



keeping [in touch]

DeafBlind Ontario Services | Spring 2021

ARRAY SERVICES + DEAFBLIND
ONTARIO SERVICES ARE NOW
ENRICHING LIVES, ONE *TOUCH*
AND *SIGN*, AT A TIME TOGETHER AS
DEAFBLIND ONTARIO SERVICES.



DeafBlind
ONTARIO FOUNDATION

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Deafblind Awareness Month

Community Partners

DeafBlind Ontario Services is grateful to the following organizations who have accepted people we support as volunteers or employees, giving them meaningful work experience and building confidence in their abilities:

Agilec, Alcona Esso, Ayr Branch Library, County Style (Peterborough), East Side Mario's (Aurora), Food Bank of Waterloo Region, Furry Friends (Barrie), Goodfellow Public School (Innisfil), Grandview Baptist Church (Kitchener), Holy Rosary Catholic Elementary School (Waterloo), Innisfil Fire Department, Innovation Works (London), K9 to 5 Doggie Daycare (Newmarket), Knox United Church (Ayr), London Food Bank, Meals on Wheels (Oshawa), Pepperlaw Library, Peterborough Fire Services, Salvation Army (Georgina), St. Peter's Catholic School (Barrie), St. Thomas Aquinas School (Keswick), The Peggy Hill Team – Keller Williams Experience Realty, Brokerage (Barrie), Tim Hortons (Kitchener), Wal-Mart (London), Westhill Retirement Residence (Waterloo), Windreach Farm (Ashburn), YMCA Of London – Centre Branch, Zubick's (London)

Are you interested in making a difference as a Community Partner? Visit our website deafblindontario.com or call 1-855-340-3267 ext. 262 to learn more!



We are excited to announce our amalgamation

**Enriching lives
one *touch* and
sign at a time**

On April 1, 2021, Array Services and DeafBlind Ontario Services, officially amalgamated to enhance specialized services for people who are Deaf, hard-of-hearing, non-verbal and deafblind across Ontario.

By coming together, we will be able to increase capacity, serve more people, and use resources more effectively.

“We believe we will be stronger by coming together,” said Roxanna Spruyt, CEO of DeafBlind Ontario Services. “Our combined expertise in serving these specialized populations is a natural fit.”

The organizations worked towards this partnership for over a year. With government funders looking for increased efficiencies in many sectors, including not-for-profits, DeafBlind Ontario Services and Array Services felt

that combining our expertise would strengthen services for individuals who are Deaf, hard-of-hearing, non-verbal and deafblind across Ontario.

“We’re excited by our future and working better together.”



Introducing our new logo! This combines DeafBlind Ontario Services’ logo which symbolically conveys the many facets of the organization. With newly added hands and colour scheme inspired by Array Services’ logo.

Community Services

Our Community Services are designed to reach people who are Deaf, hard of hearing, non-verbal or deafblind with customized support services. Partnerships with families, other community agencies health care settings can benefit from our expertise in support services, program planning, training, and mentorship.

Partnerships offers specialized expertise and services to individuals with deafblindness through their supporting agency.

Bridge (Sensory Loss Communication Training) provides customized training opportunities for organizations that support individuals with a sensory loss and/or communication challenges.

Tremplin focuses on community involvement during the day while allowing for participants to return home every night.

Supported Independent Living (SIL) for individuals who are Deaf, hard of hearing and non-verbal or deafblind who are able to live semi-independently within the community with minimal support.

Long Term Care provides communication support services to persons who are Deaf, hard-of-hearing, non-verbal or deafblind living in Long Term Care (LTC) or other health care settings, to ensure people continue to have access to supports in their language or preferred mode of communication.

Learn more at deafblindontario.com.



Bridge (Sensory Loss Communication Training)



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

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

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

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

Steve is completely blind in his right eye, with an eye prosthetic. In his left, he has between 10 to 20% vision, bending and moving his head to see with this eye. “We respected Steve’s decision to not use a hearing aid, which he doesn’t like. Even with the highest quality hearing aid, there are still many sounds he wouldn’t be able to hear,” Anne-Marie explains.

95% of what we learn comes from what we see and hear. As a child, it was very difficult for Steve to learn sign language. He had a hard time sitting still as well as sleeping. With a spirit for adventure, Steve often learned through discovery. “He was very curious, he would turn on the

oven burners to watch them heat or try to get outside throughout the night, he was like Houdini. We had to install a fence around the yard and lock the doors from the inside.”

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

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

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

“When I first visited one of DeafBlind Ontario Services’ locations in Kitchener, I knew it was what I wanted for Steve... somewhere he could live as independently as possible,” says Anne-Marie.

For eight years, the family waited for

a location to open in the Ottawa area. Throughout those years, Steve received support from DeafBlind Ontario Services’ *Partnerships*, which offers specialized expertise and services to individuals with deafblindness through their supporting agency.

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

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

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

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

Research Spotlight

Research spotlight on Dr. Atul Jaiswal, PhD, Rehabilitation Science, School of Rehabilitation Therapy, Queen's University; CIHR Postdoctoral Fellow, Vision Science, Wittich Research Lab, School of Optometry, University of Montréal; MSW, Disability Studies, Tata Institute of Social Sciences; BOT, Occupational Therapy, Delhi University.



Dr. Atul Jaiswal

Dr. Jaiswal has been working in the field of deafblindness as a clinician and as an academic researcher for over eight years in both India and Canada.

He received his PhD in Rehabilitation Science from the School of Rehabilitation Therapy at Queen's University. He is trained in occupational therapy and social work, with a specialization in disability studies. He is currently a CIHR postdoctoral fellow in vision science in the Wittich Research Lab at the School of Optometry, University of Montréal.

Through his postdoctoral research, Dr. Jaiswal focuses his research on public health preparedness for older adults with concurrent hearing and vision impairment (referred to as age-related deafblindness or dual sensory loss (DSL)) by addressing the barriers to accessing healthcare services and information during the COVID-19 pandemic in Canada. He finds it intriguing to know that research

on older adults with deafblindness or dual sensory loss is limited with respect to their experiences of health-care access and utilization, despite the fact that the prevalence of DSL among the baby boomer generation is increasing and meeting their health-care needs can be one of the biggest challenges for the public health system of Canada. This is the knowledge gap that he intends to address in the Canadian context through his postdoctoral research.

In Ontario, 22 per cent or 70,080 of seniors in home care and long-term care (CIHI 2016-17) reported experiencing vision and hearing loss combined. According to Dr. Jaiswal's research, around one million older adults in Canada are estimated to experience some form of DSL. A combination of hearing and vision loss impacts participation, access to information, communication, and mobility. It can lead to social isolation and affect a sense of community.

"Findings confirm that the pandemic has heightened the challenges in terms of accessibility and communication for older adults with DSL while accessing healthcare and health information," Dr. Jaiswal said. "I use my research to highlight the barriers in the society (environment) and advocate for an equitable, inclusive and just society for everyone, including those with multi-sensory disabilities such as deafblindness."

"The ultimate goal is," Dr. Atul Jaiswal said, "to enable participation and dignified quality of life for individuals with deafblindness." His research was the first of its kind that used multiple accessible modes of communication to conduct qualitative interviews directly with adults with congenital and acquired deafblindness.

In doctoral research, Dr. Jaiswal had the challenge of finding a participatory and inclusive research method that could apply to the diverse and unique communication needs of individuals with deafblindness. He was surprised to see that existing research often used family caregivers or professionals working with people with deafblindness, rather than those living with

deafblindness, to design services, policies and solutions that directly affect them.

"By using inclusive methods, this work aimed to give a voice to the under-researched population of those with deafblindness and to offer methodological guidelines for how to research with persons with deafblindness," he said. "My research is guided by the values of equity, inclusion, and social justice." This methodology has been published in SAGE Research Methods to help shape the future of inclusive research of those with deafblindness.

In his quest to eliminate exclusion of the deafblind population in research globally, Dr. Jaiswal uses his research to find answers to improving accessibility and enhancing the lives of individuals with deafblindness/DSL.

Dr. Jaiswal has worked with DeafBlind Ontario Services in developing the Stakeholder Consultation Project as well as co-authoring research articles such as Informed Consent or Assent Strategies for Research with Individuals with DeafBlindness or Dual Sensory Impairment: A Scoping Review.

DeafBlind Ontario Services coordinates research to ensure the evidence is used to enhance services for the people we support.

If you are a researcher or service organization interested in collaborating in the pursuit of advancement in the field of deafblindness, please contact Dr. Jaiswal online or via Twitter.



A Scoping Review

DeafBlind Ontario Services' participation in research strategy is gaining momentum. Our first research manuscript, *Informed Consent or Assent Strategies for Research with Individuals with Deafblindness or Dual Sensory Impairment: A Scoping Review - ScienceDirect*, was published in Archives of Rehabilitation Research and Clinical Translation Journal in February. This scoping review was conducted in collaboration with University of Montreal researchers.

There are gaps in guidelines to help researchers obtain informed consent/assent from individuals with deafblindness. This review is the first of its kind to provide an overview of such strategies, helping to bridge the gap between researchers and individuals with deafblindness during the research process. The findings are of significance to disability and rehabilitation researchers, organizations, and individuals with deafblindness, as they can significantly advance their inclusion in research and strengthen evidence on the challenges individuals with deafblindness face.

Although strategies to obtain consent from the deafblind population remain unclear, this review encourages researchers to alter and adapt the strategies identified and to create an inclusive research environment.

With the growing global population, the voices of millions of individuals with deafblindness are unheard in research, even though they have the potential to contribute towards the improvement of their quality of life.

To read the full paper, please visit
<https://doi.org/10.1016/j.arrct.2021.100115>



Come to Your Senses March 8-12, 2021

DeafBlind Ontario Foundation's first province-wide *Come to Your Senses* Challenge was a great success! Participants engaged their senses in a fun and creative way, by choosing up to 5 sensory-related challenges over 5 days and fundraising online.

During each of the 5 days, participants posted their daily challenge on social media along with the hashtags #ComeToYourSenses and #CTYSChallenge.

Creativity and imagination ran wild! The results were innovative and extraordinary, raising a grand total of \$31,769.

To all of our sponsors, teams, and supporters, thank you for your support, enthusiasm, and generosity.





**Affectionately referred
to as 'Smiley Reilly'**

REILLY'S

Residential Services

STORY

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

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

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

At seven months, Reilly was one of the youngest in North America to receive a cochlear implant, a small electronic device that stimulates the cochlear nerve, used for hearing. However, being so young, it was challenging to keep the external part of the implant on Reilly's head. "She would roll around and the external piece would pop off, or she would pull it off... We tried everything including using headbands or scarves to fix it to her head. It was a battle," says Joan.

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

Affectionately referred to as 'Smiley Reilly', Joan notes that Reilly is the happiest person in spite of everything she has overcome. "Reilly welcomes all with a

beautiful smile, she is very affectionate, expressive, and she loves hugs."

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

Reilly first received Intervenor Services when she was five at W. Ross Macdonald School for the Blind. "After Reilly got sick, her Papa, Mother, and I wanted to ensure she had the best quality of life and care; as she will need this support to live as independently as possible," says Joan.

Reilly attended W. Ross Macdonald for 15 years and moved to one of DeafBlind Ontario Services' locations in Innisfil last October. "We are relieved to have found another loving home for Reilly. It puts the entire family at ease that her life will continue to be enriched."

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

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

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

We're hiring! You can make a difference in the lives of people we support, like Reilly. Apply online at deafblindontario.com.

WIN WIN WIN!

50/50

WIN-WIN-WIN 50/50 Draw

We have joined forces to launch our first ever, province-wide ONLINE 50/50 DRAW with our partners PHSS and Community Living Chatham-Kent!

By purchasing tickets for the draw, you are supporting three non-profits and enriching the lives of people with disabilities throughout Ontario. That's what we call a WIN-WIN...WIN!

Visit www.winwinwin5050.ca to get your tickets and learn more!

The Finer Senses

We are pleased to present our 2nd virtual blind wine tasting experience on Friday, June 11, 2021.

At **The Finer Senses**, explore your senses and engage in discussion about wine pairings, varietals, regions, and more. This is a fun and unpretentious evening of wine tasting in the comfort of home!

Your event ticket includes a 90 minute tasting, three bottles of wine, and a snack bag with food samples to complement the wine selections. New this year, an online auction beginning two weeks before the start of the event.

Visit deafblindontario.com for more and tickets. Registration closes on May 24.



Savour the Senses

Save the Date! Join us for our 2nd virtual **Savour the Senses** experience, Saturday October 23, 2021.

Imagine the delicious intertwining flavours produced by the pairing of fine chocolate, wines, and whiskey. Let your palate discover flavours you never imagined - all in the comfort of your own home!

Our team of experts will guide guests through an exploration of their senses and engage in discussions about pairings, varietals, regions, and more! This event is not to be missed! Details coming soon to deafblindontario.com.

To all who believe in us...

YOU - our donors, business owners, sponsors, foundations, and community partners - make a difference in the lives of people we support. We can't thank YOU enough!

*Thank
YOU*



Come to Your Senses Sponsors



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Our Donors & Sponsors: November 2020 - March 2021

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**YARN
BOMBING IS
A FORM OF
STREET ART
WHERE YARN
THAT IS KNIT,
CROCHET, OR
WRAPPED,
ADORNES AN
OBJECT IN A
PUBLIC
SPACE.**



deafblindontario.com

YARN BOMBING

We are participating in a global yarn bombing initiative to raise awareness about deafblindness in June 2021. Each knit or crochet square will be attached to cover a designated space, symbolizing the coming together of people in the field of deafblindness.

**JOIN DEAFBLIND ONTARIO SERVICES' YARN
BOMBING PROJECT. SUBMIT YOUR 20X20 CM
SQUARES BY MAY 14.**