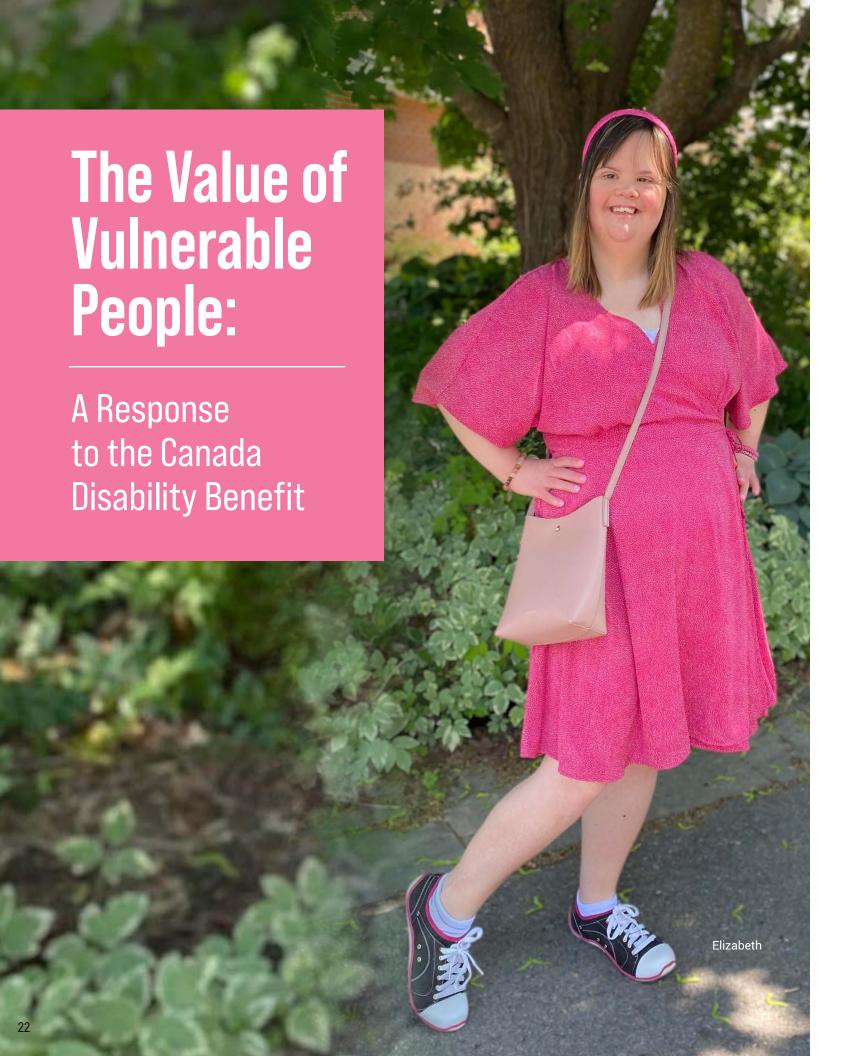
Saturday, June 15th

Step Beyond Stereotypes!

Join us coast-to-coast for the 2024 Down Syndrome Walk on June 15th! Find an event near you, register a team, or make a donation to show your support for the Down syndrome community in Canada.







It is hard to believe that while a staggering 1.4 million people with disabilities in Canada live in poverty, the government of Canada has decided to allocate a maximum of a mere \$2,400 per year, per adult to the Canada Disability Benefit. That equates to \$6.66 a day, falling far short of what most individuals need to cover the extra costs that can come with living with a disability. That is already an ineffective amount of financial assistance without even mentioning the skyrocketing cost of living expenses that all Canadians are struggling with in 2024.

Extensive consultations were conducted between the government and the disability community about the development of the Canada Disability Benefit, but given the announcement in April, the overwhelming opinion is that those recommendations were disregarded.

By not providing adequate access to financial security benefits, which are a right of all Canadians, the government is essentially placing the burden of care onto the already weighted shoulders of caregivers. These are real people, with diverse needs and hopes who make contributions to society. Caregivers are not a faceless, limitless answer to Canada's healthcare and social support inadequacies.

"A society is judged by how it treats its most vulnerable population. \$6.66 per day is a slap in the face of these lovely humans and their families. My son has Down syndrome and could possibly use this benefit, but there are many others who could really use such a benefit if it was actually hinged on true living costs and inflation. How many people feel 'less than' when they saw this announcement? I feel like we treat our communities with exceptionalities with so little care and this announcement is a manifestation of that."

"\$6.00 a day was never mentioned in either consultation. What was mentioned was that they were hoping it would be the equivalent of the guaranteed income supplement given to seniors, which I believe is just over \$1,000 dollars a month. They made the community wait four years just to get \$6 a day. They keep saying it's a starting point, but action needs to be taken and it needs to be taken now."

- Mancy Howson

Over 27% of people living in Canada are disabled; this is an issue that impacts us all that we cannot afford to ignoreⁱⁱ. We need to continue pushing to ensure that the government fulfills its promise to give people with disabilities the access to financial security benefits that they deserve. Please contact your local MP and tell them the current Canada Disability Benefit is not enough.

"Many years since the federal government first promised the Canada Disability Benefit - despite claims of needing this time to consulting with folks with disabilities - the details announced in Budget 2024 are nothing the disability community was calling for: the amount is far too little, the eligibility is barrier-ridden (in contravention of an amendment I secured to the legislation), and it won't even start until next July.

It seems to be the version of the CDB announced is more about making non-disabled Canadians think the federal government is helping people with disabilities than actually doing what they promised. It's clear more advocacy is needed. My team and I will continue to advocate alongside vou."

-- MP Mike Morrice

"Moving forward, we must deliver a consistent message to our MPs - the Budget announcement has failed people with disabilities and strong amendments are required to ensure that the Federal Government fulfills its promise to lift people in this community out of poverty. Increase the benefit, tie payments to inflation, ensure eligibility for all people with disabilities and secure a commitment from the provinces and territories that claw backs will not apply. Let's get this right, people's lives depend on it.



LLB, B.Comm

"I want to tell you about my daughter, Elizabeth. Elizabeth is a photographer, artist, and an advocate to all who are different or vulnerable on this earth. She loves all kinds of music, is a social media darling, and loves to watch her favourite tv shows on her iPad. Elizabeth is also a survivor of a horrible, tragic bus accident that happened January 11, 2019. The Westboro Bus Crash, as it is known in the news. Elizabeth continues to live with trauma, nightmares, OCD, and PTSD. She was on her way to being an independent, successful, vibrant member of the community she lives in, but that accident changed her world.

We were able to get some support for her with therapy, art therapy, physiotherapy, occupational therapy, and recreational therapy to help her become more independent again, to help her feel safe again, but she still has a long road ahead of her. Our auto insurance paid for the therapies, but all that stopped at the 5 year mark.

As her parents, we never imagined that we would be full-time caregivers to our daughter. Part-time absolutely, but we had dreams and she still has her dreams of working, marrying her boyfriend of 9 years Kris, and moving in together. So when we heard about the "extra" money from the government, we thought there would be some additional financial support for her programs.

But when I heard the announcement, I thought, 'that's typical.' Vulnerable people who live with differences never get what they need to live as respectful, dignified, supported, valued members of their community.

Elizabeth's day programs vary in cost depending on what we can afford that year, but pretty much anywhere

from \$10,000 - \$13,000. When we do our taxes we get about \$2,500, Elizabeth gets ODSP, and we get \$5,500 from DSO, but unfortunately we have had to cut all her therapies and two social programs because we can't afford it. I'm an EA with the school board and I am retiring in three years. My full pension will be about \$24,000, so I'm afraid we will have to cut even more of her programs then.

That's our middle class reality as a couple who are caregivers to our daughter and also my mother-in-law, who lives with Alzheimer's. So I would love to know from the government, how does the Canada Disability Benefit help us?"

-Lyne Filion

Mother to 30-year-old daughter Elizabeth living with Down syndrome



In order for the Canada Disability Benefit to be effective for people like Elizabeth, Lyne, and millions of others, the community has requested that the benefit meet the following requirements:

- The benefit amount must be a minimum of \$1,000 per month, indexed to inflation, to bring people with disabilities above the poverty line (when combined with provincial benefits).
- The benefit must be in addition to existing provincial disability benefits without claw backs so that it does not deter employment.
- The benefit should not be limited to those who have been approved for the Disability Tax Credit; any individual who currently receives either federal or provincial disability benefits should automatically qualify, and multiple easy and accessible application methods should be established, along with a straightforward appeals process.
- Means testing should be based on individual income, not household income.

Disability Community Voices

We asked our community members to voice their opinions on the Canada Disability Benefit announcement. We will be sharing these comments with the government as we demand they uphold their commitments to our community.

"I know so many people who are now seriously considering MAiD, because it is easier to get MAiD in this country than to access basics needed to survive (affordable housing, affordable food, access to quality public healthcare, etc.) Can't say I'm shocked but I'm deeply disappointed." - Hannah Q.

"Disability is now mandated to be poverty." - Anonymous

"Not even enough for a return transit ride." - Frances

"Our son has Down syndrome and cannot live on his own with that amount of money and high rents. For years they have been asking for our input but don't listen. Our time is valuable and should not be wasted." - Mary L.

"Why is there an income threshold on eligibility for the disability tax credit for families? Many families have a full-time caregiver parent for an adult or child with Down syndrome. These families should be able to have income splitting to ease the tax burden and give families more of their own money back to make decisions on how to best support their loved ones." - Jacqueline W.

"I'm an older mom and my daughter (my only child) will likely outlive me for several years. I worry about her future and her community." - Mary C.

"I'm a solo caregiver and I am so tired of struggling. Poor community support, poor government support. Very poor inclusive and equitable job opportunities. Quality of life is only for some people? Adults with special needs get the rug pulled out from under them as if they suddenly stop needing services? We keep getting pushed to the edge and I'm scared for our future." - Cheryl R.

"In the time they have been discussing it, rent alone has gone up more than \$6/day. Food has gone up more than \$6/day." - Judy G.

"It takes much more than people think for disabled people to live." Cheryn K.

Disability Without Poverty 2023 Report.

[&]quot; 2022 Canadian Survey on Disability, Statistics Canada.

Self-Advocate







1. What causes are important to me personally?

Standing up for myself and for everyone around me and being a loyal supportive person for everyone around me.

2. Why is this cause important to me?

This cause matters to me because it's really important for me to be confident to stand up for myself and for everyone else. Being a loyal supportive person are the most important qualities in a romantic relationship and in a friendship.

3. What changes would I like to see to make things better?

I really want my friends to stay loyal to me and I want them to support me through

4. How do I advocate for my cause?

I advocate for my cause by looking for people to show me that you will always support me and stay loyal to me.

fason:

1. What causes are important to me personally? Jobs and housing.

2. Why is this cause important to me?

This cause is important to me because the people with disabilities, or not, need to make the same amount of money.

3. What changes would I like to see to make things

Help for people with disabilities to get jobs and accessible housing. Funding to assist people with disabilities in accessing housing.

4. How do I advocate for my cause?

I advocate for my cause by starting discussions about increases in rent prices. I want the prices to go back to the original price, and groceries as well.

Rebecca:

1. What causes are important to me personally?

This magazine is advocacy. We can speak out for any reason that we want. Not just Down syndrome, but for other people with disabilities.

2. Why is this cause important to me?

This cause matters to be because my family and my dad and my friends are all important to me. I want to show the world that I can break stereotypes.

3. What changes would I like to see to make things better?

Access to paid work for people with Down syndrome and other disabilities. Accessibility at the workplace. Having opportunities to make and connect with friends like my friends Cassidy and Jason who share the same genetics as me.

4. How do I advocate for my cause?

I advocate for my cause by sharing what my friends and family are going through and writing about myself, friends, and family in places like this magazine.

Darryl:

1. What causes are important to me personally?

Being able to have a job, or a merch business. How to get rich.

2. Why is this cause important to me?

This cause matters to me because I want my own store. I need to know how to get merch set up. I need volunteers to help me; we do it together.

3. What changes would I like to see to make things better?

We need people selling stuff. Be very good to each other. Great volunteers who do a very good job. Be free to make

4. How do I advocate for my cause?

I order from merch stores and help volunteers. We do it together. I need my friends. Take care of each other to be good, very happy.



1. What causes are important to me personally?

Ableism and standing up for people with disabilities. Having a job. Racism. Using my SpeechAssistant app.

2. Why is this cause important to me?

My work at Luppolo. I put plates and small plates in the dishwasher, then I stack up the silver ones (condiment cups). I work hard and make my own money. My SpeechAssistant app helps me find my words. It helps me

3. What changes would I like to see to make things better? Lots of money to help my mom with grocery shopping and buying food.

4. How do I advocate for my cause?

Socials. Watching video games on Youtube. Making videos.



Cassidy:

1. What causes are important to me personally?

My important cause is anti-bullying because the cause is personally important to me.

2. Why is this cause important to me?

This cause matters to be because nobody should be bullied. Bullying is a problem. The people could get hurt. Bullying can get out of line for people and kids feel like they want to hurt themselves or even more than that, and get sent to the hospital.

3. What changes would I like to see to make things better?

Stop the bullying and stand up. Use your voice and speak up and don't forget to wear your pink shirts.

4. How do I advocate for my cause?

I advocate for my cause by wearing my shirt and standing up for people and kids who are getting bullied. Please visit bullyingcanada.ca.





1. What causes are important to me personally?

Singing in Russian, playing a show, Ukrainian dance with my family like my sister, cousin, and nephew, and current events in Moscow.

2. Why is this cause important to me?

This cause is important to me because it is part of my culture. I want to date Russian boys.

3. What changes would I like to see to make things better?

Having help with dating. I want to go out on a date.

4. How do I advocate for my cause?

I advocate for my cause by talking about dating. I want people with disabilities to have happy, healthy relationships.





- 1. What causes are important to me personally? My business.
- 2. Why is this cause important to me?

This cause matters to me because I want to grow my business.

3. What changes would I like to see to make things better?

I am in 12 stores from Langley and Surrey to Whistler, Kamloops, North Vancouver, and Toronto. I want to be in more stores.

4. How do I advocate for my cause?

I advocate for my cause by being an entrepreneur, being a role model to show people I am successful.



1. What causes are important to me personally?

The important cause that's personal for me is the polar bears.

2. Why is this cause important to me?

It matters to me because they need protection.

3. What changes would I like to see to make things better?

I will change to make them better and help global warming so they can be free.

4. How do I advocate for my cause?

I advocate to help them to make sure they are healthy and strong so they can thrive in the wild, also for people and animals to be able to help each other out.



- 1. What causes are important to me personally?
- 2. Why is this cause important to me?

It matters because I lost two grandfathers to cancer as well as some of my friends, too.

- 3. What changes would I like to see to make things better?
- 4. How do I advocate for my cause?

I advocate by doing a head shave in memory of those who have passed and those who are fighting cancer. I have been doing this since 2-16 and so far I have raised approximately

28

Matthew:



1. What causes are important to me personally?

Sports and athletics. I would like see more people with Down syndrome compete in any other sports like elementary school and high school and college sports. Also sports in their community as well. I had a chance to play in elementary school on the boys volleyball team and also had the chance to play Ice hockey in my community as well.

2. Why is this cause important to me?

It shows that people with Down syndrome can compete in higher levels of sports with everyone else, and show what skills that we have to impress the coach. We can show the coach the reason why to play us in the games.

3. What changes would I like to see to make things better?

I would I like to see any team give us a great chance to play the game that we enjoy playing.

4. How do I advocate for my cause?

The way to advocate is to talk to the coach to ask them to give us the opportunity to give us a chance to show what we can do to impact their team.

fanet:

1. What causes are important to me personally?

The cause that is important to me is all about inclusion - like schools, communities and workplaces....just about anywhere. But a big cause for me right now is that parents and support workers should do things with people instead of for people to foster independence.

2. Why is this cause important to me?

This cause matters because in the past I had experienced people assuming I could not do things and they did things for me. That made me feel really bad. I wanted to be encouraged to do things on my own. And it happened for me that I was able to get my own apartment and more independence. That made me feel really good and proud of myself.

3. What changes would I like to see to make things better?

The changes I would like to see are changes in schools and programs for support workers so they learn how to give the right kind of support. More people who have different abilities or self advocates should talk to the students in these programs.

4. How do I advocate for my cause?

This is how I advocate: I am Canada's ambassador with DSI (Down Syndrome International) and I do lots of webinars and projects and help with resources. I am on the Board of Directors and on some working groups. Also I am a Special Olympic athlete leader and I advocate by doing speaking engagements and mentoring younger athletes. Recently I spoke to Human Services students at a local college telling them about my life.



Connecting Canadians with Down syndrome to opportunities for meaningful, paid employment.

Join for Free at CDSS.ca/Inployable

Announcing the New Community Learning Webinar Series!

We invite you to join us every month for a new opportunity to learn and connect! In this new Community Learning Webinar Series, you will hear from experts and self-advocates on important topics like fitness, nutrition, mental health, caregiver support, seeking employment, and healthy aging. You will also have the opportunity to ask your questions in exclusive Q&As!





Learn more about upcoming webinars and register for free at CDSS.ca/Community-Learning

Meet Your Mindsets Mentors

When you join the Mindsets Wellness Program, you'll get the chance to learn new sports and activities through one-to-one videos from the Mindsets Mentors! Each mentor is a skilled athlete with Down syndrome

who wants to share their love of fitness with you. From skating to weight lifting to swimming to Taekwondo, try them all and find something you like! Learn more about our Mindsets Mentors and how to preregister for the program at CDSS.ca/Mindsets



Meg Ohsada Figure Skating



Kyle Landi **Weight Training**



Aaron Waddingham Taekwondo





Down Syndrome VIRTUAL CELEBRATION

June 15th at 7:00pm EST

Join special guest host Madison Tevlin after the Down Syndrome Walk on Saturday, June 15th for a nation-wide virtual celebration!

Sneak Peek Screening of "A New Story: Power of the Walk" Documentary Mini-Series

A Special Message from Your Down Syndrome
Walk Ambassadors across the country

JOIN THE CELEBRATION!

Facebook.com/CdnDownSyndrome

Exclusive Interview with Madison Tevlin

➢ Big Announcements from CDSS

>>> With Guest Host

Madison Tevlin!

Société canadienne de la trisomie 21

INTRODUCING THE **NEW EMPLOYER'S GUIDE TO INCLUSIVE EMPLOYMENT**



Learn the best practices for inclusive recruiting, interviewing, and onboarding from this new resource for business owners and teams! You'll also find employment stories, real workplace scenarios, and information on speaking respectfully to and about an employee with a disability. Download your copy of the Inployable Guide for Employers and learn more about Inployable at CDSS.ca/Inployable.

JOIN OUR COMMUNITY

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33

CDSS.ca

Wayne Leslie Departs as DSRF CEO

It was with a mixture of gratitude, sadness, and excitement for the future that we bid farewell to CEO Wayne Leslie on March 29, 2024. Wayne has moved on to become the Executive Director of the Kettle Society in Vancouver.

In Wayne's six and a half years with DSRF, he significantly strengthened the organization and led it to a new level of impact. Today, more families are accessing more DSRF programs, services, and resources in more ways than ever before.

In particular, Wayne's steady leadership through the COVID-19 pandemic guided the organization through the most challenging time in our 29-year history. We emerged from this difficult period not merely intact, but operating at an even higher level, having developed creative and effective new ways of serving our clients and families.

Director of Development Jason Campbell will serve as Acting CEO of DSRF until a permanent CEO is selected. Jason will be supported in his role of Acting CEO by the other members of DSRF's leadership team: Director of Education Programs and Services Eleanor Stewart, Director of Therapy, Behaviour and Family Support Susan Fawcett, and Director of Communications + Sustainability Glen Hoos.

The Board of Directors has begun the search process for DSRF's next CEO. We are grateful for Jason's willingness to serve in this capacity until the position is filled. We are confident that the organization will continue to thrive through this transitional period and into the future.

DSRF's Down Syndrome Academy Adds Medical and Autism Courses

Since its launch last fall, DSRF's Down Syndrome Academy has attracted over 500 users engaged in self-paced online courses on a variety of topics related to Down syndrome, including mental health, sexuality, supporting students in the classroom, Down Syndrome 101, and more.

This spring, we added two new courses to the library: Down Syndrome for Medical Professionals and Dual Diagnosis: Down Syndrome + Autism.

Down Syndrome for Medical Professionals equips OB/GYNs, pediatricians, and family doctors to support patients with Down syndrome throughout the lifespan, from diagnosis through old age. This course delivers expertise from some of North America's leading Down syndrome specialists including Dr. Marilyn Bull, Dr. Peter Bulova, Dr. Jonathan Santoro, Dr. Eileen Quinn, Dr. Elizabeth Head, Dr. Brian Chicoine, Dr. Brian Skotko, and Dr. Aven Poynter, along with the professional team of the Down Syndrome Resource Foundation.

Dual Diagnosis: Down Syndrome + Autism helps families, caregivers, and professionals navigate the complexities of a dual diagnosis of Down syndrome and autism from a compassionate and professional perspective, with insights from both families and clinicians.

Learn more and enroll in the Down Syndrome Academy at DSRF.org/Academy.



Summer Fun

DSRF's popular summer camps return for six weeks of fun this July and August. Teens and young adults with Down syndrome will enjoy a unique special activity each week, including photography, fitness, hip hop dance, and more. Plus, let the



force flow through you at our first ever Star Wars Camp: The Rebellion! Learn more and register at DSRF.org/summer.

Sustainability at DSRF

DSRF is committed to sustainability and disability justice, and to creating a safe and healthy environment in which people with Down syndrome can live and thrive. This commitment is reflected in the recent expansion of the role of our Director of Communications Glen Hoos, who is now DSRF's first Director of Communications + Sustainability.

In this role, Glen will:

- Lead and develop DSRF's overall sustainability strategy; including identification of opportunities to improve the environmental sustainability of DSRF's operations
- Educate DSRF stakeholders, including staff, clients and families, and the broader Down syndrome community about the risks associated with climate change for individuals with intellectual and developmental disabilities
- Lead and develop DSRF's advocacy efforts to ensure those with Down syndrome are represented in climate planning and policy development

For more information, please contact glen@dsrf.org.

Down Syndrome



Resource Foundation

FRIENDS OF DSRF

Thank you to all the generous donors who took the 3-2-1 Challenge on World Down Syndrome Day. Including a matching donation of \$3,210 from the BC Maritime Employers Association, over \$9,400 was raised! Donations to the campaign support critical mental health services for people with Down syndrome.

HRSDC has provided DSRF with three Canada Summer Jobs grants, allowing us to hire two summer camp leaders and a graphic design assistant. We are grateful to the Government of Canada for this support.

Thank you to the dozens of volunteers, hundreds of runners, and thousands of donors who made Run Up for Down Syndrome a huge success! Special thanks to

our sponsors: presenting sponsor Upper Canada, media sponsor CTV, t-shirt sponsor LiUNA, the Answer Company, the BC Maritime Employers Association, Mott Electric, Save on Foods, Starbucks, and KPMG. Through your support, you are helping people with Down syndrome thrive at every stage of life.

UPCOMING AT DSRF

Run Up for Down Syndrome: Jun 2, 2024

Up the Down Market Vancouver: Sept 19, 2024

Up the Down Market Calgary: Oct 10, 2024

Up the Down Market Toronto: Oct 30, 2024

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The LowDOWN

A Down Syndrome Podcast









