



**Canadian
Deafblind
Association**

Supporting Access
and Opportunity
for All

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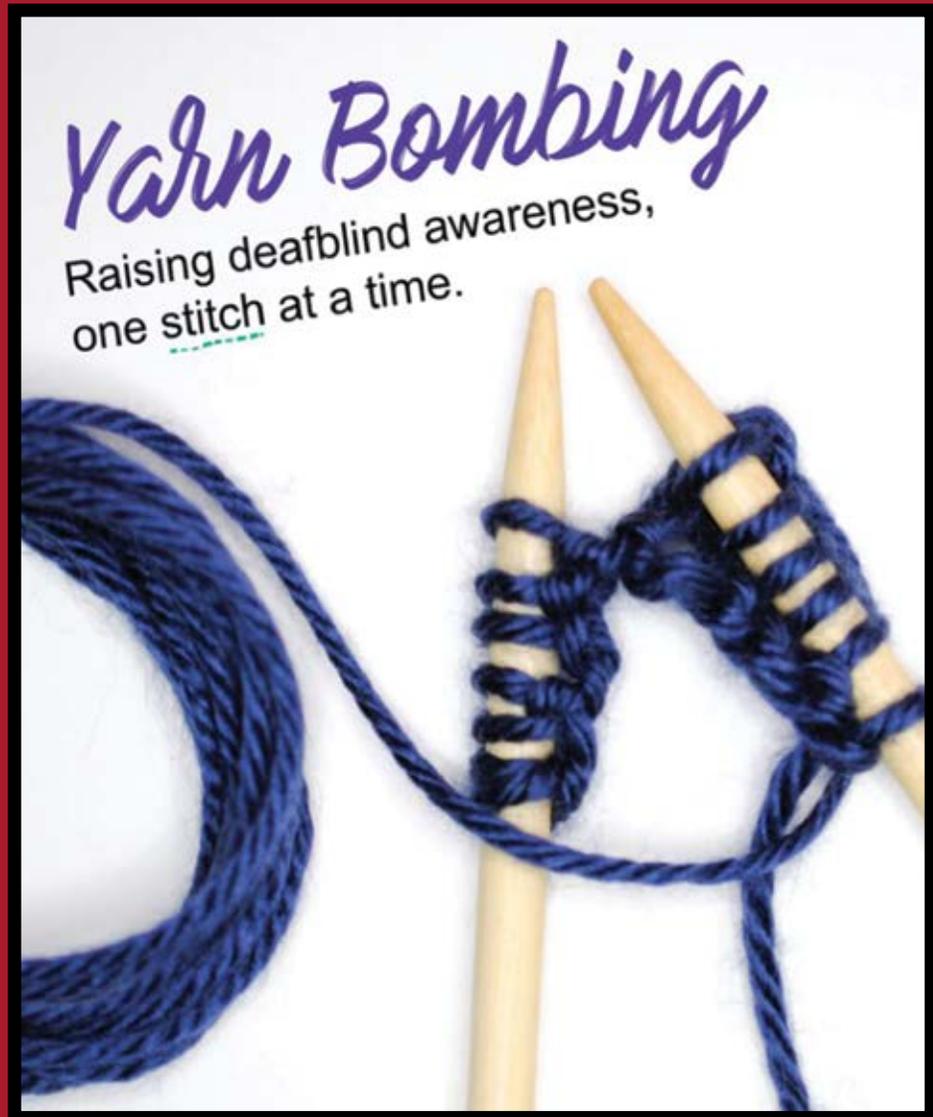
Imagine...

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

Edition 44, No. 2

Summer 2021

Intervention



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- Lesson #7 from Charlotte's Web
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Yarn Bombing for Deafblind Awareness

June 2021

Yarn bombing is truly a global movement! In June, 20 countries came together to yarn bomb for deafblind awareness.

Each #YB2021 installation around the world was constructed by people with deafblindness, those in the field and supporters with the common goal of increasing awareness and knowledge of deafblindness.

Congratulations on an amazing, unique and creative awareness initiative. Stay tuned for details on how you can get involved in 2022!



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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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A Message From the President of CDBA National

Carolyn Monaco



2021 Annual General Meeting, CDBA National

It is with great pleasure that we announce the upcoming 46th Annual General Meeting of the Canadian Deafblind Association on Saturday, Saturday, September 25, 2021 from 1:00-3:00 pm EST. Because of the COVID pandemic, the AGM will be offered via Zoom to all who would be interested in attending. A Registration Form can be obtained from our website www.cdbanational.com or by contacting the National Office info@cdbanational.com. Meeting registrants will be sent a link to enable attendance.

There may be Director-at-Large positions open for 2020-22 on the CDBA National Board of Directors. Should you know of a CDBA member (nominees must be members 30 days prior to the Annual General Meeting) who would be a suitable candidate that you would like to nominate and who would be willing to let their name stand for election, a Nomination Form is available on the CDBA National website www.cdbanational.com. Information regarding the time commitment and the individual knowledge and skill set required of National board members can be obtained by contacting our executive director Tom McFadden at the CDBA National Office tmcfadden@cdbanational.com. Should you be unable to attend the meeting in person, please make your vote count by filling out a Proxy Form, also available at www.cdbanational.com.

As always, in addition to my President's Report as well as year-end summaries from Executive Director Tom McFadden, auditor Peter Shennett, and our Chapters, there will be several other important matters to discuss and be decided. We really hope you will free up some time to join us on Saturday, September 25, 2021 for our 46th Annual General Meeting.

Sincerely,

Carolyn Monaco
President, CDBA National



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 <p>Dbi Africa Conference May 12th - 14th 2022 Nairobi, Kenya Call for papers, 1st Deafblind International Africa Conference 2022</p> <p>Theme: "Deafblind Reality in Africa: Meeting the Sustainable Development Goals - Opportunities and Challenges"</p> <p>Deafblind International cordially invites you to submit your research papers, survey papers, case studies and academic papers in the aforesaid area. https://www.deafblindinternational.org/conferences/africa/</p> <p>Important Dates</p> <table border="0"> <tr> <td>Abstract submission deadline: 22nd November, 2021</td> <td>Start of Online registration 1st February, 2022</td> </tr> <tr> <td>Acceptance and notification 14th January, 2022</td> <td>Final paper & PowerPoint Submission 28th January, 2022</td> </tr> </table>	Abstract submission deadline: 22 nd November, 2021	Start of Online registration 1 st February, 2022	Acceptance and notification 14 th January, 2022	Final paper & PowerPoint Submission 28 th January, 2022	<p>About the Conference</p> <p>Dbi Africa Conference draws the roadmap towards Deafblind reality in Africa. It will connect persons with deafblindness, parents, families, practitioners and researchers all across the continent and beyond. It will highlight the work being done in Africa, create awareness among stakeholders that deafblindness is a unique disability and enhance access to quality services for persons who are Deafblind. It subscribes to the adoption of Agenda 2030 with the focus on leaving no one behind. It will advance the practices fulfilling Disability rights and sustainable development goals in Africa and beyond.</p> <p>Conference Sub-themes</p> <ul style="list-style-type: none"> • Education and Transition of Persons with Deafblindness • Families of Persons with Deafblindness • CBR for Persons with Deafblindness • Research, Policy and Advocacy for Persons with Deafblindness <p>Conference Delivery Blended Conference</p> <p>More information</p> <ul style="list-style-type: none"> • https://www.deafblindinternational.org/conferences/africa/ • @africadb • dbiafricainconference@gmail.com <p>Dbi Vision: To be the International association which promotes the awareness and knowledge of deafblindness as a unique disability and to influence for appropriate services for people who are deafblind around the world.</p>
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Editorial From the National Executive Director

Tom McFadden



Welcome to this summer 2021 issue of "Intervention" magazine. I sincerely hope that you are all enjoying this COVID summer as best you can and have had a chance to experience some holiday time. My Board of Directors has had a very busy year dealing with the challenges presented to them by the continuing pandemic and related service issues across the country. But there is continued hope that recovery is just around the corner.

Within the pages of this issue, we spotlight the global efforts of 20 countries to celebrate Deafblind Awareness Month this past June. You'll find more uplifting stories of generosity, emotional strength and persistence that reflect our sense of optimism for the future. Among them: the determination of a deafblind mother who loves running marathons; how two young grade 8 students parlayed a school project called the "Kingdom Assignment" into a very successful fundraiser for CDBA; how the "Deafblind Potter" with Usher Syndrome became a social media overnight sensation; and efforts by deafblind woman to share disabled people's

fears as the COVID lockdown eases. And once again, you will certainly enjoy the 7th installment of "Lessons from Charlotte's Web".

Celebration of June 2021 as Deafblind Awareness Month was so different

June 2021 marked the 7th anniversary since the Senate of Canada recognized June as Deafblind Awareness Month. This year, in addition to the many celebrations and proclamations in towns and cities across this country, the focus of efforts by like-minded organizations in the field of deafblindness was participating in a Deafblind International (DbI) global initiative called "Yarn Bombing". Activities in Canada were coordinated by a working group comprised of people with deafblindness, professionals from the field and organizational supporters whose common goal was to increase awareness and knowledge of deafblindness. In this issue we have tried, through pictures, to give you a taste of what went on in Canada and in 20 countries around the world.

PIGLET: The Unexpected Story of a Deaf, Blind, Pink Puppy and His Family

Anyone who has ever owned a pet, whether it be a dog or cat, knows how quickly and seamlessly it can become an important part of one's family. And occasionally a pet comes along to serve as a gently reminder that, with a little extra consideration, support and love, the rewards that come back are priceless. Well, there is a book now available about an adorable, deaf, blind pink dog that has been described as "a charming, inspirational memoir about empathy, love, and kindness". It follows the story of how Piglet became the mascot for facing challenges with his resilience and good attitude, despite his sensory challenges.

This book is well worth a read! www.pigletmindset.org

I leave you with this positive-thinking quote:

"The best and most beautiful things in the world cannot be seen or even touched – they must be felt with the heart"

– Helen Keller

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Story of Haley & Layla



Our names are Haley Das Neves and Layla Hashim. We are grade 8 students at Georges P. Vanier School in Chatham, Ontario. Our class was assigned a project by our teacher Mrs. Bechard, called the "Kingdom Assignment". All students received \$25 to start a business. We needed to make and sell our product then donate all proceeds to a charity of choice. The charity chosen needed to be a special charity that has a special meaning behind it. Layla chose the Chatham Women's Shelter and Haley, the Canadian Deafblind Association. We decided to combine our \$25 each and do a business together. We decided to make chocolate bark. There were 3 different kinds of chocolate we made. Overall, we sold a total of \$1716.00, giving each charity \$858.00.

Haley chose to donate to the Canadian Deafblind Association, because when she was 11 years old, she saw a blind man in the McDonald's parking lot. She felt really bad for this gentleman and started to cry. Haley felt so bad that she told her mom she wanted to give him her eyes. She made a promise to her mom that she would make a big donation to the blind foundation someday, but she never had the opportunity to do this yet. Now, she finally gets to make her donation. Haley hopes that she can make a difference in someone's life.

Deafblind Mom of 2 Loves Running Marathons, Traveling. 'I Can Do Anything'

Kristen Powers

7News



Jaime Recht is a Maryland mom of two who is deafblind and determined. She attended Gallaudet University where she met her husband of almost 30 years. Their two sons are in their twenties and learned American Sign Language as their first language.

Recht said she was born deaf and has usher syndrome, which causes her vision to slowly get worse with age.

"I may lose more of my vision, perhaps become completely blind, or not. I'm hoping with research perhaps there is a cure for Usher Syndrome; however, I keep plugging away. As a person that's over 50, it's fine. I'm going to do what I'm going to do. I don't let it impact me. I don't worry about it. I'm living life optimistically every day," she said.

Recht is a great cook and said she loves to teach her sons how to cook. Growing up, she would do a lot of things very independently with them, like take them shopping, to the pool, out to eat, and on trips.

"I used to read them bedtime stories at night, using American Sign Language so they could learn," she said.

Recht is also an avid runner. She has run six marathons and plans to run a few more.

"I will do anything no matter what it takes to succeed and overcome myself with these limitations. I am determined to show people that I can do anything else and that I'm a mother just like any mother," she said. "I do not let my visual impairment or limitation limit me in any way. I can do anything, just like anybody else."

Here is Recht's advice to other mothers this Mother's Day:

"Your attitude should be positive, no matter who you are or what challenges you may have. Perhaps you use a wheelchair, you're blind, or have any other issues. Don't let it affect you or limit you. Be positive. Have a positive attitude. That's going to be effective."



DeafBlind Potter Becomes Famous Overnight on TikTok

Jeff Zevely

www.cbs8.com



Two friends shared Kelvin Crosby's story on social media and millions of people responded.

These days with social media platforms such as TikTok, people can become famous overnight. In this Zevely Zone, I went to Clairemont to meet the DeafBlind Potter. Kelvin Crosby, 33, lives with a rare genetic disorder called Usher Syndrome Type II which affects his hearing and vision. Kelvin was born with a hearing impairment and slowly throughout his life became legally blind.

Throughout his journey, Kelvin revisited the pottery wheel many times and it helped him grieve through the stages of vision loss. He started encouraging others to experience the healing power of the wheel, which led him to become the DeafBlind Potter. His company is on a mission to support other individuals

with disabilities through pottery.

"Go big or go home," said Kelvin from his home ceramic studio. Kelvin believes his life is a lot like a lump of clay, in the right hands with the right attitude, he can shape his destiny in a work of art.

"We are going to make a vase. My favorite thing to make," said Kelvin. "I really didn't think that being an individual with a vision loss and a hearing loss would give me a chance to tell my story in a way that would empower other people."

Kelvin says his vision impairment is a lot like trying to see through a sheet of wax paper. "I can no longer see pictures, I can no longer see my wife," said Kelvin who has been married for 10 years. He has a video that shows people what he can and cannot see.

"If you were looking at the pottery wheel

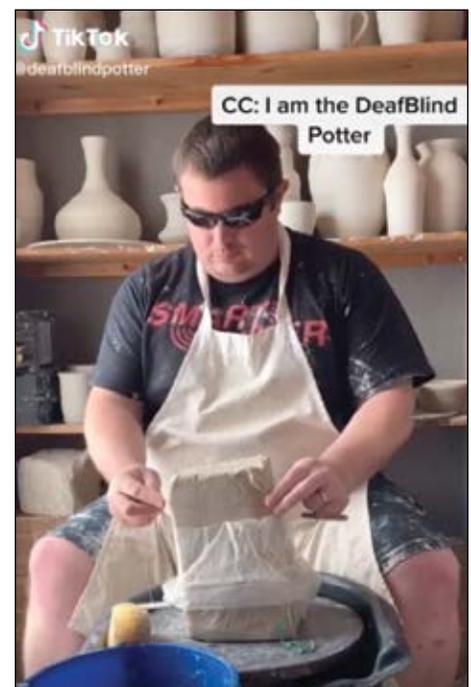
this is what you would see, and this is what I would see. Another example, this is what you would see in the studio and this is what I would see," said Kelvin.

We met two of Kelvin's friends at his studio. Last Fall, Michaela and Natalie Harding shared Kelvin's story on TikTok. "We filmed our first TikTok posted it and didn't really think much of it," said Natalie.

The sisters were hoping for a couple of hundred views, but hundreds of thousands of people showed they truly cared about Kelvin.

"Then we posted another one a few days later and it got over a million. Yes, our third video got over a million views," said the Harding sisters.

"He just amazes me what he can do. Nothing stops him," said Kelvin's mother Cheri. "I couldn't do it with eyes and I ask him, and I ask him how can you do that and make it and he just feels it. He sees with his hands. He says he sees



better without eyes than with eyes."

The DeafBlind Potter company has become the definition of a cottage industry. Kelvin is making trademark coffee cups and selling them online. DeafBlind Potter mugs always have three signature rings.

"The one on the top is joy, the second on in the middle is perseverance, and the one bottom one is character," said Kelvin. To fill those cups, Kelvin has even launched his own coffee brand.

"I drink a lot of coffee to keep going and keep moving," said Kelvin with a big laugh.

The life lesson? Just because you can't see something, doesn't mean it isn't real. Kelvin can't see his art but finds hope in every piece of pottery he makes.

"Even though I can't see them, I am always finding that every piece I make

has joy in it and perseverance," said Kelvin. "The best way I can describe it is that it feels humbling knowing that my struggles are helping so many different people's lives. I don't need eyeballs to

see, and I don't need ears to hear I can still run a business."

If you'd like to support Kelvin's journey and purchase a mug or custom piece of pottery, visit www.deafblindpotter.com



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 #7

Technology: If you can't beat 'em, join 'em!



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.

Screen-time is a word that instantly creates a common ground for parental discussions. No one is immune to the pervasive grip it has on family dynamics and challenges. Returning to the era of the single-family television set in the living room, is sadly not an option. Technology associated with screens has now become a cornerstone of educating our youth. And how savvy our offspring have become with technology. Which of us has not gone to a Gen-Z or Y with a computer problem that we could not solve? They seem to be wired to manage these devices with innate abilities from birth.

Charlotte, who was Deafblind, knew how to use Facebook long before I did. (I have always been slow to embrace cutting edge technologies.) With my permission, her young

interveners started her on Facebook. I had almost no clue what it was all about. Charlotte learned quickly and loved using Facebook. She proudly collected 'friends' and I recall how she once boasted early on that she had 99 friends. I was duly impressed. However, not having sat in on the home tutorials, I hadn't realized I needed check in from time to time to see who her friends were. Once I did, I could teach Charlotte the importance of blocking some of the undesirables.

Access to Facebook and her cell phone truly lessened the isolation that is common with the Deafblind. Charlotte was diagnosed as legally blind, but she was fortunate to have enough vision at 20/200 to see most photos adequately, and read large print. She had become proficient with Zoom Text, which enlarges print helping her to read the posts. Charlotte managed to keep in touch with so many acquaintances' lives. She was even 'friends' with my real-world friends who had become users before I had made my own debut on Facebook. I would hear from her at the dinner table that Kat got a new horse, or Leanna was pregnant again. I have no doubt that the motivation to participate on Facebook



greatly improved her literacy skills. As she used American Sign Language as her main form of communication rather than speech, she would need to become a proficient reader and writer. She spent



at least an hour a day catching up on the people in her life on Facebook.

Around this time, we thought Charlotte was also ready to use email. Although we did give her Hotmail, I eventually decided that Charlotte would benefit more by continuing to share my email. Not only could I monitor her plans and communications, but I could also expose her to dialogues of a variety of themes: social, medical, business, and so on, in the hopes of expanding her vocabulary and providing her with examples of the range of interactions that she didn't have access to experiencing. I had read, and also saw first hand, that incidental learning due to deafblindness is so limited that it has a significant impact on learning and cognitive development. When you can't hear the radio, or television, or someone else's conversation, even when it is in the background



and not directed at you, you are at a disadvantage to acquiring information. The same goes for visual information that you don't receive because you can't see what is happening outside your periphery.

The next logical step was to get Charlotte a phone to text with. We had tried TTY but it was problematic for her, and she gravitated quickly to texting. However, the cell phones at that time did not have adjustable font sizes and she struggled to read and write her messages. Regardless, she was determined to use this technology. It was one more mode that provided her a means of becoming more independent. Soon enough, smart phones appeared on the scene and with them was not only font size that could be adjusted, but other features, such as the built-in camera. We bought her one, of course. (As an aside, Charlotte was truly a visual person, so she delighted in taking and viewing photos. While she enjoyed looking at photos on her devices, she still spent hours perusing the little photo albums that I had put together before digital photography, developing photos from my camera film at Walmart or London Drugs.)

Life was better when she was at last easily able to text us from all locations.

Now Charlotte was able to let me know that the handi-bus hadn't yet picked her up, or that she'd missed it. On more than one occasion, the city bus would go by our home bus stop, so she would text that she was waiting for me to get her at the train stop a 10-minute drive down the road. I don't know that I would have let her ride public transport if she hadn't had a cell phone. I was so appreciative for this technology that kept us connected! It provided her and us the confidence we needed to take such risks to encourage her independence. She could now make her plans with her interveners, and also

change plans quickly, as is the way we all seem to function now. A cell phone also gave her more personal privacy. I realize that I had to accept that as part of her process of maturing.

There were a few other functions that Charlotte quickly learned to access on her smart phone; besides the camera function which she loved so much, the video chat capabilities on Facebook Messenger, Face Time and WhatsApp afforded her the opportunity to send and receive messages using American Sign Language. And, as the acquisition of technology is unavoidable, the next 'screen' was, of course, an iPad. A bigger screen to see a sign language message was a huge bonus.

The dilemma for today's parents in setting limits on screens, one that is likely here to stay. I can only imagine how challenging this is. For individuals with special needs, the continual advancement of technology has the potential to enhance their lives as never before. As much as it can isolate people, it can also bring people together. Right now, as I sit here typing, I am so grateful for the convenience of a word processor on my old HP computer, allowing me to share my stories so easily. I am also grateful for the storage capability of devices that have allowed my memories of Charlotte to be accessible whenever I need them.



June is Deafblind Awareness Month!



DEAFBLIND AWARENESS MONTH
Make a wave from coast to coast

MOIS DE LA SENSIBILISATION À LA SURDICÉCITÉ
Créez une vague d'un océan à l'autre

Organizations providing services for Canadians who are deafblind joining global efforts to raise awareness

June 1, 2021 – Members of the deafblind community are joining a global awareness campaign to build awareness about people who are deafblind and engage in “yarn bombing” or tactile art installations across Canada through the month of June.

Yarn bombing is an activity that takes knitted, crocheted or loomed pieces of yarn and attaches them to objects or structures in public places as a form of street art to build awareness.

With June designated as Deafblind Awareness Month, both Nationally and Provincially, individuals who are deafblind, friends, families and knitting and crocheting clubs across Canada are joining Deafblind International networks to build awareness on a virtual scale. June is the birth month of Helen Keller, one of the most internationally recognized people with deafblindness.

At a time when many of us are experiencing increased feelings of isolation, for the over 1% of Canadians who are deafblind, the pandemic has had an even stronger effect by placing limits on their efforts to communicate, whether it is to express themselves, engage with their social networks or even participate actively in their communities.

Yarn bombing has been a unique way to connect people virtually to express themselves through their yarn creations and share their efforts on social media.

Penny Leclair, Co-Chair of the NDBAM Committee adds, “yarn bombing is

a safe way to draw public attention to our awareness efforts, especially those who do not know anything about deafblindness.”

“It is my hope to motivate other people who are deafblind to get involved in bringing awareness of our needs and abilities to the public. I am always looking for ways to make others more aware of what life is like for Canadians who are deafblind,” says Penny, a member of three boards of directors; Canadian National Society of the Deaf-Blind, CNIB Deafblind Community Services, and Barrier-Free Canada - Canada Sans “Barrières.”

To help spread awareness, community objects and landmarks across Canada were yarn bombed throughout the month of June. This initiative symbolized the coming together of people in the field of deafblindness with the goal of sparking conversations with Canadians about the experience of and need for appropriate services for individuals who are deafblind.



Yarn Bombing in Canada and Around the World



Smiley Reilly Brings 'Unexpected Light'

Newmarket Today
www.newmarkettoday.ca



After Reilly got sick, her Papa, Mother, and I wanted to ensure she had the best quality of life and care; as she will need this support to live as independently as possible,' says her grandmother

"She is my angel, my special girl... We have a deep bond and always have," says Joan, also known as Nanny by her granddaughter, Reilly. "I was there the day she was born... and when she got sick."

At three months, Reilly developed flu-like symptoms and was rushed to SickKids in Toronto. There she was diagnosed with Pneumococcal Meningitis, a bacterial form of meningitis, a serious infection of the thin lining that surrounds the brain and spinal cord. Just a few weeks after Reilly became sick, the vaccine for meningitis was approved in Canada.

As a result, Reilly sustained significant losses, including profound hearing and vision loss. Deafblindness is a combination of hearing and vision loss that is unique to each person. It can impact access to information, communication, and mobility.

At seven months, Reilly was one of the youngest in North America to receive a cochlear implant, a small electronic device that stimulates the cochlear nerve, used for hearing. However, being so young, it was challenging to keep the external part of the implant on Reilly's head.

"She would roll around and the external piece would pop off, or she would pull it off... We tried everything including using headbands or scarves to fix it to her head. It was a battle," says Joan.

Reilly was two when the family discovered that she has some vision. "Her Papa brought home some LED lights; when we plugged them in, Reilly began to move toward the light."

Affectionately referred to as Smiley Reilly, Joan notes that Reilly is the happiest person in spite of everything she has overcome. "Reilly welcomes all with a beautiful smile, she is very affectionate, expressive, and she loves hugs."

Hugs are very important to Reilly, as she communicates through the sense of touch. Intervenors are professionally trained to act as the "eyes" and "ears" of the individual with deafblindness through the sense of touch.

Reilly first received Intervenor Services when she was five at W. Ross Macdonald School for the Blind.

Reilly attended W. Ross Macdonald for 15 years and moved to one of DeafBlind Ontario Services' locations last October. "We are relieved to have found another loving home for Reilly. It puts the entire

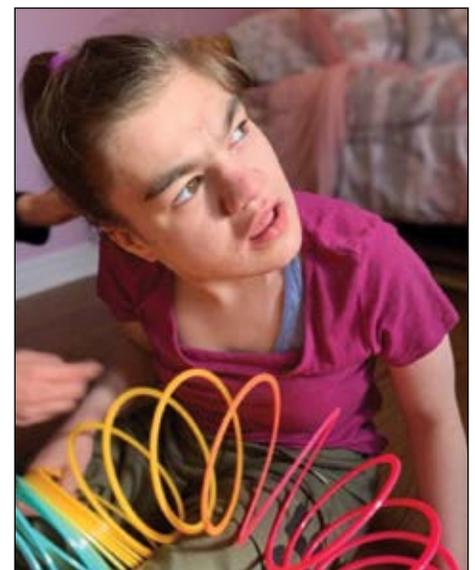
family at ease that her life will continue to be enriched."

"Reilly's move to her new home was a seamless transition. She fit right in with our team of intervenors. It feels like Reilly always belonged here... Her happy soul lights up everyone around her and you can't help but giggle when she giggles. Reilly has brought unexpected light to everyone at our location in Innisfil during a difficult time with the pandemic," says Tellie, an intervenor at DeafBlind Ontario Services.

DeafBlind Ontario Services is committed to providing a high quality of life for people with deafblindness, this commitment is ingrained in their values.

"Every small leap and bound gives our family hope for a better quality of life and future for Reilly," says Joan.

More than one per cent of Canada's population or approximately 466,420 people are deafblind, like Reilly. DeafBlind Ontario Services provides accessible residential and customized support services across the province. Their holistic approach to Intervenor Services empowers people with deafblindness to achieve their goals and dreams. Learn more at deafblindontario.com.





Canadian Disability Policy Alliance & Canadian Disability Participation Project

May 2021

COVID vaccination receptiveness among people with disabilities

Between December 2020 and April 2021, 459 Canadians with disabilities participated in a survey about their willingness to be vaccinated against COVID-19 when the opportunity arose. This was part of a larger survey on the *impact of COVID-19 on disabled people in Canada*. In this sample, 73% said a definite “yes” to vaccination, 7% a definite “no”, and 20% were undecided. Women were more likely than men to say “no” (10% vs 2%). Other results must be interpreted with caution, because of small numbers of respondents in some categories, but people in New Brunswick and Manitoba, and people with intellectual disabilities appear to be least willing to be vaccinated.



A vision of Canada where people with disabilities enjoy full participation and citizenship, supported by a coherent framework of legislation, regulation and programs.

You can now make donations online!



Through a partnership with CanadaHelps.org, it has never been easier to make a one-time or monthly recurring gift directly through CanadaHelps portal. This service offers an instant electronic receipt, and you can feel good knowing that your transaction is safe using advanced security technology.

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.”



34th Annual "Lend-a-Hand" Charity Golf Classic Raises Much Needed Funds for Canadian Deafblind Association



Tournament Volunteers L to R: Bruce Lockhart; Carolyn Monaco; Kim McFadden; Sawyer James; Erin McFarland



Wine Tasting Hole Sponsor Shafic Rawdah, Chief Operating Officer, Bottles & Barrels

On Monday, August 23rd a turnout of 72 golfers enjoyed a terrific day on the course for the 34th annual “Lend-a-Hand” Charity Golf Classic, generously sponsored for the second time by Cooperators Insurance Justin M. James & Associates Ltd. This year’s event was held at the challenging Carlisle Golf Club in Carlisle, Ontario.

Despite the strict COVID protocols in place, the fun-filled day saw golfers and volunteers enjoy an “on the go” lunch, a BBQ pub-style dinner on the patio after their round, amazing prizes and some healthy competition and comraderie, all while helping out a worthy cause. CDBA as always was grateful for the hard work of a dedicated core of volunteers - Carolyn Monaco, Kim McFadden, Erin McFarland, Sawyer James, and Bruce Lockhart.

TOURNAMENT WINNERS:

Men’s Low Team: Ross Taylor, Cal Whiffing, Alex Whiffing, Gerard Comeau

Ladies Low Team: Dianne McDonald, Barb McKeown, Jenny Davey, Vicky Dawson

Mixed Low Team: Bill Clark, Dave Homulos, Jean Homulos, Jo-Anne Flood

Ladies’ Closest to the Pin: Tammy D’Andrea

Men’s Closest to the Pin: Mark Kent

Most Accurate Drive: Tammy D’Andrea

Longest Putt Made: Jonathan McMahon

WestJet Gift of Flight: Kim Oram-McFadden

50/50 Draw: Jean Homulos

CDBA National is very grateful for the generosity of our **Title Sponsor** Justin James & Associates on behalf of the Cooperators; **Lunch Sponsor** Turtle Bay Pools & Leisure; **Cart Sponsor** Paragon Home Capital; our 18 **Golf Hole Sponsors** as well as those who kindly donated prizes for our raffle table. We also wish to sincerely thank **WestJet Airlines** for its “Gift of Flight” donation to our raffle table.

This event raised nearly \$11,000. These funds will go towards a wide range of activities for persons who are deafblind and their families, carried out by CDBA National through its National Support Fund. Since this tournament started in 1987, it has raised more than \$675,000 for Intervention services and emergency supports for persons who are deafblind and their families.



Title Sponsor Justin James of The Cooperators with CDBA National ED Tom McFadden



50/50 Draw Winner Jean Homulos



Canadian Deafblind Association 2021/22 Board of Directors



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All people who are deafblind will live rich meaningful lives.

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Seeing, and Hearing the World in a Different Way

Tim Stones

www.dispatchlive.co.za



Tim Stones, left, who is a Deafblind person, with his guide, Andrew Liddle, exiting the water after the swim leg of the South African Para Triathlon national championships, held in Maselspoort in Free State on April 2021. In June, which is also Deafblind Awareness Month, Stones and Liddle represented South Africa at the Para All Triathlon Championships, in Sharm el Sheik in Egypt, winning a bronze medal.

When people meet me for the first time, I am quite certain that the description “deafblind” is not the first thought that springs to mind.

After all, in most interactions, I don’t look or sound like I imagine most people would think of as a stereotypical deafblind person. But the truth is, this is a part of who I am. I am Tim, and yes, I am indeed deafblind.

June is Deafblind Awareness Month. Deafblindness is a unique disability, where the combination of hearing and vision loss affects a person’s ability to communicate, access information and get around independently.

Most deafblind people are not completely deaf or completely blind, often maintaining some degree of use in both senses. However, the combination of the dual sensory impairment has an impact on several aspects of everyday life.

Even where the loss in each sense is mild, the impact can be significant as the senses work together and one sense would usually help compensate for the loss of the other.

I lost most of my hearing through oxygen deprivation at birth.

I have bilateral sensorineural deafness.

This was not picked up at birth,

however, and I was only correctly diagnosed and fitted with my first pair of hearing aids just before my sixth birthday, when I learnt to speak and to read for the first time. At the age of 12, diagnosed with myopia, I started wearing glasses as well.

After matriculating from St Andrew’s College in Makhanda with a first-class matric, I proceeded to UCT, ultimately graduating with an MA in religious studies and later a postgraduate diploma in journalism from Rhodes.

After six years working as a researcher with the National Institute for the Deaf, in Worcester, where I designed and led training for deaf people across Africa in leadership and management skills, I served Rhodes University as their disability adviser, before joining the Daily Dispatch as a journalist.

Over the years both my hearing and vision have continued to deteriorate. Three years ago I acquired a cochlear implant in my left ear as I had by then become profoundly deaf.

My audiologist doesn’t fully understand why this progression has been as drastic as it has been, given the source of my deafness was a loss of oxygen at birth and, as such, further deterioration, especially to this degree at my age, would not be usually expected.

Myopia usually stabilises by the time a person is about 20 years of age. Mine has never stabilised.

I am now legally blind — defined as vision that is best corrected to 20/200, or periphery vision of less than 30°.

The way my eye specialists have explained what is happening to me is that I have high myopia, which is also

progressive or degenerative.

The biggest issue I face is that my retina is losing functioning, and quite rapidly, as there has been a significant decline in my vision over the past three years.

The cruel irony is that this drastic loss of vision coincided with my hearing deteriorating. I thus cannot rely on either sense to compensate for the significant decline of the other.

When I think of my life now as a deafblind person, I mostly see it as a blessing.

Yes, of course there is no escaping the hard realities that especially the decline in my vision have brought.

I feel this most poignantly in having lost my ability to secure a driver's licence, as my vision is so far off the mark that the optometrist's chart used for tests for those who wish to avoid the long queues at the traffic department doesn't even include my prescription.

And with losing the right to drive comes a loss of independence, a greater need to rely on others when transport is an absolute necessity.

Thankfully my wife and I are very fit, and we live a short walking distance from the shops. Being sporty, it's become a welcome chance to boost our weekly mileage!

As I still have some vision, and can access sound through my cochlear implant and hearing aid, I do not battle

with communication as much as many deafblind people do.

However, navigating communication in the Covid-19 lockdown has been a huge challenge.

One cannot lip-read through masks, and assistive listening devices do not always enable one to follow what is being said.

Coupled with vision loss, and the need for social distancing, there have been many moments, especially at the shops, where much has been completely lost in translation.

Thankfully, most times I have my wife, Mercia, with me. I am her ears (she is also deaf, and relies completely on lip-reading), and she is my eyes.

I help her to know what is being said (when I myself have worked it out!), and she alerts me to what I may not have seen, or might bump into. We make a great team.

The greatest blessing that has come from being deafblind has been the extraordinary opportunities it has provided to experience things I would never otherwise have imagined doing.

I have had the privilege of representing my country as a sportsman in deaf athletics, deaf rugby and para triathlon (and a call-up to the national para cycling team), and have travelled to several countries, experiencing diverse cultures and peoples.

Being active in para sport has played

a pivotal role in helping me hold on to joy in the midst of the mountains I face daily.

I chose to respond to learning that I had become legally blind by channelling much of my energy into sport.

As a deafblind person, sport for me has become a metaphor for hope, purpose, and living one's best life no matter what barriers or challenges we encounter along our path.

I face more barriers these days, more challenges, but sport, and dreams, keep me grounded, focused, and full of joy.

We create our own destiny, led by God, inspired by His constant goodness and grace, filled with wonder and awe that we are because He is.

How can one not marvel and rejoice, despite the mountains we all face in one form or another?

Reflecting on happiness, Helen Keller said: "Your success and happiness lies in you. Resolve to keep happy, and your joy and you shall form an invincible host against difficulties."

Choose to be happy.

I choose to focus on the amazing adventures and experiences and opportunities that have come my way because I am deafblind.

I see it as a way of being, and an incredible way to experience this world.



Join **DeafBlind Ontario Services** for the second virtual Savour the Senses experiences taking place Saturday, Oct. 23 from 7:30 to 9 p.m.

A team of experts - chocolatier, sommelier and whiskey maker - will guide guests through an exploration of their senses, and engage in discussions about pairings, varietals, regions and more right from the comfort of participants' homes.

Participants will receive everything they need for this intimate 90-minute pairing, by contactless delivery. Packages will include three varieties of fine chocolates, two bottles of wine, and a Moonshine sampler for two. New

this year is an online auction beginning two weeks before the event.

Tickets are \$90 per package and proceeds support those who are Deaf, hard of hearing, non-verbal and deafblind.

Registration begins Aug. 5 at <https://deafblindontario.com/foundation/events/> or call 1-855-340-3267, ext. 289.

Wezel-Peterson Embraces her Identity as a Deafblind Individual

U.S. Army Corps of Engineers, St. Paul District

www.dvidshub.net

Molly Wezel-Peterson was born in South Korea. At nine months old, she was adopted by an American family and brought to Minnesota. Both of her parents are hearing. Wezel-Peterson is the only deafblind member of her family; her siblings are all hearing as well. The family is not fluent in sign language, but instead use a system of home signs to communicate with Wezel-Peterson.

"The communication part was hard for me," Wezel-Peterson said. She started out in mainstream school, but the communication between her and her parents became a challenge, especially with her parents' divorce happening simultaneously. She transferred to the Minnesota State Academy for the Deaf, or MSAD. At MSAD, Wezel-Peterson thrived with socializing with other students who are deaf and being able to communicate with them.

Wezel-Peterson attended the Rochester Institute of Technology/National Technical Institute for the Deaf, where she majored in business technology, and Metro State University where she focused on business administration, getting a bachelor's degree. Those studies led to working in business offices as an administrative professional.

Wezel-Peterson did not always identify as a deafblind person. She grew up being deaf until the school staff diagnosed her with Usher Syndrome (a syndromic cause of combined deafness and blindness) at age 10. "Growing up, I knew what Usher Syndrome was, but I didn't know it also applied to me," Wezel-Peterson said. Later, Wezel-Peterson asked her mother about the diagnosis and found out that her parents had known that Wezel-Peterson had it from the start. "You were born that way," they told her.

Wezel-Peterson shares that her mother was adamant that deafblindness would not stand in the way of her daughter's

success in life. "My mom wanted me to be independent and believed that I could do anything I put my mind to and be successful in life," Wezel-Peterson said. She has not relied on parental assistance and believes in learning the responsibilities that come with life – such as paying for college without parental assistance – as a form of empowerment.

Wezel-Peterson has worked for the St. Paul District since 2012. "Many engineers there have no time to focus on the administrative part of their jobs. That's where I come in," Wezel-Peterson said. Her responsibilities include transferring informational data, timekeeping, monetary reimbursements and other office-related duties. Her duties support the 45 people in the hydraulics and hydrology branch.

Wezel-Peterson said the most appealing part of her work is being around people. "All the workplace banter and fun moments – I relish those moments!" said Wezel-Peterson. She adds that it's important to be positive and encourage one another, which leads to higher morale among the employees. With the current coronavirus pandemic, the social part has been reduced due to the safety restrictions in place. "I'd much rather be working at the office and among people, as I thrive from being among like-minded folks," Wezel-Peterson said. Isolation has been a very different experience for Wezel-Peterson, but she hopes that it won't last much longer.

She also adds that her workplace has been very accommodating to access needs connected to being deafblind. Tools she uses at work include zoom text, a larger computer monitor screen and making sure her access needs are being met. They also ensure Wezel-Peterson can participate in meetings by providing American Sign Language interpreters, which stemmed from a



Molly Wezel-Peterson, hydraulics and hydrology branch administrative assistant.

prior meeting where Wezel-Peterson stood up, informing the department that interpreters were needed more frequently to ensure equal participation.

Wezel-Peterson adds that there are six deaf employees in the district, and those interpreters put them on an equal footing with their hearing coworkers. "Sometimes you need to stand up for what you need to succeed at work, including your communication access needs." She encourages deaf people to educate their hearing coworkers and bosses about communication options and preferences, deaf culture history and norms and share opportunities to learn sign language. "Even if it's just covering the basics, it does go a long way," Wezel-Peterson said.

Outside of work, Wezel-Peterson enjoys working out, going for walks or running, and socializing with friends. She would like to spend more time with her family, but it's hard as they don't live nearby.

Wezel-Peterson offers the following advice, "This is for everyone, whether you are deaf, or deafblind – you come first. – You can empower yourself to be successful in your life. Be sure to share positive encouragement and do not pull each other down. We as deaf or deafblind, we can do anything we put ourselves to, to stand up for ourselves in life."

Easing lockdown: Deaf-blind Woman Shares Disabled People's Fears as Lockdown Eases

Hugh Fort

www.getreading.co.uk



Molly Watt, 26, says disabled people will need time to adjust to lockdown easing

A deaf-blind businesswoman has warned people with disabilities may need help as normal life slowly starts to return.

Molly Watt says the coronavirus pandemic has had a severe impact on the lives of disabled people and that many will face a lot of stress and anxiety when they come out of shielding and isolation.

She is working with disability charity Sense to make people aware of the difficulties many disabled people are facing as the country eases out of lockdown.

Molly, who is from Maidenhead, has Usher Syndrome, a condition which causes gradual sight and hearing loss. This means she cannot see well enough to comply with social distancing regulations and would struggle on public transport.

She said: "I think there are mixed feelings. There will be a lot of anxiety around it. I, and a lot of other disabled people, will have to build up my confidence again once things start to come back. For example, it will be quite daunting for a lot of people to start using public transport again."

She added: "As I'm deaf-blind, there isn't a way I can keep the two metre distance from people. I have to trust others to do so, so things like going food shopping could become quite daunting for people. I know a lot of people have been avoiding

it, either getting people to go for them or doing it online. Disabled people tend to get very used to isolation and it will take a while for them to get out of that."

Coronavirus has had a shocking impact on the lives of disabled people. Six out of every 10 deaths has been a person with a disability, according to Office of National Statistics data.

Many disabled people have had to shield for months at a time and those classified as Clinically Extremely Vulnerable (CEV) are continuing to shield, despite an 85 per cent vaccine rate amongst this group.

Research from Sense shows disabled people have concerns about health, cuts to social care and fear of being not able to comply with social distancing measures.

Isolation and loneliness has also spiralled with 61 per cent of people surveyed describing themselves as "chronically lonely".

The charity surveyed more than 1,000 people. More than half said they were fearful of going out in public because of concerns over their health and not feeling safe.

And 39 per cent of people said they were anxious because they can't comply with safety measures, like social distancing or wearing a mask.

Molly, who is 26 and runs a business working to make websites more friendly for blind and deaf people, added: "I'm concerned how long it will take for me to feel confident enough to be as independent as I was before the pandemic.

"It took me many years to get to where I was pre-Covid. I can't afford to spend years building it up - I need to work. I need to see my friends, my family. But will I be able to cope, mentally? I honestly don't know how long it'll take this time round."

She said her advice to people would be to be considerate and open-minded towards disabled people and to ask them if they need any help.

Richard Kramer, Sense chief executive, added: "The severe impact of the pandemic has meant that many disabled people are now fearful and anxious about going out into public, and unless we support and prioritise them, isolation and loneliness will become a bigger problem.

"We must recognise that cuts to services and reduced support have contributed to the isolation that people are experiencing, and reinstate community services, while ensuring mental health support is available for those that need it. Our local communities also have an important role to play in ensuring that disabled people are not left behind as we move out of lockdown. The changes that we make to adapt to social distancing rules, such as increased outdoor dining, must be planned with the needs of disabled people in mind. Sadly, in recent weeks we have heard too many reports of people not being able to navigate the high street because pavements are blocked.

"Let's show patience and understanding if someone is unable to wear a face covering, and provide that extra space to someone we pass on the pavement – it may really help to put them at ease."



Molly has concerns about how long it will take her to feel as confident as she felt before

The Andrew Love Memorial Award of Excellence

This award is presented to a graduating student of the George Brown College Intervenor for Deafblind Persons Program who has shown outstanding ability in working as an Intervenor with a child with deafblindness. The award winner receives \$150 from the Andrew Love Trust Fund and a certificate provided by George Brown College. The award was first issued in 1993.



2020 Recipient: Sara MacLean-Walsh



2021 Recipient: Sarah Porter

Association of Visual Language Interpreters of Canada Certificate of Recognition

The Association of Visual Language Interpreters of Canada is a non-profit, professional association for interpreters whose working languages include a sign language. AVLIC was established in 1979 and has several Affiliate Chapters across the country. AVLIC is the only certifying body for ASL-English interpreters in Canada through the means of our Canadian Evaluation System. Among a variety of services, we offer a Professional Conduct Review Process to maintain quality and accountability to the field of interpreting.



2021 Recipient: Kawthar Itani

The Canadian Deafblind Association - George Brown College Award for Excellence in Field Placement

This award is presented to a graduating student who demonstrated outstanding achievement in the Field Placement component of the George Brown College Intervenor for Deafblind Persons Program. The award winner receives \$100 from CDBA National and a certificate provided by George Brown College. The award was first issued in 1998.



2020 Recipient: Carson Finkeldey



2021 Recipient: Tabatha Morin

News From CDBA British Columbia

CDBA British Columbia Theresa Tancock, *Family Services Coordinator*



CDBA-BC is having a fantastic summer season, from June's National Deafblind Awareness Month to our currently running Summer Intervention and Virtual Recreation Programs.

We were so very fortunate to have had not only our Provincial Government, but also many British Columbia communities, share in the National Deafblind Awareness campaign this past June, making declarations, lighting up in blue and participating in our yarn-bombing! Below is a list of the declarations and activities.

The BC Provincial Government officially declared June 2021 as Deafblind Awareness Month and we are fortunate that the following cities also declared the same:

- City of Surrey
- City of Vancouver
- City of New Westminster
- City of Victoria
- City of Richmond



The following community landmarks within British Columbia were lit up in BLUE on various dates throughout the month to raise awareness for Deafblind Awareness Month:

- New Westminster: Anvil Centre
- Burnaby: Lougheed Hwy/Gagardi Way intersection decorative lights
- Vancouver: City Hall, BC Place, Sails of Light
- Fort St. John: Centennial Park
- Duncan: World's Largest Hockey Stick and Puck
- Surrey: Civic Plaza
- Victoria: Parliament Buildings Ceremonial Entrance, Front and Rear Fountain and Confederation Garden Park Fountain



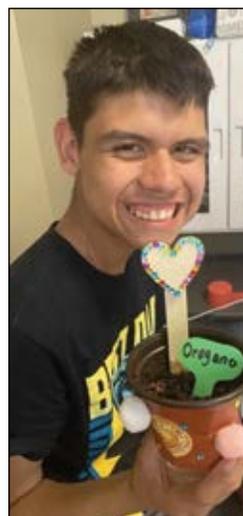
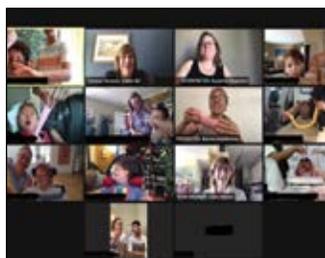
The following BC communities participated in our Yarn-Bombing initiative:

- Penticton: KVR Middle School
- Vancouver: Sir James Douglas Elementary
- Burnaby: Sheep at McGill Library
- RSCL Woodward's House, Richmond



Intervention support to children with deafblindness throughout BC. In conjunction with this program, we have also had fun creating, singing and sharing stories with many of the families we support and our members with deafblindness through our Virtual Recreation Program. To date, we have played Emoji Bingo, planted herbs in our decorated plant pots, made bubbles and bubble wands and have made edible slime and slushies.

We are looking forward to more activities before summer's end and our Intervenor Resource Team will be coordinating further virtual activity sessions for the Harvest season.



News From CDBA New Brunswick

CDBA New Brunswick Kevin Symes, *Executive Director*



It has not been as busy with outings as much as it usually would be, because of Covid. Our clients are making the best of it though by staying active and doing small outings. Some clients have been able together in their regional groups and other have been able to travel a bit to see clients from other regions as well. All in all our clients have been having a good time even with the struggles of Covid. Below are some things our clients got to do and the people they were able to get together with.



Holly, our Fredericton Intervenor Winning "Intervenor of the Year" For 2020.



Our Fredericton client, Eddy, enjoying the outdoors with his Intervenor.



Michelle, our Fredericton client, decorating cookies for Clubhouse.



Craig, our Moncton client, celebrating the New Year With his Intervenor's family.



Cathy Jo, our Saint John Client got to meet up With Sheena, our Fredericton client to have some fun in our Snoezelen Room.



Matthew our Bathurst client, volunteering at a food bank by packing bananas.



Henley, Our Fredericton client, showing off her new glasses, she is pretty proud of them.



Owen our Fredericton client, enjoying playing on his keyboard. He loves musical instruments.



Matthew and Kevin, our Bathurst clients waiting to enjoy their Christmas dinner at Pizza Hut with their Intervenor.



Sheena, one of our Fredericton clients, enjoying one of the walking trails in the Fredericton area.

CDBA-NB Inc., did our Yarn Bombing on June 3rd, 2021 down at the legislature building in Fredericton. Our clients had a lot of fun with this event and they were very helpful. Here are some picture of that day.



News From CDBA Saskatchewan

CDBA Saskatchewan Dana Heinrichs, *Executive Director*



June is Deafblind Awareness month and we were pleased to have the full month declared in Saskatchewan. Lots of social media posts, the SaskTel Centre was lit up in blue on June 15th to commemorate and CNIB received news/media coverage on their new services, deafblindness and Intervention. CDBA Sask. also hosted their 36th Annual General Meeting on June 15 via Zoom.



CDBA Sask. wishes a warm farewell to Nova Coubrough, who had been a resident with CDBA since the inception of our agency. Nova has moved back to her home community with family to enjoy an early retirement.



It has been a great year of celebrations; 3 residents have reached milestone years in birthdays. Norrie and Leslie are 50 and Erin turned 40. Happy Birthday and cheers to many more!



A large number of staff and Residents received their 2nd COVID vaccination in July. This brought a huge relief for so many to have the protection and provide new opportunities to reintroduce community involvement. A few have had the chance to go to their family homes for visits or have family come to them to visit. Scott had been staying in his parents' home during the pandemic and was now able to return to the group home in July.



With the hot summer in Saskatchewan we have been going to parks, walks along the river and day trips to the local lakes or hikes in our provincial parks.



At CDBA we have been taking things slowly when it comes to community involvement until we see how the infection rates play out. One of our CBO partners has provided a safe return to work option for our residents and they all have enjoyed the opportunity to return to work once a week and will be increasing this frequency in the fall to 3 times a week.



September 1st brings the return of our annual Lend A Hand Saskatchewan Classic golf tournament. Since we were not able to run it last year, we are reconnecting with our supporters and crossing our fingers it once again is a success. We also had a volunteer over the summer who organized a fundraising campaign collecting donations from local businesses and running an online auction with McDougal Auctioneers.

'Deaf-Blind' Swimmer Denied Personal Care Assistant at Paralympic Games Refuses to Participate

Rodolfo Vieira

www.californianewstimes.com



Three-time gold medalist Becca Meyers recently had to make the very tough decision of dropping out of the Tokyo Paralympics after being denied a personal care assistant.

The blind-deaf athlete recently took to her official Instagram account to share the "gut-wrenching" story with all of her fans and to explain the details behind her decision.

According to the swimmer, the United States Olympic & Paralympic Committee has allowed her to have a trusted PCA – her mother – since 2017, but this time her request was denied.

A Reasonable Request

Following the controversial decision made by the committee, Meyers said that she was angry, disappointed, and, most of all, sad for not being able to represent her country in the competition.

Meyers claimed that, as a deaf-blind athlete, a trusted PCA is a reasonable and essential accommodation for her to be able to compete and that, as a disabled person, she shouldn't be fighting for her rights in 2021.

In the post, the gold-medalist wrote that

the USOPC not only denied her request but also told her "repeatedly" that she did not need a PCA that she trusts.

The USOPC informed Meyers that the reason behind their decision was that there would be a single PCA on staff available to assist her and the other 33 Paralympic swimmers at all times.

Speaking for Future Athletes

Meyers explained to her fans that she understands that, due to the COVID-19 pandemic, there are new safety measures and limits when it comes to non-essential staff but that she still required a trusted PCA.

The 26-year-old ended her message by saying she is speaking up for the future generations of Paralympic athletes in hopes that they never have to experience the pain she has been through and that "enough is enough."

How COVID-19 Affected Her

Meyers, who was born with Usher Syndrome, a rare genetic disorder that causes hearing loss and visual impairment, shared that the pandemic changed everything for her.

She believes she was given no other choice.

Usually, the athlete relies on her guide dog Birdie to move around, but the first trip to the Apple store near her house after the pandemic made her very nervous. She recalled:

"Everyone was wearing masks, which inhibits my ability to read lips. The store layout had changed, which made it difficult for Birdie and me to get around."

Meyers felt the effects of the pandemic more than anyone else due to her disability, but she is "used to being forced to become comfortable in uncomfortable surroundings."

Disappointed

She was looking forward to being at the Paralympic Games, which she considers a haven for athletes with disabilities as they are able to compete on a level playfield with all the support systems, amenities, and protections.

Meyers wanted to, once again, bring home a medal, like fellow Americans Simone Biles and MyKayla Skinner, but ultimately she believes she was given no other choice but to step away from the Games.



This Robot Uses Tactile Sign Language to Help Deaf-Blind People Communicate Independently

Eva Botkin-Kowacki

news.northeastern.edu

Jaimi Lard gets into position. She cups her left hand over the device, spreading her fingers across the top of it, and raises her right hand. When Lard is ready, Samantha Johnson presses a few keys on a laptop wired to the robot and then, with a mechanical buzzing sound filling the air, the device begins to move.

When the whirring stops, three of the fingers of the robotic hand are pointing directly upward, while the tips of the thumb and pointer finger are touching, forming a circle. Lard uses her left hand to feel what position the robotic hand is in, then moves her right hand to make the same sign.

“F, perfect!” Johnson exclaims.

The robotic arm, built by Johnson, a bioengineering graduate student at Northeastern, is designed to produce tactile sign language in order to enable more independence for people who, like Lard, are both deaf and blind. Lard is one of the members of the deaf-blind community that is helping Johnson test the robot and giving her feedback on how it could be improved.

“I’m very excited for this new opportunity to help improve this robot,” Lard says, through an interpreter.

Johnson came up with the idea for a tactile sign language robot, which she has named TATUM, Tactile ASL Translational User Mechanism, as an undergraduate student at Northeastern. She took a course in sign language as a sophomore and through that class, Johnson interacted with people from the Deaf-Blind Contact Center in Allston, Massachusetts, to work on her skills.

People who are deaf can communicate with their hearing friends and family through visually signed language, but for people who are both deaf and blind, language must be something they can

touch. So that means that people who are both deaf and blind often need an interpreter to be present with them in-person for interactions with others who do not know American Sign Language, so they can feel what shape their hands are making.

“When I was watching the interpreter sign, I asked, ‘How do you communicate without the interpreter?’” and the answer was simply, “We don’t,” Johnson recalls.

The goal of developing a tactile sign language robot, Johnson says, is to create something that can be used for someone who relies on American Sign Language as their primary communication language to be able to communicate independently, without relying on another person to interpret. She sees the robot as potentially helpful at home, at a doctor’s office, or in other settings where someone might want to have private communication or an interpreter might not be readily available.

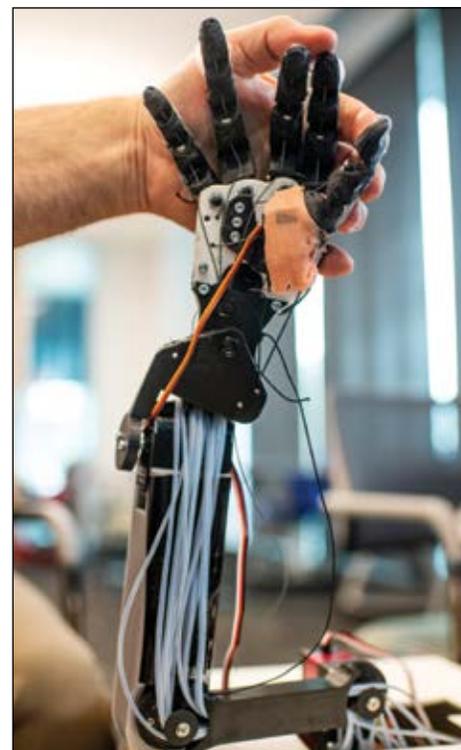
Johnson is still in the early stages of developing the robot, working on it as her thesis with Chiara Bellini, assistant professor of bioengineering at Northeastern, as her advisor. Right now, Johnson is focusing on the letters of the American Manual Alphabet, and training the robot to finger-spell some basic words.

The ultimate goal is for the robot to be fluent in American Sign Language, so that the device can connect to text-based communication systems such as email, text messages, social media, or books. The idea is that the robot would



be able to sign those messages or texts to the user. Johnson would also like to make the robot customizable, as, just like in any other language, there are unique signs, words, or phrases used in different regions and some signs that mean different things depending on the cultural context.

Johnson will be working at the MassRobotics facility in the fall to build on this prototype.



Mum's Agony as Son's Body Swelled Up Leaving Him Deaf, Blind and Unable to Walk

Dominic Moffitt

www.lancs.live



A mum has bravely opened up about her five-year struggle caring for her severely disabled son. Laura Stinton, from Burnley, says she was convinced that she had committed a grievous sin in a former life after her boy Henry was born with acute brain damage, Hydrops, and scoliosis.

Her son also suffers with stage five spastic quadriplegia, the most severe form of cerebral palsy, rendering Henry blind, deaf, and unable to walk. The four-year-old has endured seven major surgeries and visited the hospital on a near daily basis for a number of years.

Now, Laura says that she can no longer look after her son unless she is able to buy a new home that can be suitably adjusted to her son's needs. "Looking after Henry is a 24-hour job, if I write down my day I'm doing something with him every single hour," the 29-year-old told LancsLive.

"He can't walk or sit up, he can hardly move his head, so I'm carrying him everywhere, up the stairs, getting him to and from bed, and out of the bath. Henry can't

feed himself or go to the toilet or do his medicines, he's completely dependent on me or his grandma, everything is done for him. The amount of equipment I have just to look after him fills up the house, as soon as I walk in it feels like I'm in a hospital. It's been very difficult but you have to get up in the morning and get on with it."

On October 11, 2016, a 24-year-old Laura gave birth to her first child Henry, via emergency caesarean. Born six weeks premature, and with the umbilical cord wrapped around his neck, Henry's entry into the world was riddled with complications. It took more than 11 minutes for doctors to resuscitate the newborn who was initially unresponsive, before he was whisked away to the Neonatal Intensive Care Unit (NICU).

Laura said: "I couldn't hug him for two weeks, that was the worst thing ever. I had just had a baby with these severe problems and all I could do was touch his fingers; that was about it. I could barely see his skin through all the tape, wires and plugs."

Henry weighed just 2lb 6oz when he was born but was plagued by further issues when doctors discovered that he had been born with Hydrops, an intense swelling of the body, causing the newborn's kidneys to fail. Once Henry had been drained of fluid and stabilised, he weighed just 1lb 9oz.

After six weeks on the ward, Henry was diagnosed with severe brain damage, scoliosis, and severe cerebral palsy which

affected his entire body. Blind, deaf, and unable to walk, Henry's condition was overwhelming for Laura.

Henry spent most of his early life going to and from hospital, sometimes being rushed into intensive care units after Laura noticed issues with his breathing.

By 2018, Laura was taking her son to the hospital twice a day and she had to quit her job as a barber, the following year, to become Henry's full-time carer. Henry underwent seven major surgeries on his airways, the last of which almost cost him his life and saw the toddler spend six weeks in the NICU.

Laura said: "I kept having thoughts in my head, I knew Henry would never see his mum because he's blind; it made me so upset. What made it worse was that I had a lot of friends and family who had kids around the same time who were the same age as Henry. I was seeing them all grow and progress while Henry was left behind."

A typical day caring for Henry is no mean feat; Laura administers twenty different medications to her son on a daily basis, giving him vital drugs that preserve his muscle tone and alleviate the symptoms of acid reflux. Henry is unable to feed himself, to go to the toilet, or even move, unaided, and Laura spends her day tending to his every need. But even the turbulent years endured by the duo has not dampened their relationship.

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- Field experience may be completed across Canada in your community through George Brown College partnerships

Famous Social Media Deaf, Blind, and Pink Dog Piglet Making Big Impact

Shawn Cabbagestalk
www.wjbf.com

Meet Piglet: a deaf, blind, pink puppy with a purpose. After being adopted by a veterinarian in Connecticut, Piglet's infectious positive mindset rapidly evolved into a global sensation. He has almost hundreds of thousands of followers across social media.

He and his human, Melissa Shapiro, joined weekend Good Morning Augusta anchor Shawn Cabbagestalk to talk about his life, the quest to teach others about the power of empathy, love, and kindness, and his new book, "PIGLET: The Unexpected Story of a Deaf, Blind, Pink Puppy and His Family" by Melissa Shapiro, DVM with Mim Eichler Rivas.

The book is described as a charming, inspirational memoir about empathy, resilience, and kindness. It follows the story of how Piglet became the mascot for facing challenges with his good attitude and will serve as a gentle reminder that with a little extra



consideration, support, and love, the rewards that come back are priceless.

Follow Piglet at:

Instagram: [@pinkpigletpuppy](https://www.instagram.com/pinkpigletpuppy) / 245k followers

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Website: www.pigletmindset.org



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