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Deafblindness – An Overview

Definition

Vision and hearing are major senses through which people gain information about the world in order to learn, function and interact with others. Individuals with deafblindness are not able to access this essential visual and auditory information in a clear and consistent way. (Understanding Deafblindness, Issues, Perspectives and Strategies)

An individual who is deafblind is one who has a combined loss of vision and hearing. Neither vision or hearing can be used as a primary source of accessing information. (The Canadian Deafblind and Rubella Association definition) This is a functional definition, based on the combined effects of the losses rather than on a specific degree of loss to one or the other of the senses. The two sensory losses multiply and intensify the impact of one another, creating a severe disability which is unique.

A combined loss gives a person a distorted picture of the world and leads to immense difficulties in communication, mobility, learning, and interaction. All those with deafblindness experience sensory deprivation, and are isolated from the world to varying degrees. Each person requires a unique educational approach - a range of learning opportunities and a variety of teaching modalities (auditory, visual, kinesthetic, and tactual) in an accessible environment – in order to ensure he/she has the opportunity to reach his/her full potential. The challenge for each individual is to make sense of the world using the limited information that can be accessed.

Implications

- The child’s experience of the world is determined by his/her physical contact with objects and people in the environment.
- The child who is deafblind has limited access to information and will face challenges in developing mobility, communication, social interaction and with learning.
- The child experiences difficulty with anticipation, motivation, communication and feedback from the environment.
- Incidental learning opportunities are greatly limited and conceptual development and experiential learning differ significantly from that of other children.
- Mobility must be encouraged with a more accessible environment provided and specific skills including spatial and object permanence taught by an Orientation and Mobility instructor.
• The child who is deafblind may be unable to detect enough information to understand what is going on around him/her and to experience control over the environment. This can lead to confusion and frustration, which may manifest as aggression, stress, withdrawal or self-stimulation.

• The child requires another person to intervene or assist in passing on the auditory and visual information the child cannot detect. This person is the intervenor.

Programming

• A team approach is needed to assess the how the child learns and through which channels he/she gathers and processes information.

• All aspects of the child’s world must be addressed comprehensively (i.e., vision cannot be addressed in isolation from the auditory ability). The impact of the dual sensory impairment creates a very high level of need that cannot be addressed only through strategies used for the deaf or the blind.

• Programming should help the student learn to:
  - Interact meaningfully with the environment.
  - Experience and accept new things.
  - Make meaning of the input received.
  - And most critically, communicate effectively.

• Programming should be:
  - Structured and organized.
  - Allow for an increasing range of experiences in various environments which grow over time.
Manitoba Education and Advanced Learning
Supports to School Divisions for Students who are Deafblind

The Program and Student Services Branch has consultants working with students who are Blind and Visually Impaired and Deaf and Hard of Hearing who work together to provide support to schools. Schools may refer a student who has a combined vision and hearing loss such that neither of the senses can be used as the primary source of learning (the combined effect of the dual sensory loss is the determining factor rather than the degree of loss to one or the other of the senses).

Upon receipt of a referral, the following actions may occur:

- Consultants will be assigned to the school;
- Consultants will meet school staff, student and other team members involved to gather background information;
- If the student meets criteria as a student with deafblindness, a functional assessment will be conducted in tandem with school team;
- Following assessment, a team meeting would be called to review the written report and discuss programming, equipment, resources and training based on student and school needs;
- Programming support could include strategies to support the development of concepts, communication, mobility, academics, life skills, recreation/leisure and transition; and
- The student would be placed on a caseload with Manitoba Education Consultants and service would be determined by need and severity of the disability. If the school division has their own teacher of the Deaf and Hard of Hearing, the Manitoba Educations Deaf Education Consultant may or may not be involved, depending on the need.
Resources available for working with Students who are Deafblind

Textbooks:

A Guide to Planning and Support for Individuals who are Deafblind (J. McInnes, editor 1999). Authors address identification of Deafblindness, planning and intervention, development, family support and education. It aims to set forth standards for programming, implementation and evaluation.


Remarkable Conversations – Perkins School for the Blind, 1999
Written by teacher, for teachers. It looks at needs and how to address in the classroom. Includes examples of case studies with a heavy focus on communication throughout the school years and into adulthood. Good photos and additional readings and resources at the end of each chapter.

Understanding Deafblindness (two volumes) Ski-Hi Institute 2002. This 918-page 2-volume curriculum is for parents, interveners and service providers working with children and young adults who are Deafblind and their families. It covers all aspects of Deafblind programming including communication, concept development, vision, hearing, family issues, touch, sensory integration, intervener role and services, physical education, additional disabilities, orientation and mobility, community support and evaluation.

Assessment:

Assessment of Vision & Hearing of Deaf-blind Persons by Lea Hyvarinen (1990). Looking at assessment with the role of the interpreter discussed. Information on visual skills and what they mean as well as discussion on audiology and hearing devices.

Child-Guided Strategies: The Van Dijk Approach to Assessment with two DVDs including guidebook and forms (2009). This is a large print book on the guiding principles to conduct an assessment that follows the Van Dijk approach. It is organized into 8 observation areas. There is DVD viewing of a few children being assessed.
Worksheets with sample information on forms are provided along with some suggested intervention strategies for the children in the DVD.


*Oregon Project - 6th edition (2007)* with *Skills Inventory booklets and Activity Binders* designed for Assessment of Visually impaired pre-schoolers in several domains. There are age levelled skills with a separate binder of suggested activities to aid in development in that domain. This tool would be used by a team of professionals (OT, PT, SLP, O&M, early educators and parents.

**Booklets:**

*Assessing Communication and Learning in Young Children Who are Deafblind or Who Have Multiple Disabilities – Office of Special Education Programs, C. Rowland Editor (2009)*. This manual is divided into three sections – Getting Started, Gathering Information, and Interpreting and applying results. <http://www.dsu.edu/oidd/d21/com_pro/db_assess_ab.cfm>

*Functional Assessment of Sensory Status of Children who are Deafblind – New Jersey Technical Assistance Project* by Petroff, Ruetsch and Scott.

*Home Talk – A Family Assessment of Children who are Deafblind by W.S. Office of Special Education Programs – web resource, 2011*. This was developed at Oregon Heath & Science University and Columbia University – see <dblink@tr.wou.edu>

*Resource Packet on Deaf-Blindness –Tennessee Dept. Of Education* – This is an overview of the disability, with a definition, standards and eligibility guidelines and service delivery consideration for the state. There is an emphasis on recommended educational practices vs. procedures for assessment.

**Daily Living Skills:**

Calendars for Students with Multiple Impairments including Deafblindness by Robbie Blaha (2001). Illustrated book of some ideas for concrete calendars or schedule boards with tactile objects and symbols.

DVD's:

Four booklets with DVDs on Making Meaning, Core Principles of Intervention, Contact and Social interaction and Transition to the cultural language. Taken from Nordic and Dutch facilities/some language barriers on DVDs.

Deafbliness & The Intervenor – Ski-Hi Institute, 2010

Introduction to Tactile Communication by Hope Centre

Sensory Perspectives – Ski-Hi Institute including
1. Core principals of Intervention, 2. Contact and Social Interaction,

Using Tactile Signals and Cues – 3 DVD set by Hope Centre

Video – Hand in Hand – It can be done

Materials:

Sample Tactile Object cards – made by Media Production Services Tactile/Braille, Manitoba Education. Cards showing daily living tasks such as snack, bathroom and leisure time.
Sources for Educational Materials

American Foundation for the Blind
<www.afb.org>

Hope Inc.
<http://hopepubl.com/products.php?cat=1>

Perkins School for the Blind
<www.perkins.org/resources/>

Senses Foundation
<http://www.senses.asn.au/shop/>

Please note: Materials and DVD's from countries other than Canada or the USA will use different sign languages than the American Sign Language used with students here.
Recommended Deafblind Websites

**BC Provincial Outreach Program for Students with Deafblindness**
<http://www.sd38.bc.ca/BCDeafblindOUtreach/>

**Canadian Deafblind Association**
<http://www.cdbanational.com/indexe.html>

**Deafblind International**
<www.deafblindinternational.org>

**Deafblind Resources**
<www.deafblindresourcesarticles.blogspot.com/>

**Dr. Jan van Dijk**
<http://www.drjanvandijk.org>

**HOPE Inc.**
<http://hopepubl.com/index.php>

**National Consortium on Deafblindness**  
*(the largest information base in deafblindness in the world)*
<http://www.nationaldb.org/>
<http://www.nationaldb.org/DB101.php>
<http://literacy.nationaldb.org/> (literacy website)

**Perkins School for the Blind**
<www.perkins.org>

**Resources for working with Deaf-Blind people - David Bar-Tzur**
<www.theinterpretersfriend.org/db/rsorcs.html>

**Texas School for the Blind and Visually Impaired**
<http://www.tsbvi.edu/>

**Vision Education Alberta**
<http://www.vision.alberta.ca/resources/deafblind/dbwebsites.aspx>

**Please note:** Websites from countries other than Canada and the United States will illustrate different sign languages than the American Sign Language used with students here.
Webcasts

Permission was granted by the Training and Educational Resources Programs Perkins for us to list a variety of their informative webcasts that is available on the Perkins School for the Blind website. Please go to <www.perkins.org/resources/webcasts/>.

**CHARGE Syndrome: An Overview by Pam Ryan**
Pamela Ryan, Perkins School Psychologist, offers an overview of the characteristic features of CHARGE Syndrome and discusses the very diverse ways these features may manifest themselves in children. She discusses some of the early medical complications that many children face and how these issues affect development and learning.

**CHARGE Syndrome: Behavioral Issues by Dr. Timothy Hartshorne**
Dr. Timothy Hartshorne addresses the topic of Behavioral Issues in CHARGE Syndrome. Dr. Hartshorne is a Professor of Psychology at Central Michigan University (CMU) and has been interested in CHARGE Syndrome since 1989 when his son was born with the syndrome. He is also the director of the CHARGE Syndrome Lab at CMU. The webcast includes the following chapters: 1. Introduction, 2. Sensory Deficits and Behavior, 3. Behavior, 4. Common Behavior Diagnoses, 5. Resources.

**CHARGE Syndrome: Providing Physical Therapy by Dr. Maryann Girardi**
Maryann Girardi, PT, DPT, ATP, talks about the challenges of providing physical therapy to children who have CHARGE Syndrome. Maryann describes the impact of the CHARGE Syndrome on balance and muscle tone as well as strategies for establishing a successful treatment plan. The webcast includes the following chapters: 1. Introduction, 2. Establishing Communication, 3. Creating a Treatment Plan, 4. Therapeutic Movement and Motivation, 5. Active and Passive PT, 6. Setting and Adjusting Goals, 7. Outlook for Improvement.

**CHARGE Syndrome: Teaching Strategies for Children by Sharon Stelzer**
Sharon Stelzer, a long term teacher in the Perkins Deafblind Program, discusses the impact of the CHARGE Syndrome upon the student, and strategies a teacher can implement to create a good learning environment. Establishing schedules and structure as well as offering the student opportunities to make choices are stressed. Sharon also discusses the benefits of helping students with CHARGE Syndrome learn the art of negotiation.
CHARGE Syndrome: The Impact on Communication and Learning
by Martha Majors
Martha Majors explains the physical, sensory and neurological issues shared by many children with CHARGE and how these issues can affect their success in school. Martha, who has served many children in CHARGE in the Deafblind Program at Perkins, offers guidance for educators in developing an effective educational program that will improve the emotional wellbeing and success in learning for students with this syndrome.

CHARGE Syndrome: Preparing for the World of Work by Wendy Bridgeo
Wendy Bridgeo focuses on the importance of preparing students for life after school and beginning that planning well in advance of the post-school transition. She shares teaching strategies for helping students with CHARGE achieve success in work environments and provides examples of those strategies using real life situations.

Child-Guide Assessment by Dr. Jan van Dijk
Dr. Jan van Dijk of the Netherlands shares his expertise related to Child-Guide Assessment. Dr. van Dijk has over 50 years of experience working with students with deafblindness. He discovered long ago that typical assessment methods are not successful for these individuals. The child-guide approach is recognized and used throughout the world.

Conversations: A Personal Reflection About Deafblindness by Barbara Miles
Barbara Miles, a well-known as an author and lecturer, discusses her approach to engaging in conversations with students who are deafblind. She encourages people to think of how they converse with their friends and try to replicate the elements of those successful interactions in a way that is accessible to a child with limited vision and hearing. For example usually people initiate a conversation because the other person expresses a willingness to talk, through a smile or some other cue. Miles offers alternative strategies for making that connection when the person with whom you want to converse can neither see or hear you.

The Communication Portfolio by Susan DeCaluwe
Susan DeCaluwe discusses the development of the Communication Portfolio for learners with deafblindness and multiple disabilities. This tool, which is jointly developed by family members and professionals, creates a common and very personalized view of the learner's communication skills, abilities and challenges across all environments.

Cortical Vision Impairment by Ellen Mazel, M.Ed.
Ellen Mazel, M.Ed., talks about the diagnosis of cortical vision impairment and the resulting implications. Ellen shares strategies for assessment and intervention and emphasizes the importance of early intervention. This webcast provides excellent information for parents and teachers who are just learning about cortical vision impairment. The webcast includes the following chapters: 1. Introduction, 2. Evolution of Intervention and Assessment, 3. Assessment and Strategies for CVI Characteristics, and 4. The Benefit of Early Intervention.
Creating Vocational Portfolios for Students with Significant Disabilities
by Mary Zatta
School-to-Work helps educators to create meaningful vocational experiences for their students with significant disabilities and to develop vocational portfolios, essential tools as students’ transition to adult life. The book School to Work, is currently available in the Perkins store.

Early Literacy for Students with Multiple Disabilities or Deafblindness
by Deirdre Leech
Students with multiple disabilities, including deafblindness face many learning challenges. They do not learn literacy in typical ways. Often they do not have exposure to books and literacy based materials. Children with hearing loss may not have heard stories read aloud, and may not have used books on tape. The goal for these students is to maximize access using specialized formats.

Families as Partners in the Educational Team
by Dr. Katharine Shepherd & Susan LaVenture
Dr. Katharine Shepherd, Project Director: Parents as Collaborative Leaders Program and Susan LaVenture, Executive Director: National Association of Parents of Visually Impaired Children share their expertise and passion for supporting parents in developing leadership and advocacy skills. As keynote speakers for the Discover Conference, Katie and Susan share their personal and professional experiences to illustrate the powerful role that parents play in children’s lives.

Good Sleep Strategies by Veronika Bernstein, Ph.D
Veronika Bernstein, Ph.D. describes the challenges faced by children with visual impairments and their families in developing good sleep habits. Dr. Bernstein provides a variety of strategies that may be used to address this challenge. The webcast chapters are: 1. Introduction, 2. Why We Sleep, 3. Melatonin Production and Sleep Patterns, 4. Development of a Circadian Rhythm without light perception, 5. Visual Impairment and Anxiety Issues, 6. Sleep Time Routines, and 7. Teaching a Child to Sleep.

Issues in Social Skills & Sex Education by Tom Miller
Tom Miller talks about Social Skills and Sex Education for Children and Youth who have sensory impairments. Tom Miller has worked in the field of education of children who are blind, deafblind or with multiple disabilities since 1974. He is currently the Education Director of the Educational: Early Intervention and School Age Services (Birth-22). Over the course of his professional life, Tom has had a great deal of involvement in the development and implementation of social/sex education programs and consults and lectures both nationally and internationally on this topic. The chapters in this webcast include: 1. Introduction, 2. The Early Development of Social Skills, 3. Modeling Behavior for Children Who Are Blind, Visually Impaired or Deafblind, 4. The Importance of Development of a Sexual Identity, 5. Sexuality and Social Development, 6. Teaching Self-Protection, 7. Challenges.
**Love: Challenges of Raising a Child with Disabilities by Jane Bernstein**
Jane Bernstein, a parent and author of “Loving Rachel” and “Rachel in the World” (books which look at life with her daughter who has developmental disabilities) was the keynote speaker at the 26th New England Regional Seminar for Children with Visual Impairments and Their Families (birth-7 years of age). This webcast is a tape of her keynote presentation.

**Mealtime Skills by Sue Shannon**
Sue Shannon, an occupational therapist at Perkins School for the Blind, describes some of the challenges faced by students who are blind in learning mealtime skills. It focuses on and provides video demonstrations of effective strategies for teaching the skills of pouring, serving, utensil use and cutting. Sue's book, *Help Yourself: Mealtime Skills for Students Who Are Blind or Visually Impaired*, is available in the Perkins Products store.

**Reflections on Deafblindness: Hands & Touch by Barbara Miles**
Barbara Miles, a well-known author and lecturer, discusses the unique function hands serve for individuals who are deafblind. For people with vision and hearing impairments, hands become eyes, ears, and a voice. Barbara’s realization that hands have so many critical roles changed the way she interacts with the hands of children who are deafblind.

**Social Skills for Children and Youth with Visual Impairments by Tom Miller**
The ability to develop friendships and interact with other students is a common concern for parents of children with visual impairments. This Webcast demonstrates how to analyze and adapt teaching strategies to teach social skills to students who are visually impaired or deafblind on an equivalent level with their peers. Tom's presentation on Social Skills for Children and Youth with Visual Impairments is part of a larger book called *Welcoming Students with Visual Impairments to Your School* and is currently available in the Perkins store.

**Tangible Symbols by Elizabeth Torrey**
Elizabeth Torrey is a Speech and Language Pathologist in the Early Learning Center at Perkins School for the Blind. She has extensive experience working with children with visual impairments who are at the early stages of language development. In this webcast, Elizabeth talks about the use of "tangible symbols," a term originally coined by Charity Rowland, Ph.D. and Philip D. Schweigert, M.Ed, to support the development of communication in children who experience a variety of severe communication disorders and who are unable to use abstract symbols. The webcast draws from the work of J. Van Dijk as well as the work of Rowland and Schweigert. Ch. 1: Introduction, Ch. 2: What Are Tangible Symbols, Ch. 3: How Tangible Symbols Should Be Presented, Ch. 4: The Benefits of Using Tangible Symbols, Ch. 5: Considerations When Developing Tangible Symbols, Ch. 6: Behavioral Benefits. For more information, visit Perkins Scout.
Teaching Tactile Graphics by Lucia Hasty
Lucia Hasty has held teaching and administrative positions in special education for more than 30 years. Retired from education, she is a consultant, presenting workshops and developing training materials for a variety of audiences. In this webcast Lucia discusses spatial relationship and graphic literacy, moving from models to graphics and strategies for teaching students to read tactile graphics. Ch. 1: Introduction, Ch. 2: Spatial Relationship and Graphic Literacy, Ch. 3: Moving from Models to Graphics, and Ch. 4: Strategies for Reading Tactile Graphics.

The Impact of Deafblindness on the Family by Marlin Minkin, M.S.
In this webcast, Marlin Minkin, M.S. addresses the issues that families struggle with related to raising children who are deafblind. Marlin is a psychologist with extensive national and international experience working with families of children who are deafblind. Marlin's webcast addresses the following topics: 1. Introduction, 2. Common Responses to a Diagnosis of Deafblindness, 3. Parent to Parent Support, 4. Sibling Issues, 5. Personal Experiences and Professional Advice, 6. Self-Care and Accepting Help, 7. Planning for the Future, and 8. Redefining Hope.

Vision Issues for People with CHARGE Syndrome by David Brown
David Brown offers an overview of the impact of CHARGE on vision and the resulting behaviour of the student with this syndrome.
Training Opportunities for Staff

Intervenor training programs:

a) Douglas College (BC)
   Deafblind Intervention Certificate Program
   (10 courses)

   Contact: Provincial Outreach Program for Students with Deafblindness
   PH: 1-604-668-7810, E: <deafblind@sd38.bc.ca>; <http://popdb.sd38.bc.ca/>

b) George Brown College (ON)
   Intervenor for Deafblind Persons Program
   (2 years, 4 semester course)
   <http://www.georgebrown.ca/Marketing/FTCal/comsrv/C108.aspx>

   Contact: George Brown School of Deaf and Deafblind Studies
   PH: 1-416-415-5000 ext. 2185, E: <deafstudies@georgebrown.ca> OR

   Betty Jean Reid, Intervenor for Deaf Blind Persons Program Coordinator
   PH: 1-416-415-5000 ext: 2357, E: <bjreid@georgebrown.ca>

c) The W. Ross Macdonald School (Brantford, ON)
   Deafblind Resource Services two-day training institute: An Introduction to
   Deafblindness & Intervention (2 day institute courses available online)
   <http://www.psbnet.ca/eng/schools/wross/events/files/Sept2011_Deafblind_2day_training.pdf>

   Contact: Mary Cousineau, Secretary, Deafblind Resource Services
   PH: 1-519-759-0730 ext. 290, F: 1-519-759-1293; E: mary.e.cousineau@ontario.ca

Intervenor Competencies:

Schools may find it helpful to access the Intervenor competency framework for a list of
knowledge and skills that an intervenor should acquire/possess.
Intervenor Competency Framework for Canada on the CDBA website:
<http://www.cdbanational.com/competencies.html>
Additional Resources in Manitoba

Central Speech and Hearing Clinic
CNIB (Canadian National Institute for the Blind)
Communication Centre for Children - SMD Services
Intervention Manitoba
Preschool Aural Rehabilitation Program – Prairie Mountain Health - Brandon
Resource Centre for Manitobans who are Deafblind (RCMDB)

Associations

Canadian Deafblind Association
<http://www.cdbanational.com/indexe.html>

Canadian Deafblind and Rubella Association (CDBRA)
<http://www.cdbra.ca>

Canadian National Society of the Deafblind (CNSDB)
<http://www.cnsdb.ca>