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Imagine...

...Life without sight, Life without hearing, Life without BOTH

Edition 45, No. 1

Winter 2022

Intervention

TOUCHING LIVES

A History of
Deafblindness
in Scotland



by **Drena O'Malley** MBE

Inside:

- Lesson #8 from Charlotte's Web
- News from CDBA Chapters
- 18th Deafblind International World Conference
- CDBA National Support Fund
- Top Five Braille Books
- One Man's Vision for Inclusion of PWDs
- Deaf vs Deafblind Casting Controversy
- A New Language is Born in the NW
- Deafblind & Intervenor Studies Certificate
- Finding New Joy in Life & Art
- Deafblind Awareness Month June 2022

Connecting the World One Stitch at a Time: Yarn Bombing

Join DeafBlind International (DbI) again in June 2022 for a movement that will build awareness about deafblindness on a global scale. That's right, yarn bombing is back by popular demand!

Last year, over 20 countries participated in DbI's first yarn bombing initiative, leaving colourful, tactile displays on trees, built landscapes, houses and community spaces around the world!

Yarn bombing is a form of street art where yarn that is knit, crochet, or wrapped, adorns an object in a public space. By coming together to yarn bomb objects in as many cities and countries as possible in June, we strive to foster connections and unite a community with individuals, service and advocacy groups in the field, DbI members and partners, and the wider global public.

Let's connect the world one stitch at a time! Grab your knitting needles, crochet hooks, colourful yarn and learn more about #DbIYarnBombing2022 online: <https://www.deafblindinternational.org/yarn-bombing/>. Register your project by February 28th by submitting your Information Form to s.marren@deafblindontario.com.



**CONNECTING THE WORLD
ONE STITCH AT A TIME**

#DbIYarnBombing2022



In This Issue...

Page

Connecting the World One Stitch at a Time: Yarn Bombing.....	2
Message From the CDBA National Board of Directors; Carolyn Monaco, President.....	4
Editorial from the CDBA National Executive Director	5
Deaf Leeds Woman 'Lost the Things She Loved' After Going Blind in Lockdown.....	6
Top Five Braille Books Loaned Out at The Barrie Public Library in 2021	7
18th Deafblind International World Conference.....	7
Deaf, Blind and Heart-Warming: One Man's Vision for Inclusion of PWDs.....	8
"Touching Lives"- A History of Deafblindness in Scotland.....	9
Canadian Deafblind Association National Support Fund.....	9
Charlotte's Web #8 Cartoons Aren't For Every Kid.....	10
"Being Deaf Is Very Different From Being DeafBlind" Controversy Over Helen Keller Casting	12
DeafBlind Ontario Helps Twins Thrive As Individuals, While Remaining Together.....	14
A New Language Has Been Born in the Northwest	15
Christmas Lockdown Another Level of Isolation for Those with Deafblindness.....	16
Piglet, My Deaf, Blind Puppy, Has a Message For You.....	17
Deafblind Woman Finding New Joy in Life and Art.....	18
New Data Products on Persons With Disabilities.....	19
How Deafblind Seattle Transit Riders Shared Their Stories With Crosscut.....	20
Creating Feel-Good Books for Children Who Are Deafblind.....	21
Deafblind Model Launches Awareness Project in Mallorca	22
Deaf-Blind Artist Behind Card & Clothing Brand: 'Always Be Yourself'	23
How do I become a member of CDBA?.....	23
'As a Family, We See Life So Differently': Deafblind Son, Brother Finally Has a Home to Call His Own	24
News From CDBA British Columbia	25
News from CDBA New Brunswick	26
News from CDBA Saskatchewan.....	27
Back-to-Class Bittersweet For Some at Ontario Schools For The Deaf, Blind.....	28
DeafBlind Services Gives Man Second Career Opportunity.....	29
2022 "Lend-A-Hand" Charity Golf Tournament	30
Deafblind & Intervenor Studies Certificate Program	30
Canadian Deafblind Association 2021/22 Board of Directors.....	31
CDBA National and Chapter Contacts.....	32

The Canadian Deafblind Association (CDBA) was formerly known as the Canadian Deafblind and Rubella Association (CDBRA). "Intervention" magazine is published twice yearly in the Spring/Summer and Fall/Winter.

The Managing Editor would be pleased at any time to receive photos, articles, news items, letters, notices of future conferences, meetings and events, as well as stories about deafblind children, their families and adults - young and old.

All written material should be in the English language and may be edited for length. Opinions expressed in articles or letters are those of the author and not necessarily representative of the views of CDBA. "Intervention" magazine is available electronically and in print form to CDBA members, their families, and others upon request without subscription. Please contact:

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Message From the CDBA National Board of Directors

Carolyn Monaco, President



Welcome to this Winter 2022 edition of Intervention magazine. We hope that you find it interesting reading but your feedback is very important to all of us at National.

We have a couple of recent developments to share with you. CDBA National has been working with a filmmaker to create a much-needed awareness video which will focus on our 11 "Principles of Intervention". The video will utilize a series of short video clips from chapter senior staff and Intervenorers to portray the individuals with congenital deafblindness that CDBA supports across Canada. The video will be 10-12 minutes in length and will include voiceover captioning and examples of intervention strategies and communication systems. Video clips will also be posted on our website to correspond with each of the 11 Principles.

With regard to our National website, CDBA National will soon begin a make-over designed to update its look, feel and accessibility. Content will essentially remain the same with the addition of more photos and a review of the drop-down menus within each category on the horizontal toolbar.

CDBA National is also considering the establishment of a memorial scholarship for Intervenor students to honour the legacy of Wayne Turnbull who was deafblind and a strong supporter of CDBA Alberta and the field of deafblindness generally. Many details including eligibility criteria still must be worked out.

Lastly, CDBA National has been invited by the Office of Disability Issues to participate in an engagement process to support the development of the Government of Canada's first ever Disability Inclusion Action Plan (DIAP) and a proposed Canada Disability Benefit. The proposed benefit would support the financial security of working-aged persons with disabilities.

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HOLD THE DATE! **47th ANNUAL GENERAL MEETING**

CANADIAN DEAFBLIND ASSOCIATION (National)



Saturday September 24, 2022, 1:00 pm – 3:00 pm EST
Virtual meeting via Zoom

Look for Registration, Program & other information to be posted in the coming weeks www.cdbanational.com

Editorial From the National Executive Director

Tom McFadden



Welcome to this Winter 2022 issue of "Intervention" magazine. On behalf of my Board of Directors at CDBA National, let me wish all of our readers a New Year filled with hope as the world begins to slowly emerge from the pandemic armed with new learnings about all disabilities, including deafblindness, and a renewed awareness of the importance of diversity, inclusion and equity in every service we provide.

Within the pages of this issue, we spotlight World Braille Day (Jan.4) and the birthday of braille inventor Louis Braille, with several library favorites. You'll read uplifting stories of perseverance, emotional strength and persistence that reflect our sense of optimism as we learn to live with COVID. Among them: one man's "vision" for inclusion of persons with disabilities; the determination of a woman living with Usher Syndrome who "lost the things she loved" during lockdown; and a deafblind woman who found new joy in life and art. You will uncover the history of deafblindness in Scotland, as well as a new language, born in the Pacific Northwest, which prioritizes touch called "Protactile". And once again, we have for you the 8th installment of "Lessons from Charlotte's Web".

June 2022 as Deafblind Awareness Month

June 2022 will mark the 8th anniversary since the Senate of Canada recognized June as Deafblind Awareness Month. Once again, in addition to the many celebrations and proclamations in towns and cities across this country, the focus by CDBA and like-minded organizations in the field of deafblindness, will be on "Yarn Bombing" - a Dbl global initiative that inspired immense interest in more than 20 countries around the world. Activities in Canada will once more be coordinated by a working group comprised of people with deafblindness, professionals from the field and organizational supporters whose common goal is to increase awareness and knowledge of deafblindness.

Winds of Change

After more than 30 years with CDBA-SK, including the past 11 years as Chapter Executive Director, Dana Heinrichs has decided to move on as the new CEO of Mennonite Nursing Homes Inc. We all wish her well in her new venture. She will be missed. At the same time, we welcome newly-hired CDBA-SK Executive Director Leanne Kerr, and look forward to working with her!

I leave you with this thought: "One of the happiest moments in life is when you find the courage to let go of what you can't change" Author unknown.

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Deaf Leeds Woman 'Lost the Things She Loved' After Going Blind in Lockdown

Mellissa Dzinzi

www.leeds-live.co.uk



Alison Bull pictured with her dad John Bull and guide dog Bella

Alison Bull, has Usher Syndrome - and knew she would eventually lose her sight

A deafblind Leeds woman who lost her sight completely during lockdown is taking on an epic challenge to prove she can still 'make a difference'.

Alison Bull, 44, was diagnosed with Usher Syndrome when she was only five years old - the rare condition meant she was born deaf and gradually lost her sight as she grew up.

Throughout her life, Alison knew she would lose her sight eventually but this didn't stop her from enjoying sports such as skiing, climbing and canoeing. But she eventually had to give her much-loved hobbies up as her eyesight deteriorated.

Sadly, she lost her sight completely

during lockdown which Alison says was "tough" and caused her to lose confidence.

However, with the help of her dad John Bull, 75, and running group Ripon Runners, Alison will be guided through her challenge across the Yorkshire Three Peaks where she is determined to complete 24 miles and 1585m of ascent over three days.

She hopes the challenge will bring back some of her confidence she had before lockdown and raise funds for Sense, a charity that supports people with complex disabilities, including people who are deafblind like herself.

"When I was younger I knew I would eventually lose my sight," Alison said. "I would feel very upset and think 'why me?' But I guess I just got used to it, my family say I am very strong-willed.

What was hardest was when I couldn't play the sport I wanted anymore. I used to canoe, climb, ski and now I can't do these things that I love. It is hard becoming less independent as my sight has deteriorated.

"I never attended mainstream school. I went to St John's school for deaf children and then onto a deaf college in Doncaster. At school, the focus was on communication by voice, so I only learnt British sign language when I was 11. Learning this was really helpful. I made a lot of friends in the deaf community, we have our own very strong community.

"I am very strong-willed so I have gotten used to my disability and the changes. Losing my sight in lockdown was really tough however and I have found it hard. People are really helpful when you ask for it. I live with a personal assistant, she is paid for 16 hours a week, she is deaf but has sight. My parents also help me a lot with the day to day activities."

She added: "I want to complete this challenge for myself to show I can still make a difference, help others and highlight the loneliness and isolation that I feel. Everyday life has new challenges that really knock my desire to get up and go, but that's not how I want to be seen or be. Doing this will make me feel proud of myself."

Sense Community Fundraising Manager, Angela Court-Johnston said: "We're incredibly grateful to Alison for taking on this fundraising challenge for Sense. She has shown determination during a challenging time and we admire her desire to complete this hike. It is thanks to people like Alison that Sense is able to support children and adults who have complex disabilities or are deafblind."

Top Five Braille Books Loaned Out at The Barrie Public Library in 2021

Janis Ramsay
www.simcoe.com



Jan. 4 is World Braille Day, to celebrate the birthday of braille inventor Louis Braille, and here is a list of the top five braille books loaned out at the Barrie Public Library in 2021.

1. The Berenstain Bears and the Blame Game by Stan Berenstain. The Berenstain family series has been a classic favourite for many young readers through the years.

2. Canadian Fire Fighters (in my Neighbourhood) by Paulette Bourgeois. Brought to you by the same author as the Franklin books, this explores kids' questions about firefighters.

3. Eh? to zed: a Canadian ABeCedarium by Kevin Major. This book shares some Canadian words from each province, including cultural icons.

4. Chrysanthemum by Kevin Henkes. It tells the story of a mouse whose parents

thought they had picked out the perfect name for her, until she went to school.

5. No dragons for tea: fire safety for kids (and dragons) by Jean Pendziwol. It introduces children to fire safety after a girl invites a fire-breathing dragon home for tea, and he accidentally sets the house on fire.



SAVE THE DATE!

The 18th Deafblind International World Conference is coming to Ottawa, Canada on Saturday, July 22 to Friday, July 28, 2023!

With the theme of "Global Connections: The Future in Our Hands" the conference will be a hybrid affair, which means you can attend in person, or virtually!

Our hope is to connect with more people than ever before. As more information becomes available you can stay informed by visiting

our social media channels and our website at deafblindnetworkontario.com/. Canada welcomes you to join us in our beautiful national capital, Ottawa, Ontario in 2023. Let's stay connected, the world is at your fingertips.

Deaf, Blind and Heart-Warming: One Man's Vision for Inclusion of PWDs

Donah Mbabazi

www.newtimes.co.rw



Jean Marie Furaha's goal is to continue advocating for those with disabilities. He is the chairperson of Rwanda Organisation of Persons with Deafblindness.

Jean Marie Furaha is a man of opinion and intent. Although our interview was done with the help of sign language, it was easy to perceive his zeal and determination in imposing purpose to his life and that of others.

Furaha lives with both visual and hearing impairment. As we spoke, he would hold onto his interpreter to feel the hand shape he was making as he spelt out his words.

He wants advocacy and a better life for those living with disabilities. That's his goal and vision he has always had ever since he lost sight.

The 54-year-old was born with hearing and speech impairment, and only lost his sight later in life, something he says put a halt to so many dreams he had in life.

But this didn't stop him from pursuing a purposed life.

"I faced so many challenges but the main one was communication. My biggest worry is not being able to communicate with my family; I can't watch news and know what's happening in the world. It's like living alone in the world a very big challenge for me, Movement is also a challenge, though innovations such as the 'white cane' are trying to address this. Accessing different services is hard too, I am sure others face the same. This is very tough, for example when I want to go see a doctor, without an interpreter, it is impossible for me. So, we are left at the mercy of others who in most cases think for us," Furaha reveals.

Motivated by these tough situations he endures daily, Furaha decided to learn tactile sign language and braille in order to be able to communicate and lead a fuller life, for him and others.

He knew that as long as he was able to write at least, somehow he would be able to tell the rest of the world about the challenges people living with disability face, more so the 'deafblind,' and do advocacy on how to improve their lives.

In the process, he became part of an organisation-Rwanda Organisation of Persons with Deafblindness- where he serves as the chairperson.

Along with his interpreter, Furaha is able to carry out his duties diligently, ensuring that society becomes inclusive and develops enhanced standards of living for people with Deafblindness.

His organisation also works to ensure that more people learn sign language in order to have access to information and be able to speak to other people.

It also serves to bring together persons with disabilities and offer them a space where they can share their opinions, that way, ensuring the observance and protection of their rights.

"As a family here at the organisation, our role is to do advocacy such that those who didn't get a chance to go to school, get some education. But also, get a chance to interact with others, because it can be lonely out there for us."

Desire for inclusion

"Even though I got this chance and privilege of serving others, I still face challenges. Most people think we are not capable of being useful to society," Furaha shares, adding that some parents are still ashamed of their children who have disabilities to the extent of locking them in houses.

"A parent can have a child that neighbours know nothing about. They consider them hopeless and lock them inside houses. It can be traumatising for such children and this remains a big challenge. Advocacy is still needed," he says.

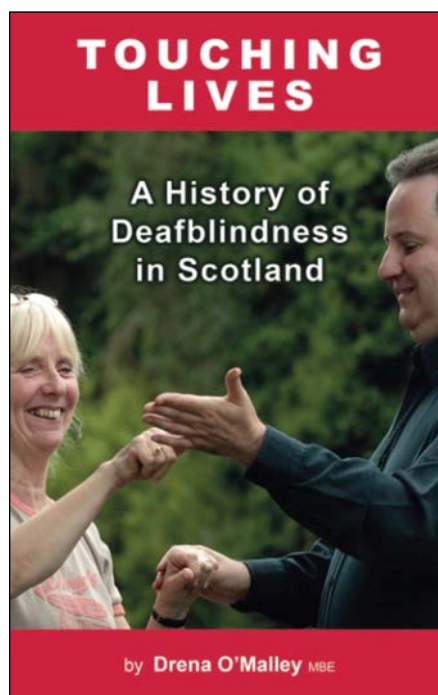
As a leader, Furaha believes he would have done more than leading the organisation but communication is his biggest barrier. Nonetheless, he is thankful for the impact he is making.

He is also grateful for the different platforms that work hard to ensure the rights of those living with disabilities are fulfilled and respected.

His goal is to continue advocating for the disabled and ensure mind-sets for society in general are changed.

“Touching Lives”- A History of Deafblindness in Scotland

Drena O'Malley



About the author

Drena has been involved with deafblind people since 1989 and became CE of Deafblind Scotland when it became a separate Scottish charity in 2001. When she retired in 2017, she resolved to write the history, not only of well-known deafblind people, but of the Scottish deafblind people with whom she had been involved.

“Touching Lives” tells the stories of deafblind people not only from history but includes those who currently face the challenges that Usher Syndrome and deafblindness bring.

Deafblind peoples’ stories are recorded, both their achievements and disappointments, in a matter-of-fact way and the book recounts how they sought to influence what happened not only in

the organisation, but also in society, and at all levels of government.

As both a BSL and Deafblind Manual Interpreter, Drena O'Malley was, and remains, fascinated with tactile communication. “Touching Lives” gives an insight into the world of those who rely on it.

This book will be of interest to people across the world whose lives are affected by deafblindness including professionals who work in the field. So little is written about adults who have acquired deafblindness, and in particular those who have Usher syndrome.

The book is published in print and on Kindle by Amazon.co.uk. It is hoped alternative formats can be made available over time. Currently an audio recording is being made.

Canadian Deafblind Association National Support Fund

Purpose:

The purpose of this National Support Fund is to provide CDBA members living in Canada who are deafblind with another funding option to assist them with the purchase of:

1. Intervention services during or as the result of an emergency
2. Intervention services for individuals confined to a hospital
3. Specialized education or recreation programs
4. Specialized equipment
5. Other services or equipment resulting from specialized or unique circumstances

The funds provided are short term and are to supplement other sources of funding. They are not intended to replace funding which may be otherwise available nor are they to be of an ongoing nature.

Emergency:

will be defined as—an unplanned event for which the individual or their advocate has had less than 14 days to prepare.

Supplemental:

will be defined as—adding to other funding sources which may be insufficient to cover Intervention Services during short-term hospital stays or specialized education or recreational programs, the cost of such programs or specialized equipment etc.

Criteria for Funding:

Persons Qualifying:

1. Those individuals who have been identified as deafblind and/or in a deafblind service program.
2. The individual or their immediate family must be a member of CDBA for a minimum of six months

prior to the submission of the funding application.

Application for Funding:

Requests for funding may be received from any source on behalf of any qualifying individual from across Canada. The application form is available for download on the CDBA National website www.cdbanational.com or by contacting the CDBA National office info@cdbanational.com or by calling (905) 331-6279. Requests must be submitted in writing.



Lessons From Charlotte's Web

By Frances Jablonca

Lesson #8

Cartoons Aren't For Every Kid



Frances Jablonca, of the CDBA AB writes about her experience as a mother of a child with deafblindness. Charlotte MacKinnon passed away in 2015 at the age of 22 but her spirit remains strongly in memory.

My last Charlotte story highlighted how wonderfully useful technology was to Charlotte, and also how it helped myself and Rob, as her parents, to augment her education and communication. This article speaks to how we learned about, and attempted to overcome, the limitations of Charlotte's dual sensory loss so she could have some entertainment from the screen technology that was available to us while she was growing up in the 90's and early 2000's. Charlotte had CHARGE Syndrome, rendering her deaf and legally blind with 20/200 vision, no macula for fine focus and a radius of around 5 feet or closer for her best range of distance vision. Although she lacked depth perception, she could however identify color. The irises in both eyes were never joined, leaving her without a full field of vision in the upper quadrant from left to right. When she scanned the environment in front of her, there were gaps that neither her doctors or we, her parents, could quite predict or define. We did know however, that she saw better in

her lower field of vision, likely one reason why she put so much importance on everyone's footwear!

As a youngster, Charlotte would turn her whole head to try and fill in these random gaps, but over time she eventually learned to scan just by moving her eyes from left to right or vice versa. It wasn't a perfect science for her and there were times she wouldn't see that a cupboard door at eye level was open and would bump her head. We'd hear her hoarse little yell, which I'm sure was an instinctive curse, and we'd know she'd hit something. I recall instances when I might be walking across the kitchen and she hadn't seen me at all in her irregular peripheral sight line, perhaps focusing instead on something that caught her eye in the opposite direction. Conversely, if I thought I could sneak past her, she would inevitably see me. Not that I wanted to avoid her, but if I had forgotten something while trying to leave the house, and didn't want to stop and take the time to sign to her, I might try to get by her surreptitiously. Signing, especially where visual loss is concerned, requires one to be located in the correct position and proximity. It takes time, no matter that you happen to be in a hurry. For those who haven't used visual communication, it is easy to underestimate the efficiency factor of a spoken language.

So what does this information have to do with cartoons? Specifically why didn't Charlotte enjoy watching them? (Every adult, parent or guardian knows a lot of entertainment value for kids is garnered from cartoons. It is almost an oxymoron for a child not to want to watch cartoons.) So, as the title of this article implies, the lesson Charlotte taught us very quickly was that cartoons were a visual nightmare for her. This was directly related to her specific vision. Animation usually exaggerates human features or emits the 3 dimensional quality of human forms. Often the characters are animals that don't closely resemble real animals, with inaccurate

colors and features, and yet behave like real people. Movements by animated characters are often erratic and not true to life in speed. You get the idea. What Charlotte was best able to follow on a TV screen were slower moving characters, with scenes that progressed in a continual time sequence without jumps to the future or past. Important also for Charlotte's visual needs was to have very simple backgrounds with little visual clutter, similar to the concept of an Interpreter of the deaf wearing plain, solid- clothing rather than clothing with a busy pattern.

So, if not cartoons, we needed real-life TV shows and movies with specific criteria for Charlotte so she could use technology for some of her entertainment. Her vision was unique, and the specific way that she perceived was always a bit of a mystery. Live events in large venues such as music concerts, plays or ballets, sporting events, parades, or any event that took place more than 5 feet away were not feasible for her to attend.

Furthermore, as Charlotte relied completely on ASL, unless she had a slow moving story on TV or video, acted out in ASL (there were not many out there when she was young), she would have had to read subtitles. This too was problematic as the print was too small for her to read and the words moved too quickly for her to capture and follow.

We exposed her to quite a number of TV programs and movies that we thought would fit her specific criteria over the years. We looked for acting and plots that were deliberate and moved slowly. Then, we'd summarize the storyline for her before, during and after watching it. In the end, there were only a few favourites that she absolutely loved and watched over, and over, and over again.

She was mildly interested in Barney and Sesame Street. She had Bert and Ernie dolls, and loved these, as she seemed to relate to their simplistic faces and colors

being much more interesting than a pale, flesh-toned doll. However, it was the Mr. Bean series that fascinated her, there being no dialogue whatsoever and with acting that was completely self-explanatory. We could not approve of him as a role model, but he certainly kept her entertained. (Us as well, though we did let her know that much of his behaviour was childish and unacceptable). His full length feature, 'Mr. Bean's Holiday' brought the whole family together on more than a few Friday nights for popcorn and laughter.

Another favourite was Mr. Rogers. She enjoyed watching the portion on the show where he would feature a factory where something was produced, be it a canning factory, or shoe manufacturing. I remember when Mr. Rogers featured a concert pianist. Since we recorded some of these shows, Charlotte would replay this pianist over and over again. One day she'd pulled up a tiny 3 ft by 3 ft yellow, plastic piano with rainbow coloured keys that we owned. Sitting down with it in front of the TV, she gave me a concert with all the dramatic flourishes identical to those of the artist on the screen.

Her two other favorite full length movies



were "The Wizard of Oz" and the remake of "The Parent Trap" with Lindsay Lohan. She watched them over and over again. She especially relished the slap-stick humour and replayed a comedic scene endlessly wherein the twins' father's faulty love interest goes camping with them, and the twins pull her mattress out onto the lake while she is sleeping on it, inevitably waking up and falling into the lake. Charlotte thought this was hilarious and couldn't get enough of it. She would also memorize scenes from "The Parent Trap" and act

them out much to my enjoyment, as I watched how accurately she could mimic the movements and facial expressions of the actors.

She identified especially with the main characters who were young girls, and who had red hair like herself. She had figured out how to do a selfie with Dorothy using the pause button on the Video recorder, which we kept long after we got the DVD recorder, and using the selfie mode on her iPad.

Eventually, Charlotte began to bring the characters of these two movies and some of the TV shows into her story writing. She melded the real people in her life, like our family members and relatives, and her close friends and Intervenor into make-believe stories with Dorothy, the Tin Man, the twins Hallie and Annie, Bert and Ernie, Mr. Bean and, of course, herself. These stories always had comedic themes with issues involving little dramas such as her white cane, or someone's walker being stolen or people's shoes being hidden, or someone being locked out of their home and having to sneak into someone else's home to sleep. We even photocopied pictures she had taken of the movie characters for her to create little books along with her stories. These projects became her creative writing outlets, and I wonder if they were also an outlet to sort out problems and incidents she experienced in her reality. In any case, she got a lot of mileage out of the shows that she could relate to.

We came to observe quickly how Charlotte had her own acting streak with how much she loved to mimic and act out scenes, and how she adored dramatic events. Perhaps it just ran in the family, as both her siblings performed in drama and musical theatre during school. Though we avoided taking her to live events because of her vision, when her siblings performed in community plays or high school musicals, if the venue was small, we would sit in the front row with her, all prepped so she knew what the story line was, and sign the basic gist of the story pointing out the action for her. It was difficult to know what she had grasped, but I wanted to believe

that she had enjoyed being included in a family activity, and that she loved getting dressed up, and feeling part of the ritual of an evening out. When video technology became more accessible it meant we could get a hold of these performances in DVDs of VHS format to have her view



it again at her leisure. Occasionally there were performances given by the deaf community and we were grateful for the Interpreters provided. Charlotte would be seated an optimal 5 feet away and watch the Interpreters. Unfortunately, with her vision challenges, she would only be able to watch the Interpreters and not the actors. Although it still wasn't ideal, the best part for Charlotte was the social time in the lobby, after the performance, catching up with her friends in the deaf community.

Happily, for a few years, Charlotte had a wonderful opportunity to try her hand at acting when she joined a deaf drama club, run by one of the most resourceful people I know, Stephanie Muendel-Moehr, who is deaf herself. She organized this drama club for deaf youth under the umbrella of Inside-Out Theatre in Calgary. Stephanie's determination and dedication to integrate the two deafblind members to be an integral part of the group was inspiring. She organized numerous events for these young actors to perform for the public. The acts were artistic short sketches, either thought-provoking or humorous and fun, but always professional and entertaining. When a video was produced, Charlotte became a captive audience, watching the fruits of her own acting.

“Being Deaf Is Very Different From Being DeafBlind” Controversy Over Helen Keller Casting

Keely Cat-Wells

www.forbes.com

A Quiet Place star, Millicent Simmonds, is set to take on the role of DeafBlind American author, disability rights advocate, political activist and lecturer Helen Keller in *Helen & Teacher*, which is an upcoming film about Keller's relationship with Anne Sullivan, her translator and companion, according to The Hollywood Reporter.

After Simmonds posted the news to her social media platform, it sparked controversy within the Deaf, DeafBlind and Disabled communities due to Simmonds being Deaf but not DeafBlind. In a video response to the news posted by Loni Friedmann, who is DeafBlind, and works as an ASL instructor with her own business teaching ASL classes online; Functional ASL, Friedmann said "Deaf people do not understand what it is like to be DeafBlind". The unauthentic casting conversation within the entertainment industry is not a new one, movies such as *Me Before You*, *The Upside*, *Theory Of Everything*, and *Come As You Are*, are among those that include disabled characters played by actors without the lived experience.

Mary Harman, a deaf Latina disability rights expert and activist says, "Unauthentic casting is an issue because of the significant harm it causes; this is both covert and overt. When people consume media — whether it's movies, TV shows, or advertising — perceptions and world-views are created. It's incredibly important that those perspectives are as accurate as possible. The disability experience is a spectrum. People with disabilities, including those who are deaf, DeafBlind, and low vision, face a unique set of barriers and struggles and adopt distinct cultural elements. When somebody plays a character with a disability that they do not have in real life, not only is an

authentic portrayal impossible, but this also creates narratives that are false and harmful, regardless of intent or framing. The magic of storytelling can highlight the unique, rich cultural experiences of disability. However, this gets lost when disability is inauthentically portrayed."

The entertainment industry holds incredible power. The U.S. media and entertainment (M&E) industry is the largest in the world. At \$717 billion, it represents a third of the global M&E industry. The U.S. industry is expected to reach more than \$825 billion by 2023, according to the 2018-2023 Entertainment & Media Outlook by PriceWaterhouseCoopers.

Venesse Guy, who identifies as she/they and is a Black mixed DeafBlind woman. Is an astrologer and is the founder of AstroWoke, which provides ultimate access to astrological content in ASL, stated that "a performer's lack of lived experience, especially as a DeafBlind person, may obfuscate the audience's cultural understanding instead of enlightening them. It may give people the impression that DeafBlind actors do not exist, or that DeafBlind people can't represent ourselves. We should provide authentic representation to uplift our DeafBlind community. Roles like this are employment opportunities for DeafBlind people and they can open doors toward the future. For young DeafBlind members, having accurate representation and role models would immensely impact their lives and boost their self-esteem. We should be given more opportunities to show our identities and community. Conscious casting should be implemented and actively acknowledged within the Hollywood environment."

Harman says "The media harnesses immense power in normalizing things, including the disability experience,

which is an integral part of the broad spectrum of humanity. 1 in 5 people in the U.S. and over 1 billion people worldwide have some form of disability. That's approximately 15% of the world's population. Yet, the stigmatization of people with disabilities persist. I believe the media has played and continues to play a significant role in this, in large part due to how we are misportrayed to mainstream society/audiences. Committing to inclusion on all fronts within the entertainment industry can go such a long way in addressing that."

Simmonds is Deaf, and her talent, skill and global success have been big wins for the industry and Deaf community, but should the casting of this project have been conducted differently? Friedmann commented "having a DeafBlind actor for a DeafBlind role shows the most authentic perspective because only they know the lived experience. People get a lot of their perspectives from characters in TV and movies, so, it's important to have the right people for specific roles." Friedmann provides various clear examples:

- Deaf roles for Deaf people.
- DeafBlind roles for DeafBlind people.
- Black Deaf roles for Black Deaf people.
- Indigenous Deaf roles for Indigenous Deaf people.
- People of Color Deaf roles for People of Color Deaf people, and so on.

Similarly, Harman says, "I believe production should have committed to ethical casting. To me, that means bringing onboard DeafBlind individuals from the get-go, searching far and wide for blind and DeafBlind talent, and casting actors who possess the authentic lived experiences of the role. DeafBlind individuals must have an active involvement in all aspects of production."

A story about Helen Keller seems like a step in the right direction. Hollywood is beginning to highlight disabled lead stories, stories about disability culture and history. Whilst this is an important direction for Hollywood it must be taken with caution, Guy says "it is such a noble moment that they have decided to make a film about Helen Keller's life. However, the character Helen Keller is outdated due to whiteness, privilege, and elitism. If we are retelling her story today, we should seek to recognize and celebrate the diversity in our DeafBlind community and the movie's result would ultimately enhance." Harman also mentioned, "while it's usually great to see movies centred around people with disabilities, I think Haben Girma, John Lee Clark, and other DeafBlind activists have done an excellent job of explaining how this harm isn't as obvious to laypeople. For instance, to the entertainment industry, it seems there is only one DeafBlind story to tell: Helen Keller's. The danger in this is it reduces the experiences of DeafBlind people to a single story. It's important to consider the full spectrum of DeafBlind contributors, especially DeafBlind people of colour."

Hollywood still has a long way to go before it can be deemed equitable by many communities. Guy says "the entertainment industry could be more inclusive by looking at who is on-set, in production meetings, and behind the camera. Instead of sidelining the DeafBlind community in the hiring and casting process, they should be aligned and merged into the crew, or brought in as casting consultants. We would feel more normalized and confident by being included in producing. Directors and producers may view hiring interpreters, Certified Deaf interpreters, or accessible resources to smoothly communicate with DeafBlind people as obstacles. However, following the American Disabilities Act (ADA), everyone should know that communication access is a legal right. It is easy to accommodate disabilities and it's the right thing to do. The entertainment industry should be held more accountable from the inside,

instead of marginalized groups doing the labor. Harman wants to "see more roles played by disabled actors, and that disabled actors are not limited to characters with disabilities. Take Lauren Ridloff's role as Makkari for instance. Makkari was initially a white hearing man. When you take disabilities and other identities out of the boxes society put them in, possibilities are endless."

Harman also believes a significant reason we continue to see people with disabilities miscast is the lack of people with disabilities among writers, directors, producers, and others involved in the process. "Reversing this trend will probably result in more authentic portrayals."

There is often the misconception that DeafBlind, Deaf and Disabled talent is not easy or possible to find, to this point Guy says "performers can be found by networking through the Deaf community, there are talented DeafBlind people out there hoping for opportunities like this. The Deaf community is truly small, so imagine how small DeafBlind community is. A Deaf actor accepting a DeafBlind role just shows there is still a huge lack of support from the Deaf community towards DeafBlind individuals. [Another misconception] about the DeafBlind community that we cannot see at all. In reality, there is a spectrum of DeafBlind people and how we cope with our journey. So again, authentic casting is the key to helping society understand who DeafBlind people are, and how to accommodate us more effectively. Audiences should be exposed to more authentic portrayals of people with all disabilities, including DeafBlind people."

In addition Guy mentions "some Deaf (and hearing) people will overshadow DeafBlind people if an opportunity comes their way. Accessibility is a large part of this lack of representation both in front and behind the camera. Harman says "captioning isn't as widespread as one would think; trailers, interviews, and other forms of content put out by the industry need to be accurately captioned."

In addition to authentic representation,

accessibility and diverse stories, we need intersectionality. Harman mentioned, "many people with disabilities adopt multiply-marginalized identities, such as Black deaf, Latinx, and DeafBlind people. That said, it's important to make casting decisions while taking into account multiple identities a character has."

Progress is being made, but we must remember the effects unauthentic portrayals have on a greater level, Harman says "the effect is very real and lasting. In essence, every time people with disabilities are miscast, other creators are sent a message that it is okay to do the same. Thus, false and harmful narratives are created for the consumption of mainstream society. The impact of this can be devastating. It perpetuates disparities in employment (in 2020, 17.9% of persons with a disability were employed compared to 61.8% of people without a disability, according to the U.S. Bureau of Labor Statistics) and subjects our communities to oppression in all corners of society. The disability community is not a monolith. The disability experience is a spectrum; being deaf is very different from being DeafBlind."

To build a more inclusive industry for everybody including DeafBlind talent, Harman says "it must be made clear in casting calls that DeafBlind talent is wanted and sought after. You will attract DeafBlind talent. DeafBlind communities will also be sure to advertise the casting call and reach out to talent they believe should consider auditioning."

Some key takeaways and final thoughts by Guy and Friedman. Guy says "unpacking your sighted and able-bodied privilege is the key approach to this whole controversy. Don't be too attached with your privileges, share them with us so we can all succeed together. How can we thrive without being acknowledged? How can we build a strong foundation and structure of community alone? We need non-DeafBlind people to recognize us. We are complex humans. Stay open and listen to a different array of DeafBlind and BIPOC."

DeafBlind Ontario Helps Twins Thrive As Individuals, While Remaining Together

NewmarketToday Staff
www.newmarkettoday.ca



For 21-year-old identical twins, Scott and Ian, twinkling Christmas lights are a significant sight of the holiday season

Bright, shining strands of light adorn homes around the world. Inside, candles flicker and trees glimmer. Their opulence and beauty illuminate dark, snowy winter nights.

For 21-year-old identical twins, Scott and Ian, twinkling Christmas lights are a significant sight of the holiday season.

“Born premature, Scott and Ian have quadriplegic cerebral palsy, epilepsy, and complex medical challenges. At two, we learned they are both deafblind,” said their mom, Paula Watson.

Deafblindness is a combination of hearing and vision loss that is unique to each person and impacts access to information, communication, and mobility.

“In learning that Scott and Ian have some light perception, we developed this sense in every way we could... Through sensory toys with lights, music, and sounds, in addition to physio and occupational therapies.

Over time, we trusted the doctors, therapists, and other members of ‘our team’ to address the boys’ needs, while also ensuring we had time to love and play together as a family.”

In early 2020, DeafBlind Ontario Services became part of the Watson’s team, when Scott and Ian moved into one of the non-profit’s supported living homes.

“DeafBlind Ontario Services’ intervenors, professionals who act as the ‘eyes’ and ‘ears’ of people with deafblindness, mean the world to us. They are dedicated to ensuring consistent and holistic person-centered plans are in place for each person supported to live full, meaningful lives.

They consider the boys’ likes, dislikes, and goals. Scott is very serious; he is wiser than his years and a real thinker. Ian is always smiling and ready to crack jokes. The two love to be around each other,” said Paula.

“DeafBlind Ontario Services’ approach means that Scott and Ian continue to thrive as individuals, while remaining together. It is wonderful to see them live independently of their father and I, while continuing to be the same happy and confident people we have always encouraged them to be.”

The Watsons are looking forward to Scott and Ian visiting for the holidays. Along with sensory holiday traditions, like music from the Little Drummer Boy, holiday movies, a visit from Santa, a bright, twinkling Christmas tree, and a delicious dinner with loved ones.

“We plan to have lots of Christmas music and Christmas lights of course, while creating new memories,” said Paula.

A New Language Has Been Born in the Northwest

Sage Van Wing

www.opb.org

It's not often a new language emerges.

But in the last 15 years, a new language was born right here in the Pacific Northwest. It's called Protactile, and it was created by a group of DeafBlind people who prioritize touch.

One of the people at the center of creating this new language is Jelica Nuccio. She recently moved to Monmouth, Oregon, where Western Oregon University just received a grant for \$2.1 million from the U.S. Department of Education's Rehabilitation Services Administration, or RSA, to help train Protactile language interpreters.

DeafBlind people like Nuccio have traditionally used variations on sign language to communicate, but it can be easy to miss important details in a language that is designed to be seen.

"We can't grow if we always are only getting things secondhand from other people who are seeing them in the world firsthand because people are uncomfortable shifting to a tactile ground," Nuccio said. "There have been years and years and years of isolation for DeafBlind people."

Protactile was born when Nuccio first took over the Deaf-Blind Service Center

in Seattle. At that point, she began to advocate for DeafBlind people to communicate with each other without the use of interpreters. "I said no, we don't need interpreters between us in our midst 24/7. We can run this thing ourselves directly in contact with one another," Nuccio said.

"The original intention was not to create a language: it was simply to be in communication with each other directly.

"Once we got in touch we realized that we were happening upon some different communication practices," Nuccio said. "So we brought in some other DeafBlind people and we started interacting using those communication practices. We got a linguistic anthropologist involved. We basically created a space where everyone is DeafBlind and Protactile and asked: 'If the world was just full of DeafBlind people — there were no hearing or sighted people on the planet — what would we do? How would we do it?'"

Nuccio says the experience of learning and creating the Protactile language has changed her life.

She now runs a business called Tactile Communications, which trains DeafBlind



individuals to be more autonomous. She is also the lead trainer for the DeafBlind Interpreting Institute at Western Oregon University.

"I really realized how devoid of the human experience information can be when people aren't connected and touched directly," Nuccio said. "So touch and Protactile language is the foundation for my life. It truly is. I mean, it allows me to function in the world."



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To learn more visit the link from our website at www.cdbanational.com. Thank you for your support in ensuring that, "All people who are deafblind will live rich meaningful lives."

Christmas Lockdown Another Level of Isolation for Those with Deafblindness

nationvalleynews.com



Megan and a professionally trained intervenor, Julie.

The sights and sounds of the holiday season are a vivid memory, relived year after year. Neighbourhoods aglow with twinkling lights, trees adorned with beautiful decorations, warm laughter of loved ones, and the unmistakable murmur of countless shoppers echoing through the mall. Things were different this year, for everyone.

For the first time in her life, Megan, a woman with deafblindness, did not spend Christmas at home with her family.

"We will drop off her presents and stocking to her home, one of DeafBlind Ontario Services' residential locations, as well as FaceTime with Megan and her intervenor on Christmas day," says Kathy Momtahan, Megan's mom.

Deafblindness is a combined loss of hearing and vision that impacts access to information, communication, and mobility. At just eight months old, Megan's family learned that she is deafblind and has Zellweger Spectrum

Disorder, a degenerative neurological disorder.

"Learning how to parent a child with deafblindness was a big challenge... It was difficult finding specialists who knew about her disorder. We had to do our own research and take her out of the country for answers and what treatment was available," says Kathy.

People with deafblindness often face additional medical challenges, making them an especially vulnerable group. The people supported by DeafBlind Ontario Services, like Megan, have been in lockdown since March, keeping them safe during the pandemic. We all know what it's like to be in isolation. Now, imagine how this affects someone with deafblindness.

Intervenors are professionally trained to act as the "eyes" and "ears" of the individual with deafblindness through the sense of touch.

"Intervenor Services means that Megan has specialized support that knows her Communication methods and preferences, her health and safety needs, all the while planning for a fun and rich adult life," says Kathy.

With a disability that is already isolating, the need for specialized Intervenor Services is vital now more than ever. This holiday season, DeafBlind Ontario Services' intervenors across the province will bring a sense of comfort and normalcy during a difficult time.

"As a child, Megan enjoyed being with her family during the holidays. With some hearing in her left ear and a cochlear implant on her right, Megan enjoyed listening to Christmas carols and all the hustle and bustle of activity, not to mention getting extra servings of chocolate pudding around Christmastime," says Kathy.

"DeafBlind Ontario Services has given Megan the best adult life we could envision for her, with trained and caring intervenors supporting her. She has matured a great deal in the last few years and has adapted to living away from home much better than we expected," says Kathy.

DeafBlind Ontario Services provides accessible residential and customized support services across the province, including in Ottawa, Embrun, and Vars.

Their holistic approach to Intervenor Services empowers people with deafblindness to achieve their goals and dreams.



Megan and her Mom, Kathy, Christmas 2002.

Piglet, My Deaf, Blind Puppy, Has a Message For You

Melissa Shapiro

www.ctinsider.com

A few years ago, my husband and I agreed to foster a tiny deaf and blind puppy until his rescue group could find a permanent placement for him. We already had six dogs and weren't looking to add another. I figured it would be fun to care for the adorable pink baby dog, but my fantasy immediately turned into a nightmare. Piglet was an anxious screaming mess when he arrived.

Over the next few weeks, by holding and comforting him, teaching him tap signals to communicate and providing a consistent routine that he could count on, we helped our foster baby realize that he was safe and part of a family. He bonded with all of us, gained confidence, and his screaming subsided.

In the hopes of finding him his forever home, I posted adorable pictures and videos capturing Piglet's integration into our household on his growing Facebook page, "Piglet, the deaf blind pink puppy." His followers were enchanted by Piglet's determination as he mapped his way around our house and yard and connected with his family and friends. It was heartwarming to watch our other rescued dogs accept and include Piglet when they played together, ate together and snuggled together. I made it two months before caving to the power of the tiny pink puppy. I apologized to my husband while making the executive decision that we would be Piglet's forever family.

Within a few months, Piglet's adorable pictures and videos had captured the attention of people from all over the world. They saw something more than a disabled dog running up our back stairs for a treat, finding his "Favorite Dad" for a cozy nap and doing group tricks with our other dogs. They recognized the intense will of a tiny dog who wasn't meant to survive, let alone become an ambassador for other disabled animals and people

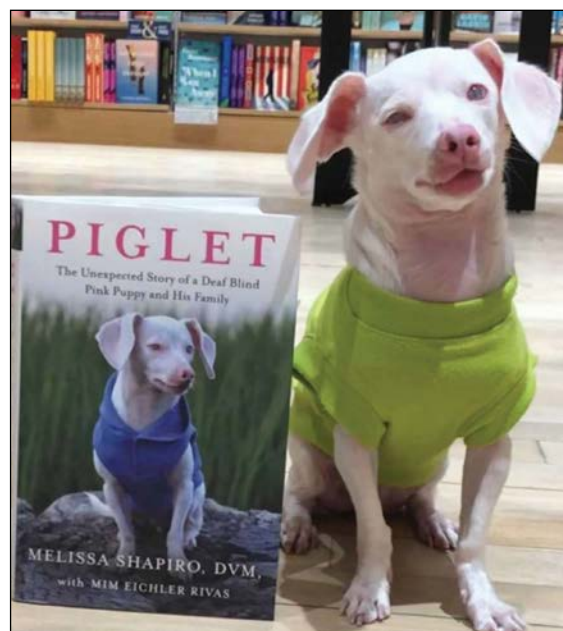
and a symbol of resilience, inclusion and kindness.

Piglet's positivity is tangible. He systematically learned to optimize his senses of smell and touch to keep track of what's happening around him. He doesn't miss a thing. He is diligent in maintaining close contact with his family, friends and dog pack, which is refreshing to observe. His efforts to connect are reciprocated by the people in his life as well as his social media followers, who fall in love with the little dog they only know through pictures and videos.

Tricia Fregeau, an innovative third-grade teacher in Massachusetts, recognized Piglet's potential to inspire her students as part of her growth-mindset curriculum. The children fell in love with Piglet, and he became the class mascot. Ms. Fregeau coined the phrase "Piglet Mindset," and we collaborated to create Piglet Mindset educational outreach, a free downloadable program for teachers to use in their social and emotional learning classes. Two years later, we added Piglet's Inclusion Pack, using the example set by our other very kind, gentle dogs to teach acceptance, inclusion, empathy and kindness. Piglet Mindset is housed on our website PigletMindset.org and is supported by our nonprofit organization Piglet International Inc. The program is used in schools across the world.

Everyone who hears about Piglet, sees a Piglet video or meets him in person wants to learn all about him. The impact Piglet has on children and adults of all ages and backgrounds makes him an extraordinary and disarming teaching model.

With Piglet's profound disabilities, it might be natural to feel sorry for him. But his



feisty determination to live a happy, full life is palpable. He uses what he has and lets nothing get in his way. And this is what his people find so motivating.

We think of Piglet as an intense, focused individual who happens to be deaf and blind. Piglet is the whole package. His positive Piglet Mindset truly inspires others to bring that same positivity into their own lives. His model is simple and highly effective across the board, from elementary school children doing difficult math problems together to executives preparing an important contract and from seniors with progressive mobility issues to cancer patients who are undergoing rigorous chemotherapy. We hear from people every day telling us how much Piglet means to them as they face their own daily challenges.

Melissa Shapiro is a veterinarian in Westport. To learn more about Piglet, visit PigletMindset.org, follow Piglet on Facebook and Instagram, and read "Piglet: The Unexpected Story of a Deaf Blind Pink Puppy and His Family." The children's picture book "Piglet Comes Home" will be published in June 2022.

Deafblind Woman Finding New Joy in Life and Art

Cathy Dobson
thesarniajournal.ca



Heather McKay and her daughter Talice Connelly.

Every morning, Talice Connelly organizes her day.

In a row of empty baskets she places specific items to indicate what she plans to do. A sweatband in one means a walk; craft scissors in another reserves time for artwork.

She also takes the lead on household chores such as cooking and laundry.

What might sound mundane for many isn't for Talice, 42. She's been deaf and blind from birth.

"When I first saw her cut vegetables I was amazed to see someone who is blind use a sharp knife and cut everything so uniformly," says Anne Marie MacDougall, who co-ordinates the five intervenors who facilitate her day. Intervenors are the eyes and ears of the

deafblind and help Talice 24/7 to live in her own townhouse.

She was born at St. Joseph's Hospital in Sarnia with cataracts on her eyes and a limited ability to hear only very high or very low sounds, said her mom Heather McKay.

"I had German measles (rubella) in my first trimester and she was born deaf and blind with some organs in the wrong places," she said.

Numerous surgeries improved Talice's eyesight and allowed her to see shapes and colours, but only for brief periods. She has been legally blind for life and ultimately had to have her eyes removed.

Her mother was determined to provide as much life-quality as possible.

Talice's health is challenged and communication is always a hurdle, but in recent years she has started to enjoy things more and connect more easily. She smiles often, said her mom.

"Every deafblind person is totally different. But I believe that when you lose some of your senses the others become enhanced. That's why Talice can sense when someone in the room is angry or sad or laughing."

"She is very smart and very adaptable. Her cognition is fine," added MacDougall who has worked with Talice for years.

"She literally changed my perspective on life. With all her challenges, she's so happy."

Shortly after Talice was born, her mother learned to sign so she could

teach her daughter to communicate with her hands.

“She learned ‘food’ right away.”

Though she’s never heard a melody, she loves to feel the vibrations from live music and move to the beat.

McKay advocated for her daughter to attend the W. Ross McDonald School for the deafblind in Brantford, where Talice was educated from the age of six to 18, followed by a year of life skills training.

Though she’s lived at Sarnia’s Faethorne Place in her own home for 17 years, she struggled with heart problems and low energy levels.

But three years ago, her life changed drastically for the better.

Major heart surgery at Toronto General Hospital replaced two heart valves, which not only resolved critical health problems but also lifted Talice’s mood and made her more social and outgoing.

“The surgery gave her a new lease on life,” said McKay. “She is an amazing woman and I am so proud of her.”

Before Talice communicated only when necessary, using Exact English to sign it was time for water, food or a nap.

But post-surgery, she communicates much more and is happy “90% of the time,” said MacDougall.

“The girls who help Talice are really in tune with her,” said McKay. “I can’t say enough about them.”

The pandemic stopped Talice from doing many things she loves, including shopping and swimming at the beach.

But the lockdowns have also spawned a new appreciation for art. She has always enjoyed crafts and today spends a lot of time painting.

This year, she even started selling her art on her personal Facebook page.

“Her intervenors will help blend paint colours and dab it on the canvas, then Talice takes over,” her mother said.

“She makes amazing tactile paintings using driftwood and is even getting custom orders.

“She is doing so well. I am so happy for her.”

New Data Products on Persons With Disabilities

Since 1992, December 3 has been recognized worldwide as the International Day of Persons with Disabilities. It aims to promote the rights and well-being of persons with disabilities, as well as focus our awareness on how persons with disabilities navigate social, political, economic, and cultural life.

More than 6 million people live with a disability in Canada. It is therefore crucial that Canadians have access to current and reliable data on this population group. That is why Statistics Canada regularly publishes high-quality statistics on accessibility and disability, in collaboration with Employment and Social Development Canada.

New resources on persons with disabilities

The Engagement and Stakeholder Relations Division of Statistics

Canada invites you to take a look at its [most recent releases on Canadians with disabilities](#):

- The infographic [‘Workers with disabilities receiving payments from the Canada Emergency Response](#)

[Benefit \(CERB\) program, 2020’](#)

provides a profile of Canadians with disabilities who received CERB payments from March to September 2020.

- The article [‘Age of Disability: From Onset to Limitation’](#) examines the age of onset, the age when limitation began, and the period of time from onset to limitation for different disability types.
- The first episode of our recently launched [podcast](#), Eh Sayers, focuses on the new challenges and opportunities experienced by persons with disabilities during the pandemic.

You can also visit the Statistics Canada [Accessibility Data Hub](#), a central location for data related to accessibility and disability. It includes data tables, articles, infographics and interactive data visualization tools.

Better data on persons with disabilities

To meet the growing demand from Canadians for more detailed data about certain population groups, including persons living with disabilities, Statistics

Canada has begun implementing its **Disaggregated Data Action Plan**.

By disaggregating data, that is, breaking down large data sets by categories such as disability type and severity, age, region, gender, ethnicity, income level, or a combination of these categories, Statistics Canada is better able to highlight important differences in the experiences of different groups. We cannot improve what we cannot measure, and to measure properly, we need to fully understand the contexts people live in and the barriers they face.



How Deafblind Seattle Transit Riders Shared Their Stories With Crosscut

Lizz Giordano

crosscut.com



Lynn Chase and David Miller communicate while riding the light rail to the Northgate station. Not fully blind, Chase uses what limited vision she has to detect when the train emerges from the tunnel to know that her stop, the Northgate station, is next.

Through interpreters and tactile sign language, they explain how changes to buses and the light rail affect daily life.

I talk fast, too speedy for most people. I often have to remind myself to slow down to be understood, especially during interviews. That thought sat in the back of my mind as I entered a windowless conference room for my first interview involving an interpreter – two, in fact. Speaking slowly would be extremely essential to give space for my questions to be translated into a touch-based sign language.

I was at The Lighthouse for the Blind in South Seattle to interview Lynn Chase and Chris Loomis, for a story about navigating public transit as riders who are both deaf and blind. Chase was first up. Immediately after she entered the

room, one of the interpreters introduced herself and listed everyone else present. Everyone around me knew tactile sign language and communicated their own hellos.

To communicate through tactile sign language, the receiver places their hands lightly upon the back of the hands of the signer to feel the shape and movement of the signs. It can be done one- or two-handed.

Chase was led to three pre-arranged chairs that faced each other forming a triangle, and she and the two interpreters took a seat. When not signing, each interpreter kept at least one hand in physical contact with Chase, either on her arm or knee.

About every 15 minutes, the interpreters shift who is the lead. Their fingers never left Chase's body as they circle her to

switch seats. They told me interpreting through tactile sign language is often done in tandem due to the physicality of the job, fingers and hands constantly moving as they translate from a signed language into a spoken one and back. Even when not the lead, the interpreters still help translate.

After I'm introduced, I take a breath and start the way I do almost every interview: by asking Chase to spell her name, noting to myself to slow down. But Chase beats me, and starts to describe the pros and cons of her new light rail route. She uses non-tactile sign language since she was communicating with someone who was sighted.

A few minutes later I started my questioning. We quickly get into a rhythm, all four of us.

Trying to form a connection during any interview is challenging, but having to do that across a language I don't speak was something I never had to do before. As I completed each of my interviews for this story, I really wanted to connect with Chase and Loomis directly, not through an interpreter. And the only way to do that was through touch.

Like many parents of young toddlers, I know about half a dozen signs, including thank-you. After my interview with Loomis, I awkwardly tried to mimic how the interpreters slowly swung their hands under his, meeting his cupped palms to initiate communication. I brought our hands toward my face and then back towards him to show my appreciation.

My movement was a little too forceful, so Loomis graciously gave me a lesson on how to guide his hand. For a second, we shared a moment through touch.

Creating Feel-Good Books for Children Who Are Deafblind

James Beattie

www.rte.ie



Sorcha Nallen, Anne Sullivan Foundation

A project creating accessible books for children who are deafblind is expanding across the country.

The Deafblind Literacy Project was launched by the Anne Sullivan Foundation last year, with the aim of increasing learning, communication and personal development amongst children who are deafblind.

Volunteers have been trained and provided with materials to create tactile books.

The charity's Deafblind Literacy Officer, Sorcha Nallen, said: "We now have about 700 people participating in the project. A lot of them are Transition Year students. To make a book more accessible for children who are deafblind, we ask our volunteers to add something to the book to give it a tactile element."

While most children have access to books at home and at school, a child who is deafblind may have limited books to choose from.

Among the volunteers taking part in the project are Transition Year students from Loreto College in Bray, Co Wicklow.

16-year-old Clodagh O'Keeffe made a book showing how different farm animals feel, using materials like wool and feathers.

She said: "You can feel the book that we made. It helps you know what the animal feels like. We did a few different animals like a pig. We cut out

fabric so you can feel what a pig feels like, we also used wool for a sheep."

One of Clodagh's classmates, Milly Yan, created a more accessible version of



Milly Yan with her accessible version of "The Grinch"

The Grinch Who Stole Christmas.

Milly said: "We made the font larger and the words easier for the kids. We made the books tactile so the kids could feel the textures too. It was really fun."

The books made by volunteers are being delivered to special schools.

Ms Nallen said: "The feedback has been really great. The teachers have said they are really useful. It is allowing children who are deafblind to have the same opportunities as their peers."

The Anne Sullivan Foundation says it hopes to eventually create a network of tactile school libraries across Ireland.



Two transition year pupils in Loreto College, Bray, holding the book they made.

Deafblind Model Launches Awareness Project in Mallorca

www.majorcadailybulletin.com



Mireia Mendoza is 27 years old, blind and deaf and her passion is fashion.

With the help of photographer Pau Torrens, beautician Nancy Pujol and designer Hugo Micaelo, Mireia starred in a special photo shoot on the terrace of the Horizonte hotel.

"The Mireia project arose from this collaboration, it raised awareness about deafblindness and was a learning process for all of us," says Portuguese designer Hugo Micaelo, who's been based in Mallorca for 20 years. "The red dress that Mireia wears for the photo shoot costs 2,100 euros and I made it for María Rico to wear at the Miss Grand Spain gala in 2017. It's embroidered with rhinestones, is made with elegant transparent fabric, has a suggestive neckline and a 6-metre long organza skirt."

Meanwhile, photographer, Pau Torrens, who has 15 years experience in fashion and cinema, prepared his equipment and fine tuned the locations for the shoot.

"At first there was some concern about how we would communicate, but Mireia was accompanied by a girl who spoke to her in sign language and translated everything back and forward," explains Torrens. "Little by little everything started to flow and I am very satisfied with the experience and the result."

Mireia Mendoza first sashayed down the catwalk during Milan

Fashion Week in 2019 and shortly after that she worked the Mercedes-Benz Fashion Week in Madrid.

The fashion world is extremely difficult for an able-bodied model to navigate and even more so for someone with a disability, but Mireia says taking part in two of the world's most famous shows was empowering.

"I had the opportunity to walk the catwalk in Milan and at that moment I realised that nothing is impossible for me and that I can do absolutely everything I want to. It's also when my personal project, MM Deafblind Model was born," says Mireia who has Usher Syndrome and type 1 diabetes.

"I had a cochlear implant from the age of 4 and when I was 10 I developed an eye disease called retinitis pigmentosa, which causes progressive loss of visual field," she explains.

"With this initiative I want to show the world that people who are deafblind or have other disabilities are also a valuable

part of society."

Mireia's main goal is to raise awareness about deafblindness and Usher Syndrome.

"People with deafblindness have trouble seeing and hearing, but we are not all the same and the most important thing is that we are people like everyone else," she says. "The project also aims to open the doors to the world of fashion to everyone and eliminate the barriers that exist in our society; to achieve equality, full inclusion and universal accessibility through awareness of the population," adds Mireia.

She hopes that doing photo sessions with different professionals from the world of fashion and taking part in fashion shows and other events will help to publicise her project.

"Our long-term goal is to be able to hold informative talks in schools, Institutes and Training Centres and to work with interested companies," she says.

Mireia is not the only deaf and blind model on the catwalk.

"There are some fashion companies that discriminate against people like me with disabilities, but accessibility, inclusion and diversity is what I want to achieve and to work with me is to work for that," stresses Mireia.

Hugo Micaelo, Pau Torrens and Nancy Pujol say they were extremely impressed with Mireia's professionalism.

"She is a very intelligent woman with a great ease of communication and working with her has been a pleasure, but above all a great learning experience," they said.

The photo shoot lasted for more than five hours, the results are excellent and can be seen on social media networks and the websites of those involved.

Deaf-Blind Artist Behind Card & Clothing Brand: 'Always Be Yourself'

Jacqueline Mroz
njmonthly.com

Fuzzy Wuzzy Design features Christian Markovic's handcrafted artwork.

"I started drawing in preschool when I was only three," says artist Christian Markovic. "I was learning words and how to talk, so I would draw pictures to tell stories. I was drawing everything—animals, people, monsters," he says.

Deaf since age two, Markovic was eventually diagnosed with Charcot-Marie-Tooth disease, a degenerative nerve disorder. By the time he was 20, he was declared legally blind, though he persisted and, in 1997, became the first deaf graduate of Savannah College of Art and Design. When finding work after graduation proved a challenge, Markovic launched Fuzzy Wuzzy Design, a company that features his handcrafted designs on greeting cards and clothing. The Morristown resident says he named

the company Fuzzy Wuzzy because that's how everything looked to him as he gradually lost his sight.

Early on, Markovic created his work on a Mac computer, using a zoom program to magnify his designs by up to 10x so that he could see them, but by 45, Markovic was completely blind, deaf and mobility impaired.

Now, Markovic has an assistant who helps him design his work. He continues to draw and paint ("I always loved to paint, as I liked the freedom of creating and mixing the colors myself," he says) and recently took up sculpting. His work can be found at the General Store in Montclair, Just Jersey in Morristown, and Whole Foods Markets in West Orange and Morristown. His message to other people dealing with impairments? "Always be yourself."

To see Markovic's work, visit fuzzywuzzydesign.com.



How do I become a member of CDBA?

Becoming a member is very easy; you may either download a copy of our membership form at www.cdbanational.com/become-a-member or complete the membership form online.

Once completed, please mail/fax/scan and e-mail your form to our main office. Memberships may be paid by cash, cheque, or credit card.

'As a Family, We See Life So Differently': Deafblind Son, Brother Finally Has a Home to Call His Own

NewmarketToday Staff

www.newmarkettoday.ca



Steve and his triplet brothers - Kevin (left), Steve (middle), and Philippe (right).

"Let them" was Anne-Marie's response to people staring at her son, Steve. Without communication skills, Steve often screamed as a child...a form of expression. But, he could not hear the sound or volume of his frequent screams. Steve is deafblind.

Deafblindness is a combination of hearing and vision loss that is unique to each person. It can impact access to information, communication, and mobility.

Weighing just one pound and 14 ounces, Steve and his identical triplet brothers were born premature at 28 weeks. "At birth, I learned that Steve had vision loss due to retinopathy of prematurity. Before he was a year, I knew that he had hearing loss too. This was more difficult to determine, but around two, Steve was diagnosed as profoundly deaf. Steve also has chronic kidney disease," says Anne-Marie.

Steve is completely blind in his right eye, with an eye prosthetic. In his left, he has between 10 to 20 per cent vision, bending and moving his head to see with this eye. "We respected Steve's decision

to not use a hearing aid, which he doesn't like. Even with the highest quality hearing aid, there are still many sounds he wouldn't be able to hear," Anne-Marie explains.

Ninety-five per cent of what we learn comes from what we see and hear. As a child, it was very difficult for Steve to learn sign language. He had a hard time sitting still as well as sleeping. With a spirit for adventure, Steve often learned through discovery. "He was very curious, he would turn on the oven burners to watch them heat or try to get outside throughout the night, he was like Houdini. We had to install a fence around the yard and lock the doors from the inside."

After years of sleepless nights and screaming, Steve was prescribed medication that helped him to reestablish his internal clock. "It was a game changer," recalls Anne-Marie. From there, he learned *Langue des signes Québécoise*, LSQ for short. Anne-Marie learned some LSQ too, noting that she practises this skill more often with the team at DeafBlind Ontario Services.

DeafBlind Ontario Services' residential programs provide accessible, barrier-free, affordable housing, and access to intervenor services 24/7. Intervenors provide visual and auditory information to individuals with deafblindness. By facilitating the exchange of information and assisting with communication methods, intervenors empower people with deafblindness to thrive.

Anne-Marie first learned about DeafBlind Ontario Services through Centre Jules-Léger, the province's only French-language school for children who are deaf or hard of hearing, blind or have low vision, are deafblind, or have learning disabilities.

"When I first visited one of DeafBlind

Ontario Services' locations in Kitchener, I knew it was what I wanted for Steve... somewhere he could live as independently as possible," says Anne-Marie.

For eight years, the family waited for a location to open in the Ottawa area. Throughout those years, Steve received support from DeafBlind Ontario Services' Community Services – Partnerships, which offers specialized expertise and services to individuals with deafblindness through their supporting agency.

Steve moved into DeafBlind Ontario Services' new location earlier in 2020. "Steve and our entire family are so happy. He has come a long way, initiating conversation and increasing his knowledge of LSQ with consistent support from intervenors."

"Steve has a home to call his own now, living as normal of a life as possible. Although it is difficult right now with social distancing, my goal is for him to socialize more, meet friends for coffee, or invite friends and family over for dinner in the future, to become more and more independent in his daily living. Achieving this will be possible because of Intervenor Services," says Anne-Marie.

Today, Steve still taps into his sense of discovery and curiosity to learn. "On his own, he puts his finger into his glass to determine when a drink is poured to the right level. He also brings his iPad close to his face so he can see a picture. He learned to slide from one image to the next using his nose... it's very clever."

"When you go through something like Steve has experienced, it's really difficult. But, I am glad it happened to us. As a family, we see life so differently and appreciate the small victories. Every time Steve learns a new LSQ sign, we are so excited it's unbelievable," says Anne-Marie.

News From CDBA British Columbia

CDBA British Columbia Theresa Tancock, *Family Services Coordinator*



CDBA-BC Winter Frolics!

Our Virtual Recreation Program continues to be a huge success – bringing smiles to the faces of the children and youth we support and chatter to our ears. This Winter, we held two activity dates, creating Penguins and Christmas Trees and Snowman Snow Globes and Sensory Lights. Music and stories were shared as we focused on our creations. In addition to these two events, we held a Christmas Sing-along, which was attended by Santa Claus, himself! This brought such joy to the faces of all! These events were in conjunction with our Winter Intervention Program, offering Intervention Support to the children and youth with deafblindness throughout BC.



...And what did we learn with Santa?



- Santa is 1751 years 'young'
- Santa's favourite cookie is Chocolate Chip with sprinkles (but he likes ALL cookies)
- Cookies and Hot Chocolate keep Santa warm on Christmas Eve
- Santa's reindeer are all female
- The Elves eat: bark, frogs, candy cane sandwiches and berries
- Our favourite animal: dogs (but we also like owls, chameleons, and wild cats!) 'Lego' has a Santa Claus figure, Mrs. Claus figure and a Christmas Tree that lights up!
- Santa looks in the mirror every morning and says: "You are

love, you are loving, and you are lovable" (then he brushes his teeth!)

In the month of September, the US - Canada Intervenor Community of Practice (of which CDBA-BC is a participant) hosted an event with the topic of "Experience Books".

This was an opportunity to network, connect with and share experiences with Intervenor extending across the US - Canada border. This event took place virtually over Zoom.

Our next "Munch 'n' Learn" is on February 11, 2022; the topic being "Adapting Craft Activities". These sharing opportunities are being offered every few months to Intervenor across Canada and the US.



News From CDBA New Brunswick

CDBA New Brunswick Kevin Symes, *Executive Director*



Greetings from New Brunswick.

Many thanks to the CDBA-NB Inc. Board of Directors and office staff for their commitment to remain positive and continue to move forward during these challenging times. We now have Shenna, one of CDBA-NB Inc. clients, contributing to the efficient running of the office by working in the role of Administrative Support staff person.

The Covid-19 has caused many challenges especially with camp and fundraising however we are hoping that soon we will be enjoying having everyone together again creating positive memories and having a good time.

The photos below are examples of some the activities that did happen.



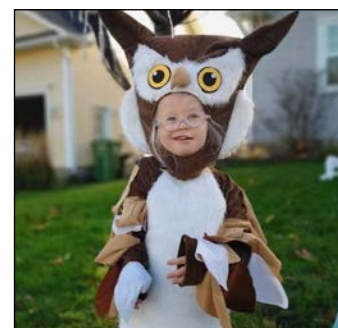
Fredericton client Kelsi enjoying time at Kingswood



Moncton client Craig and Intervenor Dorothy Happy Halloween



Fredericton client Eddy and Intervenor Jolene



Fredericton client Henlay the little Owl



Happy New Year from Moncton clients Craig, Robbie and Intervenor Dorothy



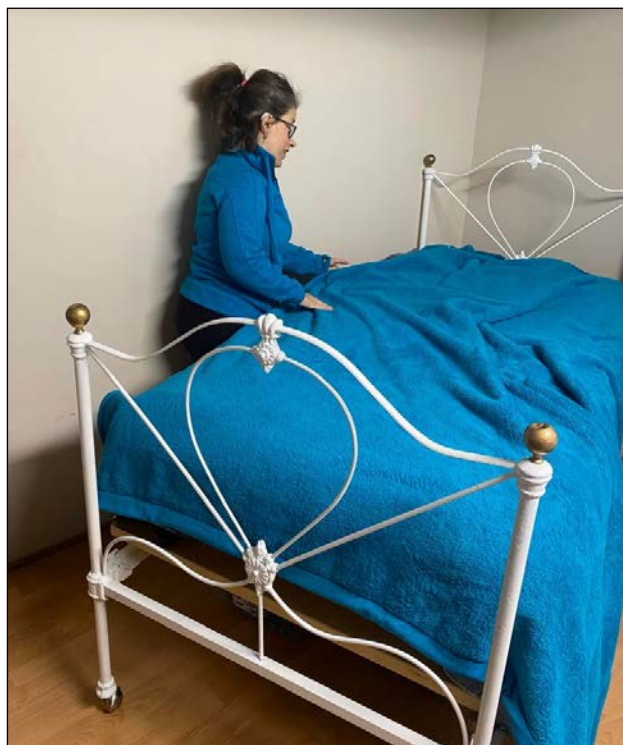
Matthew Bathurst client having Chinese take out Christmas lunch with Intervenor Audrey



Fredericton client Jamie saw a Christmas movie followed by a chocolate chip cookie date



Fredericton client Steven making his very first gingerbread house



Saint John client Cathy Jo masters making her bed. Good job.

News From CDBA Saskatchewan

CDBA Saskatchewan Leanne Kerr, *Executive Director*



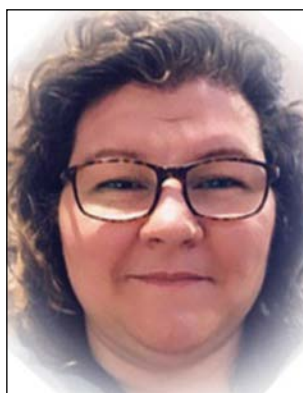
The end of 2021 was the start of some pretty big changes at CDBA-SK. Our long-term Executive Director Dana Heinrichs resigned from our agency. We were saddened by her decision to move on but excited for her and her new venture. We would not be who we are today if not for the contributions, sacrifices and love that Dana (and her family) have made for CDBA. Dana Heinrichs leaves a legacy here at CDBA-SK that will bear fruit for many years and her influence will continue to provide us guidance and inspiration.

The Chapter Board of Directors recently concluded an exhaustive search for Dana's successor, and are pleased to announce the hiring of Leanne Kerr as our new ED. Leanne has been with our Chapter for more than 15 years and brings a rich history of experience and qualifications to the position. Welcome Leanne!

Last year's annual Lend-A-Hand Saskatchewan Golf Classic was a huge success, raising just over \$20,000!

Several of the Individuals went to visit their families in various parts of the province over Christmas this year. We were all quite excited that they were able to go as that was not the case last year. We have been limiting our exposure to the community, but continue to attend Cosmopolitan Industries day program 3 times per week. Only the Individuals from CDBA-SK attend together in order to provide a bit more protection from crossing over with other agencies.

We are looking forward to a spring filled with spending as much time as possible outdoors and hopefully getting back to regular programs.



CDBA Saskatchewan Al Love, *Chairman*
(as the new CEO for Mennonite Nursing Homes Inc.)

Dana Heinrichs started with CDBA in July 1991 as an Intervenor and within three years became a Residential Program Coordinator. In 2004 funding was provided for an Administrative Assistant and Dana was promoted into this position, but after a year the position was defunded and Dana returned to the Residential Program Coordinator position.

In 2010 Dana became our new Executive Director and remained in this position until late 2021 when a new opportunity enticed her away from the Saskatchewan Chapter. This was a great loss to us as her dedication, work ethic, sound thinking, and overall personality made CDBA SK a great organization, great homes and a great place to work.

Over the years Dana took and provided much training such as Mandt, Basic Skills Training, Comprehensive Personal Planning & Support Policy Training, and CDBA's Intervenor Training. She built strong relationships with all of the Individuals as she has worked at all of our homes over the years. She oversaw the new build of the Overholt group home (now Michael's Manor) as well as the major renovations on all of our other group homes.

Dana's commitment was evident and surely was part of the success she had over the years through applications for grants, work done, and support attained. Dana had the ability to articulate strongly the importance of what we were doing and who we were doing it for.

Dana built and nurtured professional relationships with community partners such as other Community Based Organizations, Community Living Service Delivery (Social Services), MacDermid Lamarsh (Major Sponsor/partner for Golf Tournament) and many more. Her involvement with National CDBA was invaluable to our Chapter as well.

Dana was instrumental in keeping our organization current through technology and continually looking at way to improve systems and processes. She was a mentor to those she led and always held true to her beliefs and standards. She led by example and loved what she did. Dana believed in the philosophy of "Do with, not for" and always had the best interests of our participants and CDBA in the forefront.

Back-to-Class Bittersweet For Some at Ontario Schools For The Deaf, Blind

Calvi Leon

963bigfm.com

The three-hour drive between home and school is finally over for Stephanie Antone and her 11-year-old daughter, but not her mother's frustrations.

While most of Ontario's two million kids returned to class and their regular routines early in January amid an Omicron-delayed restart of the school year, that wasn't the case for Antone and her low-blind daughter, Yehati.

Instead, like many families who rely on special provincially operated schools for those who are deaf and blind, the Oneida of the Thames mother and her daughter commuted to Brantford so she could attend school in person after a residential program there for students like Yehati was shelved in late December as COVID-19's highly contagious Omicron took hold in Ontario.

Friday, Ontario said it will restore residential programs this week at the schools, which serve both day students and others who live there. Reopening the lodgings also means weekly transportation that Yehati and other kids depend on, to get to school and back home on weekends, will resume.

"I feel a huge sense of relief," said Antone.

"None of the parents should have to be commuting every day to have your child attend school in-person. None of us should've had to pay thousands and thousands of dollars out-of-pocket for hotel and Airbnb expenses," she said, of parents who shifted closer to school so their kids could attend in-person classes.

Still, while she welcomes the move to resume the school lodging, Antone said she and other parents are frustrated by what they saw as a lack of communication by the province. She said she found out first through her daughter — not the school — that the

residence would re-open Sunday.

"(Yehati) came into my room just about 10 a.m. (Friday) and said, 'Yay, I'm going back to school. I said, Really? I haven't got an email,'" Antone said.

"The principal made an announcement for the students, but we (hadn't) received anything. Nothing," she said.

Parents were notified Friday evening that lodging would re-open Monday, according to a union official.

That means nearly three-quarters of the students at the W. Ross Macdonald school, from kindergarten to Grade 12, will go back to living there during the week.

The provincial schools "support some of the most exceptional students in Ontario," Education Minister Stephen Lecce said in an emailed statement. "We committed to returning these children to class, knowing how critical in-person learning is to their academic success, development and their mental and physical health."

Ontario operates seven so-called provincial and demonstration schools, including two in London, for students with special needs. The London schools include the Robarts school for the deaf and the Amethyst school for those with severe learning disabilities. Besides Brantford, other schools are located in Milton and Belleville.

Antone could have resorted to online learning for her daughter, but said that option comes with barriers including eye strain and little motivation.

"How do you have a blind child learn online?" she asked.

For Yehati, living in an accessible residence with access to school, life skills and new friends creates a world of difference, her mother said.



W. Ross MacDonald school for the blind in Brantford.

"I feel really happy that it's open again because all the students that are in lodging get more support than we would have online," Yehati said.

The activity that excites her the most? "Goalball on Wednesdays," she said. The sport is designed specifically for those who are visually impaired or blind.

The return of residential programs comes with tightened public health and safety measures, from required three-ply masks to increased COVID-19 screening and testing for staff, students and family members, along with stricter isolation protocols.

That move followed a memo sent to staff that said Ontario's chief medical officer of health had deemed demonstration schools and lodgings a "high-risk congregate setting for the purposes of (COVID-19) contact tracing, isolation and PCR testing," with the tighter precautions needed because of the mixing of day and residential students including some with complex needs.

While COVID-19 remains a concern,

Antone said she's confident her daughter's school — which has never had an outbreak — can keep students safe.

"Their lodging quarters are bigger than my house," she said.

The reopening of the residences came amid petitions and social media posts by parents and students.

David Sykes of the union representing teachers at the schools, the Provincial Schools Authority Teachers, also pushed

for the move, and said the union's focus will now return to resources and programs at the schools which he said have been eroded in recent years, leaving fewer deaf and hard of hearing children getting the critical early intervention support they need.

"Our struggle doesn't change," said Sykes. "It changes our messaging only in so far that (the union) wanted us to speak to the lodging, unfairness and question the decision-making. Now, our

focus is back to where we were before."

Antone said better transparency is needed between provincial school officials and families, who don't have a school board to go through with the system run directly by the province.

"So, what does that mean for me as a parent?" she asked. "We don't have a lot of avenues."

Lecce's office did not respond to a question about parental concerns over communication with the schools.

DeafBlind Services Gives Man Second Career Opportunity

BradfordToday Staff
www.bradfordtoday.ca

Jeremy Davis' second career is about giving back, helping others to live their best lives in a collaborative and team environment.

"As a man in my 40s, I was nervous about going back to school to pursue a second career in a Personal Support Worker (PSW) program... I had worked in the automotive industry for a number of years. Taking classes, using technology for post-secondary learning, and being responsible for another's personal care needs were all factors I considered," said Jeremy.

"However, while I was skilled at moving cars through the shop, I ultimately knew I needed more."

A student placement with DeafBlind Ontario Services provided Jeremy with valuable learnings and paved the way to a fulfilling second career. "I was looking for a placement with an organization where I could utilize my critical thinking skills, personal care skills, and lived experience," said Jeremy.

Intervenors are professionally trained to support people with deafblindness – a combined loss of vision and hearing – acting as their 'eyes' and 'ears' through the sense of touch.

By facilitating the exchange of information and assisting with communication methods, intervenors empower people with deafblindness to thrive.

"During my placement, I really saw that the intervenors were masters at bringing the outside world in. I learned that I love making a difference in the day-to-day lives of the people we support, advocating for their needs, and contributing to their independence."

Jeremy did not leave his student placement. Today, he has been with DeafBlind Ontario Services working as an intervenor for nearly four years.

"I finally feel valued, this is my second family. Our team supports one another to learn, share, and contribute, while providing holistic care for the people we support."

Jeremy's advice for anyone seeking a new or second career is, "the integration of lived experiences, transferrable skills, and maturity help me to give more of myself as an intervenor. It is important to not discount experience gained in other industries or educational backgrounds that can be applied to a new role."

To build awareness of this rewarding



career choice, a new National Occupational Classification Code (NOC 42203) now includes "intervenor" and "deafblind intervenor" roles. Employment and Social Development Canada (ESDC) and Statistics Canada released this new code in late 2021 and will fully implement it this year.

DeafBlind Ontario Services strives to be a top employer in the field, dedicated to helping employees develop their talents and nurture their career aspirations through extensive and ongoing training and mentoring. The organization is hiring in many regions across the province. It's a new year, start your rewarding career.

DeafBlind Ontario Services provides an array of services to people who are Deaf, hard of hearing, non-verbal, and deafblind that are customized to each individual's unique needs, method of communication, and goals to enrich their life. Learn more and apply online: <https://deafblindontario.com/careers/>.



Save the date for the
2022 Lend-A-Hand Golf Tournament!



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in support of the Canadian Deafblind Association

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- Study professionalism, values, ethics, health & aging
- Interact with deafblind community members virtually and in-person
- Field experience may be completed across Canada in your community through George Brown College partnerships



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