

Meeting the Needs of Children with Hearing Loss & Vision Loss

Susan Wiley, MD, Cincinnati Children's Medical Hospital Center
Tabitha Belhorn, Ohio Hands & Voices
Leanne Parnell, Ohio Center for Deafblind Education
EHDI 2015



Introductions

- Susan
- Tabby
- Leanne
- Audience

When you hear the word
deafblind, what comes to mind?

<https://www.youtube.com/watch?v=WwNqMKIPmAw>

Deaf children are 2-3 times more likely to develop vision problems than hearing peers.

(Guy et al, 2003, Caban et al, 2005, Al-Abudjawad et al 2005, Nikopolous et al)

Simulation Exercise

- Ground rules for Safety
 - Make sure you communicate with your partner
 - Reach out for support if you need it
 - Take your goggles off if you feel sick to your stomach

Rules of the exercise

Vision Simulation Exercise

How to Lead a Person Who is Blind or Low Vision

- Decide which side you will stand on (usually the blind person's dominant side/hand)
- Stand one step in front of the person
- Bend your inside arm to 90 degrees
- The blind/visually impaired person will grab ahold of your bent elbow
- Walk at a normal pace.
- If you come to a doorway or a narrow spot, straighten your arm and move it slightly behind you.
- The blind/visually impaired person will know when you by your arm movement and height when you are going through a doorway or up or down stairs.

Vision Simulation Exercise

Rules of the exercise

1. We have placed yellow and pink post it notes randomly around the room. The person with the goggles needs to find one and bring it back to their seat.
2. Partners: walk behind or beside your partner to 'spot' them and make sure they do not fall or hurt themselves.
3. On the way back to your seat, the sighted person will lead the 'blind' person back to their seat.

Vision Simulation Exercise

- How did you feel with the goggles on?
- How was the communication with your partner?

Objectives

- Be able to define deafblindness using the federal definition recognize the variability's within this disability, identify strategies to allow EI providers and medical providers to work together to identify and monitor children who are at risk to be deafblind.
- Describe aspects of EI services appropriate for children who are deafblind and their families and strategies and techniques to support communication and early literacy skills.
- Identify 5 IEP services and supports that may assist a child who is deafblind when transitioning from EI to preschool

Definitions

- Educational Definitions
 - Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.
 - Visual impairment including blindness means an impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness.
 - <http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CA%2C300%252E8%2C>

Definitions

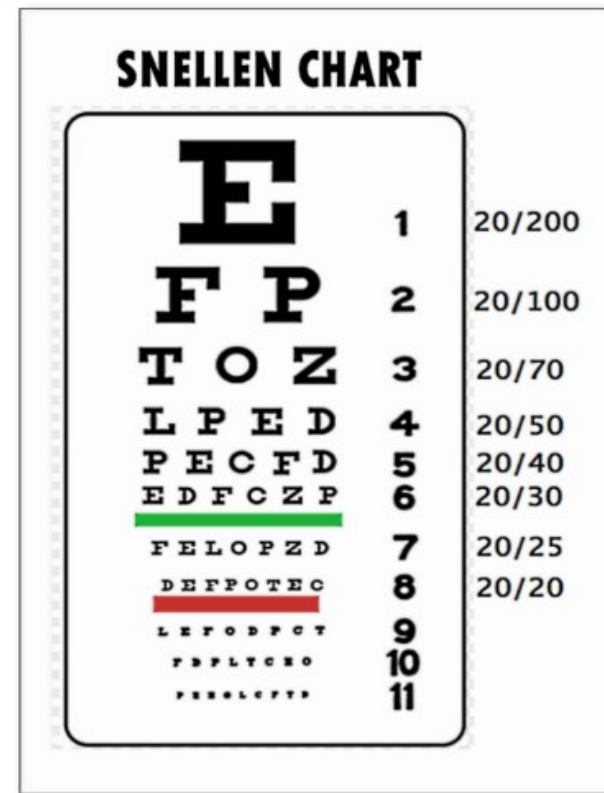
- Medical Definitions (Cole Eye institute)
 - **Low vision** is the loss of sight that is not correctible with prescription eyeglasses, contact lenses, or surgery. This type of vision loss does not include complete blindness, because there is still some sight and it can sometimes be improved with the use of visual aids.
 - **Low vision** includes different degrees of sight loss, from blind spots, poor night vision, and problems with glare to an almost complete loss of sight.
- The American Optometric Association defines low vision as two categories:
 - "**Partially sighted**": the person has visual acuity between 20/70 and 20/200 with conventional prescription lenses.
 - "**Legally blind**": the person has visual acuity no better than 20/200 with conventional correction and/or a restricted field of vision less than 20 degrees wide.

Breadth of skills in deaf-blind

- Mild to severe on vision
- Mild to severe on degree of hearing loss
- Mild to severe on cognitive abilities
- Mild to severe on other medical complexities

Vision Acuity Levels

- Vision acuity is a number that indicates the distance at which you can read an eye chart compared to someone who has perfect vision.
- A visual acuity measurement of 20/70 means that a person with 20/70 vision who is 20 feet from an eye chart sees what a person with unimpaired (or 20/20) vision can see from 70 feet away.



Vision Acuity Levels

- “Normal” Vision: 20/20
- Minor Visual Concerns: 20/25 – 20/50
- Low Vision: 20/70 – 20/200
- Legally Blind: 20/200 or worse, or a field restriction of 20 degrees
- Light Perception Only
- Totally Blind
- **level represents the best eye with correction*

Visual Impairments in Deaf/HH: How Common is it?

- Deaf children are 2-3 times more likely to develop vision problems than hearing peers (Guy et al, 2003, Caban et al, 2005, Al-Abudljawad et al 2005, Nikopolous et al)
 - 15% incidence of refractive errors hearing children
 - Approximately 40% in group of deaf children
- Syndromes such as Usher Syndrome, CHARGE syndrome
- JCIH recommendations:
 - All children should have a full ophthalmologic evaluation
 - Need **regular** vision evaluations

Why Vision Matters: Visually Related Developmental Milestones

Infant

Alert with widening of eyes to visual stimulus or face 8-12 inches

Momentary eye contact with adult

1 month

Follows visual stimulus in horizontal arc 60 degrees on either side of midline

Follows visual stimulus vertically 30 degrees above and below horizontal midline

2 months

Horizontal tracking across midline

Follows moving person 6 ft. away

Prolonged eye contact with an adult

Smiles in response to a smiling face

Raises head 30 degrees from prone position

3 months

Eyes and hand follow smoothly through 180 degree arc

Regards own hand

Looks at objects placed in hand, begins visual and motor coordination

4-5 months

Spontaneous social smile in response to familiar adult

Reaches on sight to a 1 inch cube presented 12 inches away

Notices raisin presented 12 inches away

5-6 months

Smiles at mirror image

7-8 months

Picks up raisin by raking

Sits up

8-9 months

Visual attention to details of object, such as facial features of dolls

Pokes at holes in pegboard

9 months

Neat pincer grasp

Crawling

12-14 months

Perceives motor tasks, for example, stacks blocks and places pegs in round hole

Stands and walks

Why is it Important?

- Vision provides motivation to move and develop
- Vision is critical in language development
 - Seeing sign language
 - Lip-reading
 - Reading facial expressions, non-verbal communication
 - Development of Literacy

How do we identify deaf-blindness

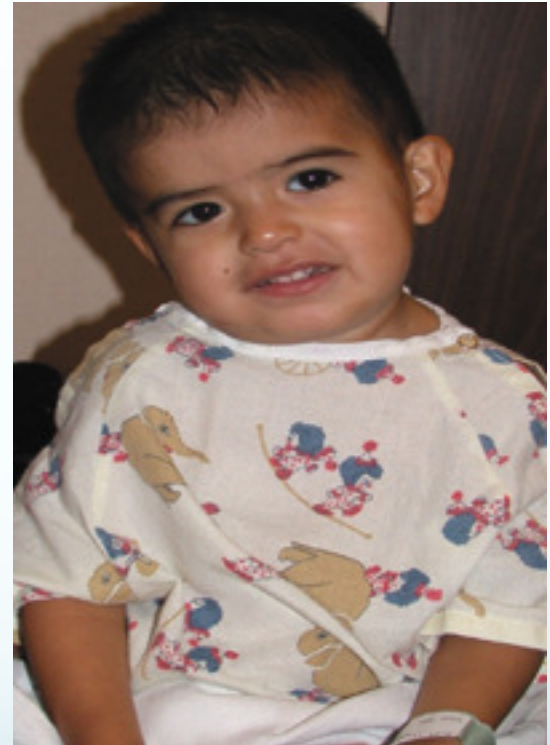
- Understanding risk factors and monitoring
- Recognizing concerning visual behaviors and eye findings
- On-going monitoring (without risk factors)

Concerning visual behaviors

- **Any time:**
 - Does not look at faces, give eye contact
 - Rubs eyes
 - Squints/closes eyes/cries, turns away from bright lights
 - Tilts/turns head to look
-
- **If not occurring by 3 months of age**
 - Does not notice objects above or below the head
 - Notices objects only on one side
 - Does not notice objects above or below head

Red Flags for Vision Concerns

- Poor visual regard
 - Poor tracking (up or down)
 - Wiggling eyes
 - Wandering eyes
 - Head tilt
-
- Use of checklists can be helpful:
 - OADBE checklist
 - NY resource
 - TX informal vision skills inventory and an auditory skills inventory



Concerning visual behaviors

- **If not occurring by 5-6 months of age**
- Doesn't visually follow moving objects
- Doesn't reach for objects
- Over or under-reaches for objects
- Seems unaware of self in mirror
- Seems unaware of distant objects

Concerning visual behaviors

- **Older ages**
- Covers or closes one eye when looking
- Does not look at pictures in books
- Holds books or objects close to eyes
- Stops and steps/crawls over changes in floor texture or color
- Trips over/bumps into things in path

Notable Eye Concerns

- Far-away look in eyes
- Cloudy or milky appearance of eyes
- Droopy eye lid(s) (ptosis)
- Jerky or wiggling eyes (nystagmus)
- Random eye movements
- Squinting, excessive blinking
- Unequal pupil size
- Watery, red, irritated eyes or eyelids

Risk factors for Hearing and Vision Problems

- Family history of vision problems
- Prematurity/NICU related problems
- Birth asphyxia
- Infections (congenital CMV, toxoplasmosis, rubella, meningitis)
- Traumatic brain injury
- Certain syndromes (genetic testing has provided earlier identification of Usher Syndrome)

Syndromes associated with HL and vision impairment

- CHARGE Syndrome (CHARGE Syndrome Foundation www.chargesyndrome.org/)
- Usher Syndrome (www.usher-syndrome.org/)
- Stickler Syndrome
- Treacher Collins Syndrome
- Goldenhar Syndrome
- Infantile Refsum's

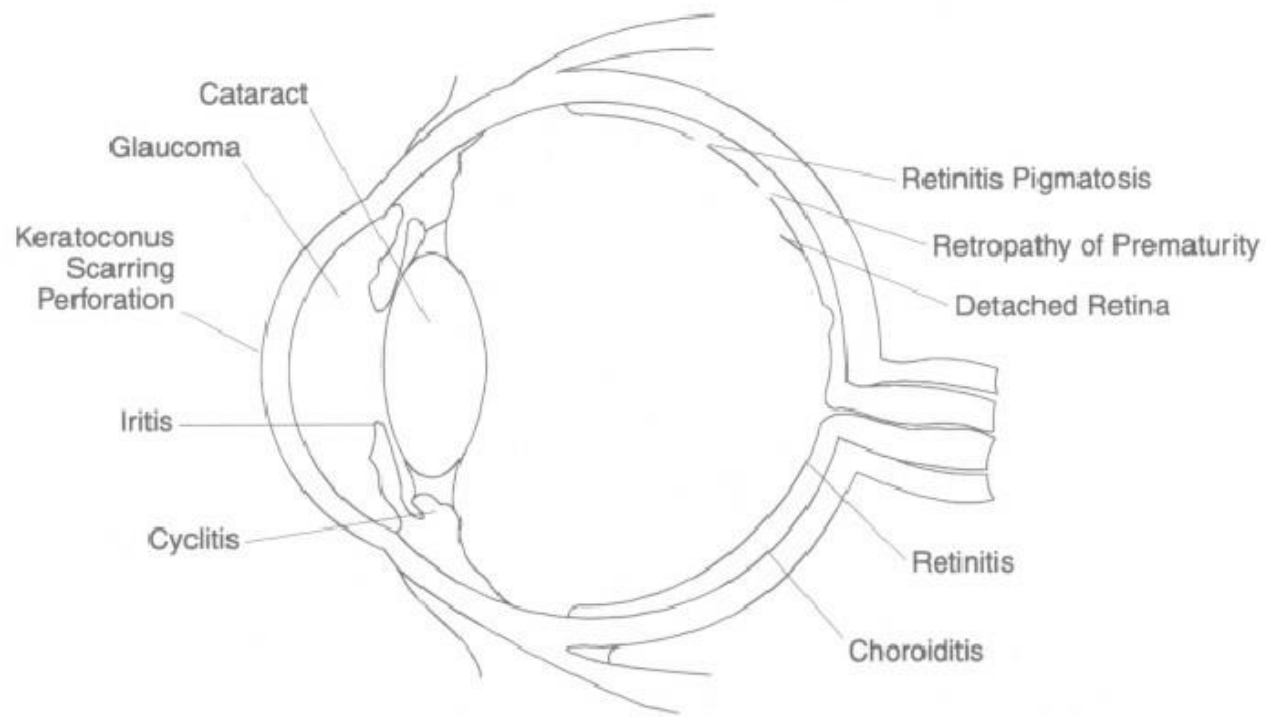
Some conditions affecting vision

- Strabismus
- Cataracts
- Glaucoma
- Retinitis pigmentosa
- Retinopathy of prematurity
- Depth perception (unilateral coloboma, strabismus)
- Coloboma (total blindness to field cut)
- Optic nerve atrophy
- Nystagmus
- Albinism
- CVI
- Visual field cut

Vision Simulations

<http://www.acbvi.org/albums/Vision/slide1.html>

Conditions of the eye



Strabismus

- Crossed eyes
- Double vision
- Eyes that do not align in the same direction
- Uncoordinated eye movements (eyes do not move together)
- Vision loss in one eye, includes a loss of the ability to see in 3-D (loss of **depth perception**)



Normal eye alignment



Crossed eyes (strabismus)

Some causes of strabismus

- Family History
- Apert Syndrome
- Cerebral Palsy
- Congenital rubella
- Hemangioma near the eye during infancy
- Incontinentia pigmenti syndrome
- Noonan syndrome
- Prader-Willi Syndrome
- Retinopathy of Prematurity
- Retinoblastoma
- Traumatic brain injury
- Trisomy 18



Normal eye alignment



Walleyes (strabismus)

Pseudostrabismus

- Due to broad nasal bridge
- Epicanthal folds
- Normal light reflex
- Normal cover-uncover test



- It is never bad to refer just in case as the delayed treatment of strabismus can cause permanent vision impairment

Cataracts

- Cloudy covering of the lens of the eye
- Usually decreases the perception of color, causes light sensitivity, and blurry vision
- Can be due to a number of problems
 - Syndromes (Trisomy's Refsum, Usher Syndrome)
 - Congenital infections (CMV, toxo, rubella, herpes)
 - Trauma to the eye
 - Drugs (such as steroids)

Cataracts

- Cloudy coloration to the lens



- Vision simulation



Glaucoma

- Increased pressure within the eye that can get worse
- If the pressure is not treated effectively, there is progressive pressure on the optic nerve which affects vision
- Usually peripheral vision is affected and then eventually blindness (from pressure on optic nerve)



Retinitis Pigmentosa

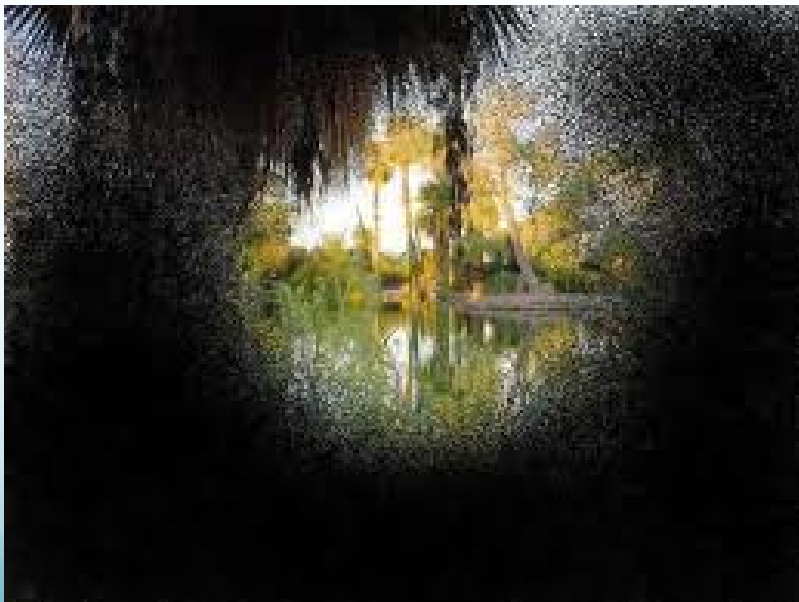
- In retinitis pigmentosa, retinal degeneration occurs and melanin pigment migrates into the retina and deposits
- The condition first begins with the **rods** being slowly destroyed resulting in night blindness and progressive loss of the peripheral field of vision
- This continues to worsen and leads to tunnel vision
- Cone degeneration also occurs and as it progresses, the tubular vision further constricts to the point that central vision is reduced and difficulties occur seeing in the day as well

Retinitis Pigmentosa

- Both eyes are usually affected with this hereditary condition
- Onset is usually between ages of ten and twenty (Lucas, 1989)
- Vision loss is gradual with adolescents often exhibiting difficulty traveling at night, difficulty moving from outdoors to indoor lighting as well as doing certain activity such as playing sports due to a loss of peripheral vision
- As the condition progresses, total blindness can result later in life (Apple & Rabb, 1991)

Retinitis Pigmentosa

- Alstrom Syndrome
- Usher Syndrome



What It's Like



This is how a street scene looks with normal vision.



Example of Retinitis Pigmentosa

Usher Syndrome

- Type I
 - profound SNHL at birth
 - Retinitis Pigmentosa (RP)
 - balance problems
- Type II
 - moderate to severe SNHL
 - RP
- Type III
 - acquired or progressive SNHL
 - RP
- Questions to ask for USI:
 - Late walking
 - Trouble skating or riding a bike with training wheels
- Questions to ask for RP
 - Trouble going from light to dark places (movie theaters)
 - Trouble seeing at night
 - Misses signed conversation from side (seems stuck-up)
 - Gets hit from balls in sports thrown/kicked from the side

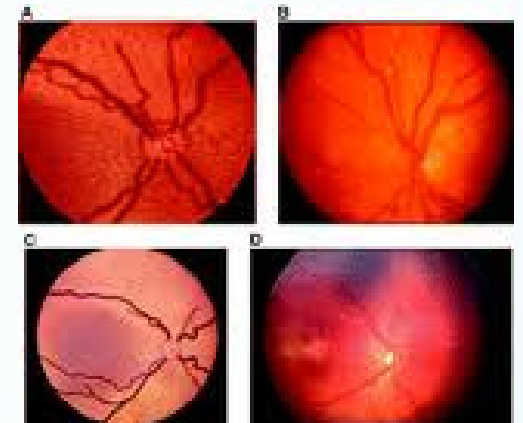
Usher Syndrome

- Diagnosis:
 - Electroretinogram (ERG) will have abnormalities by age 2
 - Vestibular testing
 - Gene studies (Boys Town National Research Center www.boystownhospital.org)



Retinopathy of Prematurity

- ROP is an abnormal growth of blood vessels which occurs in the immature retina (Biglan, Van Hasselt, & Simon, 1988)
- About 90% of the cases are mild and spontaneous regression of these abnormal blood vessels may occur with minimal scarring and little to no visual loss (Flynn, 1987) but are at higher risk for strabismus
- In more severe causes, the abnormal blood vessels extend into the vitreous and may cause retinal detachment, severe visual loss and/or blindness (Biglan, Van Hasselt, & Simon, 1988)
- Children with retinopathy of prematurity have a higher risk of myopia, strabismus and glaucoma



Depth Perception

- Can occur from:
 - Unilateral vision loss (may be a reason not to drive)
 - Amblyopia
- Problems with depth perception can impact “balance” and motor skills
- Troubles going up and down stairs
- Difficulties moving from one flooring to another (tile to carpet)
- Over or under-shooting when trying to pick up a small object

Coloboma

- A missing piece (cleft, notch, gap) anywhere along the eyelid/eyeball
- Depending on where it occurs, may impact greatly (on the optic nerve) or very little (only on the eyelid or iris)
- If the retina or optic nerve is involved, there is usually a blind spot or field loss corresponding to the site of the defect (Apple & Rebb, 1991)

Coloboma

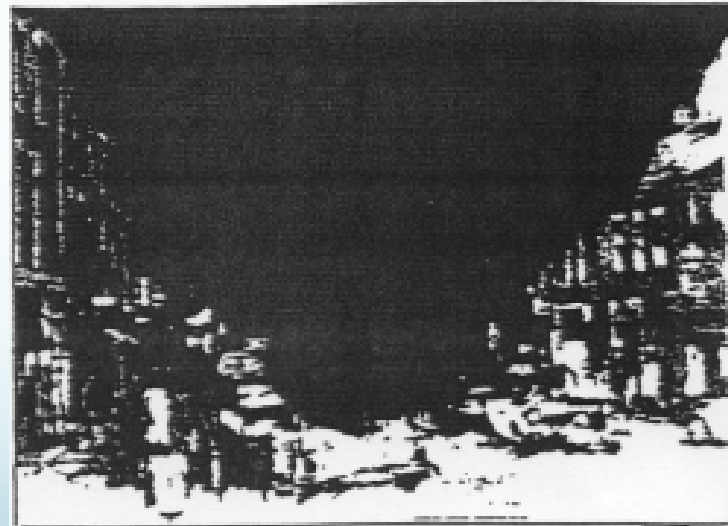
- Depending on where the field cut is, may have problems seeing above (low overhanging tree limbs) or below (what is at the feet, curbs, toys on the ground)
- A field cut can cause a head tilt (to get the best vision of where they need to see)
- There may be a decrease in visual acuity, as well as such concomitant visual abnormalities as strabismus or nystagmus
- Usually associated with a syndrome (such as CHARGE, Trisomy 13)

Coloboma

- Iris coloboma

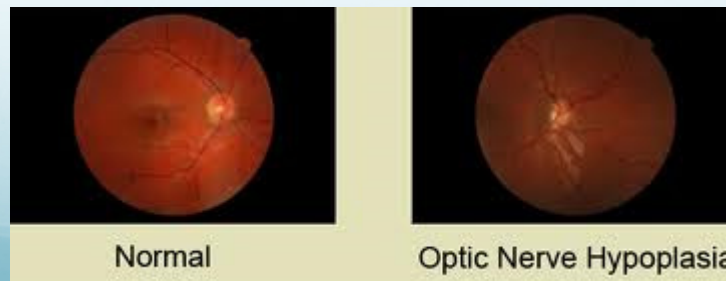


- Large visual field cut



Optic nerve atrophy

- Atrophy of the optic nerve can be hereditary and/or can be caused by numerous diseases and disorders (e.g. retinitis pigmentosa, tumors, hydrocephalus, and head trauma)
- Central visual loss and field losses are often present with the visual loss typically being roughly proportional to the amount of nerve atrophy (can have total blindness)



Congenital optic nerve hypoplasia

- Incomplete development of the optic nerve causing variable degrees of visual impairment
- It is often associated with neurological disorders and endocrine problems (septo-optic dysplasia)
- Can't really make the vision clearer (like a faded photo)



Microphthalmia/Anophthalmia

- Some children may be born with microphthalmos, which is extremely small eyeballs
- It is common in children who had congenital rubella and is associated with poor visual acuity and nystagmus



Nystagmus

- Nystagmus consists of involuntary, rhythmic eye movements, primarily in the horizontal plane
- Movement can be vertical, diagonal, or rotary and can be fast or slow
- Drifting eye movements may be present and present as slow searching movements with no evidence of fixation
- When nystagmus is present during the first year of life, it may be indicative of the presence of a bilateral vision loss
- It can also be due to a neurological impairment (i.e. hydrocephalus)

Nystagmus

- When nystagmus occurs later, the individual may have poor visual acuity in the affected eye, although binocular vision may be unimpaired
- Nystagmus is usually associated with congenital visual abnormalities (Hoyt, 1987)
- In some instances of congenital nystagmus, the brain adjusts to the eye wiggle



Albinism

- Skin, hair, and eye discoloration are caused by abnormalities of melanin metabolism
- Photophobia
- Decreased vision due to foveal hypoplasia, high refractive error, and/or nystagmus
- Strabismus due to abnormal decussation of optic nerve fibers

Albinism

- Nystagmus - Earlier onset of nystagmus correlates with degree of foveal hypoplasia
- History of easy bruising or recurrent infections in patients with Hermansky-Pudlak syndrome and Chediak-Higashi syndrome, respectively
- Decreased hearing associated with some forms of X-linked ocular albinism



Cortical Vision Impairment

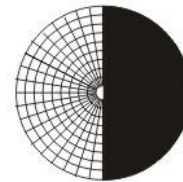
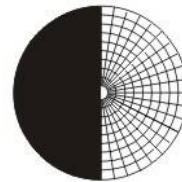
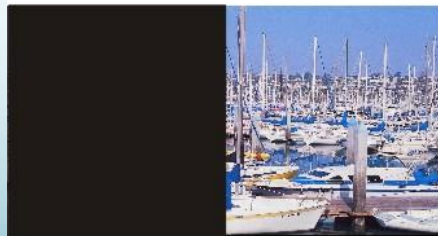
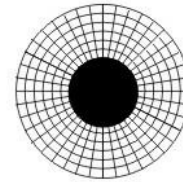
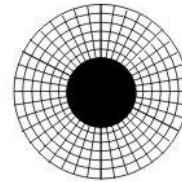
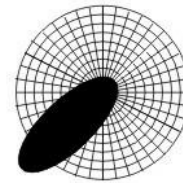
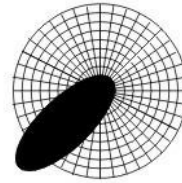
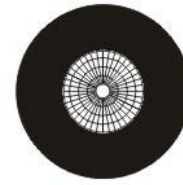
- Cortical visual impairment (also known as cortical blindness) is a term used to describe damage to the visual pathways or cortex of the brain
- The eye shows no pathology, however the brain is unable to process the incoming visual information
- The resulting visual impairment may range from partial loss of visual acuity to blindness, depending on the exact location of the damage
- Visual field defects may be present as well

Cortical Vision Impairment

- There are several causes of cortical visual impairment:
 - closed head injury, drowning, prolonged convulsion, meningitis, and hypoxia resulting in brain damage (birth asphyxia, cerebral palsy)
- With some of these, visual improvement may occur over time
- Hydrocephalus, which is not adequately treated with shunting, may also result in a visual loss (as well as causing optic nerve atrophy)
 - Some improvement in vision may occur after shunting, but this is not always the case (Buncic, 1987)

Visual Field Cut

- Normal visual fields include areas of peripheral and central vision
- Peripheral vision losses include losses in the outer portions of the visual field (e.g. retinitis pigmentosa)
- Peripheral field loss results in a reduced angle of vision, or limits how much a person can see at one time
- A person with a peripheral loss will find it difficult to see in dim light and travel independently at night



Functional Vision Assessment

- A teacher of the visually impaired is essential in the provision of services to children with dual sensory impairment
- The eye exam/ophthalmology exam only gives limited information about vision
- Getting a sense of how a child uses their vision and the best approach to provide information is critical

Functional Vision Assessment

- May assist you in determining:
 - Best lighting (light focused on the item, backlighting with a light box, etc)
 - Best angle or presentation of information
 - Best font size/contrast needs
 - Best speed with which we can present information (visual tracking)
 - Most visually relevant information for the child
 - Tactile adaptation of materials

Identifying Deafblindness

- Red Flags and Algorithms
- Early Intervention Services!

Early Intervention Domains

- Physical
- **Communication/Language**
- Self Help
- Social-Emotional
- **Cognitive**

Vision's importance in developing communication for Deaf/HH

Deafblindness: is a disability of access

What is Communication?

...a process by which information is exchanged between individuals through a common system of symbols, signs, or behavior

~Merriam-Webster



Communication vs. Meaningful Communication

- The difference between the two of these is the child's ability to convey their wants and needs (*communication*) verses the ability to tell someone about their day, or to express why they like one thing over another, or to teach them about safety (*meaningful communication*)
- Getting to meaningful communication starts with building a foundation of basic communication and concepts when the child is young

Communication and Language

- How do you think children who are deaf/blind learn concepts to support language development?

The Importance of Communication

- The most important thing you can do for a child who is deafblind is to develop a communication system early
- Children who are deafblind will retreat inside themselves when they have no outside stimulus; they have no idea that an entire world exists outside of their reach
- Building concepts and communication gives them a reason to explore and learn about their environment

Communication

What ways have you seen children who are deaf-blind communicate?

<https://www.youtube.com/watch?v=F8DiZbCu3TM>

Communication and Language

- What are ways children communicate?
- Communication vs language
- Hierarchy of communication skills
- Pre-linguistic communication, language development and how vi and d/hh impact communication

Forms of Communication

- Gestures
- Facial Expressions & Body Language
- Signed Languages, including modified forms
- Spoken Languages
- Total Communication
- Touch Cues
- Tangible Symbols
- Tactile

Communication Options and adaptations

- Consider using some of the tools from the deaf-blind CI study (language maps, gestural hierarchy)
- Touch cues, object cues, picture cues (depending on vision), gestures, sign/speech, written language

Communication Skills of a Deafblind Child

Obvious

- Speech
- Sign
- Pictures
- Drawings
- Communication boards and systems

Less Obvious

- Moving you to an object
- Standing near an object
- Eye gaze
- Withdrawal
- Changes in muscle tone
- Acting out

Touch Cues

- A touch cue is a touch that is done in the same place and the same way right before you do something with the child
- It lets the child know that something *familiar* is about to happen
- It allows the child to remain calm and helps him feel safe

Touch Cues

- Many children who are deafblind are tactually defensive, not knowing when or where or how they will be touched, or even if it will be pleasant or hurtful
- Touch Cues alert the child that *something* is about to happen to them
- Touch Cues are often used throughout a person's life

Examples of Touch Cues

- Tap a child on the upper right arm before picking him up
- Tap or rub a child's thighs before changing his diaper
- Rub the back of the child's hand before putting your hand under his for hand-under-hand exploration

Tangible Symbol Systems

- Tangible Symbol Systems is a method of communication that uses concrete, rather than abstract symbols
- Examples include:
 - cup = drink
 - washcloth = bath time
 - shoe = going outside
- www.designtolearn.com

Tangible Symbol Systems

- Another form is a calendar box
- Communication Board



Tangible Symbol Systems

- A tangible communication system is a natural progression from the touch cues as a child gets older and begins to understand concepts such as bath time, eating, and going places

Tactile Communication

- Tactile communication is most often thought of as tactile sign language
- Other forms of tactile communication include Braille, Tadoma, and Print on Palm (all three of these are for older children and adults)



Tactile Sign Language

- For tactile signing with a young child, use the Hand-Under-Hand technique while signing to the child
- Emphasize or repeat words/concepts you want the child to understand (more, eat, finish)

Pre-Braille Activity

- Using the Hand-Under-Hand technique, poke holes in a piece of paper. Turn the paper over and let the child rub his hand over the bumps you made from the holes
- Develop concepts by creating the outline of an object, such as a flower or a house (use a coloring book picture as a template). When the child feels the bumps, you can sign and say 'flower' (and maybe give him a flower) to help create that concept.

The Importance of Hands

- Deaf children rely on vision to learn language, communicate, and explore the world
- Blind children rely on hearing and touch to learn language, communicate, and explore the world
- Deafblind children rely on touch and any residual hearing and vision to learn language, communicate, and explore the world
- Never grab a child's hand and put it on/in something
- Always use the Hand-Under-Hand technique

Hand Experience

1. Pick a partner
2. One person will put the goggles on; the other person wait for further instruction.

Hand Experience - Part 1

1. We will hand out plates and hand sanitizer
2. Squeeze a large amount of hand sanitizer on the plate.
3. Without saying anything, pick up your partner's hand and quickly put it in the hand sanitizer, trying to flatten their hand.

Discussion: How did that make you feel?

Hand Experience – Part 2

1. Sighted person- without saying anything, slide your dominant hand under your partner's dominant hand
2. Lift your hand straight up and move it toward the plate and hand sanitizer
3. Introduce their hand to the hand sanitizer by moving your hand out from under their hand slowly so that they touch and feel the hand sanitizer.
4. They always have the option to remove their hand whenever they want.

Discussion: How did this approach make you feel?

Family Participation in Early Intervention

- Establish a relationship
- Trust
- Respect
- Flexibility
- Guide
- Model

Early Literacy Skills

- Building a Foundation*
- Early Emergent Literacy*
- Emergent Literacy
- Writing
- Vocabulary Development
- Comprehension
- Increasing Fluency
- Expanding Literacy

www.literacy.nationaldb.org

Building a Foundation

- Develop a trusting relationship with the child.
- Find communication opportunities through the day.
- Design learning experiences that are meaningful to the child.

www.literacy.nationaldb.org

Early Emergent Literacy

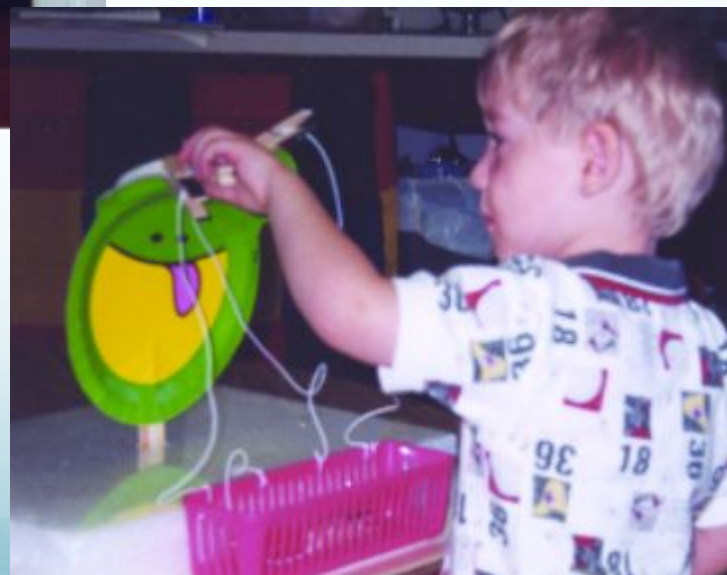
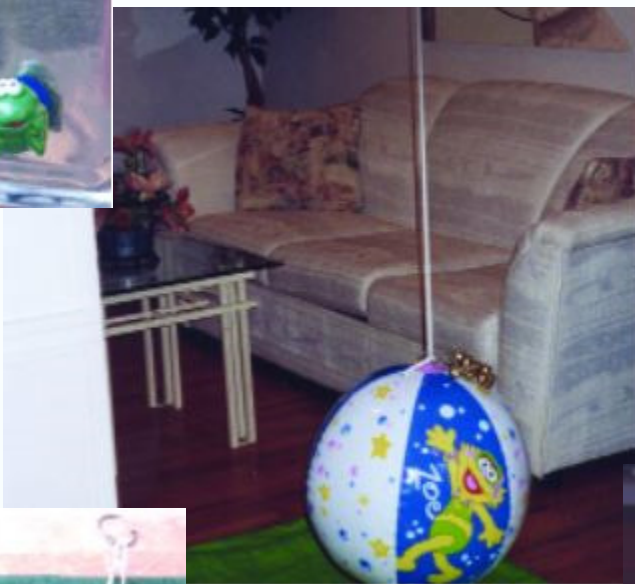
- Model reading and writing behaviors.
- Embed the use of objects, symbols or words throughout the child's day.
- Incorporate rhythm, music, finger play, and mime games.
- Provide opportunities for handling and exploring reading and writing materials.
- Teach print and book awareness.
- Teach name, name sign of child and of persons the child interacts with regularly.
- Embed literacy learning activities into routines.

www.literacy.nationaldb.org

Creating Safe Play Spaces

- High Interest, multi-sensory materials
- Anchored down
- Self-initiated Exploration
- Easily adaptable
- Individual use or with others
- Inexpensive and Easy to create

Examples



Let's Create Your Space

Interacting with a Deafblind Child

- Don't be afraid
- Ask questions
- Learn about the child's useable vision
- Learn about the child's residual hearing

Deaf vs. Deafblind

Deaf /Hard of Hearing Child

- Focus on Visual
- Visual Presentation
- Voice Qualities
- Facial Expressions

Deafblind Child

- Focus on Tactile
- Hand Under Hand Technique
- Voice Qualities
- Facial Expressions
- Focus on Movement

Early Intervention Strategies

- Can add cases or role play
- Desensitizing for hand play
- Hand under hand and practice
- Appropriate cueing (shoulder tap)
- Importance of fragrances

More Information on EI for DB

- Hold Everything
- National Center on Deafblindness
- “Strategies for Creating Communication-Rich Environments for Children who are Deaf-Blind,”
*Maurice Belote, California Deafblind reSource
Spring 2008, Volume 13, Number 2, page 5*

What's Next?

TRANSITION!

What's with the alphabet soup?

Part B

ESY

Part C

O&M

IFSP

TVI

IEP

TOD

SEA

SLP

LEA

AVT

ETR

IDEA

Comparison

Part C

- Birth to 2 years
- Eligible based on current development delays or “at risk”
- Support is family focused
- Natural Environment

Part B

- 3 years to 21 years
- Eligible based on IDEA criterion
- Support is child focused
- Least Restrictive Environment (LRE)

Transition Timeframes

- 9-12 months
- 6 months
- 3 ½ months
- 90 days
- On or Before 3rd Birthday

Who's Who in Transition

- EI Provider
- LEA
- Service Coordinator
- Teacher of the Deaf/Teacher of the Visually Impaired
- Deafblind Specialist

Evaluations of Students

It's Tricky!

Covers @ FirstCovers.com

100

How do we get appropriate evaluation?

- Evaluator knowledge and expertise
- Vision
- Hearing
- Neurological Evaluation (Sensory & Cognitive)
- Fine and Gross Motor Skills
- Communication (Receptive & Expressive)
- Functional Assessments
- Parent Input

Evaluation Tips

- Take a team approach
- Seek Assistance
- Use appropriate evaluation tools & assessments
- Prepare and ask questions
- Consider contacting state Deafblind project

IEP Considerations

TEAMWORK

- Student Desires
- Student Desires
- Need Area
- Related Services
- Accommodations
- Modifications

IEP Need Areas

- Academic
- Functional
- Behavior
- Social
- Communication

IEP Considerations

- Supports to address environmental needs
- Levels of support staff needed
- Student's specialized equipment needs
- Presentation of subject matter
- Materials needed
- Self-management and/or follow through needed
- Testing adaptations
- Social interaction support

**Developing an Effective IEP for Children with Deaf-Blindness: A Parent
Mini-Guide: Perkins School for the Blind, 2011*

More IEP Considerations

- Equal Program Access
- State and District Assessments
- Placement
- Needed Personnel Development
- Special Considerations
 - Communication Needs
 - ESY
 - Braille
 - Assistive Technology
 - Behavior Needs
 - Transition to Adult

Possible Related Services

- Teacher of the Visually Impaired (TVI)
- Orientation & Mobility Specialist (O&M)
- Vision Therapist
- Intervener
- Psychological Services
- Occupational Therapy/Physical Therapy
- Medical Services
- Teacher of the Deaf/Hard of Hearing
- Educational Audiologist
- Interpreter
- Speech Language Pathologist (SLP)
- AVT Therapist
- Deafblind Specialist
- Paraprofessional
- Parent Training & Counseling

Possible Accommodations & Modifications

- Amplification
- Assistive Devices
- Communication
- Instructional
- Physical Environment
- Curricular Modifications
- Evaluation Accommodations & Modifications
- Other

Case Review



The Ohio Center for Deafblind Education

Providing services in Ohio for individuals birth through 21 years with deafblindness including free collaborative technical assistance to families, educational personnel and service providers through training and information dissemination.

The Ohio Center for Deafblind Education is a grant-funded project awarded to the School of Education and Health Sciences Grant Center, University of Dayton, by the U.S. Department of Education with support from the Ohio Department of Education.

www.ohiodeafblind.org

OCDBE

- Part of the nationwide system of state projects to improve the needs of deafblind children
- Conduct yearly state census
- Collaborative Approach with other state and national agencies and organizations
- Meeting Stakeholders Needs

State Deafblind Projects

- For more information about services in your state for children who are deafblind, please contact your state Deafblind Project. Follow the link below for a list of contact information for each state project:

<https://nationaldb.org/members/list?type=State+Project>

Putting it all together

- A combination of
 - establishing realistic goals with family as the hub
 - using structured salient assessment/planning tools
 - trying creative and varied approaches
 - observing what happens and adapting as needed
- May be an effective tool-kit for complex children

Goals/Planning

Rules to guide instruction

- **Focus on the donut, not the hole**
- Celebrate successes great and small
- If a dead man can do it, **it is not an appropriate objective**
- Use **meaningful contexts** to make concepts explicit
- “I would tell them to be an advocate for your child and let the professionals know how your child is reacting.”

Dr. T. Jones, Gallaudet University

Team Building

- Strive towards common goals
- Listen actively
- Communicate effectively between/among team members
- Be confident in what you know and recognize when you don't know something
- Learn from others/collaboration
- Be open to new ideas and strategies
- Think outside the box
- Consider co-treatment when appropriate
- Try something and tweak it when it doesn't work

Resources

DB Resources: State Deaf-Blind Educational Centers

THE OHIO CENTER FOR

DEAFBLIND EDUCATION

Home | Join Our Mailing List | Contact Us

Home Services Resources Census About Us Contact Us

The Ohio Center for Deafblind Education

Providing services in Ohio for individuals birth through 21 years with deafblindness including free collaborative technical assistance to families, educational personnel and service providers through training and information dissemination.

The homepage features a grid of images showing diverse individuals: a young man in a red shirt making a hand gesture, a woman and a young girl smiling, a woman sitting on a bench, a man kissing a baby, a young girl with glasses, and a young boy.

• <http://ohiodeafblind.org/>

DB Resources



NATIONAL
CONSORTIUM ON
DEAF-BLINDNESS

Home
About NCDB
Contact NCDB

News and Announcements
About Deaf-Blindness
Text Only Version
en Español

For Families

Technical Assistance

Personnel Development

DB-LINK Info Services

- Selected Topics
- DB-Library
- People and Programs
- NCDB Products
- Conferences and Trainings
- Research to Practice
- Deaf-Blind Perspectives
- New Publications



–<http://nationaldb.org/>

National Consortium on Deaf-Blindness

- DB-LINK: many good articles, references
- Deaf-Blind Perspectives: a newsletter
- Up to date list of conferences and professional development workshops
- Family page: stories, articles
 - I wish I had known about non-verbal ways to communicate with my daughter Sara when she was much younger. When Sara was 10, we were introduced to a wonderful educator who specialized in non-verbal communication. Dr. Mary Morse came to Sara's class to talk to the school team about object communication and calendar boxes. It changed our lives for the better. Sara learned that objects represented activities and she loved the power that this knowledge gave her in school and at home.
 - ~ Janette Peracchio, Connecticut

<http://www.nationaldb.org/FFWish.php> (6 minute video)

Perkins School for the Blind



Search Perkins

- Inside Perkins School
- Community Programs
- International Programs
- Living With Vision Loss
- Teaching Resources
- News & Events
- About Us

Home > Teaching Resources > Educational Publications > Deafblindness: Educational Service Guidelines

- Teaching Resources**
- Curricular Resources
- Educational Publications
 - DB Guidelines
- Resource Packets
- Samuel P. Hayes Research Library
- Scout: Information on Blindness & Visual Impairment

Deafblindness: Educational Service Guidelines

Deafblindness: Educational Service Guidelines offers state and local education agencies a framework from which meaningful, appropriate programming for students who are deafblind can be developed. These guidelines identify the knowledge and skills educators need to assist their students who are deafblind reach their full potential and become successful, contributing members of our society.

Click on the following Chapters and Appendixes to jump to a description of the section.



www.perkins.org/resources/educational-publications/deafblindness-educational-service-guidelines/

Perkins School for the Blind

- Information on vision impairment
- Training opportunities (webcasts, library)
- Outreach services for students
- Families have attended evaluations
- Summer programs

Perkins Webcasts

- **CHARGE Syndrome: An Overview**

By Pam Ryan

In this webcast, 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 talks about some of the early medical complications that many children face and how these issues affect development and learning.

- **CHARGE Syndrome: Teaching Strategies for Children**

By Sharon Stelzer

Sharon Stelzer, a long term teacher in the Perkins Deafblind Program, discusses the impact of 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 talks about the benefits of helping students with CHARGE Syndrome learn the art of negotiations.

- **CHARGE Syndrome: The Impact on Communication and Learning**

By Martha Majors

This very insightful webcast explains the physical, sensory and neurological issues shared by many children with CHARGE and how these issues can affect their success in school. Martha Majors, who has served many children with 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.

Perkins Webcasts

- **Conversations: A Personal Reflection About Deafblindness**

By Barbara Miles In this webcast, Barbara Miles, a well-know 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

In this webcast, Susan DeCaluwe discusses the development of the Communication Portfolio for learners with deafblindness and multiple disabilities. This tool, that 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.

Perkins Webcasts

- **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.

- **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.

Questions





**OHIO
HANDS &
VOICES™**

Tabitha Belhorn

*tabitha.belhorn@
ohiohandsandvoices.org*

Dr. Susan Wiley

susan.wiley@cchmc.org



THE OHIO CENTER FOR



DEAFBLIND EDUCATION

Leanne Parnell

lparnell@ohiodeafblind.org

