

Canadian Deafblind Association - BC Chapter



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The Canadian Deafblind Association

The CDDBA National was formed in 1975 by parents of children with deafblindness who were attending the W. Ross Macdonald School for Students who are Blind and Deafblind in Brantford, Ontario.

Initially, the CDDBA was an advocacy organization representing a small group of children born with deafblindness largely from the congenital rubella epidemic. Its mission has been expanded from advocacy to include service provision, awareness,

public education and research. The CDBA is inclusive and represents all Canadians with deafblindness. Many adults and children who are deafblind remain isolated and underserved in Canada. This causes a ripple effect that puts their health and safety at risk, puts tremendous strain on their families, and ultimately our communities.

The CDBA continues to broaden our outreach and education efforts to ensure that those who are deafblind and most vulnerable in Canada receive basic services that ensure their well-being.

Become a Member & Support the Deafblind Community in Canada and BC!

Go to the CDBA National website and sign up!

<https://www.cdbanational.com/become-a-member/>



**Canadian Deafblind Association
National**

Why become a member of CDBA?

Having Membership will give you an opportunity to:

- **Share the Mission**
 - Join with families, consumers, professionals, advocates and Intervenors to assist all persons who are deafblind to achieve, with Intervention, the best quality of life.
- **Be an advocate**
 - Participate in a wide range of activities on behalf of individuals with deafblindness, including political action, public awareness, communications, and fundraising.
- **Enjoy "Intervention" news magazine**
- **Network**
 - Share knowledge and ideas with fellow family members, advocates, professionals, peers, and Intervenors at meetings and conferences and through the Internet via Facebook, Twitter and the CDBA website.
- **Support educational opportunities**
 - Involve yourself in provincial workshops and seminars on deafblindness as a delegate, planner, volunteer, sponsor and/or donor.
- **Receive information**
- **Benefit from CDBA's international connection**
 - Opportunities to meet and learn from professionals, consumers and family members from around the world and discover similarity of goals through CDBA's international connection with Deafblind International (DbI)
- **Apply to the CDBA National Support Fund**
 - Emergency and/or supplemental financial assistance is available to eligible CDBA members and their families
- **Belong to your provincial chapter (such as CDBA - BC Chapter)**
 - Members with deafblindness will receive the following benefits from CDBA-BC:
 - Family Events
 - Virtual Recreation Program
 - Summer Recreation Program
 - Hospital Services Intervention Program

Deafblind Awareness Month

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

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

June 2021 - Members of the deafblind community are joining a global awareness campaign to build awareness about people who are deafblind and engage in "yarn bombing" (a form of street art where yarn that is knit, crochet, or wrapped, adorns an object in a public space) across Canada through the month of June.

These tactile art installations will be constructed both nationally and provincially by people who have deafblindness, their families and loved ones, advocates, and Deafblind International networks to build awareness and influence people on a virtual scale across Canada.



Meet the Burnaby's Eco-sculpture cow and calf, and their friendly flock of sheep! The yarn bomb artwork has been created and displayed as a part of Deafblind Awareness Month. This patchwork quilt knits together a variety of colours and weaves to represent our wide variety of community groups that help to enable and support everyone.

The following BC communities will be participating in our Yarn-Bombing initiative:

- Penticton :KVR Middle School
- Vancouver: Sir James Douglas Elementary
- Burnaby: Cow and Sheep at McGill Library

We have Helen Keller to thank for prompting us to celebrate Deafblind Awareness Month in June. Helen Adams Keller (June 27, 1880 - June 1, 1968) was an American author, political activist and lecturer and was the first person with deafblindness to earn a Bachelor of Arts Degree. She is renowned internationally for her perseverance and achievements and is an inspiration to us all. Thanks to the Intervention support of Helen's Intervenor, Anne Sullivan, Helen Keller was able to overcome the isolation in which she lived and learned to communicate and savour the wonderful moments and experiences this world has to offer.



Proclamations and Illuminated Landmarks



We are so very grateful to our Provincial Government and the following communities for proclaiming June 2021 as Deafblind Awareness Month:

- New Westminster
- Richmond
- Surrey
- Vancouver
- Victoria

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

Landmarks across British Columbia and Canada will be lit up in blue to commemorate June as National Deafblind Awareness Month!

The following community landmarks within British Columbia will be lit up in BLUE throughout the month to raise awareness for Deafblind Awareness Month:

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



DEAFBLIND AWARENESS MONTH

Make a wave from coast to coast

MOIS DE LA SENSIBILISATION À LA SURDICÉCITÉ

Créez une vague d'un océan à l'autre

The 15th International CHARGE Syndrome Conference

Mark your calendars!

The CHARGE Syndrome Conference will hold a virtual symposium: "Show Must CHARGE ONline", in July 16-18, 2021. They will offer both live and pre-recorded sessions that will interest families of individuals with CHARGE of all ages and professionals. They will also host special evening events so families can join together virtually as a CHARGE community.

Parents have described the conference as a rite of passage, a family reunion, a place to meet and network with others facing the same challenges, learn from professionals (medical, clinical and educational), and leave better informed about how to help their child.



Go to the link below and register!

<https://www.chargesyndrome.org/for-families/conferences/>

History:

The first CHARGE conference was held in 1993 in St. Louis, Missouri. It was attended by over 250 people, including about 50 children with CHARGE.



Since then, the biennial conference has grown in its significance and impact, attracting over 1,235 attendees and over 250 individuals with CHARGE at its most recent 2019 conference in Dallas, Texas.



Congratulations to the Little Ones Who are Transitioning to Kindergarten!



Leonel Ashiku



Leonel's family are "so happy and looking forward to Leonel going to kindergarten," said his father. They "can't wait to pick him up from school!"

Leonel's family arrived in Canada from Albania in 2014. Soon after his birth, the family realized Leonel had many issues and they weren't sure if he should go to preschool or not. They were worried and stressed on what to do to help and support their child. But once they were introduced to the community Early Intervention teams, including CDBA-BC's Early Intervention Program, they were surprised and pleased with the results. Leonel entered preschool and was happy. His classmates played with him and were happy to see him every single day! Fatmir said, the "team at school was very good with Leonel and were amazing" in helping him prepare for kindergarten in the fall.

The Intervenors established a good communication system for Leonel. The family is now prepared and looking forward to the transition to kindergarten thanks to the Intervenors that had supported and helped Leonel.

Elda, Leonel's mother, said the family are hoping that Leonel will be able to say, "Hi; Bye to his friends," exploring with the class," and most importantly, "he will be happy." Some advice I can give to other parents beginning the CDBA-BC Early Intervention Program is, "Do not worry about it," said Fatmir. "Take them to preschool and then to kindergarten. You will be surprised, and it will change your life and happiness. It's also a good way for parents to have time to breathe and take a moment to catch-up with your thoughts when your child goes to school." The team will help alleviate some of the stress and anxiety that you have about your child. So, "Don't worry about it."



Amara Behr

Raina is a young mother who is excited about her son entering preschool, and daughter transitioning to kindergarten in the Fall. She's very proud that her daughter Amara, who has Trisomy 18 (also known as Edwards syndrome), is going to kindergarten. Raina hopes Amara "is going to enjoy [her new] school and have a social life" with her classmates!

Raina was hesitant and worried whether or not to register her for preschool. They were introduced to the community early intervention team, including CDBA - BC's Early Intervention Program which allowed her to have Intervenors who supported her communication needs. The intervenors were "great and fantastic" which helped Raina make the decision of Amara going to preschool easier. Today, young Amara communicates with people through her object binder, using (a little bit) sign language, and a PODD system (Pragmatic Organisation Dynamic Display - a book or device that contains symbols and words to support communication between people with complex communication needs and their communication partners, whether that's carers, family, friends or support workers).



Raina is "feeling good about the transition" to kindergarten. She has good communication with the Child Development Center (CDC), CDBA-BC and the School Board. Raina was provided with a good supportive team that understands the level of care and support for Amara. For instance, the EAs and preschool Intervenors learned about Amara's subtle communication and her equipment. Currently, the Intervenors are teaching Amara some new routines and building in more deafblind communication strategies to prepare her for the transition. Raina "feels confident and excited that Amara is ready for kindergarten" thanks to the Intervenors support and help. Raina hopes that the new school will have a solid plan in meeting with her child's needs and the Intervenors or EAs are well trained to pay close attention to Amara's attitude and communication cues. "When school is ready, she is ready," said Raina* "We are making sure we are opening doors and not limiting her."

This upcoming summer, Amara will be participating in the Summer Intervention Program. She will be enjoying new activities and developing social relationships with other children.

Reference:

<https://novitatech.com.au/equipment/podd-communication-books/>

Congratulations for Graduating High School! Hoping You All Will Have a Splendid Journey in Entering Society



Bryan Hu

Bryan is a hard-working and engaging individual. He will be graduating this year and walking across the stage in his graduation gown and cap. Currently, he is applying for UBC and SFU to take social sciences. He plans to become a policy maker and make a better place for the disability community, “Fighting rights and support for individuals,” and also, become an advocate for persons with disability.

Bryan has retinal dystrophy with severe-to-profound hearing loss, and cerebral palsy. Bryan became an independent young man because he was well supported by his Intervenors. The school and at-home Intervenors were very helpful with his academics and achieving his school goals. He enjoyed the intervention program that also gave him an opportunity to “meet new people” and interact with the community.

Bryan is an out-going and active individual. For instance, he co-hosted The Variety Children’s Charity Telethon (children’s fundraiser) in 2018, and was able to help raise 5.5 million dollars. He also enjoys playing chess and solving challenging puzzles such as playing Tetris. He did have an opportunity to take a trip to Ottawa as a candidate for the Forum of Young Canadians program; however, due to the pandemic he was unable to go last year. In the future, he hopes to travel across Europe such as Germany, France, Britain, and also, visit some historical sites like Japan.





Bryan had some advice to give to other students with deafblindness:

- “it’s important to learn self-advocacy.”
- It’s important to learn and understand about yourself and your needs to help yourself improve and prepare what’s to come next. This is so that the Intervenor(s) around you can find a system that works for you and help achieve your goals. “It can be challenging [and exhausting], but it’s worth it.”
- “Face the challenges and do your best and try to survive it. [You] can’t run away from them, so do your best!”
- Lastly, “enjoy the world” and enjoy yourself. There is so much more to discover!

Katie Ladd

Katie is a bright young woman who is graduating from high school this year. She’s thankful to her Intervenor(s) for supporting and making the work much more manageable. Although there is no grand graduation ceremony due to the pandemic, she’s “so excited to be graduating and having no more school!” Heritage Christian Online School will be sending the graduation gown and cap to signify her achievement in finishing school. In June, there will be one grand celebration, her graduation as well as her mom’s extra special birthday and her sister’s anniversary. In the future, she plans to work with dogs and cats at B.C - SPCA (British Columbia Society for the Prevention of Cruelty to Animals).

Katie and her family make an annual trip to Guatemala. She was born there and adopted at 2 years old along with her puppy companion Mumble (pictured here). Katie toured ‘The Painted Chair’ facility (where people with developmental disabilities are employed to up-cycle wood furniture and sell it and used clothing) and hopes to participate in their program as an adult.

Her favourite ride in the local amusement park is the Tornado (an attraction of swing chairs that will elevate you to new heights).

She’s hoping after the pandemic, she will be going to Disneyland to meet all the characters in the movie Avengers and Descendants.



Reference:

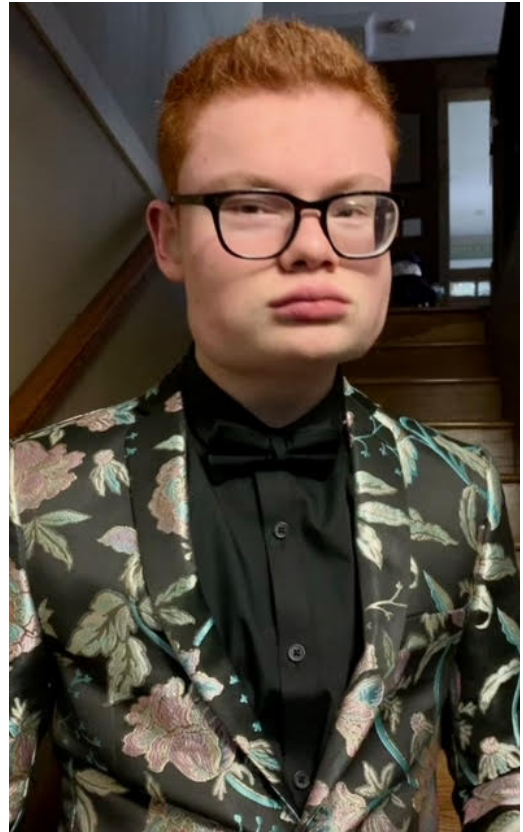
<https://www.timeschronicle.ca/the-painted-chair-in-oliver-honoured-to-host-mla-linda-larson/>

Logan Campbell

Lorelei is a stay-at-home mother. Her son, Logan, is a 19 year old laid back and a respectful person who has a good sense of humour. Lorelei said, "He has an excellent memory like a steel trap". Logan loves school and loves to wander around looking for something interesting. Logan is always "anticipating the next step" and moving forward.

While Logan graduated last year, he took an extra year to graduate to allow for a smooth transition into adult life. Unfortunately, due to Covid-19, the transition did not go as planned and he was not able to get into an adult services program. In the end, Logan was able to enjoy his school life with good relationships with his teachers and great support from his Intervenors. He looked forward to going to school every day.

Due to the pandemic, it was difficult for Lorelei to find a suitable adult program for Logan; however, luckily there are a few open and hopefully Logan can be registered into the program during the summer. Lorelei said that all she wants for him is that "he will be happy!"



Thunder Thomas

Debbie is so proud of her 27-year-old son, Thunder, (who has acquired deafblindness) to have grown to such a fine and independent young man. He lives in his own apartment attached to their family home in which he would host rock band parties monthly before the pandemic. Thunder's bedroom is modified to be a personal snoezelen sensory room: a relaxing space that helps reduce his agitation and anxiety, and engages and delights him with it's lights and aromatherapy. Thunder is now participating in the community gardening program.

In the beginning, school was overwhelming for Thunder. There were personal challenges involved as well as the school learning how to support and communicate with him; however, once they found a communication system that suited Thunder's needs, the results were amazing.

Thunder's school intervenors communicated with Thunder through touch cues, object cues, and a calendar system and routines. In grade 3 to grade 7, the school's communication system for him was phenomenal. Thunder was included in every aspect in class. For example, during poetry class, one child wrote a poem about him. In grade 9, Thunder had a PATH done. He became well acquainted with his peers and with his Intervenors after a year of interacting with them. Thunder trusted them and allowed his Intervenors to support him.

When Thunder graduated school, his mom was feeling emotional and accomplished. She was so happy that Thunder went to school and had a beautiful school life thanks to his Intervenors. He had a great and trusting bond with them at school. Thunder's "intervention Program did really well in helping and supporting him." It helped him prepare him for adult services.

The transition to adult life was quite challenging for the family. Debbie had to fight hard for funding to support Thunder's adult life. The best avenue to support Thunder was to establish a microboard: a small society comprised of 6 individuals called, 'Thunder's Rolling Adventure Society.'

Some advice Debbie had for other parents is "Don't put too much pressure on yourself. Take advantage of the Intervention Program. The extra work is worth it." Because now, my child Thunder is an independent and happy young man living in society!

Reference:

<https://www.snoezelen.info/>





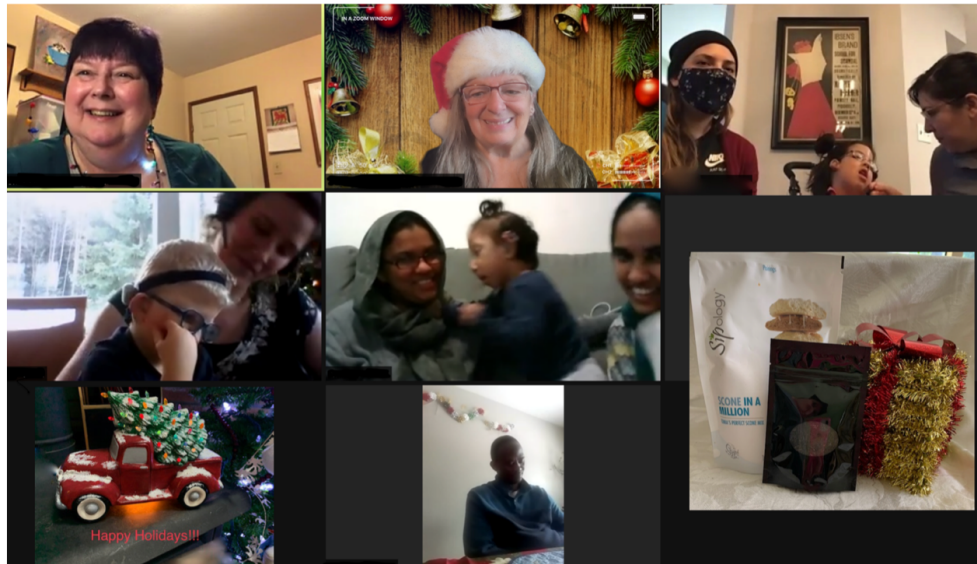
It's Time for a Coffee Break!



The Early Intervention Program started our Coffee Break get togethers last October. Initially we polled the families to find out the best days and in the end we decided to meet bi-weekly on Tuesday nights at 7 pm and Saturdays at 10:30 am. It's been a great way for families to meet on Zoom to share ideas and stories. We have been covering so many different topics including sensory toys, hand under hand, kindergarten transition, etc!



For the Winter Holiday Season we decided to have a special High Tea! We sent the families a package of scone mix and a special blend of tea. Families made the scones up ahead of time with their little ones. We had 6 families join us on December 19th and had a lovely tea party! We also sang some carols and even had a special story. It was a great way to celebrate the Holiday Season!



Have You Heard About the Modular Arm?

Deafblindness is an information gathering disability. With a modular arm, your child can have consistent access to information, in a position that works best for them. It frees up the Intervenor's hands to focus on Intervention, providing learning opportunities in all areas of development.

The modular arm is not just an iPad/Tablet holder, it is so much more! It's a tool that will provide your child with consistent access & information to many experiences that were unavailable in the past.

The arm can clamp onto various items:

- wheelchair or standing frame trays
- walker frame
- kitchen table
- high chair
- coffee table
- stand it on the floor
- clamp it to a chair leg sideways

You can turn the V clamps around to hold different sized items. This tool gives your child access to what is on the arm in a variety of supported positions:

- while sitting
- standing
- kneeling or even lying down



BE CREATIVE & HAVE FUN!!!!

Hand under hand together you can; play with toys, read books, work on apps on the iPad/Tablet, do puzzles, enjoy sensory exploring to name a few activities. You can adjust the arm forward/backwards, up/down as needed at the time to expand on your child's skills.



Make learning safe, fun and predictable.

Suggestions - Keep the activity items you are going to use close by in a basket or brightly coloured box. Once your child becomes familiar with the activity box, you can develop object cues for each activity so that your child can start to make choices of which activity they would like to do.

Building your child's skills over time.

Modular arm routine time, 'Start to Finish'. Your child can choose what they would like to do from the object cues. Together select the toy from the basket/box. Together you can set up the activity, do the activity together, when finished take it down together and put the item back in the box.

The Learning Possibilities...

- **Cause & Effect** - Your child touches the items on the modular arm, it moves, makes a sound, play music etc.
- **Concepts** - Learn on/off, up/down, push/pull, colours, textures, shapes etc. depending what is on the arm.
- **Eye hand/body coordination** - Learn to look and reach with either or both hands, movement, fast/slow, if you set it up on the floor or in a lower position exploring with their feet, or whole body.
- **Fine/gross motor skills** - Learn about finger touching, reaching, body movement, hand search/movement, grasp, batting, release grasp, push/pull, up/down.
- **Self-initiated action** - Builds curiosity, interest in play, independent play, communication (requesting more, making choices and exploration..



- **Body awareness** - head control, leaning forward, items on their lap, where their hands are, foot and leg exploration
- **Visual skills** - Learn to search, track, fixation, shift of gaze, colour comparison, scanning.
- **Listening skills** - Learn about sound awareness, pitch, turn taking, localizing, control over object, loud/quiet, identifying sound item
- **Social development** - Learn how to play with others, take turns, make a request for more play.
- **Total communication** - Learn to communicate more, all done, finished, on/off, in/out, open/closed, turn page, push/pull, go/stop/ on/off, up/down, fast/slow/, colours etc.

In the above photos you will note that a black sheet has been placed behind the modular arm. This has been done to reduce the visual clutter in the background.



- Sitting independently
- Colour contrast, beads on table
- Watching **beads** move
- Reaching and pulling beads - using helping left hand
- Open & closing hand to grasp
- Listening to the sound of the beads on the table
- Will reach with left hand & use right hand to help

****Beads go back to where they started, making his visual tracking & reach predictable. Beads started close, then parents moved them farther away so he could work on tracking and his reach.****

Summer Fun in the Virtual World!

This upcoming summer, the CDBA-BC's Virtual Summer Recreation Program welcomes children and youth with deafblindness, their families and Intervenors together for an exciting program, using a virtual platform.



There will be Zoom sessions for:

- Arts & crafts
- Painting
- Storytelling
- Baking delicious goodies
- Cooking
- Games & activities

and many more fun and pleasurable things!



Our thanks to the Douglas College practicum students for their hard work in developing many of our projects, such as this newsletter.