What is Deaf-Blindness?

When Multiple Disabilities Include Hearing & Vision Loss

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Florida & Virgin Islands Deaf-Blind Collaborative

www.deafblind.ufl.edu

IDEAs that Work
Office of Special Education Programs

Goals of Training

Participants will understand:

- The impacts of sensory loss (hearing & vision loss)
- The diverse nature of “deaf-blindness”
- Appropriate referral sources and practices.

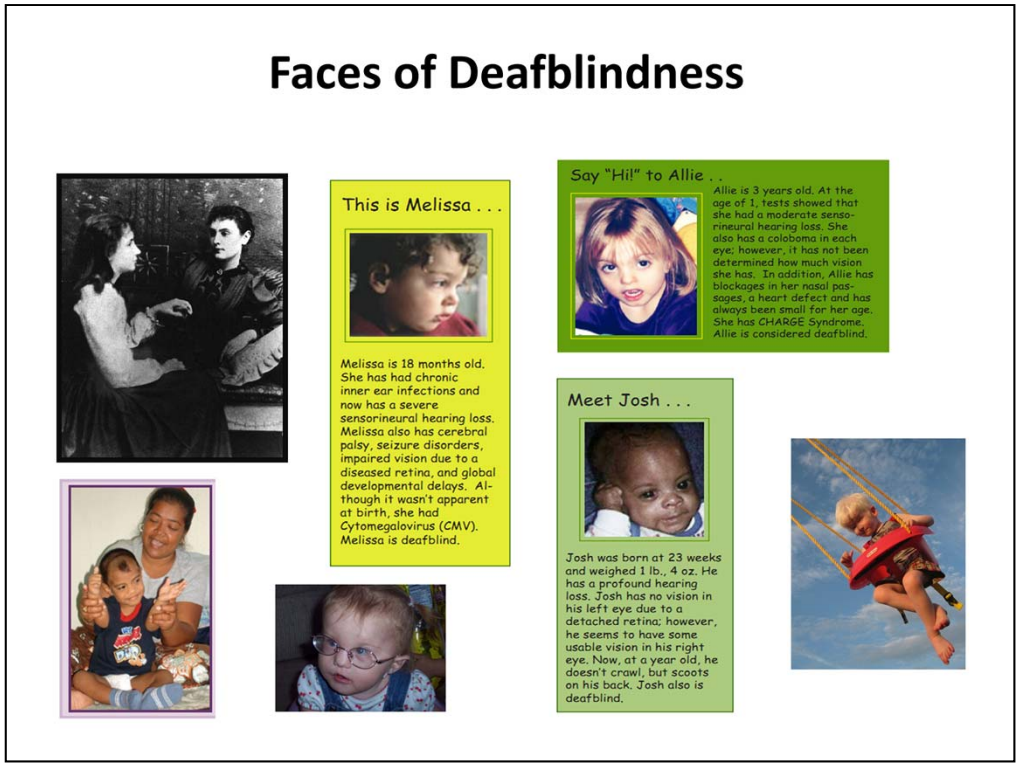
The Diversity of "Deafblindness"

- Although "deaf-blind" implies a total absence of vision and hearing, this is not the case with most individuals who are deafblind.
- Most children and youth who are deaf-blind have some useable hearing and/or vision.
- There is no single profile of a learner who is deaf-blind.
- Deaf-Blindness is estimated to affect 1 – 2 per 1,000 individuals with disabilities.

Discuss the individuality of deaf-blindness with examples of children / students on your state census (Noah).

Detail different combinations of sensory loss to make the point on diversity: blind with mild loss; deaf with cortical visual impairment, etc.

"Once you have met one individual with deaf-blindness, you have met ONE individual with deaf-blindness."



Many times the person that is most recognized / remembered as being deaf-blind is Helen Keller.
While Helen and her teacher Annie Sullivan played an important role in increasing awareness
of the educational needs of someone who is deaf-blind, there are many very different faces of combined vision and hearing loss.

Deaf-blindness:

**BOTH VISION AND HEARING*

loss are DIAGNOSED OR SUSPECTED

- Usually some usable hearing and vision

- More than 90% of children with combined vision and hearing loss have additional disabilities or health problems

- Having multiple disabilities or complex health problems often keeps combined vision and hearing loss from being recognized or addressed

Most teachers of children who are blind/visually impaired, and teachers of the deaf/hard of hearing,
have overview training in deaf-blindness,
but these teachers do not usually have the equivalent of a deaf-blind specialist.
These professionals, like other educators and related service providers, will need training specific to working with a child who is deaf-blind.

Other Terminology

- Co-Occurring Sensory Loss
- Dual Sensory Impairment / Loss
- Combined Vision and Hearing Loss
- Multidisabled (with sensory loss)

Even if students are identified as having multiple disabilities,
rather than *deaf-blindness*,
the impact of the combined vision and hearing loss
MUST BE RECOGNIZED AND ADDRESSED (NCDB, 2007)

Children who meet the criteria for their state deaf-blind project may or may not qualify for hearing loss and vision loss services from their schools/districts and other agencies.

Different states may use different umbrella names. Parents may have a preference for how their child's dual sensory loss is described.

What Is Hearing Loss?

- Mild loss (26-40 dB loss)
- Moderate (41-55 dB loss)
- Moderately severe (56-70 dB loss)
- Severe (71-90 dB loss)
- Profound (91+ dB loss)
- Suspected or Functional hearing loss
- Central Auditory Processing Disorder
- Diagnosed progressive loss or fluctuating hearing loss

Note the impact of ear infections (fluctuating hearing loss).
Simulations of what hearing loss can sound like:
https://youtu.be/it4ZjKQ2WMQ
www.youtube.com/watch?v=4YxEuI1kHn8&NR=1
https://youtu.be/ar1Dq-M2ok4
https://youtu.be/JYU8dazc79A
https://youtu.be/ln8NHzVfJkQ
https://youtu.be/9-rM0OgKLZo
https://youtu.be/04t-qpiT5-A

Simulations of what hearing loss can sound like:

https://youtu.be/it4ZjKQ2WMQ

https://youtu.be/ar1Dq-M2ok4

https://youtu.be/ln8NHzVfJkQ

https://youtu.be/9-rM0OgKLZo

www.youtube.com/watch?v=4YxEuI1kHn8&NR=1

https://youtu.be/04t-qpiT5-A

https://youtu.be/JYU8dazc79A

What Is Vision Loss?

- Low vision (visual acuity of 20/70 to 20/200)
- Legally blind (visual acuity of 20/200 or less or field restriction of 20 degrees or less)
- Light perception only
- Totally blind
- Diagnosed progressive loss or fluctuating vision loss
- Cortical or Cerebral (brain-based) vision loss (CVI)
- Learning impacted by vision – Functional Vision Loss

https://youtu.be/dPC_--R-Ma0?list=PL-u_LvTBjntGh7iI3C1LMuDkg5mht83Lo

Some conditions may result in a temporary label of deaf-blindness whereas others will confirm a long term label of deaf-blindness.

For example, a child with strabismus and amblyopia AND hearing loss may or may not continue to be considered deaf-blind based.
Cortical Visual Impairment (CVI) may be accompanied by optic nerve atrophy. This is usually a SYMPTOM of the underlying condition—CVI.

https://youtu.be/v9CawJSUy2c?list=PL-u_LvTBjntGh7iI3C1LMuDkg5mht83Lo

https://youtu.be/LS-SgDaqYKM?list=PL-u_LvTBjntGh7iI3C1LMuDkg5mht83Lo

https://youtu.be/dPC_--R-Ma0?list=PL-u_LvTBjntGh7iI3C1LMuDkg5mht83Lo

https://youtu.be/6rbHOAtBNew?list=PL-u_LvTBjntGh7iI3C1LMuDkg5mht83Lo

Who is Deaf-Blind?

	Normal Hearing	Hard-Of-Hearing (mild-mod)	Deaf (severe to profound)	Progressive Loss	Central Auditory Processing Disorder
Normal Vision		Hearing Loss	Hearing Loss	Hearing Loss	Hearing Loss
Low Vision	Visually Impaired	Deaf-Blind	Deaf-Blind	Deaf-Blind	Deaf-Blind
Legally Blind	Visually Impaired	Deaf-Blind	Deaf-Blind	Deaf-Blind	Deaf-Blind
Progressive Loss	Visually Impaired	Deaf-Blind	Deaf-Blind	Deaf-Blind	Deaf-Blind
Cortical Visual Impairment	Visually Impaired	Deaf-Blind	Deaf-Blind	Deaf-Blind	Deaf-Blind

*INCLUDES OBSERVED (Functional) or SUSPECTED SENSORY LOSSES

There are different types of vision loss (ocular, cortical, or both) and hearing loss (conductive…. CAP)

Range of vision loss may be different in each eye, in each ear. Vision loss may be more or less severe than hearing loss.

The yellow boxes define the learners who have combined vision and hearing loss.

Critical Factors that Influence the Impact of Deaf-Blindness

*Cognitive impairments (66%)

*Communication / Speech / Language

*Physical impairments (57%)

*Complex health care issues (38%)

*Behavior challenges (9%)

*Other (30%)

- It is estimated that more than 90% of children who are deaf-blind have one or more additional disability or condition.

From 2007 NCDB *What is Deafblindness* handout

Florida Demographics

Approximately 545 children / young adults with deaf-blindness

Additional Disabilities Reported:

Cognitive impairments (52.4%);

Physical impairments (42.6%);

Complex health care needs (38.6%)

The number of children / young adults (ages 0-22) currently registered with the FAVI Deaf-Blind Collaborative
UNDERESTIMATES the number of children who cannot use their hearing and vision effectively
for communication and learning.

Ask Yourself…

1. Does the learner have enough vision to compensate for his or her lack of hearing?

2. Does the learner have enough hearing to compensate for his or her lack of vision?

3. Is the child able to use vision and hearing effectively to gather information, communicate, and learn?

*If the answer is no to any of these questions, the learner may be defined as being deafblind.

***The learner may rely greatly on a sense that has even significant compromise.**

***Assumptions cannot be made about how a learner with deaf-blindness uses remaining senses. A child with visual loss may still be a visual learner, etc.**

***Touch may or may not be a dominant learning avenue initially.**

The learner's willingness to be touched or use touch may be compromised without a personal relationship with another person and/or without the use of hand-under-hand guidance.

How is Deaf-Blindness Confirmed

- Eye Care Specialists confirm visual diagnosis, status, treatment options, and prognosis
- Audiologists confirm auditory status and listening device options.
- School personnel observe functional status of vision and/or hearing.

Presenter's Notes:

Customize to your state eligibility criteria and personnel qualified to make the determination of sensory loss.

Impact of Deaf-Blindness

- Reduced Sensory Input = Limited access to information
- Social and Emotional / Relationships

  — Much of our early bonding occurs through use of eye contact, reading and responding to body language, facial expressions, and sounds.
- Communication
  - Receptive
  - Expressive
- Motor / Movement
- Cognitive / Learning / Academics
- Activities of Daily Living / Self Help

This is a not a sequential list . Each domain influences the others. Social emotional affects relationships with everyone that the learner comes into contact with – at home, in the community, on the job, etc.

One of the biggest concerns with deaf-blindness is the feeling of isolation. There may be a tendency to focus inwardly unless people and the world are safe and inviting.

The Challenge of Deaf-Blindness

- The challenge faced by people with both hearing loss and vision loss is much greater than just the sum of the two losses.
  The problem is not additive, but multiplicative.

  (-vision) x (-hearing) = (challenge)2

- In many ways, deaf-blindness is a disability of access to information and communication.

Access = incidental learning, viewing items in a room / classroom, seeing print

Communication = hearing sounds or other's voices, watching body language, etc.

Deafblindness affects EVERY aspect of an individual's life.

"People rely upon information about the world around them, in order to learn, function, and interact with others. Vision and hearing are the major senses through which this information is access. Individuals, who have vision and hearing loss or deafblindness, are unable to access this essential information in a clear and consistent way. Deafblindness is a disability of access – access to visual and auditory information."

(Alsop, Blaha, & Kloos, 2000)

***Vision loss typically affects incidental learning, concepts development, and mobility.**

***Hearing loss typically affects communication and socialization.**

***All degrees of combined vision loss combined and compound the individual sensory losses.**

***There is not a domain or aspect of a learner's life that will not be influenced by dual sensory loss.**

***The more we understanding about the affects of deaf-blindness, the better we can work to alleviate and minimize potential challenges.**

Importance of Identification

Concomitant vision and hearing loss is likely to impact all facets of development.
Early identification helps to ensure:

• early treatment of sensory loss conditions to optimize sensory function

•appropriate intervention to optimize development and learning

•access and input/output (receptive/expressive) needs are identified and supported (strategies and/or adaptive equipment)
to optimize communication and participation

Research has proven that support variables affect a learner's outcomes.

Example:
Child identified at an early age with a congenital dual loss versus an older student who has a loss such as later vision loss with Usher syndrome.

Accessing Information Impact

- If a child can access information, he or she can learn. Access is our job.
- Vision and hearing are our distance senses
- Hearing is our only sense that can “bend around corners.”
- Vision takes in more information all at once than any other sense (gestalt and detail).
- Even mild hearing / vision loss can have serious impact.
- Learners who are deafblind are not limited by what they can learn but by how much and what we teach them using effective strategies

Fragmented or distorted information may occur with a vision and/or hearing loss.
Give an example of a real student and missing or distorted information
Example: an adult person with deaf-blindness not knowing that the internal portion of an apple was not red because she only was taught that apples were red

Communication Impact of Deaf-Blindness

- The learner may not understand that actions influence or cause something to happen.
- Opportunities to acquire symbols to represent communication may be limited or reduced.
- All learners need repetitive, meaningful exposure to use of objects, symbols, sign language, speech, etc.
- If a learner cannot express wants and needs, behavior issues are likely to develop.
- Unconventional behaviors may not begin as communication, but can be shaped as intentional communication.

Reading cues is an ongoing communication skill. Deaf-blindness often means limited ability to read communication partner / caregiver cues. Communication can occur through facial expressions, body movement, gestures, sign language, words, etc.

A learner may use atypical actions or sounds to indicate needs that may be recognized by some caregivers / providers and not understood by others—based on familiarity with the student.

Learning Impact

A great deal of learning comes from observing and imitating what others are doing.

- Child may develop unique learning style.
- Concept development
  - External / internal world confusion.
  - May develop fragmented or distorted concepts due to lack of full experience.
  - Abstract concepts may be more difficult to learn

http://nationaldb.org/NCDBProducts.php?prodID=29

***External / internal world confusion – learner's understanding of where he or she leaves off and the world begins.**

***Abstract concepts – the light from the moon, a cobweb, etc.**

***Note trouble distinguishing between a concrete and an abstract concept. Concrete = apple. Abstract = time tomorrow.**

***Important to set the stage by preteaching the needed concepts of a classroom task or lesson. Concepts will need to be taught directly.**

Learning Impact

- Incidental learning
  - More likely to require formal / deliberate instruction on “topics” others acquire incidentally
- Mental imagery
  - Challenging to construct mental images of simple objects
- Academics
  - Access to the general education curriculum
  - Accommodation and modifications
  - Access to materials, technology , and equipment
  - Adapted materials / equipment

Give an example of incidental information to help ensure the audience understands this concept (pencil sharpener).
Example: a child is exposed to potatoes and all the many ways that a potatoes can be prepared … but does not know what a real potato feels like because he or she has never handled an uncooked potato.

All students should and must have access to the general education curriculum and content standards.

There is not a separate educational curriculum for learners who are deaf-blind (Note: Expanded Core Curriculum for students who are blind).

Movement Impact

- We learn through our movement and exploration.
- Vision loss may impact postural tone.
- Poor or absent vestibular and/or proprioceptive function will impact balance and movement.
- Vision loss impacts learning and moving through imitation.
- Seeing objects and hearing sounds influences motivation to interact with the environment
- When vision and hearing is impaired, motivation to move may be diminished.
- There may be challenges with concentrating on moving when being asked to communicate (etc.)

***May need to highlight what task is the most key at a given time – moving through space successfully versus moving and being involved in a conversation.**
***Need to know the learner and be considerate of what task may need to take priority.**

***Need to be able to move to help understand where you are in space.**

***The role of the O&M Specialist is key for the use of early mobility devices, a long cane, travel instruction, etc.**

Impact of Deafblindness: Emotional Attachment

- Challenges to emotional attachment and bonding for **both** caregivers and child.
- Much of our early bonding occurs through use of eye contact, reading and responding to body language, facial expressions, and sounds.
- A confusing or unpredictable response from infant/child that is difficult to interpret can lead to a weak or unpredictable response from the child.

***Parents, Siblings, Teachers, Neighbors, Friends, and Peers are all affected by the various needs and differences associated with hearing and vision losses.**
***This can impact bonding, attachment, and relationship development tremendously.**

***The early effects of these challenges can result in life-long social and emotional impacts.**

Activities of Daily Living / Self Help

Deaf-Blindness may impact all areas of self care:

- Role of incidental learning / imitation
- Sleeping may be on a different schedule
- Feeding / Eating may be affected
- Further complications due to health concerns
- Need for appropriate role models for self care

***Must address early concerns affecting feeding, sleeping, toileting.**
***This domain may dominate early intervention / education / rehabilitation**
***Health concerns may influence self care – e.g., catheters, feeding tubes**
***Use of peers with age-appropriate self care.**

The FAVI Deaf-Blind Collaborative

- How do you refer a child? 352-273-7530 OR 800-667-4052
- What happens after a child is referred?
  Family & team can receive
  individualized (child-centered) support and assistance.
- What assistance can be provided?
  Consultation, referrals, networking, training
- Where is assistance provided?
  Home, school, community . . .
- Is there a cost? NO
- What are the benefits?
  ACCESS, Communication, Educational Benefit . . .
  RESOURCES http://deafblind.ufl.edu

Presenter's Notes:

National Resources

- National Consortium on Deafblindness (NCDB)
- National Family Association for Deaf-Blind (NAFDB)
- American Association of the Deaf-Blind (AADB)
- Helen Keller National Center (HKNC)

Presenter's Notes:

List is hyperlinked. If you have internet connection, you can click on each of the underlined names to get directly to the site.

Support Variables

- Family / Community Support
- Financial Support
- Educational Team Support
- Adapted Equipment Support
- Specialized Instruction Support

Presenter's Notes:

Research has proven that support variables affect a learner's outcomes.

Impacts of Deafblindness

- Sensory
- Social and Emotional / Relationships
- Communication
  - Receptive
  - Expressive
- Motor / Movement
- Limited access to information
- Cognitive / Learning / Academics
- Activities of Daily Living / Self Help

Presenter's Notes:

Be sure to describe that this is a not a sequential list – but that each domain will be discussed separately. One domain influences the next.

The project may want to switch the order of the slides per their perception of what comes first etc.

Deafblindness affects EVERY aspect of an individual's life.

Presenter's Notes:

There is not a domain or aspect of a learner's life that will not be influenced by dual sensory loss. The more we understanding about the affects of deafblindness, the better we can work to alleviate and minimize potential challenges.

Collaboration is Critical

- Unique demands are placed on families who have a child with a vision and hearing loss
- Many professionals will be involved with a child who has a hearing or vision loss
- Successful transitions require careful and respectful teamwork
- Appropriate monitoring of child progress requires all members to watch carefully

(Chen, 1997; Miles, 1995)

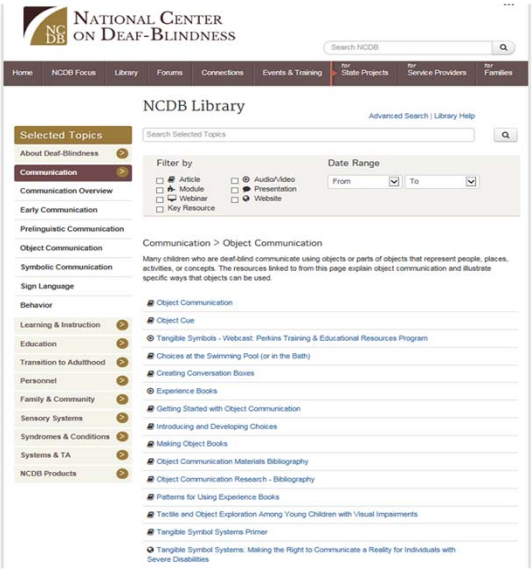
Fortunately, there are a variety of partners and resources available to assist families
in responding to multiple disabilities that include sensory loss—
including the FAVI Deaf-Blind Collaborative.

Tools: Communication

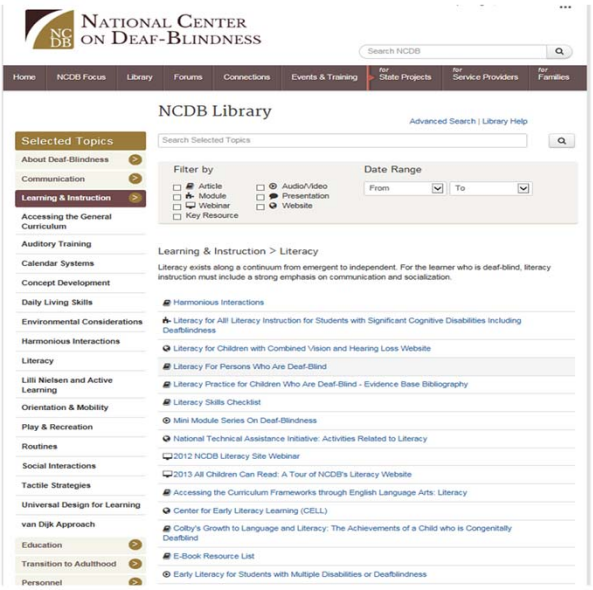
- Object Communication

- Calendar Systems
- Tangible Symbols
- Intervener
- Learning Manual Sign Language
  American Sign Language (ASL) / Signed English (SEE)
  Tactile Sign Language

Resources on Communication



Resources on Learning



Tools: Object Communication

Tips for Home or School

Creating Conversation Boxes

By: MaryAnn Demchak

May, 2007

What is a Conversation Box?

Often children will participate in exciting activities at school or at home. We want them to share this excitement and "talk" to others about the activity – either at home or at school. However, limited conventional communication skills can make it difficult for some children to "talk" with others. Creating conversation boxes can be one answer to creating conversation opportunities. Conversation boxes allow us to use object symbols as the basis of a conversation for children who understand object symbols (rather than understanding drawings or photos as symbols). One example of a conversation box one that was created for attending a track meet. The photo at the top of the page shows this conversation box, which in this case is just a shoe box covered with contact paper. The water bottle with colored marbles inside of it serves as the "title" of this box (more about this title later).

Stored within the box are various objects related to the activity: The objects related to the activity should be those that are key to the activity **from the child's point of view.** It is important to note that what the adults think is most exciting or interesting might not be the most exciting or interesting aspects as far as the child is concerned.

"Conversation phrases" were created and placed in the lid of the box as shown above and in the close-up below. The phrases are written as if the child was talking, even though the child might not have the verbal skills to say particular words or phrases. For example, when the child removes the blanket from the conversation box and hands it to a communication partner, the phrase in the box lid helps the partner to understand what the child is saying: "It was really cold and I liked being wrapped in my blanket." In this example, the bag of rocks represents "I was bored at the track meet. We had to wait a long time to see my brother. I really liked playing in the rocks." Yet another example – the bottle with the marbles represents "When my brother ran, we cheered and made noise."

When the child removes an item from the conversation box, the communication partner uses the phrases to ask questions, make comments, and so forth. The child leads the conversation by "being in charge" of the items in the box and can "talk" about any of the objects from the activity.

Back to the title of the conversation box: you want to be sure to give each conversation box a title that represents the most interesting part of the activity **from the child's point of view.** In this case the conversation box for the track meet is labeled with the noisemaker made from the water bottle because this is what the child appeared to enjoy the most.

Making Your Own Conversation Box

Step 1: Observe the child during various activities to determine those that are particularly exciting or interesting to the child. Identify those "topics of conversation."

Step 2: Throughout the activity, observe the child to plan the objects you will need as symbols. You will also plan the conversational phrase that will accompany each object.

Step 3: Write the conversational phrases on small, study cards that can be attached to the lid of the conversation box.

Step 4: Cover your phrase cards with contact paper or laminate them to increase their durability.

Step 5: Velcro your phrases to the box lid so that the cards are easily be changed when you want to create a new conversation box.

Step 6: Gather the object symbols for the conversation box and add them to the box.

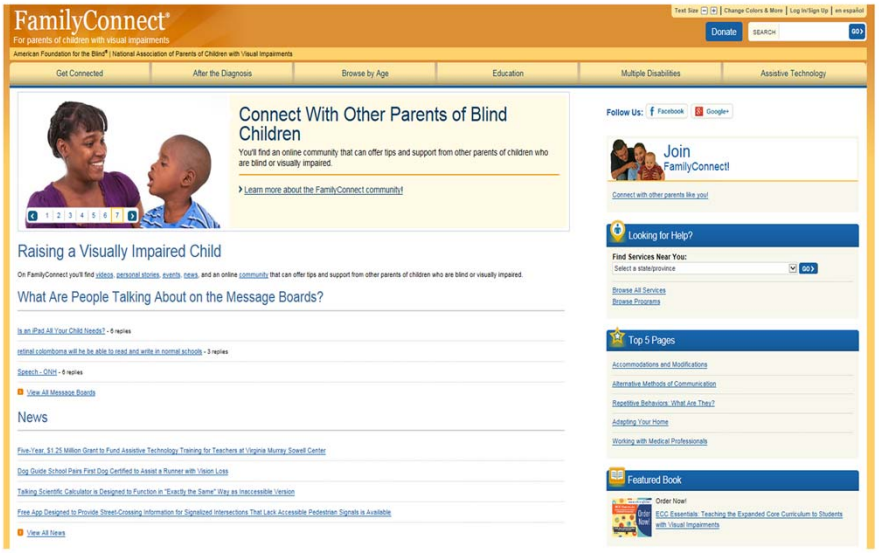
Step 7: Use the conversation box over and over to have meaningful conversations with the child.

Tools: Calendar Systems

Texas School for the Blind & Visually Impaired
Media Library

Interveners

Networking


FamilyConnect
For parents of children with visual impairments
American Foundation for the Blind | National Association of Parents of Children with Visual Impairments
Donate
Get Connected
After the Diagnosis
Browse by Age
Education
Multiple Disabilities
Assistive Technology
Connect With Other Parents of Blind Children
You'll find an online community that can offer tips and support from other parents of children who are blind or visually impaired.
Learn more about the FamilyConnect community!
Raising a Visually Impaired Child
What Are People Talking About on the Message Boards?
News
View All News
Follow Us:
Facebook
Google+
Join FamilyConnect!
Connect with other parents like you!
Looking for Help?
Find Services Near You:
Browse All Services
Browse Programs
Top 5 Pages
Accommodations and Modifications
Alternative Methods of Communication
Repetitive Behaviors: What Are They?
Adapting Your Home
Working with Medical Professionals
Featured Book
Order Now!

Learning Online!

- http://deafblind.ufl.edu/resources/online-learning-2/
- https://nationaldb.org/search/search/?sitesearch=apps (you can also follow them on Facebook, Twitter, and YouTube)
  https://nationaldb.org/library/list/40
- http://www.perkinselearning.org/ (you can also follow them on Pinterest, Facebook, Twitter, and YouTube)
- http://www.pathstoliteracy.org/ (you can also follow them on Pinterest, Facebook, Twitter, and YouTube)
- http://www.wonderbaby.org/ipad-apps-and-accessibility (follow them on Pinterest, Facebook, Twitter, and YouTube)
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