66TH CONFERENCE ON EXCEPTIONAL CHILDREN

Deafblindness: What Teachers and Service Providers Need to Know

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SELF-ASSESSMENT: A Journey of Change

PUBLIC SCHOOLS OF NORTH CAROLINA
State Board of Education | Department of Public Instruction

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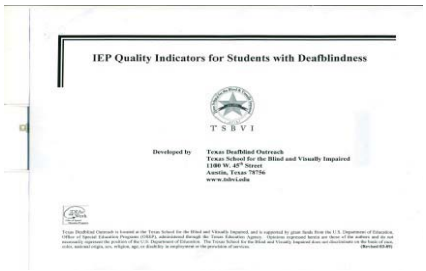
Unique Needs of Students with Deafblindness

Each Student with Deafblindness is a Unique Individual

- Each student has different degree of hearing loss and vision loss
- Some have etiologies that affect other areas such as motor or cognitive
- Students with the same syndrome may have a milder or more involved form of the syndrome


IEP Quality Indicators for Students with Deafblindness

TSBVI

Developed by Texas Deafblind Outreach
Texas School for the Blind and Visually Impaired
1100 W. 45th Street
Austin, Texas 78756
www.tsbvi.edu

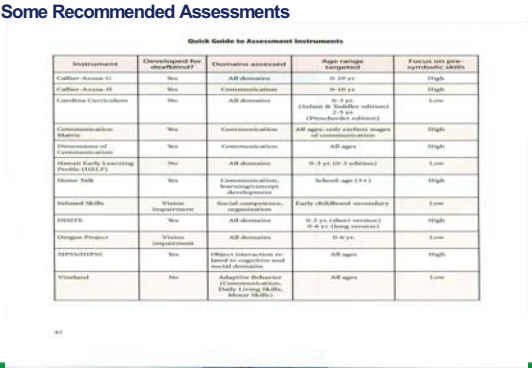
Things to Consider and Address for All Students with Deafblindness

- Inappropriateness of typical assessment tools for this population
- Communication difficulties
- Isolation and limited social experience
- Difficulties in understanding routines at home or school
- Difficulties in moving through the environment
- Difficulties in coordinating various specialists

How to Appropriately Assess the Student with Deafblindness?

- Assessments should be developed with students with deafblindness and mulitple disabilities in mind
- Evaluators should have knowledge of the particular child and knowledge of deafblindness

Some Recommended Assessments



Quick Guide to Assessment Instruments

Instrument	Developed for deafblind?	Domains assessed	Age range targeted	Focus on pre-symbolic skills
Callier-Azusa-G	Yes	All domains	0-10 yr.	High
Callier-Azusa-H	Yes	Communication	0-10 yr.	High
Cardiac Curriculum	No	All domains	0-3 yr. (Infant & Toddler edition) 2-5 yr. (Preschooler edition)	Low
Communication Matrix	Yes	Communication	All ages: only earliest stages of communication	High
Dimensions of Communication	Yes	Communication	All ages	High
Hawaii Early Learning Profile (HELP)	No	All domains	0-3 yr. (0-3 edition)	Low
Home Talk	Yes	Communication, learning/concept development	School-age (3+)	High
Infused Skills	Vision impairment	Social competence, organization	Early childhood-secondary	Low
INSITE	Yes	All domains	0-2 yr. (short version) 0-6 yr. (long version)	High
Oregon Project	Vision impairment	All domains	0-6 yr.	Low
MPSS/HIPSS	Yes	Object interaction related to cognitive and social domains	All ages	High
Vineland	No	Adaptive Behavior (Communication, Daily Living Skills, Motor Skills)	All ages	Low

SELF-A
A Journey of Change
ILDREN

How Will the Deafblind Student Communicate?

- Complete an appropriate communication evaluation
- Based on the evaluation consider a variety of communication strategies including; gesture, touch cues, object symbols, pictures, augmentative communication devices, sign, speech print and Braille.
- The child may have different modes of communication for receptive and expressive (for example receptive through audition and expressive through augmentative communication)

Heaven using aug. comm.

How can the student with deafblindness be made aware of routines and activities at home and school

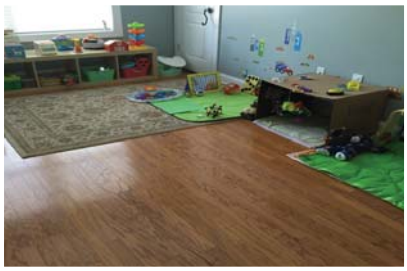
- Calendar systems
  - provide a concrete means for the student to understand what will happen during the day
  - may incorporate objects, pictures, line drawings etc. bases on the child's abilities.
  - student should have access to the calendar throughout the day

Isolation and limited social experience
Inappropriateness of typical assessment tools for this population
Communication difficulties

How can we keep child from being socially isolated?

- At and early age promote communication between parent and child
- Consider an intervener for school age students
- Find ways for children with deafblindness to interact with each other
- Specifically address social interaction on the child's IFSP or IEP

Ryan using his schedule at home



Orientation and Mobility

- Orientation and Mobility Specialists are trained to teach children with visual impairments how to move about independently in their environments and learn skills including use of a cane or pre cane, use of low division devices and electronic travel aids depending on the needs of the student.

How to Address the Difficulties of Working As a Team with the Many Specialists Involved?

- Difficult in Early Intervention
  - Use parent as primary person
  - Compare notes at IFSP meetings
  - Observe other providers if possible

School Age

- Add a goal on the IEP for frequent meetings of the child's team

From the Early Interventionist for Children who are Deaf or Hard Of Hearing Perspective

Why this is a difficult population to work with for the average provider?

- Lack of understanding of what is DeafBLindness
- Not having Deafblind strategies in our tool box

Close your eyes

- Imagine not knowing what is coming next. Hands moving you around like a sack of potatoes and not having control of what's happening. Your world would be an unpredictable, scary and threatening, place.
- Now also imagine you don't have the language ability to communicate how you feel or what you want.
- Think how you will react, what would you do ?

What do the average provider needs to remember about deaf-blindness.

A person who is deaf-blind struggles to make sense of the world around them but are limited in receiving complete information due to the dual impairment. Providers working with this children often complain of behavioral difficulties, lack of participation /involvement and lack of progress. My "aha" moment came when I realized that this is only a natural response to living in fear, not having control of your body and your surroundings and not been able to understand and communicate. That is when I decided to learn more about Deafblindness and what strategies could improve my service delivery.

DB Strategies and suggestions to improve interaction and service delivery to Deafblind children

1. **Use of touch cues-** "Touch cues are physical cues that are used in a consistent manner on the child or adult's body to give a specific message about what is about to happen to the person." (Maurice Belote,2009), **Visual cues** and **verbal cues**. This cues may lead to a predictability that may help to ease the anxiety which is often caused by the lack of sensory information

Remember the importance of reminding caregivers and other providers to communicate their presence through a touch and then learn to read infant cues for interaction (Salcedo,nd.).

DB Strategies and suggestions to improve interaction and service delivery to Deafblind children

1. ASSUME that the child wants interactions, that your main goals is to establish a
2. relationship (Texas School for the Blind and Visually Impaired). This will help the child feel safe with you and to trust you which will make for smoother interactions
3. When teaching a skill, find what motivates the child. Is it vibration, certain textures, cool surfaces. Nothing is too weird as long as it works!!

db straw.MPG

4. Adapt or create toys that may engage the child.

5. Structured the environment so the child can easily encounter objects in close proximity

db aid.MPG

6. Find out what distracts a child and remove it during your sessions for example: if the light from the window attracts him while you are trying to read a book with the child, turn him around away from the window.

db reading book.MPG

DB Strategies and suggestions to improve interaction and service delivery to Deafblind children

9) Daily dependable routines- this will help the child with deafblindness feel more secure and less anxious because their world will become more predictable and less chaotic. Providers need to find a way for routines to be communicated to the child. Touch cues, gestures, and use of object symbols are used to help children with deaf-blindness anticipate what's about to happen. An example : before feeding a child, touch their mouth and let them touch a spoon while saying, its time to eat,"mmm" we are going to eat.

10) Physically arranging the environment surrounding this children in a way that makes it easier to for them to understand and explore (for example: building a little room). Orientation and mobility specialists can help families to construct safe and motivating spaces for children who are deaf-blind.

DB Strategies and suggestions to improve interaction and service delivery to Deafblind children

11) Providing a rich language environment- talk/sign about everything you do or see. (thanks to hearing aids many children with DB have access to sound.

12) "Working as a team to develop learning activities strategies is challenging. Touch cues need to have meaning for the child. ..With limited hearing or vision, a child does not learn meaning incidentally. Agreeing on the most meaningful, efficient, and easy to use strategies is often an obstacle for a team. A large team brings many backgrounds and opinions to the table. Once consensus is reached, everyone needs to teach others involved with the child to use the strategies consistently. Families need to be able to voice whether they can realistically incorporate strategies (or risk a label of "not following through." (Patty Salcedo, M.A -Project Salute

DB Strategies and suggestions to improve interaction and service delivery to Deafblind children

13) Read the vision reports

14) Consistency and repetition are key – once the touch cues or routine is established stick with it

15) Respect the child !!!! Know when enough is enough. Allow them to have the power to convey "No", acknowledge this right to reject, respect it, an honor whenever possible

Touch Cues

There is no standardized list. Deciding on which touch cues to use with a specific individual will depend on how that person receives tactile information and how they prefer to be touched.

Our Communicative Intent	Possible Touch Cue
Individual who is lying down is about to be picked up	Two or three gentle taps beneath the shoulders in an upward direction
Individual is about to picked up from a chair	Two or three gentle taps in the armpits in an upward direction
Legs are about to be lifted for diaper changing	Two or three gentle taps beneath the ankles in an upward direction
Young child who is being held by an adult is about to be placed in a high chair	Two or three gentle taps on the shoulders in a downward direction
Individual is about to be suctioned	Gentle tap at the corner of the mouth with the plastic tube

When working on Communication

A way to encourage a child with DB to communicate is by starting "conversations". It can be as basic as: I do this, you do this , I do this. (splash, touch, sound). Conversations can use: body language, gestures, touch, signed and spoken words.

How to start a conversation:

1.Notice what the child pays attention to. Seek that moment and let the child know you are interested in the same thing. This will lead to a "conversation". (A conversation will look different for each child depending on their level of sensory loss or if they have glasses or amplification)

2. If a child lacks significant amounts of sight and hearing, he or she will need to know that the other person shares an interest in the same object or action. You can: touch an object along with the child just for the sheer pleasure of doing it in a no guided way, you may imitate a the child's movements, providing the child tactual access to that imitation.

3. Remember to pause after each turn and provide plenty of wait time to allow time for response.

4.Once the child responds, be ready to take your turn, the pause again, and continue doing this until the child is ready to quit.

5.Repeat these conversations frequently in order to build a relationships and trust with the child this simple exchanges will become the basis for language learning.

When working on Communication

Where do we go from there?

Once the child with deaf-blindness becomes more comfortable with the conversations they may be ready for symbolic communication such as: words/ signs presented along side with gestures and/or objects which can represent an activity. This helps with making correlations to build vocabulary and anticipating activities.

for example: ".. use gesture or sign language to name the object that [the provider or caregiver] and the child are both touching, or name the movement that they share. This naming of objects and actions, done many, many times, may begin to give the child who is deaf-blind a similar opportunity afforded to the hearing child—that of making meaningful connections between words and the things for which they stand" (Barbara Miles,2008)

Symbolic communication that can be utilized by individuals who are Deafblind by Project IDEAL

- Touch cues
- Object symbols
- Sign language
- Gestures
- Picture symbols
- Fingerspelling
- Signed English
- Braille
- American Sign Language
- Lip-reading speech
- Pidgin Signed English
- Tadoma method of speech reading
- Large print

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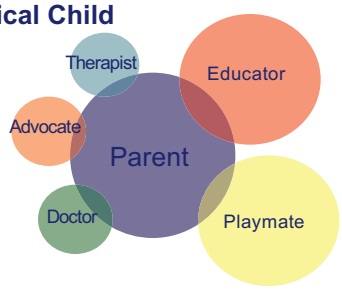
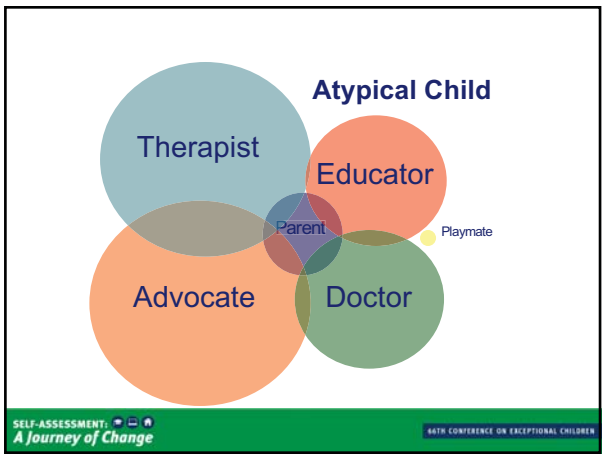
On being a parent of a child with multiple disabilities …

Typical Child




Atypical Child
Therapist
Educator
Parent
Playmate
Advocate
Doctor
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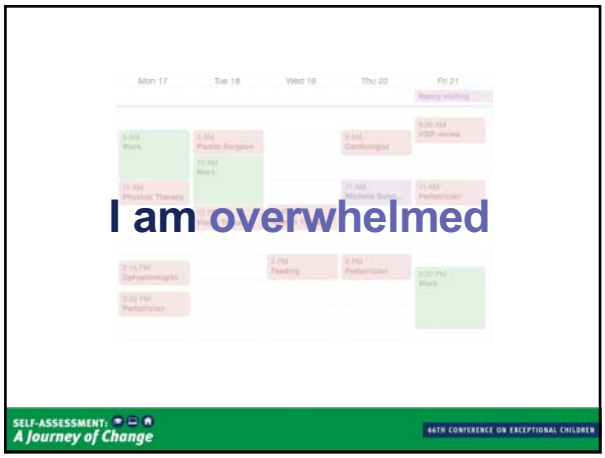
I am overwhelmed
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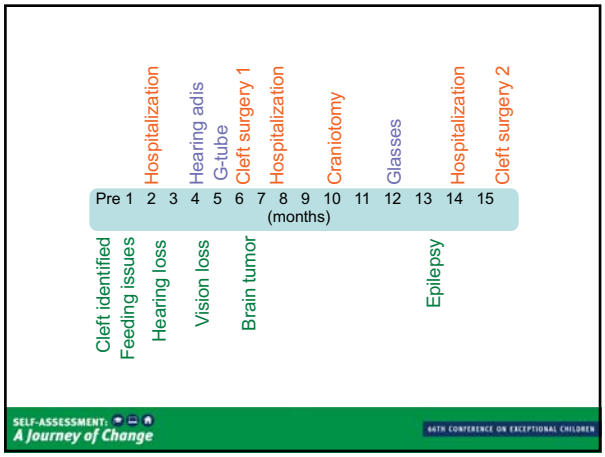
Hospitalization
Hearing aids
G-tube
Cleft surgery 1
Hospitalization
Craniotomy
Glasses
Hospitalization
Cleft surgery 2
Pre 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15
(months)
Cleft identified
Feeding issues
Hearing loss
Vision loss
Brain tumor
Epilepsy
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I am emotionally involved

Feeding Martin…

- (video)

I may be ignorant but I am not stupid

Becoming an expert… or not

- Cleft: read tons of books and blogs
- Hearing loss: read tons of books and blogs
- Vision loss: read a blog and hand-outs given by VI
- Brain tumor: didn't read a thing. Too terrified
- Epilepsy: read tons of information on the internet, (I was the one who diagnosed my son) and joined a parent group

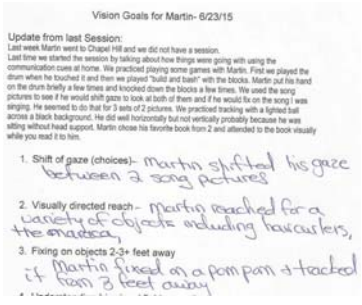
I am
trusting
you!

"I want my therapist to know that I take their time seriously and want to learn from them."

-- Parent

On therapists...

You are **specific** about my child



Vision Goals for Martin- 6/23/15

Update from last Session:

Last week Martin went to Chapel Hill and we did not have a session.

Last time we started the session by talking about how things were going with using the communication cues at home. We practiced playing some games with Martin. First we played the drum when he touched it and then we played "build and bash" with the blocks. Martin put his hand on the drum briefly a few times and knocked down the blocks a few times. We used the song pictures to see if he would shift gaze to look at both of them and if he would fix on the song I was singing. He seemed to do that for 3 sets of 2 pictures. We practiced tracking with a lighted ball across a black background. He did well horizontally but not vertically probably because he was sitting without head support. Martin chose his favorite book from 2 and attended to the book visually while you read it to him.

1. Shift of gaze (choices)- Martin shifted his gaze between 2 song pictures
2. Visually directed reach - Martin reached for a variety of objects including favourites, the maracas,
3. Fixing on objects 2-3+ feet away
   if Martin fixed on a pom pom + tracked from 3 feet away

Repetition, repetition, repetition

"I would like my therapist to understand that my child is not a circus animal that performs on command. That it may take my child a little longer to process what is being asked of him. And using the same routine order with each therapy session will result in measurable progress."

-- Donna Casteen

You excel
when you care

15 Skills that Every Employee Needs
by Gregory Ciotti

- Patience
- Attentiveness
- Clear communication skills
- Know your stuff
- Use positive language
- Acting skills
- Time management
- Ability to "read" customers
- A calming presence
- Goal oriented focus
- Ability to handle surprises
- Persuasion skills
- Tenacity
- Willingness to learn

You follow the child
not just your books

You are a
detective

You think
outside the box

You are part of a team

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" I want my therapist to know that it is a TEAM effort and Effective Communication is critical!"

-- Parent

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You are treating a whole family

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Future therapist in action…

- (video)

NC HIPP

NC Deaf Blind

You are
a link

ecac exceptional children's assistance center

Footprints Case Management

And most of all…
you are my child's
advocate!
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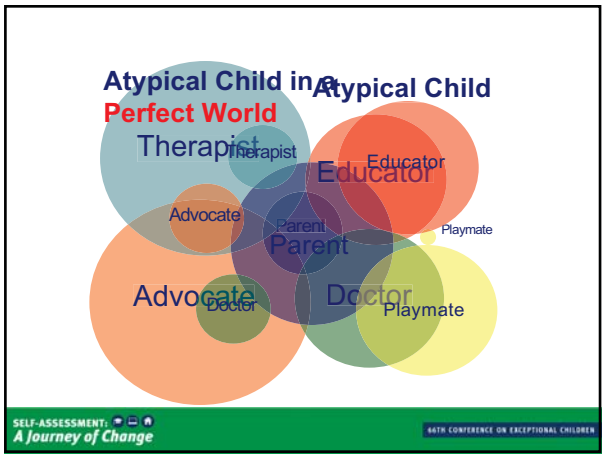
Atypical Child in a
Perfect World
Atypical Child
Therapist
Therapist
Educator
Educator
Advocate
Parent
Parent
Playmate
Advocate
Doctor
Doctor
Playmate
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