



**Canadian
Deafblind
Association**

Supporting Access
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for All

Imagine...

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

Edition 46, No. 1

Winter 2023

Intervention

The future in our hands

GLOBAL CONNECTIONS



18th International World Conference
July 22-28, 2023 🇨🇦 Ottawa, Canada



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Friday, August 12th, 2022

We are pleased to share that we have just published a new report on our most recent data. The report is available in English, French, Plain Language, and American Sign Language. The reports are available on these websites:

<https://abilitiescentre.org/disabilitysurvey>

<https://abilitiescentre.org/our-impact/research-programs/1%E2%80%99enquete-covid-19>

This COVID-19 Disability Survey report identified some issues of serious concern for Canadians with disabilities:

- The majority of respondents reported a worse mental health score (87%) and greater social isolation (79%) than the population average.
- Access to services that can support mental health and reduce social isolation (i.e., counseling, peer support, recreation and leisure programs) are still a significant unmet need for people with disabilities and their families.
- The overall level of inactivity in children with disabilities is alarming; 44% percent do not do 60 minutes of moderate-to-vigorous activity on any day of the week.

Abilities Centre and Canadian Disability Participation Project created the survey for Canadians with disabilities to share their experiences, concerns, and needs during the COVID-19 pandemic and recovery periods. We want to hear how organizations use the information, to help us decide content for the next version of the survey.

The intention of the COVID-19 Disability Survey is not to paint a picture of the situation at a specific time, but rather to identify the ongoing needs of our community and to support the development of effective advocacy tools, strategies, and measures to address those needs. The survey is updated over time to focus on relevant issues identified through the survey and informed by community members. This information is then shared back with individuals, community partners, and interested organizations through reports and presentations with specific recommendations and calls to action identified.

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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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Message From the CDBA National Board of Directors

Carolyn Monaco, President



Welcome to the winter issue of Intervention magazine!

The 47th Annual General Meeting of CDBA National took place on Saturday, September 24, 2022. Once again, the AGM was conducted via Zoom because of the lingering challenges presented by COVID. We were pleased to have participation from CDBA members and staff from across the country who otherwise would not have been able to attend in person.

We acknowledge with gratitude the outstanding volunteer contribution of retiring Board members Allan Matheis (SK Chapter Representative and Vice-President) as well as Leslie Comrie, Director-at-Large from BC. We also welcomed Christina St. Amand as the newest Director-at-Large from Ontario, and Linda Taylor, who assumes the role of SK Chapter Representative.



Christina St. Amand
Director at Large



Linda Taylor
SK Chapter Representative

The 2022 – 2023 National Board of Directors looks like this:

Carolyn Monaco, President (Ontario)
Suzanne McConnell, Vice-President (Nova Scotia)
David Brown, Secretary-Treasurer (New Brunswick)
Wanda Schellenberg (British Columbia)
Linda Taylor (Saskatchewan)
Christina St. Amand (Ontario)



The Andrew Love Memorial Award for Intervenor of the Year was presented to Donna Lagace of Moncton, New Brunswick.

The **18th Deafblind International World Conference** is coming to Ottawa, Ontario from July 22 – 28, 2023, the first time this prestigious event has been held in Canada since 2003. The Conference will be a hybrid affair, which means you can attend in person, or virtually! Visit their website www.deafblindnetworkontario.com.



Editorial From the National Executive Director

Tom McFadden



As we close the book on 2022 and with COVID-19 still not completely in the rear-view mirror, our collective attitude towards fundraising has been buoyed by the amazing generosity of our donors and the surprising success of last summer's "Lend-A-Hand" charity golf tournament. When I wrote my editorial for the summer issue, it was reported that revenues from donations and fundraising, which had fallen sharply during the heart of the pandemic, recovered nicely towards the end of 2021 and into the spring of 2022. We were therefore pleasantly surprised that this trend actually continued throughout the latter part of 2022. Such economic challenges are both short-term and long-term issues, ones that will continue to pressure CDBA National and its chapters to deliver on the things that matter most to persons who are deafblind and their families.

Inside this issue

With that, I welcome our readers to this winter 2023 issue of "Intervention". Within its pages, we celebrate persons – a deafblind golfer; a deafblind marathon runner; a deafblind cross-country cyclist; and a deafblind convention speaker & author on a mission to end "ableism" – who are deafblind by showcasing their success stories! The 10th installment of "Lessons from Charlotte's Web" educates us once more by way of a "lived" focus on the challenges faced by a family of a child growing up with deafblindness, as does an inspirational piece about "challenging misconceptions about people with deafblindness".

From the world of amazing, we learn how deafblind communities have created a new language of touch – pro-tactile ASL, and through its magic, how persons who are deafblind taught us to "see" the world differently, especially during COVID.

We also share with readers the amazing work of our CDBA Chapters in New Brunswick, Saskatchewan and British Columbia, as well as recognizing the deserving recipients of the CDBA Andrew Love Memorial Award for Intervenor of the Year, and the JT Award from the Canadian Helen Keller Centre for significant contributions to the deafblind community in the areas of awareness, expansion and involvement.

One final note – the entire CDBA family wishes to thank J. Allan Matheis of Regina, Saskatchewan for his 40 years of outstanding volunteer contributions to CDBA National, CDBA-SK Chapter and the entire deafblind community. Allan, who retired in September 2022, was a vital resource to both organizations because of his firsthand experience with, and knowledge of, the field of deafblindness. He will be sorely missed by all his friends and colleagues at CDBA.

June 2023 is Deafblind Awareness Month

June 2023 will mark the 9th anniversary since the Senate of Canada recognized June as Deafblind Awareness Month in 2015. In addition to the many celebrations and proclamations in towns and cities across this country, the focus by CDBA chapters will again be on "Yarn Bombing" - the global initiative by Deafblind International (DbI) that continues to inspire immense interest in more than 2 dozen countries around the world. Look for more information on the DbI website.

CDBA National searching for a new golf tournament Title Sponsor

Should readers know of, or be affiliated with, a company or organization in southern Ontario that might be interested in participating in next year's charity golf tournament on June 27th, please put them in touch with the National Office by email info@cdbanational.com or T/F 1-866-229-5832. Thanks.

I leave you with this thought: "A life without cause is a life without effect"...*Barbarella*

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B.C. Deafblind Man Denied Interpreter Wins Human Rights Complaint

Ben Bulmer

infotel.ca



A B.C. man who is deafblind has won a Human Rights Tribunal complaint after the organizers of a free three-day writing workshop refused to get him a sign language interpreter.

According to an Aug. 11 B.C. Human Rights Tribunal decision, Craig MacLean is deafblind and enrolled in the workshop put on by Black Card Books.

MacLean asked Black Card Books to pay for a sign language interpreter to accompany him to the workshop.

However, the company refused saying it was a free event and it was too expensive for them to provide an interpreter, but MacLean was welcome to bring his own.

The decision said MacLean attended the event without an interpreter but could not understand the presentations or communicate with other attendees and left after one hour.

"I just felt so disheartened. I was so excited to attend this workshop and I really felt just so excluded and, once again, pushed to the side, pushed to the

fringe of what most people get to do on a daily basis," MacLean said in the decision.

He later filed a human rights complaint saying the company had discriminated against him based on his disability.

The decision said MacLean is deafblind, can not hear and has very limited vision. He can, however, see a little up close.

Interpreting for deafblind people is highly skilled work and interpreters work in pairs with one sitting very close, wearing black clothes and making sure the hand gestures are small and within the field of vision.

The decision said MacLean is an avid blogger and has many ideas for books based on his own life experiences, he's also been working on manuscripts for many years.

In the fall of 2018, he saw the ad for the free three-day "Bookology Bootcamp."

The workshop was advertised as the opportunity to "publish a book and grow rich."

Ordinarily, the workshop cost \$140, but

this time the company was offering it for free.

In the decision, Black Card Books explained the workshop offers advice on how to plan, write and publish a book. However, the workshop doesn't make money but is a marketing tool to purchase the company's publishing program which costs US\$35,000.

MacLean admitted he couldn't afford the US\$35,000.

"I accept that the workshop may not have been exactly what Mr. MacLean thought it was, in terms of an opportunity to turn one of his ideas into a profitable book," the Tribunal ruled. "However, I find that there was an adverse impact on Mr. MacLean arising from the fact that he was denied the opportunity to participate in a free workshop that was available to people without his disability-related needs."

The Tribunal goes on to say this type of exclusion is "inherently harmful and diminishing of a person's dignity and feeling of self-worth."

The company said around 100 people attended the workshop and it only made one sale which didn't cover its costs. The company said it was not financially feasible for it to pay for an interpreter.

"I accept that paying for... interpreters would have increased the cost of putting on the workshop. But that does not end the analysis, because 'it will always seem demonstrably cheaper to maintain the status quo and not eliminate a discriminatory barrier,'" the decision read. "Ultimately, the issue is not whether an accommodation costs money – it often does – but whether that cost is undue."

The Tribunal found that while Black Card Books said it was too expensive, it

provided no evidence as to what it would cost the company to hire an interpreter.

The Tribunal also found that Black Card Books did not intentionally discriminate against MacLean.

"However, a violation of the Human Rights Code does not depend on intention," the Tribunal ruled.

Ultimately, the Tribunal ruled that Black Cards Books did not take "all reasonable and practical steps" to remove a

disability-related barrier.

The Tribunal ordered Black Cards Books to allow MacLean to attend the workshop in the future and pay for an interpreter of his choice.

While MacLean had argued for \$5,000 in compensation, the Tribunal said that was too much.

"In my view, an award of \$2,500 is appropriate. I accept that being excluded from the workshop hurt Mr.

MacLean and injured his dignity. At the same time, Black Card Books did take some steps to mitigate the impact by providing him with all of the materials from the workshop," the Tribunal ruled.

"Ultimately, the opportunity that he missed was likely less significant than he originally understood, being the opportunity of being sold a product he does not want to buy."

Orléans Deafblind Golfer wins Stableford Overall Title

Fred Sherwin

www.orelansonline.ca



Orléans deafblind golfer Kevin Frost with his service dog Nemo after winning the Stableford title at the recent Blind Ontario Golfing Championship in Simcoe, Ontario.

Orléans deafblind golfer Kevin Frost is the newly crowned provincial Stableford champion for blind golfers.

Frost competed at the Blind Ontario and Canadian golfing championships in Simcoe, Ontario, where he took home first prize in the Stableford category which gives points to holes based on par. For instance, a birdie is awarded three points, a par two points and a bogie one point. Points are awarded based on the golfer's handicap. Since Frost has a 24 handicap, he got an extra shot on every hole. So a par three was a

par four and a par four a par five, etc.

He also placed second for the overall for the low gross score in the B2 category with an 87, which is the lowest round he's ever played. The B2 category is for golfers with five degrees to eight degrees of tunnel vision.

Frost opened the 2022 golfing season by placing fourth at the USA Open Blind Championships competing against golfers who play year round. It was only his second round of the year.

After Florida, he traveled to Ohio where

he competed in a team event pitting the best blind golfers in Canada against the best in the United States in match play. Frost won both of his matches, but the team unfortunately fell short of the title.

In July, Frost competed at the Western Canadian Blind Golf Championship in Calgary. It was a very unsummerlike 11 degrees Celsius. He was also very sick, but still managed to finish fourth.

Frost is now preparing for the World Blind Golf Championships which will take place in South Africa next March.

But before that, he has a book coming out in September about his journey as a deafblind international athlete. Besides golf, Frost has also competed on the international stage as a speed skater and cyclist.

The book will be available on Amazon and through Barnes & Noble. A total of 250 soft copies will be up for sale with the proceeds going to help produce an audiobook for other blind individuals.

"I'm pretty excited about it. It's something I've been working on for awhile and I'm hoping it will inspire other deafblind individuals to get involved in a sport."

Through his many accomplishments, Frost continues to be an inspiration to athletes both young and old alike, physically challenged and not.

Talking with Tact

Anna Franchin

www.breakinglatest.news

There are two misconceptions about deafblind people: that they need continuous assistance and that it is not easy to communicate with them. These ideas have marginalized them for centuries.

The isolation was partly contained by the signs born spontaneously within the families. In the United States of the nineteenth century, Laura Bridgman to say her father opened her hand from one cheek to the other, drawing a mustache (similar to that of her father); a couple of generations later Helen Keller could count on dozens of domestic signs (for example, to indicate bread she made the gesture of cutting a slice and buttering it).

The braille writing system already existed. During Keller's life, which was rather celebrated in the country, other communication systems were born to facilitate those with disabilities both in sight and in hearing: the Tadoma method, in which the thumb is placed on the throat of the interlocutor and the rest of the fingers on the lips and jaw, a kind of tactile reading of the lips; the "alphabetic glove" (ie with the letters printed on it), which transforms the hand into a kind of keyboard. Then came hearing aids and cochlear implants in the twentieth century. Tactile adaptations of sign languages have also been developed, which are many in the world (there is the American one, for example, abbreviated to asl, or the Italian one, also called lis).

Touch, unsurprisingly, is always at the heart of these systems.

Concentration and effort

When we think of touch, we usually focus on the hands and fingertips. We are wrong. An article from The Conversation website explains that for deafblind people "touch involves the whole body: from the top of the head to feel the

sunlight, to the feet to understand where you are on the street". The feet help to create a kind of mental map, with which to decipher the environment while walking and recognize the characteristics of the different spaces.

Feeling and reading reality by touching it takes time and a lot of concentration, and can be very tiring at times. "You are fully aware of the limitations of your hearing and sight, and therefore your brain has to compensate, and your body has to compensate too," says one person quoted in the article. "You are desperate to get as much information as possible, in any way".

Nuccio articulated the words on Clark's hand, but also on his arms, back, chest and lower thighs.

This effort is perhaps best represented by another tactile communication system: the protactile, or pt. The pt was born about twenty years ago in Seattle, in the United States, thanks to the commitment of two deafblind people, Jelica Nuccio and aj granda (name written all in lowercase), who wanted to make tactile communication more accessible. In less than ten years, the PT has gone from being a set of communication practices to a national movement.

John Lee Clark, deafblind since adolescence, discovered this method in 2013, participating in a training course held by Nuccio himself.

The New Yorker, in a very nice article dedicated to the protactile, describes the moment when Nuccio showed Clark how it worked. They sat facing each other. Then Nuccio put Clark's hand on her knee, explaining that, as she spoke, he should have patted her to indicate that he understood, as if it were a nod from her, a practice she called back-channelling. Nuccio articulated the words on Clark's hand, but also on his

arms, back, chest and lower thighs.

After the training, Clark incorporated some of the practices he had just learned into interactions with his family. He and his wife began to use a principle of protactile known as co-presence: if she walked into a room, she touched him to let him know she was there. Previously, during meals, those who ate next to Clark interpreted what others said. Now, however, they tried to have tactile group conversations.

Without community

Terra Edwards, an anthropologist of language, and Diana Brentari, a linguist, have studied the gestures that make up the words of the protactile and have cataloged them: they can be traced, grasped, moved, slapped and so on. They also identified shared rules for combining movements. Their conclusion is that the system could be considered a language in itself. Among the colleagues, however, many disagree: the pt has many gaps; it is more like a dialect of the ASL; and above all it lacks a dense and present community of speakers.

Hundreds of thousands of people in the United States suffer from a combined loss of hearing and vision (in Italy there are about 189 thousand, according to an estimate made in 2016 by Istat and promoted by the Lega del filo d'oro). Most of them, however, found themselves in this condition as an elderly person, that is, after having been able to see and hear for most of their life. A much smaller group – around ten thousand people – become deafblind first, and one of the main genetic causes is Usher syndrome, whereby one can be born deaf and gradually lose sight.

Braille can be a nightmare for online browsing!

Among deafblind people there are only a few hundred people who use protactile every day: few. George Stern, an American writer who usually uses hearing aids and communicates orally, tells the New Yorker reporter: "I'm glad some willing people are developing pt as a language. But what will it be like where I live? I don't live in a deafblind community. I live in a mainly hearing world, immersed in a culture that does not have a good relationship with touch."

Some college students have tried to reduce the distances between these worlds by combining the special touch sensitivity of deafblind people with technology. They've designed devices that can tap and tap at a distance – a kind of primitive tactile FaceTime. But their invention could only deliver single, slow taps to a limited portion of the body, and it had none of the rich range of squeezing and pressing that a method like pt. In short, it was not a success. Today many deafblind people keep in touch using a braille display, with dots moving up and down. Except for online browsing, braille can be a nightmare! It goes better with emails, thanks to the Listservs software.

Paradoxically, it was covid-19 that accelerated this kind of attempt, which imposed physical distancing and upset

the outdoor spaces (think of the bars and restaurants that have expanded onto the sidewalks), but it has also solicited alternative solutions. A researcher and videomaker, Azadeh Emadi, and a quantum physicist, Daniele Faccio, both from the University of Glasgow in the UK, realized that something was needed to help deafblind people move independently in the environments that the pandemic had transformed. . So they tried to build a "spatial awareness" tool, capable of accurately locating people and objects nearby. The project is called Touch post-covid-19 and is funded by UK research and innovation (UKRI, a British public institution).

In a cycle of workshops launched in June 2021, the research team involved deafblind volunteers to understand how they imagined, memorized and mapped a space, with and without touch – and therefore what they might need.

The prototype of the instrument consisted of three elements: a portable radar and two wearable devices (a headband and a bracelet). The radar scanned space within a six-meter radius, detecting people and movement. This information was transformed into vibrations of different intensity in the band (to indicate the direction of a person) and in the bracelet (for the distance to the subject). But the signals

created confusion in those who received them. It would have been better to combine the two types of information into a single, always wearable mechanism. A hat, for example.

"Privileging sight over the other senses means risking losing experiences and connections, not least with those with a disability," says Emadi. "The ambition of our research, which combines a deeper understanding of the needs of the deafblind with state-of-the-art quantum technology, is not just to enable these people to participate in social life. We also want to use their unique perception of the world to enrich that of everyone else."

If you want to see the protactile at work, I recommend this video made a couple of years ago by the weekly Christian Science Monitor. While here you will find some information on a research project that focuses on another communication system for the deafblind, the haptic signals. The project was launched in 2019 by the European sign language center, in Sweden, and involves the Association of teachers of deaf / hearing impaired children of Estonia, the University of Porto, Portugal, and the Ca 'Foscari University. of Venice (which has activated a specific tactile or list sign language course).



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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."

Lessons From Charlotte's Web

By Frances Jablonca

Lesson #10

You need to play hard when life has been hard.



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.

Our daughter Madeline, Charlotte's older sister, was given a "play doctor" bag for her second or third birthday. Or maybe I bought it for her because it looked like so



much fun to play with when I saw it at Toy's R Us. (I rather think that is how our three children acquired many of their toys – by me wanting to relive my childhood.) My own mother was a nurse, so as kids we would grab her stash of syringes-intact with real needles and tensor bandages - and

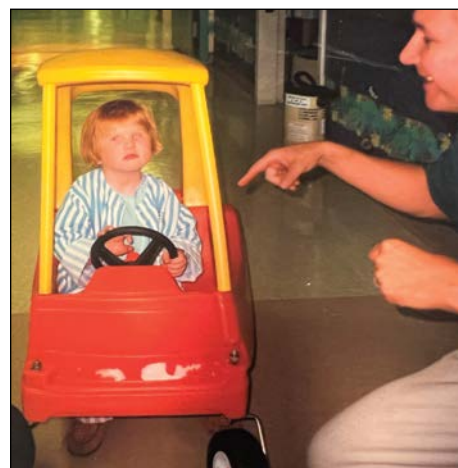
her stethoscope to set up a hospital in the backyard. All the neighborhood kids would have a role being a patient, administrator, parent or medical staff. But I digress. So, back to our little red hardcover case replete with plastic blood pressure gauge, stethoscope, syringe, scissors, small wrist cast, box of fake bandages, thermometer, pill box with no pills, and a knee banger, which I think is called a "reflex hammer". Madeline enjoyed playing with it, but it was our Charlotte who really got in miles with this little doctor kit.

From previous stories, some readers will recall that Charlotte was born with CHARGE syndrome. Her deafblindness caused her greatest communication and learning challenges, but it was her single ventricle heart which was her most serious health challenge. This heart defect caused her blood to mix, resulting in very low levels of oxygenated blood, from 79% to 82%, from birth until she had two open heart surgeries at the age of 5. The Glen Shunt and Fontane procedures would subsequently create a two chamber, one pump heart system for her. This then separated her arterial and venous blood, bringing her saturation closer to a normal blood saturation between 89% and 91%. She had better color, stamina and energy as a result. It was a miraculous procedure. Her amazing heart surgeon and the staff in Edmonton's Stollery Children's Hospital accomplished this in two separate surgeries within an 8-month period! Regardless, this new plumbing would put a lot of strain on her ventricle so it came with an estimated lifespan of 15 to 20 years. Still, it was a life-giving option for Charlotte and she thrived throughout the years during that time frame.

The innocence and trusting nature of children is a blessing, as they have no choice but to put their trust and fate in the hands of adults. However competent and skilled those magical hands may be, there still are unavoidable side-effects of these intense medical



interventions on the psyches of our special children. Depression, withdrawal, anxiety, in-creased dependence, and regression were seen by those caring for sick children... in studies (*Ibid #1*) I did not see those particular traits in Charlotte, but I do believe that one side effect was the incredibly high pain tolerance she likely developed due to the frequency of interventions, such as the drawing of blood; insertions of saline and antibiotic drips via veins in hands, feet and head; the thirst experienced after awakening from surgeries; waiting



for clearance to drink; and the constant handling from medical personal that is inevitably paired with pain of varying degrees. This began at birth and was a 'normal' part of her life. I have no doubt that it affected her cognitively and emotionally. We found that through her short, 22-year life span, she would never admit to being in pain and hated to be asked if she was feeling sick.

(Thinking back on this, was it because by admitting such, she would be whisked off somewhere for yet another test or procedure?)

What Charlotte did do in those more intense years of medical interventions was to play, play, and play! Everything revolved around hospital make-believe. Her dolls were her innocent victims. She took blood pressures, listened to heart rates, bandaged chests, removed dressings, and gave injections after



swabbing with antibacterial wipes. She played the part of surgical nurse and doctor with great precision. I saved the blue hairnets, shoe covers and masks that I was asked to wear when visiting Charlotte in ICU after surgery. Then, her cardiologist would on occasion clandestinely put a few new packages



in my handbag at follow-up visits after hearing my stories recounting Charlotte's medical-themed play. She even acquired eye protector glasses for potential spray of bodily fluids. But she really scored big when given her own authentic, used stethoscope. She often played surgeon for Halloween, and loved to listen to heartbeats of friends and family with her real stethoscope. On her silliest days, she would put her stethoscope up to an array of inanimate objects, including her sister's cello, listening for something.

While collecting the attached pictures, I noted how completely happy and engrossed in her play Charlotte appears. I knew instinctively, all those years back, that this was more than mere imaginary play. It was also more than her mimicking the medical staff that treated her. I truly felt it must have been therapeutic for her. While at play, she was in control, she was calling the shots, all the while exuding triumphant confidence. I decided to check a few websites to confirm my suspicions. Her play was indeed important. I further found research that supported the importance of play, especially when the child is repeatedly hospitalized, due to a chronic disease or disability, as it decisively contributes to emotional, mental well-being (*Ibid #2*)

Furthermore, "play is how children make sense of the world around them. In hospital, it helps them to express their feelings and worries, understand what is happening and cope with treatment ... It provides an opportunity for your child to make choices so that they can have a sense of some control... Playing with real or pretend medical equipment helps children become confident with things that are usually unfamiliar to them. This can lessen feelings of



fear (*Ibid #3*)

Together with a child's sense of imagination and a little red plastic doctor's bag, Charlotte worked through some of the most daunting experiences of her life.



1 Psychological effects of surgery on children - ScienceDirect

2 National Library of Medicine <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4733554/>

3 <https://www.kidshealth.org.nz/importance-play-your-child-hospital>

Deafblind Chessington Woman Completes First London Marathon

Nicola Lloyd

www.inyourarea.co.uk



MARATHON COMPLETE: Paige Barnes with her medal.

A 22-year-old woman who was born deaf and is losing her sight completed her first London Marathon at the weekend.

Paige Barnes, a hairdresser from Chessington, completed the marathon in just over six hours to raise money for the disability charity, Sense.

Paige has been deaf since childhood which is when she was fitted with cochlear implants to help her hear. However, in 2018, whilst Paige was studying at a specialist school for deaf students, she noticed a blur on the whiteboard.

She visited the opticians expecting a new prescription for her glasses but discovered she has Usher Syndrome

Type 3, a rare condition. People with Usher Syndrome Type 3 usually experience hearing and sight loss from childhood. Paige now has no peripheral vision, very limited vision at night-time and will probably lose more of her sight in the future.

Paige ran the London Marathon in aid of national disability charity Sense in 06:26:10. Sense supports children and adults who have complex disabilities including deafblindness.

Paige said: "The atmosphere when running the marathon was fantastic and the spectators were so loud! It was the most surreal feeling from start to end and because the support was so amazing I didn't even need to put my music on.

"My name was on my top and the amount of people shouting it gave me encouragement and was the best feeling ever. Towards the end for the last hour or so, I was struggling, in a lot of pain and was close to giving up but the spectators screaming my name helped me refocus and pushed me to the end."

Richard Kramer, chief executive of Sense, said: "We're absolutely chuffed for Paige - completing her first marathon - and showing what's possible if you never give up. Paige has helped raise awareness of deafblindness, and the money she has fundraised will go towards supporting people living with complex disabilities and their families across the UK."

Paige has raised £1,020 for Sense and extended her sincere thanks to everyone who donated to a charity she described as being close to her heart.

Deafblind Convention Speaker Wins Book Award

www.wsna.org



Elsa Sjunneson on a mission to end ableism.

Elsa Sjunneson, a keynote speaker at the May 2023 Washington State Nurses Convention, is one of eight winners for the 2022 Washington State Book Awards.

Sjunneson won in the category best memoir/biography for her book, *Being Seen: One Deafblind Woman's Fight to End Ableism*.

Sjunneson was born with congenital rubella syndrome or CRS, resulting in multiple disabilities, including sight and hearing loss. She has a prosthetic eye and partial vision in the other, and she wears bilateral hearing aids. She cannot

see well enough without a guide dog or cane, but she can see people react to her disability and often hears what they say.

Described as a “deafblind hurricane in a vintage dress,” Sjunneson’s book describes her experience at the crossroads of vision and sight, and how the misrepresentation of disability in popular culture harms us all.

At the May 17-19 Washington State Nurses Convention, she will address ending ableism against people with disabilities in the healthcare system.

Sjunneson, the subject of a 2019 PBS *American Masters* Short Documentary, said she wakes up every day with “a burning fire in my chest” to break stereotypes trying to define her.

She is a fencer, hiker, swing dancer, and speculative fiction writer who calls herself loud, snarky, and sarcastic.

Sjunneson is also an internationally published author on the subject of disability and ableism. As a deafblind activist she has worked to dismantle structural ableism. As an author, she has put a torchlight on disability stereotypes. She wrote a series of essays for *Tor.com* on how blindness is represented in movies and television shows. She wrote an opinion piece in *CNN* before the pandemic (2019) on her message to anti-vaxxers. Her mother was

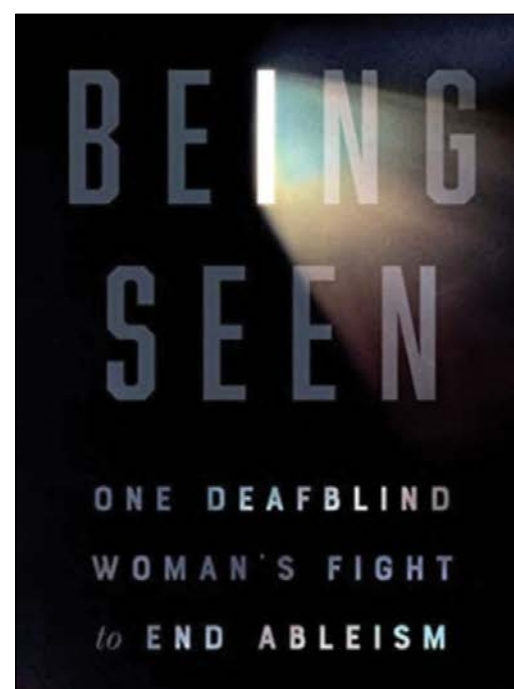
exposed to German measles when she was pregnant with Sjunneson in 1985, which led to CRS. She said her mother didn’t know she needed an MMR (Measles, Mumps, and Rubella) booster like is widely known today.

She has written guest essays in *Metro UK* and *New York Times* on how the world has wrongly portrayed Helen Keller as a fraud and a disability angel. She reported for *RadioLab* on the “Helen Keller exorcism,” and she contributed a story in *Women of Marvel #1* among other projects.

She is also a game designer and writes about inclusive game design.

Her book, *Being Seen*, was one of 243 submissions for the 2022 Washington State Book Awards. The finalists, announced Sept. 9., were selected by members of The Washington Center for the Book and The Seattle Public Library.

Sjunneson’s has a master’s degree in women’s literature from Sarah Lawrence College in Bronxville, N.Y. Her website is at www.snarkbat.com.



Overcoming Odds: Deaf-blind Jefferson Cyclist Crosses America

Kayla Nguyen
democratherald.com



Dick Hagan with the bicycle he took across the country while riding the TransAmerica Bicycle Trail.

For many cyclists, the prospect of biking nearly 5,000 miles from Yorktown, Virginia to Florence, Oregon is a daunting enough affair.

Known as the TransAmerica Bicycle Trail, this tour intimidates even the most experienced riders with its sheer distance, elevation gains and heavy equipment in tow.

Dick Hagan completed it legally blind and with significant hearing loss.

"I didn't do the tour to raise awareness about my conditions. I did it because it was my passion," said the 61-year-old at his home in Jefferson.

Hagan lives with Type 2A Usher syndrome, a rare genetic condition

characterized by stable moderate/severe hearing loss at birth, and progressive vision loss, called retinitis pigmentosa, which emerges later in life.

Growing up in Albany, Hagan cycled often as an adolescent. He dreamed of doing a self-supported bike tour and even rode to Idaho and back with his cousin at one point.

It was not until 10 years old that he began to notice that he struggled to see in the dark. Shortly after, he realized his peripheral awareness of small, fast-flying objects was slipping.

Concerned about his visual acuity, Hagan saw a retinal specialist and was told that there was nothing that could be done for him.

Retinitis pigmentosa is a degenerative disease that kills the cells sculpting the retina, weakening the ability to filter light. Night blindness begins at youth and progresses to severe vision loss through midlife, accompanied by various other impairments.

Despite the prognosis, Hagan would work a job in information technology for 33 years and cycle all the while. He joined a bike club in 2012 and would bike to the Oregon coast, the Washington coast, the Canadian border and San Diego over the next five years.

Hagan was declared legally blind at the age of 55 in 2017, he said.

"I panicked," he recalled. "I didn't know what I was going to do."

He kept working for two years following the diagnosis, until retiring from medical leave in 2019.

But his cycling days were far from over.

Hagan heard of the TransAmerica bike tour through a fellow cyclist in April. Learning that the tour took riders

through mostly rural areas, Hagan knew he could focus clearly on the scenery at bicycle speed. He entered the event to fulfill his lifelong ambition.

With his faithful bike, lovingly named “Lucy,” two guide cyclists and 90 pounds of gear, Hagan cycled for three months across North America.

“It was a good route with meeting so many helpful, friendly local people and really experiencing their cultures during our 4,228-mile ride,” Hagan said.

The TransAmerica tour took cyclists westbound through Virginia, Kentucky, Illinois, Missouri, Kansas, Colorado, Wyoming, Montana, Idaho and Oregon. The route included several national parks, such as Yellowstone and the Grand Tetons, along with small cities like Missoula, Montana and Carbondale, Illinois.

Hagan said each day “had its own pros and cons,” ranging from the steep hills of Kentucky and Missouri to the historic site of Williamsburg, Virginia.

“I can get lost on a road, because I can barely see the line,” he said. “Also, with hearing aids, there’s no sound direction. It gets kind of scary.”

Tracking just over 50 miles per day, Hagan would frequently stop to sleep in hostels or pitch tents on city hall lawns. Many businesses offered lodging to cyclists for free, he said.

Toward the end of the journey, Hagan took a nine-day break to recharge in Pueblo, Colorado. Now, he vows to never take another rest day again.

“When you stop for that long, it’s hard to get going again,” he said.

Upon completion of the tour, Hagan said he thought he did “OK physically” but was “more mentally tired.”

“These guys live and breathe cycling,” he said. “But I had fun on this tour. When I got back, it didn’t seem like that much time had passed.”

Hagan said he plans to continue outdoor cycling for at least a few more years. When his vision problems present too

big of a barrier, he will transition to indoor cycling, so he does not have to give up his favorite pastime.

Lamps and overhead lights brightly lit the space of his living room as he spoke of his experiences. He explained that it was due to his increased illumination requirement, one of the many effects from his progressive blindness.

Today, Hagan is totally night blind.

“On a clear, full moon night, I can only see the moon and everything else is black,” he said. “I can’t even find one star.”

When asked what he wants people to know about his capabilities as an athlete, Hagan responded with a simple but empowering statement.

“I may be deaf-blind, but it didn’t stop me from doing this TransAmerica ride.”

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 (866) 229-5832. Requests must be submitted in writing.





CDBA WAYNE TURNBULL MEMORIAL SCHOLARSHIP

For students enrolled in an Intervenor Program of Study



Established in 2022, the Canadian Deafblind Association Wayne Turnbull Memorial Scholarship honours the legacy of Wayne Turnbull, who was deafblind and a Board member of both CDBA National and the CDBA Alberta Chapter. Wayne was a lifelong advocate for individuals who are deafblind and their Intervenor.

Eligibility:

- Awarded to a deserving student in any area of Intervenor Studies, whether it be online or in-person, through an accredited educational institution
- Applicants must reside in Canada; however, the program of study could be outside of Canada
- Previous award recipients are not eligible to apply again

Amount of Monetary Award:

- \$2,000 Canadian towards tuition fees
- This award is payable to the post-secondary educational institution of the recipient's choice

Award based on:

- Two letters of reference submitted directly from the referee to the scholarship committee—one academic/professional, one personal
- Proof of school registration status
- Completed application form
- Letter of intent from applicant (what is your motivation for taking this course of study)

Application Deadline:

- Application form and all support documents must be submitted by May 31st
- Decision on application will be made on or before June 30th
- All applicants will be notified of approval or denial by July 15th

All people who are deafblind will live rich meaningful lives.

CDBA National—1860 Appleby Line, Unit 14, Burlington ON L7L 7H7
With Chapters In: British Columbia, Saskatchewan & New Brunswick

Application Form can be found on the CDBA National website www.cdbanational.com/awards

The Deafblind Community: Fighting Not to be Forgotten

World Health Organization

www.who.int



Frank at a conference, communicating with an interpreter using hand-over-hand signing.

Access to health is especially challenging for persons with deafblindness. To advance health equity for deafblind people, there is a need for models of care which are inclusive and people-centred, and consider the provision of care from the user perspective. In this article, a person who is deafblind describes his experience with health care and the “invisibility” that the community face.

When Frank Trigueros visits a hospital, he braces himself for possible problems. It is not the medical care that concerns him as much the communication, as a person who is deafblind.

“I cannot communicate. Normally I use interpreters to communicate directly with physicians. I cannot get around easily myself, so the interpreter guides me around to where the services are,” explained Trigueros, who was born deaf and later lost his sight.

In theory, communication is possible using a laptop with a braille keyboard, but this is time-consuming, he said. Health professionals usually want to work quickly, as do government officials, and even in conversations with his interpreters, they can be impatient.

“I have to ask them to slow down. I have been told: ‘I don’t have time to assist you’,” said Trigueros, speaking through an interpreter using a tactile sign language. “It makes my day when there’s no

problem. But generally speaking, it can get messy.”

On one occasion in hospital, a doctor did not take the time to explain what drugs he needed to take and when. “He just walked away backwards. I was mad. I had to find someone else to help me,” said Trigueros, who is president of European Deafblind and FASOCIDE, the Federation of Associations of Deafblind people in Spain.

Impact of the COVID-19 pandemic

All too often, the reality is that the health system and government simply overlook the deafblind community. A case in point is the COVID-19 pandemic, when restrictions on movement failed to consider the needs of the deafblind community. Forced isolation was a devastating setback to their independence, given their need for interpreters to communicate and move around the community. As they communicate through hand-over-hand signing, physical distancing effectively cut off communication.

“We faced opposition to get interpreters. There was no understanding from health services or the public sector,” he said.

“Interpreters were not even allowed in the emergency room [due to COVID-19 restrictions], even though we tried to explain we need them. Again and again, we had to explain who they are and why we need them.”

Some doctors were empathetic, but the community cannot rely on “people’s good will” he said, adding it was “nerve-racking” not to have the security of being able to communicate.

“The need for interpreters was not thought of in the Covid-19 protocol. We should have been contemplated in the rules to begin with.” Deafblind organizations had to protest that they had been “forgotten”, as they have done on many other occasions previously.

The system “does not care enough”

Frank said that one example of how the community gets forgotten is the government’s health card – it does not state that a person is deafblind, although the card states other disabilities on it. Because his disability is not recorded in the system, Trigueros sometimes gets calls from health centres.

“I’ve tried many, many times to tell them. I’m asking for a line on a card that would save me a lot of trouble. I don’t think it’s much to ask,” he said, adding that he was told that the software to produce the card did not allow for it.

“It shouldn’t be that difficult to put right. It is not an issue of money. The system just does not care enough.”

He said people who are deafblind were also not properly informed about COVID-19 restrictions or the virus during the pandemic. “We had to do their work of [the government of] informing [deafblind] people. I know of many who live alone and didn’t know about the virus,” he said, adding that the capacity of the non-profit organization he worked in was limited.

Aside from the invisibility of the community and the lack of understanding, another issue is funding for interpreters for deafblind people, which is limited and uneven across the country, although funding is available for people with other disabilities. “We need funding to move around. We need to have agency in our lives,” said Trigueros.

He added that he was “lucky” because he had a family. “There are [deafblind] people who do not have family, who do not have a support system. Imagine the lives of those who are live alone...,” he said. Some of them, he said, were in need of therapy. However, it was difficult to find a suitable professional with the knowledge needed to help them.

Max Fisher: Pursuing a Career as a DeafBlind Person

limpingchicken.com



If someone had told me when I first picked out my career path that I would be an organisation's first DeafBlind scientist, I would have laughed.

But then, if someone had told me that, I would have realised that what I was seeing wasn't normal after all, and that my whole life I'd been unknowingly living with a visual impairment called Visual Snow Syndrome. I probably would have booked a much needed hearing test.

It's a good job hindsight is 20:20. Truth be told, nobody has ever told me that I would be a DeafBlind scientist at all. In fact, when I was on Universal Credit after I graduated for the second time, my career advisors told me to give up.

DeafBlindness is seemingly rarer than mermaids, but I promise it's more common than you know. We all grow up being lead to believe that only one DeafBlind person has ever existed: Helen Keller, and even then her existence gets debated.

It is a common misconception that to be DeafBlind, you must have lost 100% of your hearing, and 100% of your sight, which is plainly untrue. DeafBlindness, also termed multi-sensory impairment or dual sensory loss, exists in many forms and is a spectrum, just like any other singular sensory loss.

The NHS defines DeafBlindness as a combination of sight and hearing loss that affects a person's ability to communicate, access information and get around and reminds readers that a person's ability to communicate, access information, and get around can be affected by even mild sensory loss. DeafBlindness is way more common than most people believe.

I won't bore you with the details, but my journey to "Proud DeafBlind Human" was a long one, and once I got there, it almost became my job to get other people (mostly hearing and sighted people) there too.

When I picked my career path, I was disabled, but had no idea that I was deaf and visually impaired. I thought I was hearing everything there was to be heard, and seeing things exactly like everyone else was. So I thought I only had the barriers of my physical disability, Ehlers-Danlos Syndrome.

I gleefully chose my GCSEs and my A-Levels to set myself up for a long career in science- and then went to university to study, achieving a bachelor's and a master's in pharmacology. Throughout my degrees, I was told both how much having these qualifications would help me walk straight into a job, and also how my physical disabilities were off-putting, and that I shouldn't mention them.

For some reason, I listened to cisgender, able-bodied people tell me, a transgender disabled person, how to sell myself on job applications, so I removed my key leadership skills: wheelchair basketball coaching, and being my student union's trans officer.

With these gone, my CV was bland, and it wasn't long before I came to my senses (get it?) and reinstated them, but that didn't make my job hunting any easier.

And while I was struggling to achieve my goals, Universal Credit was telling me to give up and take a job in a call centre with one of their partner sites, which, hello? I'm deaf remember? Most of the job coaches I had didn't believe that someone like me was cut out for a career in science, not all of them told me directly, but a lot of them did.

The rest of them asked me whether I was really certain I was capable of the jobs I was applying for. One said "but scientists are smart, not dis... So when can you come in for your next appointment?". Luckily for me, my particular job centre had such a high staff turnover that I didn't have to see that one for more than two appointments.

On the flipside though, with every new coach, I had to explain my disabilities and my DeafBlindness, and not all coaches even believed me. I was told that I couldn't be DeafBlind because you're sat here talking to me. I couldn't be DeafBlind because I have advanced qualifications. I couldn't be DeafBlind because I was on "intensive work search" and if I was truly disabled like that, I wouldn't be on any work search programme.

I faced a lot of ignorance, and a lot of ableism. Honestly, I believe that you shouldn't be allowed to be a job coach if you don't think Helen Keller was real, but that's just my opinion.

For 3 and a half years, I felt like I was just being told "No you can't" over and over again without any solid reason as to why not, and while at times I felt like giving up, it actually made me want to succeed even more, if only to prove a point. And that success is finally here.

I didn't do it without help. I was referred for the job by my friend who worked for the company, and he talked up my scientific skills and nothing else. He mentioned my being trans and my

deafness in passing, but they trusted him.

And while it wasn't all down to him- I still had to perform well in the interviews and get along with the team in the meet and greet, but I couldn't have got there without him reassuring the team that I was capable, and that I would make a great member of the team.

They seemingly trusted him and what he was saying about my abilities and my disabilities, than they trusted me. And while I will be forever grateful to my pal, and I feel like I owe him my life, I shouldn't have to.

I also have to tip my hat to the pandemic here too, because I was interviewed via Microsoft Teams.

They didn't have to see me walk into

their building with my symbol cane, I could turn the live captions on without them even knowing, and I could sit in the comfort of my own home without having to run around on public transport trying to get to a place I'd never been to before.

I could avoid all the things that could trigger a pain flare, and the lighting was something I could control (a delicate balance between light sensitivity and being able to see someone's lips).

They were able to see me as not just a scientist, but a person. Not the scary DeafBlind person that only exists in fairy tales.

Pursuing a career as a DeafBlind person doesn't deserve to be as hard as it is. I shouldn't have to have someone on the

inside to vouch for me, my qualifications should be enough, just like they are for everybody else.

I was told to give up an appalling amount of times. I was told that I would never achieve my goals an appalling amount of times, and it was entirely based on stigma. Not a single one of the people telling me to stop ever asked me a question about the science.

Lots of people along the way told me not to give up, which isn't real advice, but sometimes not giving up is all you can do.

Max says: 'I'm Max, a DeafBlind and Disabled scientist. I also make content about science, queerness, being trans, druidry, chronic illness, disability, and sensory loss.'

Saskatchewan Leads the Way in Special Services For the Deaf and Blind Community

By Ryan Young

www.gx94radio.com



It is estimated that approximately 466,000 Canadians over the age of 15 live with some degree of dual sensory loss, but there are many parts of the country that don't have access to deafblind services.

In Saskatchewan that isn't a worry anymore because it is just the second

province in Canada to establish specialized services that provide support for people who are Deafblind.

The CNIB Deafblind Community Services assists individuals with sight and hearing issues. This is achieved through the use of Intervenor who act as the eyes and ears of people who are Deafblind.

Tyler Burgess, Manager of CNIB Deafblind Community Services' in Saskatchewan says, "I know individuals who have run marathons with an Intervenor, have maintained employment, and have been able to lead rich and full lives with access to all the benefits of the community. If you want to

have all the opportunities open to you as a Deafblind person, you definitely need to be in a place where you have access to an Intervenor. People shouldn't have to move to access these services."

They help with communication, community access, and participation in all parts of daily life. Intervenor use a variety of methods including sign language, large print notes plus they are always adapting to each individual's needs. Typically spending about 6-24 hours a week with each individual client.

The CNIB Deafblind Community Service is funded by the Ministry of Social Services, so individuals who receive assistance have no user fee.

To start the referral process or to learn more visit deafblindservices.ca.

Challenging Misconceptions About People With Deaf-blindness

Samantha Marren

YorkRegion.com



DeafBlind Ontario Services helps enrich the lives of those living with deaf-blindness and other impairments.

"They can't live independent lives."

According to Annette Piggott, senior client advocate at DeafBlind Ontario Services, this is a common misconception about people with diverse abilities, like deaf-blindness.

Deaf-blindness is a combination of hearing and vision loss. Over one per cent of Canada's population or close to 470,000 people are deaf-blind, with over 200,000 living in Ontario.

When people think about deaf-blindness, they often think of Helen Keller, one of the most internationally recognized people with deaf-blindness. However, a person may be born with deaf-blindness or acquire deaf-blindness during their lifetime. This is an important distinction, as sensory loss can impact concept development, communication, and mobility.

In her 15 years at DeafBlind Ontario Services, Piggott has learned that independence is unique and attainable to each person and their individual needs.

"The word 'independence' is often put in a box," says Piggott. These myths and misconceptions stem from misinformation and stereotypes. Piggott aims to debunk misconceptions and break down barriers to inclusivity.

"Independence looks different for everyone. For one person, this may mean more choices, more ways to communicate preferences, likes and dislikes, or goals. For another, independence may be achieved with support in daily living, increasing the person's quality of life," Piggott said.

For individuals with deaf-blindness, this support comes from intervenors. They help people with deaf-blindness to gain independence, build their life skills, and actively participate in all areas of their lives, through an approach of "do with, not for."

Communicating thoughts, feelings and ideas is a basic human need. Another common misconception about deaf-blindness is that the person cannot communicate. Often, this is because people are misinformed about how the person communicates.

Because every person with deaf-blindness experiences a varying degree of sensory loss, each person has their own unique and individual way to communicate. The intervenor may take a total communication approach, using as many methods of communication as needed — like American Sign Language (ASL), finger-spelling, print on palm, tangible symbols, and technology with speech-generating devices, to name a few — to facilitate the exchange of information.

As an intervenor, Piggott says she's learned how to let clients take direction, while communicating in the way they feel most comfortable.

"The intervenor helps the person with deaf-blindness be the best version of themselves and live their best life with increased independence," said Piggott. "It's a rewarding career with the opportunity to not only discover the potential of each person supported, but your own potential too."

DeafBlind Ontario Services provides an array of services to people who are deaf, hard of hearing, non-verbal and deaf-blind that are customized to each individual's unique needs, method of communication, and goals to enrich their life. The non-profit organization is hiring in many service regions across the province, including in Georgina.

Learn more and apply today at deafblindontario.com/careers.

Deaf-Blind Communities Have Created a New Language of Touch

Andy Corbley

www.goodnewsnetwork.org

Growing for years out of a special group of humans in Washington state, a new human language—pro-tactile ASL, has gained recognition.

Born from the spirit of human connection, those who can neither see nor hear use another person's body as the canvass on which to communicate a nearly infinite-number of ideas, feelings, or just an old-fashioned chin-wag.

Verbally communicating humans use all kinds of additional sensory signals to aid the listener in understanding, such as making faces or hand gestures, but directly touching them, especially on the face or thigh, is reserved only for the closest human connections.

It can be strange, sometimes, for those speaking in American Sign Language (ASL) to see the literalness of certain signs—where a speaker might say “jolly” to cleverly disguise their true intention of describing a man's waist size, ASL don't have that luxury, and often have to sign a spade as a spade.

But for those who can neither hear nor see, language becomes even more stripped of its societal layers, and in a way becomes even more human.

In a first-hand encounter with a DeafBlind American, Katherine Ellen Foley, writing



for Quartz, reported that the gentlemen using pro-tactile ASL explained through an ASL interpreter, “it's the same concept as learning any other language, it's just connecting with the group of people whose language you want to learn.”

The example Foley gives is “I climb a tree,” in which the signer literally takes your arm, and does the sign for walking up the arm as if it's a tree. For lollipop, it's quite the same, only with a closed fist for the candy part. While that may be difficult to interpret, a deaf ASL interpreter explained that in all languages, context is key.

While a closed fist at the end of a forearm could represent many things, from a hammer to a lollipop, the context of the sentence will steer speakers and signers towards the appropriate inference; just as in English we can detect from the other words in a sentence whether a speaker is saying “fair” or “fare.”

There may be as many as 50,000 people in America who are blind and deaf, and the new language is catching on. A business called Tactile Communications is providing necessary training in a linguistically and culturally appropriate setting in order to promote the autonomy of DeafBlind people. In 2016, their language, which arose spontaneously entirely among their own community, was showcased at the White House.

Communication is not just the domain of words and mouth sounds—it's a form of understanding between humans. Returning to that core principle helped the pro-tactile system grow.

The founder of Tactile Communications, Jelica Nuccio, set up communication environments without the crutch of interpreters to help ensure the skill was born of a symbiosis between necessity and invention. And it's already making a huge difference to the lives of people across the country.

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, or scan and email your form. Memberships may be paid by cash, cheque, or credit card.



The Magic of Touch: How Deafblind People Taught Us to 'See' the World Differently During COVID

Azadeh Emadi

theconversation.com

As someone who is severely deaf and completely blind, I felt overnight I had lost a third sense, my sense of touch. To make matters worse, people around me faded away – voices had become so quiet that there was an eerie soundlessness all around. Nothing was making sense any more.

Issy McGrath has type 2 Usher syndrome. Completely blind and severely deaf, she has a passion for music and plays the flute. Using a combination of touch, smell and keen imagination – her “inner eye” – Issy says she frequently senses things that are beyond the grasp of sight: the “almost solid” nature of the winter air in the morning, or the enchanting atmosphere of a frozen landscape.

For Issy and many others like her, the COVID pandemic had a devastating effect on day-to-day life. “Two-metre social distancing felt like the world had turned its back on me,” she recalls. “It was too far for me to reach out and touch everything around me. Yet it’s mainly through touch that I get a sense of what a person is like.”

A retired teacher living in Glasgow, Scotland, Issy speaks poignantly about her COVID struggles in an audio diary that was part of my research into the experiences of deafblind people during the pandemic:

As I approach my garden gate, feeling around for the latch to open it, a thought occurs to me. There is a pandemic sweeping the world and maybe I will catch the virus from this wooden fence. Maybe it's on the latch I have just touched. I shake my hands to free myself from these thoughts. I make my way back to my house and wash my hands thoroughly, trying to free my mind of these fearful imaginings.

‘You can feel the energy of things’

As a filmmaker, I am constantly questioning how and what we see – and what we don’t see. This has led me to work closely with deafblind communities around the UK, to understand how their view of the world differs from everyone else’s – in an ocularcentric society that privileges vision over all other senses.

Perceiving through touch takes time. By methodically stroking different surfaces, deafblind people build up a mental image not only of a person or object, but their place in the surrounding room or landscape. Deafblind people’s hands and skin are, I think, unusually sensitive to different levels of rigidity, to the feeling of different textures, and to slight differences in movement or temperature.

John Whitfield, a training officer at Deafblind Scotland, has been severely deaf since birth and now has only 5% of his vision left. He describes how much concentration is required to understand the world around him and keep up with conversations. “Sometimes that is very, very tiring,” he admits.

Because you are so conscious of the restriction on your hearing and vision, your brain has to compensate – and your body is having to compensate too by getting information in whatever way it can. My sense of smell is heightened, for example. You are just desperate to get as much information from the environment as you possibly can, so you will use any method.

For Roger Wilson-Hindr, who lives with his vision-impaired wife in a small village in the Midlands of England, touching means more than just receiving sensory input or holding on to information. He says every tactile interaction is a chance to form

a new relationship, adding that “touch and physical contact take on greater significance if your eyes and ears are badly damaged like mine”.

Corneal scars and glaucoma suffered during childhood limit what Roger can perceive – he is able to see colour but with little definition. Trees, one of his favourite things, appear as a golden or green mass.

But when gardening, he can still “feel” the seasons through the bendability, texture and direction of the stems and branches. He says there is a “magic” to touch – “you can feel the energy of things” – and that it’s not always just about making up for a lack of vision. Deafblind people’s tactile world contains much joy.

Imagine, then, the impact for Roger and all other blind and deafblind people when COVID transformed the meaning of touch and proximity to others – from a life-enricher to a potential life threat. As Issy puts it:

Social distancing meant the world both passed me by and left me constantly conflicted. Do I allow people into my space so that I can interact and make sense of the world, risking catching the virus? Or do I ask people to respect the two-metre social distance rule, and allow a creeping sense of isolation to overwhelm my emotional wellbeing?

The importance of touch

There are two common misconceptions about deafblind people: that they require continuous assistance and are not easy to communicate with. During our research, we heard how these perceptions contribute to their exclusion from wider society and can have a damaging effect on their confidence. This was all made worse by the pandemic, as Issy explains:

Holding someone's hand provides me with so much information – to feel the fabric of someone's clothing means I can get a real sense of their being. Suddenly [with the onset of COVID], to be so far away from the scent of their perfume or the texture of their hair ... it was all gone. Even with the relaxing of social-distancing, the joy I had in reaching out to touch and link arms with other people has become subdued and cautious, as I warily navigate my world through my sense of touch.

When we think about touch, we usually think of hands and fingertips. But Roger highlights that, for deafblind people, “touch uses all aspects of our body – from the top of our head to feel the sunlight, to our feet for feeling where we are on the street”. Indeed, all of our interviewees emphasised the importance of touching with their feet – helping them to scan and perceive the environment while walking, to recognise the characteristics of different spaces and create a mental map.

As the first lockdown was easing, Issy recalls being reduced to tears in the middle of a street in her suddenly unfamiliar Glasgow neighbourhood. With cafés and restaurants expanding outside and altering the usual pedestrian layout, she found herself continually bumping into unexpected obstacles and people. As well as the frustration of having to create a new internal map of the area, she worried that people might become annoyed because of her lack of social distancing.

At the same time, she also felt a new threat from people invading her personal space:

I remember standing outside a supermarket, waiting for my husband, when someone tapped me abruptly on my shoulder and asked where the nearest car park was. Realising he had touched me was a shock and made me feel so uncomfortable. I asked if he was socially distancing and he replied that he had been trying to attract my attention for ages. Until that moment I was totally unaware he was there.

Conversations with a quantum physicist

Before the pandemic took a grip of the world, much of my research was focused on pixels. In particular, how these tiny areas of illumination join forces to create an uninterrupted experience of film without ever revealing themselves – each undergoing a different rate of change depending on the codes they receive.

This led to some fascinating conversations with a quantum physicist, Daniele Faccio from my university's physics department, about how new technology might reveal hitherto imperceptible light phenomena. His team were using single-photon cameras that can detect light waves as particles and thus “freeze” light in motion, taking photographs of a light pulse or video of light as it moves through a room.

As a videomaker, I found this technology fascinating – and I wondered if we could pool our knowledge to help blind people “watch” moving images by translating them into a tactile experience. In other words, develop a platform that could work as a form of “video Braille”.

In 2019, we began experimenting with ultrasound technology to focus soundwaves and create pressure spots that could be felt on someone's hands. In this way, we hoped we could turn pixels from moving images into a range of tactile experiences linked to a film's content (e.g. facial expressions, emotions, movement). The tactile sensations could include different temperatures, pressures and movements on the palm of each hand.

Then the pandemic intervened, our project was put on hold, and time slowed to a frustrating crawl. A saving grace, though, was my growing understanding of the way deafblind people take such care to understand their surroundings, never rushing the process of learning about a new situation. This helped me to slowly accept and learn from this extraordinary period, rather than trying to escape it.

Once lockdown ended, I tried to convey

this by filming Issy in her kitchen as she made a cup of tea and arranged a vase of purple flowers. What to sighted viewers might look like “fumbling and stumbling” (as Issy calls it) is actually her way of learning and knowing. We see her gently touching the flowers, smelling their scent, imagining their forms as she measures their length, cuts and carefully arranges them into a vase. She is taking as much time as her touch needs:

Although the way I move around might look to you like a struggle, it's not. I am putting my hand out to reach and touch things, pick things up, make sense of what's in front of me, because that is the way I interact with my world. I am drawing up a map in my mind of what's out there. So instead of thinking I am struggling, let me fumble and stumble – that is all information for me. The reward I get is that I will be, and am, a much more autonomous and resilient deafblind person.

A tool to help deafblind people

The insights offered by Issy and our other deafblind collaborators during the early days of COVID made us determined to develop a tool that could help give them some independence in navigating the newly opened-up spaces after lockdown. This shifted our attention from developing a video Braille tool to one that could accurately locate the people and objects around them.

The synergy we'd already found between arts and quantum physics resulted in our idea for a new “spatial awareness” tool. Over a series of workshops starting in June 2021, Issy and John helped our research team to understand how deafblind people imagine, memorise and map a space both with and without touch – and thus what they needed from our device.

The prototype consisted of two elements: a portable radar and wearable feedback devices (a headband and an armband). “I am going to be honest and say I felt like the borg from Star Wars,” recalls Issy, our first tester. “But wow, it was fascinating.”

The radar would scan the space up to six metres in front and to each side of the tester, tracking people as they came into range and moved about. This information was turned into vibrations of different intensity using tiny coin vibration motors in the headband and armband, which activated depending on the distance and direction of the detected person.

In our first test in a large theatre room at the University of Glasgow, Issy – having turned off her hearing aids to avoid getting any other environmental clues – was asked to indicate the direction of a person entering the near-space in front of her based on the vibrations she felt in the headband.

Most of the time, without hesitation, she correctly indicated where they were standing. It was an emotional moment for her, and all of us, when we told her about the accuracy of her answers. For the first time since she went completely blind, she was sensing where people were without relying on touch:

Goodness, it would be so nice to walk up the road with this technology. Along with Yang my guide dog, I'd have a device that can tell me much more about the space around me and what's happening – you know, how many people are in front of me, to the side, where are they? Am I walking right into a big crowd?

In our second test, Issy used both the headband (to indicate the person's direction) and armband (for their proximity) – but struggled to correctly detect how far away a person was. After a few trials, we realised the coin vibrations motors were too close together for her to differentiate the signals, and that the forearm location was also confusing. It would be better to combine the two sets of information (distance and direction) into one headband, and use the intensity of vibrations to indicate how far away the person was.

After further trials, we refined the tool enough to be implemented into a cap. From the outset, our participants had stressed the importance of creating

wearable technology that could blend in with everyday clothing if it was to be of true benefit to users such as Issy:

The fact that it could give me an extra sense of my surroundings is fascinating. I actually just wanted to say to the guys: 'Do you fancy going up Great Western Road with it now?'

'A magic that reveals the joy in the world'

In May 2022, I was giving Issy a tour of our TouchScreen event at the Centre for Contemporary Arts in Glasgow. She was immediately drawn to a video installation called *Trees*, by Wolfgang Weileder. The video shows trees in different locations being cut down.

While standing in front of the large screen, she said she could sense the trees in the video via her cane. The sound frequencies from the audio were travelling from the speakers through the ground – she was thrilled because she felt included in the experience of the artwork.

As we stood there, I shifted my attention from seeing to feeling with my feet – and I could sense the vibrations too. This new layer of experience had been imperceptible to me a moment ago, yet now I felt physically related to the trees as they were being cut down. I also became aware of the ground connecting me with Issy. The sound was touching us both.

Favouring vision over other senses means we risk missing out on a host of rich experiences and connections – not least with people like Issy, Roger, John and other differently-abled people.

So the ambition of our ongoing research – combining deeper understanding of the needs of deafblind people with cutting-edge quantum technology – is not only to enable deafblind people to play a bigger role in society. We also want to use their unique understanding of the world to enrich everyone else's.

There could be more research into technology that enables them to communicate more independently. For example, by looking at how mmWaves

(the type of radio waves used in airport security scanners) could be used to recognise hand gestures and touch-based communication beyond sign-language.

Certainly, there is more for us all to learn about the value of touch in the aftermath of the pandemic. If our eyesight is about knowing through a safe distance, touch is about forming intimate relations and becoming entangled with the surrounding world. As Issy says:

You know, as somebody who has lost their eyesight, I was just too busy trying to get on with things. You don't stop for two minutes and think: 'Well actually, I hadn't thought ... how much I rely on touch and how much it means to me. How much it helps me to visualise the world.'

For John, touch is a “holistic way of feeling” through the body. For Issy it is about “imagination” and knowing through “fumbling and stumbling”. For Roger, touch is like “magic” that reveals the joy in the world.

It is sad that it has taken a pandemic to bring greater understanding of the significance of touch – and in particular, touch deprivation – in our daily lives. But perhaps the disconnectedness we all experienced has also evoked greater empathy for the struggles deafblind people have been experiencing throughout history, such as isolation, lack of effective communication and exclusion from society.

It's time we embraced their unique insights and learn about the way they “see” and feel the world. Or as Issy puts it:

I always say to people, 'You come into my space for two minutes and I'll show you the way, in my world and my deafblind culture. The way I interact and connect with my space. Walk with me and I'll show you the way – not through your eyes ... but by connecting with me and my hands through touch.'



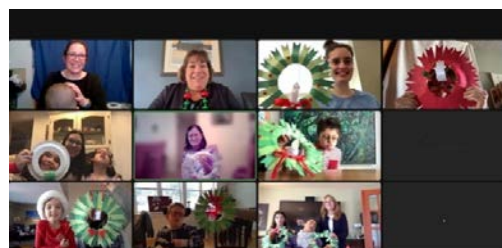
Our Early Intervention Team was busy supporting 24 children as they entered the world of deafblindness, daycare, preschool and kindergarten. This entails setting up communication systems, offering training and resources for the families and professional teams for the children they support and supporting daycare, preschool and kindergarten teams. Virtual Coffee Break sessions for the parents began in November and will continue through to April.



These workshops were followed by a one-day Sensory Clinic, which proved fun for all and resulted in an amazing gingerbread Deafblind Community.



The 2022 year culminated with a virtual visit with Santa and two more Winter Virtual Recreation activities, which occurred during our Winter Intervention Program, allowing the Intervenor and families to support and network together.



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News From CDBA New Brunswick

CDBA New Brunswick Kevin Symes, *Executive Director*



You will see in this update, all the activities and fun the CDBA-NB Intervenor and Clients had this summer. We were not able to bring everyone together again this year, because of our concern over the Covid-19 virus, however, we hope that the support that we offered to everyone to take day trips and attend activities helped in making it an enjoyable summer!! CDBA-NB will continue to monitor the ongoing and changing situation of Covid-19 and perhaps we will be able to bring everyone together in 2023.

The Snoezelen Room and Teaching Kitchen are now back and ready to go.

The National Deafblind Awareness Committee that I work with is planning a day of awareness during Deafblind Awareness Month in June. We are planning a National Day of Bowling. We would like to see Intervenor and Clients out having fun during this week across Canada. We are planning on the week of June 12th, for everyone to get out, have some fun, and send in pictures. CDBA-NB will be planning events in different cities across NB for this week.

I would like to thank our supporters and donors, for all they have given to CDBA-NB. Without their support many of the activities I spoke of above could not happen. This year we were able to increase the number of extra hours for intervention for school aged Clients. This support helps those Clients stay active and engaged in the surrounding during the summer months that they are not in school.

We have a number of clients who are employed within New Brunswick, as well as a number of clients who also volunteer at a number of places. We have included a few pictures of their day.

I hope you enjoy this update. If you have thoughts or comments, please feel free to reach out to me. Until next time.... Cheers!!



Michelle, Fredericton client, has a part time placement with CDBA-NB



Sheena, Fredericton client, has a part time placement with CDBA-NB and also volunteers.



Jamie, Fredericton client, enjoys his part time work at a local supermarket.



Sheena also volunteers at a local food bank and public library.



Matthew, Bathurst client, placed flags in local cemeteries to honor the Veterans for November 11.



Donna Lagace, NB Intervenor was pleased to receive the Andrew Love Memorial Award for Intervenor of the year 2022.



Making pie in the resource kitchen.



Client Amanda on a day trip to the zoo.



Halloween fun.

News From CDBA Saskatchewan

CDBA Saskatchewan Leanne Kerr, *Executive Director*



Now that winter is officially here, we have lost many of our outdoor opportunities to socialize and connect with our community. We are so fortunate to have so many creative Intervenorers at CDBA-SK who will plan special events and activities right in our group homes.

The Individuals, with the exception of two, continue to attend Cosmopolitan Industries at the Acadia location. This location provides smaller group settings as we are not quite ready to attend at the main building yet with so many people. One of the Individuals attends

the day program at Saskatchewan Abilities Council and the other attends school at John Dolan School. Despite the fact that we are being cautious when it comes to doing what we can to reduce the chance of illness at this time of year, all of the Individuals continue to remain busy each day.

We had a new resident move in to the Kerr home at the end of November. The transition is going really well and he is enjoying his new home and roommates. It is always exciting when someone new moves in!

This fall, the Cosmopolitan Club of Saskatoon donated \$1000 to CDBA-SK. They have been a long-time supporter of our organization and we are so grateful to be one of their chosen charities. There was a ceremony held just outside City Hall in downtown Saskatoon where we were presented with our cheque. This money was used towards the purchase of a treadmill and the rest will be for staycations for the Individuals.

Everyone is looking forward to Christmas, snacking on special treats, and spending time with family members.



Alex preparing supper for everyone



Leslie, Cathy (board member) and Johana (Intervenor) accepting the Cosmo Club donation



Tony relaxing in the sensory room



Michael enjoying his new home



J. Allan Matheis Retires

Allan's involvement with various organizations concentrating on individuals with disabilities began when his son, Michael was born August of 1971 with numerous physical and intellectual disabilities.

When Michael was ready to attend school, a group of parents of children with disabilities formed an association that had their children attend school in a church. This was the grass roots of what was the Regina Developmental Center, now known as Chip and Dale Homes Inc. Allan was initially the Vice President, then later became President of this parent-run Board.

Allan joined the RACL ~ Regina Association for Community Living in the early 1980's and took on a roll as treasurer, Vice President and then President of the Association for a number of years. During this time, several new programs were started that still exist today. Allan has been on many boards including the Saskatchewan Association for Community Living, Regina Residential Resource Committee, and Regina

Cosmo Activity Center.

When Michael began to attend the RJD Williams School for the Deaf in Saskatoon, a parent board was formed called CDBRA ~ Canadian Deafblind and Rubella Association, Saskatchewan Chapter. Allan became Vice President, and then served as President of CDBA Saskatchewan for a number of years.

Allan attended his first CDBA National meeting in 1982 at the Lions Inn in Brantford, Ontario. At the time, Allan was serving as assistant to Harold Grace, who was with CNIB and was travelling to Ontario to look at a seeing-eye dog. He was appointed that year as the Saskatchewan representative on the National Board of Directors, a position he held for 40 years until his retirement in September 2022!

Although Michael passed away in 2010, Allan continued to remain involved in CDBA at both the provincial and national levels. In September 2016, Allan was the deserving recipient of the National Cherry Bulmer Award in recognition of his outstanding volunteer contributions to the field of deafblindness. Undoubtedly his history and knowledge of services for persons with deafblindness have been a vital resource for those serving both of these organizations. He will be sorely missed by all his friends and colleagues at CDBA.

CDBA Andrew Love Memorial Award for Intervenor of the Year



This award is presented annually to a special Intervenor who displays outstanding intervention skills exemplified through a philosophy of "doing with, not for". The successful candidate will be a dedicated and compassionate individual who has devoted time and effort to enhance the quality of life of a person who is Deafblind, while demonstrating a degree of professionalism that goes above and beyond their job description.

The 2022 recipient of the CDBA Andrew Love Memorial Award for the Intervenor of the Year is Donna Lagace of Moncton, New Brunswick. The award

was presented during the CDBA National AGM on September 24, 2022.

Donna has worked with Paulette, who is a CDBA-NB client, for the past 12½ years. Donna is a strong advocate for Paulette and her needs. Paulette often suffers from social isolation, and it is Donna who will give her the little push she sometimes needs to brake through those feelings and re-engage life. Paulette lives independently with the support of Donna.

What follows is an interview with Paulette. Paulette is deafblind and her Intervenor is Donna. The answers to the questions are in Paulette's own words.

Why would you nominate Donna for this award?

She is very kindhearted, goes out of her way to help others, and she makes my life better.

How does Donna impact your life by being your intervenor?

Donna is my eyes and ears. She helps me see the world through hers.

What is one thing that stands out about Donna as your intervenor?

Donna and I are really close. We have grown a bonded relationship; we are like sisters! We have helped each other on a personal level, and she has helped me grow as an individual.

What is your favorite memory with Donna?

There are many, but one thing that we both really enjoy is our time together. We have spent hours on Donna's property on the four-by-four riding around on the trails with her dog. We enjoy painting rocks, going to the beach, and doing many other fun activities.

Donna goes above and beyond in what she does. She is well liked by the blind community and is very kindhearted. She is a very humble and helpful person. She has helped a friend of mine on disability who had a guide dog, who required very expensive dog food. She went to her local school seeking support and was able to provide my friend with three bags of dog food for Gallen. She initiated this kind gesture all on her own. Donna has also encouraged her family to help with CDBA-NB camp! Donna is very deserving of this award!

Connecting Canada One Stitch at a Time: National Deafblind Awareness Month June 2023

June is annually celebrated as National Deafblind Awareness Month, a time when many around the world celebrate and raise awareness about deafblindness. It is the birth month of Helen Keller, one of the most internationally recognized



people with deafblindness. Each year, members of the National Deafblind Awareness Month Working Group, who are service providers and people with deafblindness, come together in June to “make a wave from coast to coast in Canada”.

This year, the plan will be to again connect with countries like Africa, Argentina, Australia, Brazil, Croatia, France, Germany, Greece, Guatemala, India, Ireland, Italy, Paraguay, Switzerland, and the United Kingdom, to name a few, to take part in the global yarn bombing movement. Set to begin its 3rd year, yarn bombing is a largescale tactile arts awareness initiative of Deafblind International's (DbI)

Communication Committee, also known as ComCom.

In Canada, the Canadian Deafblind Association (British Columbia, Saskatchewan and New Brunswick Chapters), Canadian Helen Keller Centre (Ontario), Centre Jules-Léger (Ontario), CNIB Deafblind Community Services (Ontario and Saskatchewan), Connect Society (Alberta), DeafBlind Ontario Services (Ontario), Sensity (Ontario), Programme surdiversité - Institut Nazareth et Louis Braille and CRDP Raymond Deward (Quebec), as well as the Resource Centre for Manitobans who are Deaf-Blind (Manitoba) are all expected to participate

Each colorful and tactile yarn bombing installation is made up of many knit and crochet squares created by people with deafblindness, intervenors, friends and family, local knitting clubs, along with community members. Yarn bombing fosters connections and unites communities with individuals, service and advocacy groups in the field, and the wider global public.

Stay tuned as the National Deafblind Awareness Month Working Group and DbI begin to plan and lay the foundation



for this year's awareness initiative! Details will be posted on National Deafblind Awareness Month's social media channels (Facebook: www.facebook.com/NDBAM2, Twitter: www.twitter.com/NDBAM2, Instagram: [@nationaldeafblindawareness](https://www.instagram.com/nationaldeafblindawareness))



**Statistics
Canada**



**Canadian
Accessibility
Network**

Statistics Canada and the Canadian Accessibility Network (CAN) hosted a Panel on Deafblindness on December 5, 2022. This virtual event, commemorating International Day of Persons with Disabilities, was the result of discussions on awareness initiated by DeafBlind Ontario Services and CNIB Deafblind Community Services.

The purpose of the panel was to bring together the perspective of people who are deafblind and service providers to build a better understanding of the distinct disability of deafblindness for Statistics Canada employees. Facilitated by Tony Labillois, Director General, the initiative included remarks from Anil Arora, Chief Statistician and Kathleen Mitchell, Acting Assistant Chief Statistician. It also captured the perspectives of Penny Bennett, Merico Tesolin (who are deafblind) and Sherry Grabowski, Vice President, CNIB Deafblind Community Services

The event included accessibility features including ASL and LSQ interpreters, as well as captioning in French and English.

You can watch the recording here: <https://www.youtube.com/watch?v=Qr1b7IFHHBM>

Penny Bennett-Leclair Honoured to Accept the JT Award from Canadian Hellen Keller Centre



The Award was named after Joyce Thompson, known as "JT." Joyce was a visionary leader in the deafblind services sector who played a key role in establishing Rotary Cheshire Homes and Canadian Hellen Keller Centre.

This award was presented to Penny during the Annual General Meeting of CHKC, (Canadian Hellen Keller Centre), where Penny was the guest speaker for the evening. Here is what Penny had to say:

Good evening, everyone. I am honored to be the recipient of the 2022 JT award. Eleven deserving people have been recognized for their outstanding achievements and continued persistence before me, to improving the lives of people

The JT Award was established in 2010 by Rotary Cheshire Homes and Canadian Hellen Keller Centre to recognize the efforts and achievements of individuals, consumer groups or service providers who have made a significant and lasting contribution to the deafblind community in the areas of awareness, expansion, and involvement.

who are deafblind. Advocacy work progresses slowly, the work takes a lot of patience and creativity. Most people who are present here today are advocates. We should always look to the past to note that the advocacy work does bring positive results. I have seen that organizations within the

Canadian community of deafblindness are forming partnerships more than in the past. We are learning that working together we can achieve more. Though statistics Canada does not yet track how many Canadians are deafblind, we can estimate conservatively that there are over 400,000 Canadians over 18 years old who are deafblind. Given the Organizations now serve a few thousand people, we have potential clients not yet being served, this is the best reason all organizations should find ways to create partnerships to improve the lives of people who are deafblind. Joyce would be so pleased to know we are all working together in watching the dreams come true after one of her dreams for a Canadian Hellen Keller Centre came to be. We need to connect with young adults to pass the experience we have acquired onto them.

I look forward to watching how we progress and work more closely together. Thank you for this award. It is nice to be recognized for the efforts I have made toward our goal of making Canada a place that welcomes people who are deafblind into all sectors of Canadian life.

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