# The Learner with Deafblindness

braille Helen Keller

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## Agenda

Definitions – What is Deafblindness?
What is Intervention?
(In British Columbia, Canada)
Strategies and a Total Communication
Approach for Deafblindness
Team Approach
Recent Areas of Interest
Resources

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## British Columbia Special Education Policy Manual

- BRITISH COLUMBIA MINISTRY OF EDUCATION. Special Education Services: A Manual of. Policies, Procedures and Guidelines. BC Ministry of Education.

https://www2.gov.bc.ca/assets/gov/education/administration/kindergarten-to-grade-12/inclusive/special_ed_policy_manual.pdf

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## BC SPECIAL EDUCATION SERVICES: A MANUAL OF POLICIES

Supplementary funding continues to be provided to school boards in addressing the aspects of special education for students who meet criteria as Level 1, 2 or 3 unique needs.

Level 1 – includes students with multiple needs who are Physically Dependent or DeafBlind

Level 2 – includes students with Moderate/Profound Intellectual Disabilities, with Physical Disabilities or Chronic Health Impairments, with Visual Impairments, with Autism Spectrum Disorder, or students who are Deaf or Hard of Hearing

Level 3 – includes students requiring Intensive Behaviour Interventions or students with Serious Mental Illness

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## Deafblindness

An individual who is deafblind is one who has a combined loss of both vision and hearing such that neither of these two distance senses can be used as a primary source of learning.

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## Deafblindness in BC

- Definition: A student with deafblindness has a degree of visual and auditory impairment which, when compounded, results in significant difficulties in developing communicative, educational, vocational, avocational, and social skills.
- To be considered deafblind the student's vision and auditory impairments can range from partial sight to total blindness and from moderate to profound hearing loss, including unilateral loss.

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## Deafblindness – Causes B.C.

CHARGE Syndrome

Chromosomal disorders

Usher Syndrome

Meningitis

Trauma

Brain Injury

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## Deafblindness – Causes – U.S.

CHARGE Syndrome

Prematurity (hearing loss due to exposure to medications given in utero or at birth)

(R. Blaha 2018, in conversation)

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## Deafblindness - Types

**Congenital Deafblindness**: Congenital deafblindness refers to individuals who are born with both visual and hearing losses and/or who experience these dual sensory losses early in life.

**Acquired Deafblindness:** Acquired deafblindness refers to individuals who experience a combined vision and hearing loss later in life, usually after the development of language. The vision and hearing losses may be simultaneous or may occur at separate times. The losses may be acute and/or progressive.

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## Deafblindness

- Information Gathering Disability

- Deafblindness impacts a person's ability to communicate, interact and learn in a variety of environments. This also affects relationships

- Unique disability

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## Deafblindness

- Vision Impairments can range from partial sight/low vision to total vision loss

- Hearing loss can range from hard of hearing to total hearing loss

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## Intervention

The term "intervention" means to go between or to mediate between.  With regards to persons who are deafblind, intervention is the process which allows an individual who is deafblind to receive non-distorted information such that he or she can interact with his or her environment.

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## Intervenor

An intervenor is a person who provides intervention to an individual who is deafblind.

An intervenor mediates between the person who is deafblind and his or her environment to enable him or her to communicate effectively with and receive non-distorted information from the world around them.

An intervenor acts as the eyes and ears of the person with deafblindness.

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## Why can be difficult for an individual to communicate?

- Ongoing sensory issues creates limited access to information

- Difficulty in establishing relationships with others

- Adults tend to dominate interactions

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## Best Practices

- Knowledge of the Visual ability of the child

- Knowledge of the Hearing ability of the child

- Knowledge of the Physical ability of the child

- THEN Utilize all the senses - vision, hearing, smell, taste, touch, kinesthetic movement and proprioception

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## Strategies / Best Practices

- Utilize All the Senses
- Involve the Learner in the Whole Process, build up anticipation
- Learn by Doing – Do with not for
- Hand-under-Hand Techniques
- Use of Functional Skills / Functional Routines / Meaningfulness / Level of Participation / Deafblind Time
- Feedback / Confirmation
- Total Communication – receptive and expressive

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## Communication – two parts

- Receptive Communication – how a listener receives and understands a message from a communication partner

- Expressive Communication – how one conveys a message to the communication partner

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## Type of Communicator – R. Blaha

Emergent Communicator


Proficient Communicator

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## Hand-under-hand - Barbara Miles

-with very slow, gradual movement
-shared experiences
-exploring objects and joint attention
-co-active movement
-gestures
-directed pointing

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## Total Communication Approach includes:

touch / tactile cues,

environmental cues

object cues

gestures, name cues, sign language, fingerspelling

picture-symbols (e.g. board maker), line drawings

photos

Vocalizations / voice / speech, environmental sounds / cued speech

braille, print, tactile representations

technology including iDevices

Experience books / Memory books

Calendar systems

## Total Communication

touch / tactile cues

environmental cues

object cues

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## Total Communication

gestures

name cues

sign language

fingerspelling

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## Total Communication

picture-symbols, line drawings

board maker pics

photos

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## Total Communication

vocalizations / voice / speech

environmental sounds

cued speech

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## Total Communication

braille

print

tactile representations

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## Total Communication

technology including iDevices

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## Total Communication

Experience Books / Memory books

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## Total Communication

Calendar system:

Dr. Jan van Dijk initially created Calendar Systems as he realized that as sighted / hearing people, we have photos albums for our memories, however, individuals with Deafblindness do not have access to this and needed their equivalent. If one does not have this, one is always "stuck in the present" (quote by Robbie Blaha, December 2018).

We all need to have ways to have the past, present and future.

**ALL individuals with Deafblindness NEED a calendar**

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## Calendar systems using Total Communication Strategies

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## What are Calendar Systems?

- A concrete reference
- A way to keep organized
- A way to communicate
- A tool for anticipation
- A tool for motivation
- A structure for discussion and conversation

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## Why do we use them?

- To develop communication skills
- To provide security and emotional support
- To provide opportunities for concept development
- To teach and manage time concepts
- To teach time vocabulary

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## There are 4 parts to every Calendar System

- Symbols - objects, tactile symbols, line drawings, photos, printed word, Braille
- Display of Symbols - cues are the learner's words and should always be accessible
- Sequencing System - some way to display the symbols in the order the activities will be happening
- A Finished Box - a basket, bag, envelope, etc. to put the symbol into when the activity is completed

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Calendar systems are as varied as the learners who use them. The cues and the sequencing system used should be built around the learner's sensory needs, experiences and interests.

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Calendar systems can be used at any level of language ability from concrete objects to increasing levels of abstract symbolism.

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## Tactile base to each section



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## Finished Bag for cues

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## Set up for wheelchair access

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## Cues

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## Alynne's cue for bathroom



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## Clear Labeling



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## Sequence board



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- This student is pairing concrete objects with a line drawing and skipping the tracing stage. The team will know the student best and be able to design a system that works for the individual needs of each student.



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# Extended calendar



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# Moving to a paper based calendar



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## Adding a monthly calendar



## Adding specific times



## A tactile communication board

## Abstract Tactile Cues

These tactile cues were created for a student who was totally blind. He recognized all of his cues by touch. He started with concrete objects and gradually faded to these smaller abstract cues.

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## Examples of Personal Identification Cues

Each person has their own cue.
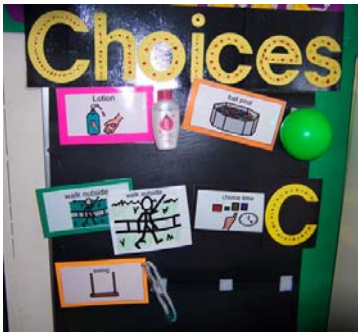Note how different each cue is in colour and texture.

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## ID bracelet

At the end of the day, have the learner help you put your bracelet in the finished box or back on the board with your picture and your name to let them know your time together is finished.

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Linda's photo and tactile cue

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START to FINISH

There is no Fairy Godmother Syndrome here!

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## DO WITH NOT FOR

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## Alynne and possible job

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## Alynne's sequence board



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## Alynne's Coffee Corner



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## Becoming a Communication Partner

A great conversation has:

1. A Way to communicate (forms)

2. A Reason to communicate (functions)

3. Something to communicate about (shared interests)

4. Somewhere for communication to happen (an environment that facilitates communication)

5. Someone to communicate with

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## Communication partner



You have to be interested,
to be interesting.     Gunner Vege

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## Key Aspects:

- We are all sensory detectives
- Have expectations for your student – Expect them to learn
- Do with NOT for
- Strive for independence within some skills
- The process is more important than the product
- Never interact "on" a child without telling the child what you will do

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## Team Approach

A student with Deafblindness typically has (and needs) a large team around them, and can include:

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## Team Approach

- Teacher / Consultant for Students with Deafblindness
- Teacher of Students - Visual Impairments (TSVI)
- Teacher of Students - Deaf / Hard of Hearing (TDHH)
- Orientation and Mobility Instructor (O & M)
- Classroom teacher
- Case manager
- Learning resource teacher
- Intervenor / backup Intervenor
- Family members

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## Team Approach (continued)

- Educational Audiologist
- Occupational Therapist (OT)
- Physiotherapist (PT)
- Speech and Language Pathologist (SLP) / SLP AAC
- other school-based professionals (e.g. School Psychologist, Assistive Technology personnel, nursing)
- Community members, where applicable
- representatives from Community Deafblind Associations

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## Team Approach

Regular meetings:

Regular and on-going meetings are critical as the team needs to learn about the student and to hear perspectives from the team members.

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## Communication

Developing Communication is paramount for our students.

A Total Communication Approach is the KEY.

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## Communication

A Total Communication Approach:

Most students who are deafblind use several modes of communication and can include signs, gestures, fingerspelling, speech, object cues, photos, pic-syms, print, braille, computer / device programs such as Touch Chat
**The TSVI & TDHH can be very helpful in designing the communication system**

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## Team Approach

What people bring to the team:

TSVI  and TDHH:

Both NEED to learn about the other main sense to UNDERSTAND the
combined impact of
VISION LOSS and HEARING LOSS

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## Team Approach

Deafblindness is
NOT
Deaf *plus* Blind

Deafblindness is
Deaf **TIMES** Blind

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## Team Approach

HOW:
Visiting together

Learning together

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## Team Approach – Role of TSVI

Reading and Interpretations of vision reports

Accessing functional visual ability (in a variety of environments), including Cortical Visual Impairment (CVI)

Environmental considerations – lighting, glare, equipment to support low vision needs in the classroom, positioning in the classroom

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## Team Approach – Role of TSVI

Helping the team look at the array of possible communication modes – sign language, cues, etc., from a **visual or tactile point of view**

Near vision considerations – size of object cues, size of photos / pictures etc. for communication strategies, including size of font, colour preferences, contrast, large print examples, high tech strategies

Teaching of visual strategies – e.g. focussing, tracking, scanning, including strategies specific to Cortical Visual Impairment (CVI)

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## Team Approach – Role of TSVI

Helping the team's awareness of visual fatigue

Bring the idea of **Concept Development** to the team to help choose concepts carefully, functionally and practically

Teaching the student how to care for their equipment, their low vision devices, technology, glasses

Teaching the student about vision, the eye (anatomy), their condition (terminology) and then how to advocate for their visual needs

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## Team Approach – Role of TSVI

Can teach the class (with the student, as they learn about self-advocacy) through simulation and activities and discussions, the reality of the student's vision needs and what helps and why

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## Team Approach – Role of TDHH

Read and Interpret hearing reports / audiological assessments

Helping the team understand the aspects and impacts of the condition – e.g. unilateral loss, bilateral loss etc., when / why hearing aids might / might not work

Work with the audiologist discussing possible equipment (in terms of the reality of the classroom/ school environment)

Accessing functional auditory ability of the child (in a variety of environments)

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## Team Approach – Role of TDHH

**Environmental considerations:** positioning in the classroom, lighting, glare, reduction of noise in the classroom and other areas of the school, the impact of noise level in the school on the student's learning and their ability to take in information

**Hearing Technology:** helping the team to understand and troubleshoot for hearing aids, FM systems, classroom sound fields, cochlear implants

General awareness of auditory fatigue

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## Team Approach – Role of TDHH

Helping the team look at the array of possible communication modes – sign language, speech, cues, etc., from an **auditory point of view.**

Teaching the student how to care for their hearing equipment, hearing aids, the microphone for the FM / classroom sound field

Teaching the student about hearing, the ear (anatomy), their condition and then how to advocate for their hearing needs

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## Team Approach – Role of TDHH

Can help with vocabulary development

Can teach the class (with the student, as they learn about self-advocacy) through simulation and activities and discussions, the reality of the student's hearing needs and what helps and why

The TSVI and the TDHH can work together to give a combined view to the specifics vision condition / hearing condition and then help the class develop strategies to help their classmate

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## Team Approach – Role of O & M

Areas that could be addressed:

Concept Development – spatial development, environmental development and body concepts

Mapping – understanding basic simple maps – one room in relation to another room, following a route; learning landmarks (that can be used for a person who is deafblind)

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## Team Approach – Role of O & M

Travel techniques – traveling within the school, using their mode of transportation (e.g. wheelchair)

Introduction of guiding

Introduction of adaptive mobility devices and cane skills

Advanced Travelers – work toward using APPS such as google maps, transit maps, working towards greater independence including their neighbourhood, community and introduction to public transportation; safe travel at night.

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## Team Approach – Role of O & M

Framework for Independent Travel (FIT) :
A Resource for Orientation and Mobility

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## Team Approach – Role of O & M

Link to FIT:

https://www2.gov.bc.ca/assets/gov/education/kindergarten-to-grade-12/teach/teaching-tools/inclusive/fit.pdf

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## Team Approach – Role of OT

**Again, learning the visual and hearing status of the student is critical – need to spend time**
Help with physical aspects of access to cues including specifics about fingers, hands, wrist placement

Help with switch placement

Wheelchair placement

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## Team Approach – Role of SLP / SLP AAC

**Again, learning the visual and hearing status of the student is critical – need to spend time**

Need to recognize the aspects of hearing loss as the majority of students do not use a primarily based speech mode

The total communication approach, using several modes is best

Embracing the idea of **exposure not assessment** in the beginning

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## Team Approach – Role of SLP / SLP AAC

Typically, start with concrete words

Size of cues, background, colour – all components need to be considered

Typically one photo / board maker pic at a time

The initial solution is often not a high tech device

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## Team Approach – Role of PT

**Again, learning the visual and hearing status of the student is critical – need to spend time**

Positioning of child, helping the team learn the specific aspects of this

Allow time to prepare for movement changes with language, cues

Prepare child with cues / objects for movement changes

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## Recent Areas of Interest

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## Recent Areas of Interest

Dr. Jan van Dijk - Child Guided Assessment

Dr. van Dijk assessment of children by observing and following their movements, emotions and interest to gain insight into each child's learning process. His child-guided method of assessing is recognized and used throughout the world.

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## Recent Areas of Interest

Dr. Jan van Dijk -  Bio Behavioural States

Deep sleep
Quiet sleep
Active sleep
Drowsy
Quiet awake
Active awake
Fussy state
Uncontrollable agitation

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Link to Dr. van Dijk's Child-Guided Strategies

Child-Guided Strategies for Assessing Children who are Deafblind or have Multiple Disabilities from

aph.org

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Link to Dr. van Dijk's Child Guided Assessment  (video)

- http://www.perkinselearning.org/videos/webcast/child-guided-assessment

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# Recent Areas of Interest

Literacy for Individuals with Deafblindness  - Perkins

This site is for individuals interested in beginning or enhancing literacy instruction for children with combined vision and hearing loss.

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Link to Literacy at Perkins

http://www.pathstoliteracy.org/

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## Recent Areas of Interest

**All Children Can Read**

The goal of this site is to provide information and resources for teaching and working with children who have complex learning challenges who are interested in beginning or enhancing literacy instruction for children who have combined vision and hearing loss.

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## Link to All Children Can Read

http://literacy.nationaldb.org/

http://literacy.nationaldb.org/files/7914/7672/3022/Literacy_Skills_Checklist_English.pdf

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## Recent Areas of Interest

**Sound travels** – how audiologists can help students with Deafblindness who are learning Orientation and Mobility travel and traffic skills

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Sound Travels: Evaluation, Collaboration, and Development Tools for Individuals who are Deafblind

- Audiology and Orientation and Mobility Collaboration Tool

- Developing Auditory Skills

- Delineation of Roles Related to Safe and Independent Travel for the Student with Deafblindness

- Importance of Environmental Sounds

- Tip Sheet for AI Teacher

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# Link to Perkins / Paths to Literacy – Sound Travels

http://www.pathstoliteracy.org/resources/sound-travels-evaluation-collaboration-and-development-tools-individuals-who-are-deafblind

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## Recent Areas of Interest

Auditory Neuropathy Spectrum Disorder (ASND)

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## Link to ANSD webinar

By Beatrice Ho  (on Alberta's website)

- https://arpdcresources.ca/consortia/deaf-hard-hearing-dhh/?index=4

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## Link to ANSD handout

This is shared with families and educators – written for infancy and early childhood

http://www.phsa.ca/bc-early-hearing/Documents/ANSD Information for BC Families.pdf

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## Recent Areas of Interest

**Toxic Stress** - research from Harvard University, the Centre of the Developing Child:

Looking at concepts:

Serve and Return,

The Science of Resilience,

The Science of Neglect

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## Links to Harvard research

- Center on Child Development Harvard University
- https://developingchild.harvard.edu/science/key-concepts/serve-and-return/

- https://developingchild.harvard.edu/resources/inbrief-the-science-of-resilience/

- https://developingchild.harvard.edu/resources/inbrief-the-science-of-neglect-video/

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## Recent Areas of Interest

Open Hands Open Access
(OHOA) training

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## OHOA Modules Overview

The Open Hands, Open Access (OHOA): Deaf-Blind Intervener Learning Modules are a (US) national resource designed to increase awareness, knowledge, and skills related to intervention for students (ages 3 through 21) who are deaf-blind and being served in educational settings

Training about deaf-blindness offered by state deaf-blind projects for teachers, paraeducators, families, and related service providers

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## OHOA

The modules, created by a diverse group of experts in the field of deaf-blindness (state and national deaf-blind project staff, parents of children who are deaf-blind, higher education faculty, teachers, educational interpreters, interveners, and more), were designed to be used as part of comprehensive intervener training programs offered by qualified agencies or institutions.

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## Link to OHOA

https://nationaldb.org/modules/ohoa/en/ohoa-overview

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## Recent Areas of Interest

**Transdisciplinary Play Based Assessment for Students with Deafblindness**

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Link to Play Based Assessment

https://www.prcvi.org/outreach/play-based-assessment-for-students-with-deafblindness/

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Recent Areas of Interest

**Recreation and Leisure Skills: Move to Include All Children**
**Dr. Lauren Lieberman**

Physical activity for students with visual impairments and multiple disabilities including Deafblindness, especially looking at Universal Design for Learning

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Link to Dr. Lauren Lieberman

https://www.prcvi.org/resources/resources-for-teachers/expanded-core-curriculum/recreation-and-leisure-skills/

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## Recent Areas of Interest

**POPDB Transition** from Secondary School to Adulthood for Students with Deafblindness in British Columbia

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## Link to Transition Document

http://popdb.sd38.bc.ca/sites/default/files/Transition Plan for Website.pdf

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## Recent Areas of Interest

**The Assessment of Deafblind Access to Manual Language Systems (ADAMLS)**

This is a resource for teams who are responsible for developing appropriate adaptations and students who are deafblind and candidates for learning manual language systems

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## Link to ADAMLS

Available as a free download from

http://documents.nationaldb.org/products/ADAMLS.pdf

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## Recent Areas of Interest

### Proficient Communicators

A group in the US are looking at students who are now appearing to have fairly good communication – a new sub-group, mostly premies.

POPDB has joined the group to look at the specific needs of these students

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## IEP Checklist - Proficient Communicators (TSBVI)

Address requisite concept (foundational concept) development through assessment and instruction.

Modify the curricular content; develop standards based IEP in core subjects.

Define comprehension check and include an individualized description in the student's accommodations.

Build time into the day for individual or small group work; add an elective or time in a resource classroom.

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## IEP Checklist - Proficient Communicators (TSBVI)

Apply adaptations and modifications to homework assignments; shorten, provide additional time, allow oral responses. Consider assigning alternative projects, and/or reducing or eliminating homework.

Consider student's technology needs. Develop a technology plan.

Monitor indications of stress. Consider counseling to support the student with stress management.

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## IEP Checklist - Proficient Communicators (TSBVI)

Consider the impact of Deafblindness on behavioral issues.

Consider the unique social skills needed for a student with DeafBlindness, include these in the IEP and provide direct instruction.

Consider the unique skills needed in self-advocacy for a student with DeafBlindness, include these in the IEP and provide direct instruction.

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## IEP Checklist - Proficient Communicators (TSBVI)

The discussion for supplemental needs and services considers the unique transition needs of a student with DeafBlindness and include these in the IEP.

Consider the need for additional resources, training and/or staff to provide in-class support (Intervener, additional interpreter etc).

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## Links to Proficient Communicators

Websites to follow:

Texas School for the Blind

Tsbvi.edu

The National Centre on Deaf-Blindness

nationaldb.org

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## Additional Guiding Thoughts:

- Being Organized is Critical - for the whole team - a Daily schedule is a life saver
- Regular Team Meetings are of the utmost importance
- Expanding Participation
- The process is ALWAYS more important than the product
- Incorporating the goals throughout the day avoids rushing in order to "work"

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## Conferences - Deafblindness

(Upcoming) **International Symposium on Physical Activity and Individuals with Visual Impairments or Deafblindness**

**May 9 - 12 2019   University of Edinburgh, Scotland**

This 4-day international symposium organised by the Scottish Sensory Centre is expected to attract over 100 delegates from across the UK and beyond. Aimed at anyone interested in sport and physical activity and people with visual impairments or who are deafblind, this conference will appeal to educators, researchers, mobility and (re)habilitation specialists, and organisations interested in sport, leisure and disability.

http://www.ssc.education.ed.ac.uk/courses/vi&multi/vconf19.html

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## Conferences - Deafblindness

(Upcoming) **CHARGE Syndrome: August 1- 4, 2019**
**Dallas, Texas**
**14th International CHARGE Syndrome Conference**
info@chargesydrome.org

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## Conferences - Deafblindness

(Upcoming) **DeafBlind International (DbI):**

**August 12 – 16, 2019** Able Australia: the 17th Deafblind
International World Conference will be held on the Gold
Coast, Australia

https://ableaustralia.org.au/dbi2019/

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## Conferences - Deafblindness

(Past) **Helen Keller World Conference:**
**June 20 – 27, 2018 Benidorm, Spain**
World Federation of the Deafblind
Theme: "Our rights: Our Voice: We Lead the Way"

**http://www.internationaldisabilityalliance.org/WFDBGA**
**HKWC2018**

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## Conferences - Deafblindness

(Past) **Network of the Americas**
**April 15 -18, 2018    Hyannis, Massachusetts**

"We're all stronger when we work together. Our conference theme – Partnerships for lifelong learning – acknowledges the importance of teamwork. By partnering as educators, service providers, consumers, policymakers, advocates and family members, together we can offer a lifelong array of support for the deafblind community – spanning from early intervention and K-12 education to programs, services and products for adults."

https://www.perkins.org/get-involved/events/dbi

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## Training Opportunities

• George Brown College, Toronto, Ontario: This is a two year training programs for Intervenors
https://www.georgebrown.ca/programs/intervenor-for-deafblind-persons-program-c108/

Some Ontario-based Deafblind Organizations may offer on-line courses:
http://www.cdbaontario.com/

 http://www.deafblindontario.com/

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## Training Opportunities

POPDB offers courses through Richmond School Distric, BC for those who work with the students that POPDB supports

http://popdb.sd38.bc.ca/

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## Resources

Communication Matrix
https://www.communicationmatrix.org/

Provincial Outreach Program for Students with Deafblindness
http://popdb.sd38.bc.ca/

Active Learning
http://activelearningspace.org/

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## Resources

https://vision.alberta.ca/

https://vision.alberta.ca/training/onlinemodules/lightbox/

Talking the Language of the Hands to the Hands by Barbara Miles
http://documents.nationaldb.org/products/hands.pdf

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## Resources

Framework for Independent Travel (FIT) A Resource for Orientation and Mobility Instruction
https://www2.gov.bc.ca/assets/gov/education/kindergarten-to-grade-12/teach/teaching-tools/inclusive/fit.pdf

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> Don't assume a door is closed;
> push on it.
> Do not assume if it was
> closed yesterday
> that it is closed today.
>
> Marian Wright Edelman, American activist

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