2019 Texas Symposium on Deafblindness
Symposium Pre-Conference Day
Deafblind 101: Basics of Understanding Deafblindness in Children and Youth

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8:45 – 4:00

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https://www.tsbvi.edu/outreach-staff

Developed for
Texas School for the Blind & Visually Impaired Outreach Programs
DeafBlind 101: Basics of Understanding DeafBlindness in Children and Youth

Presented by the Texas DeafBlind Project Outreach Team: Edgenie Bellah, Adam Graves, Chris Montgomery, Deanna Peterson, Matt Schultz, David Wiley

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Texas School for the Blind & Visually Impaired Outreach Programs

Overview

- The effects of DeafBlindness on information gathering, concept development, and emotional security.
- 5 key components to making learning meaningful for students with DeafBlindness.
- How teams work together for students with DeafBlindness.
- Connecting and interacting effectively with students who are DeafBlind.
- Using calendars, tangible communication symbols, and activity routines.

How is DeafBlindness Different?

Figure 1: Photo of young Helen Keller holding a doll and sitting with Anne Sullivan.

Figure 2: Photo of the cover of “The Miracle Worker”, a play by William Gibson, depicting actresses on stage portraying Helen Keller and Anne Sullivan.

It’s a matter of access.

DeafBlindness is an information gathering disability
What Does Access Mean Related to DeafBlindness?

Ask: Does the student have access to ongoing sensory information which is equal to that of other learners, in order to provide:

- Formal and informal learning opportunities;
- interaction with others and the environment; and
- a feeling of being connected and secure

Consider how people who are DeafBlind get information and experience the world.

DeafBlindness Affects Distance Senses
- Vision and hearing are distance senses.
- Tactile information may be most reliable.
- Information beyond arm’s length is missing, distorted, incomplete, or fragmented.

DeafBlindness Affects Access to Information from the Surroundings and Other People.
- Ability to detect, gather and prioritize information;
- Lack of experience;
- Ability to move easily;
- Language abilities.

DeafBlindness creates barriers to incidental learning.

How do we know what we know?

- **Direct Learning** – Hands-on personal experience
- **Secondary Learning** – Others purposely sharing information using communication forms and methods we understand.
- **Incidental Learning** – Casually observing surroundings and other people. (How typical people get most information, but is unreliable for people who are DeafBlind.)


DeafBlindness Affects Learning and Concept Development

- Incidental learning is absent, erratic, or undependable.
- Understanding secondary information may be difficult due to communication barriers.
- Hands-on experience is the most reliable way to learn, and essential for people with DeafBlindness.

DeafBlindness Affects how a person gets information and knows about:

- what is happening;
- what other people are doing;
- what people’s expectations are;
- what to expect.

“Mary Dignan is profoundly deaf and almost totally blind from Usher Syndrome Type 2. She practiced water and environmental law in Sacramento, California until 1997…”

“My SSP was absolutely fabulous for me, and it was a revelation to actually be able to relax and be myself while enjoying the conference, instead of being intensely busy trying to figure out what is going on. I am sure that every deaf-blind reader of this magazine well knows what it is like to work extraordinarily hard at figuring out what is going on, and then finding precious little energy left over to actually relax and enjoy what is going on.”

– Mary Dignan

DeafBlindness affects how a person experiences events and interacts with other people and environments.

- Situations may be confusing or threatening due to incomplete or distorted information from other people and the environment.
  - True story! After breakfast, I returned to my room and detected this information that hadn’t been there when I left.
    - MOVE TO
    - DILLON HALL
    - BO5
    - (HOME EC)
  - This message caused me anxiety because:
    - I didn’t know the source of the information;
    - Though some of the information is familiar, it is incomplete;
    - I wasn’t able to detect the context or intent;
    - I was unable to understand how the information affected me;
    - I could not predict the expectations of others;
    - I wasn’t even sure the information was directed toward me.
- Different perceptions of what is interesting, important, motivating, or punishing.
- Frustration about communication attempts being unrecognized or misunderstood.
- Difficulty in recognizing, trusting, and bonding with others.
DeafBlindness affects the ability to detect, gather, prioritize, and use information.

- Detect
- Gather
- Prioritize
- Use

- Sensory Impairments can lead to fragmented information.

Can you identify this visual information, which is distorted and/or incomplete?

![Figure 3: Black and white image modified with incomplete, distorted visual information.](Image)

Below is a wider view of the same picture.

![Figure 4: The same image modified with incomplete, distorted visual information, expanded to show a wider view.](Image)

- Sensory Impairments can lead to fragmented information.
- Is the distorted/incomplete information easier to use with experience, context, and explanation?

**Audiogram**

Audiogram

![Figure 5: Image of an audiogram showing the grid used to illustrate qualities of sound based on “Hearing Loss in db” (volume in decibels) and “Frequencies in Cycles Per Second” (Hertz).](Image)

**Listening Exercise**

Video with speech altered but eliminating high frequency sounds
We can improve access and enhance the lives of people with DeafBlindness by:

- Greeting and approaching students respectfully, and identifying yourself.
- Letting students observe hand-under-hand rather than guiding hand-over-hand.
- Providing information about what is happening that students otherwise miss.
- Providing information to help students know what is happening and anticipate what is going to happen.
- Creating meaningful, motivating, and recognizable routines.
- Using multiple communication forms students can understand and access: sign (visual or tactile), speech, tangible symbols, cues, gestures, calendars, etc.

What Intervention Supports Access?

- Provide consistent access to instruction and environmental information that is usually gained by typical students through vision and hearing, but that is unavailable or incomplete to an individual who is deaf-blind;
- Provide access to and/or assist in the development and use of receptive and expressive communication skills;
- Facilitate the development and maintenance of trusting, interactive relationships that promote social and emotional well-being; and
- Provide support to help a student form relationships with others and increase social connections and participation in activities.

Examples of the array of supports that lead to success for students with DeafBlindness?

- Individualized attention.
- Adapted materials and environments.
- Communication and communication development in the student’s preferred modes.
- Effective use of space, position, and movement.
- Structure, predictability, and routine.
- Trust, bonding, and security.

Examples of Supplementary Aids and Services

- Specialized Staff Training
- Assistive Technology
- Special seating arrangement
- Unique presentation of materials
- Pacing of instruction such as implementing extended wait time, or frequent breaks
- Specialized staff support.
Experiencing the World of DeafBlindness

Simulation activity

Commonly Reported Feelings Following Simulation

- Isolation
- Lack of control
- Lack of choices
- Anxiousness
- Fear
- Lack of trust

More Commonly Reported Feelings

- Frustration
- Passive cooperation
- Boredom
- Wondering how long something will last
- Wait time seems longer
- Tension- not knowing who, what, where, why

Beyond Arm’s Length

If a DeafBlind child cannot access information from a distance and is left alone with no means to predict and anticipate events, the result can be…

Implications

- Passivity
- Withdrawal
- Resistance to interactions
- Resistance to activities introduced by others
- Aggression
- Self-Stimulatory behaviors

Symptoms of Distress

- Yawning
- Going to sleep
- Hyperactivity
- Laughing or Crying
- Self-stimming
- Self-abusing
- Being aggressive or passive
Five Key Components of Instruction to Make Learning Meaningful.

(The “–tions”)

Anticipation

Video of a young child waiting for a train with her father.

Video of a cat walking on a vehicle, scared by unexpected movement of the windshield wipers.

- Information to predict what will happen reduces anxiety and confusion; increases participation and success.
- Use of cues and routines to recognize what is happening.
- Having something to look forward to is important for a sense of well-being.

Motivation

Video of people choosing the stair or escalator in a subway station.

- Activities based on interests and preferences lead to increased participation, satisfaction, and joy.
- Having choices provides feeling of control and self-determination.
- Participation with a trusted partner is motivating.

Communication

Video from the movie, the miracle worker

- Meaningful communication forms: both dynamic and static.
- Communicative function: a reason/purpose to communicate.
- Shared topics of interest: lead to turn-taking conversations.
- Opportunities to expand topics and have social exchanges.

Confirmation

Video of a coach providing feedback to a player.

- Affirming communication attempts.
- Clarifying communication both ways.
- Feedback on attempts, results, & successes.
- Knowing when an activity is starting and finished.
- “My job is to verify.”

Confirmation: Why is Patsy Doing This?

Video of a young woman who is DeafBlind using a communication device to make a bakery order.

Reflection

Video from a soap opera of a couple looking through a photo album and discussing the past.

- Reminiscing / records for remembering past experiences.
- Contemplation of how previous events relate to now.
- Processing time for careful consideration, understanding, planning, and readiness.

The 5 ‘tions:  bringing it all together

Video of a man giving people high fives on an escalator.
The Importance of Working Together as a Team

Figure 6: Image of a youth soccer team gathering around the coach.

Team Structure

- Core team members
- Extended team members
- Meeting Schedule
- Roles and Responsibilities

Figure 7: Abstract image of people labeled “Students, “Regular Ed Teachers”, “Special Ed Teachers”, “Parents”, “School Representative”, “Community Agencies”, “Child Experts”, and “evaluation Expert” hold puzzle pieces put together to spell, “Teamwork.”

Core Team Members

- Members Vary Depending on Individual Student:
  - Sensory
  - Accessibility
- Membership Can Expand Depending on Team Focus
- Continuous Input to Guide Daily Programming:
  - Review
  - Refine
  - Direct

Figure 8: Image of 4 kids on a soccer team folding their arms, the one in front holding a soccer ball.
Possible Core Team Members

- Teacher of students who are DeafBlind (TDB)
- Teacher of the Visually Impaired (TVI) +
- Teacher of the Deaf and hard of Hearing (TDHH)
- Classroom Teacher
- Intervener
- Family Members
- Student

Figure 9: Image of a young person who is DeafBlind getting information about a soccer game on TV from two people interpreting with the help of a board showing a soccer field on his lap.

Extended Team Members

Extended team members will meet less frequently than the core team and generally include:

- Administrator
- O&M
- Speech
- OT
- PT
- General Education Teacher
- Outside agency representatives

Figure 10: Image of a sports team joining their hands in the center of a circle.
Team Functions

Common to every member of the core and extended teams

- Training and learning together
- Collaboration on Evaluations
- Collaboration on IEP development and implementation

![Collaboration Chart]

Figure 11: Image shows a chart with “Collaboration” written in a box in the center, with arrows pointing outward to ovals with the words “Teamwork”, “Trust”, “Innovation”, “Exchange”, “Assist”, “Support”, “Success”, and “Share”.

Roles and Responsibilities of Core Team Members

The TDB’s Primary Role

- Provide information on the impact of DeafBlindness on student’s access to instruction
- Collaborate with other professionals, the intervener, and the family in assessment & development of the IEP
- Provide orientation, supervision, & instructional support to the Intervener
- Coordinate educational planning & communication among team members
- Provide information on the Intervener team model for the core team
- Support the intervener in preparing instructional accommodations and materials
- Provide information on students’ eligibility for the DeafBlind Child Count

Classroom Teacher’s Role

- Provide Direct instruction to the student
- Participate in DeafBlind training with the team
- Collaborate with TDB and intervener to implement modifications and accommodations in the classroom
- Maintain communication between family and school

Intervener’s Role

- Develop & maintain a trusting relationship that promotes social and emotional well-being
- Implement the IEP providing access to information usually gained through vision and hearing
- Facilitate the development and use of receptive & expressive communication
- Works one-on-one with a student with DeafBlindness
- Receives specialized training in DeafBlindness
- Acts as the eyes and ears and provides a bridge to the world
- Assists the student in gathering information to develop concepts, skills, communication, language, and relationships leading to greater independence.
- Acts as a support person who does **WITH not FOR.**
Family Members’ role

- Participates in team meetings
- Participates in developing the IEP as an equal member of the team
- Contributes information such as medical history, family life and other observations for assessment and programming
- Shares the family’s goals for student life after graduation
- Provides information from other service providers (private therapists, state agencies) to the IEP team

Student’s Roles

- Participates in discussions with the IEP team in ways that are meaningful
- Provides information to the team on which strategies are effective and which are not
- Shares personal goals and plans for their future

Meeting Schedule

Core Team

Meets regularly based on the student’s needs:

- Weekly
- Bi-weekly
- Monthly
- Quarterly

Core team should establish a system for communicating outside of meetings

Extended Team

Meets at least two times per school year:

- Planning for annual IEP meeting
- Annual IEP meeting

Extended team members may be invited to core team meetings to discuss topics specific to their discipline or area of expertise

Working together as a team helps everybody reach their goals!

Figure 12: Photo of US women’s national soccer team hugging in front of a soccer goal

Part 2 – DB 101: Interaction, Calendars, and Routines

Close your eyes and imagine…

![Image of a teenage girl and boy sitting side-by-side on a hillside.]

Figure 1: Teenage girl and boy sit side-by-side on a hillside.

**How do we become better listeners?**

What qualities do you find best describe a “good listener”?

How do we apply “good listener skills when we're with our kids?”

“It is the interested person that becomes the person of interest…”

- Gunnar Vege

**Let’s ask Harvard…**

A video titled “Serve and Return Interaction Shapes Brain Circuitry” from the Harvard Center on the Developing Child

**How to Apply Brain Science to Interaction**

- Serve and return
- Listening and talking
- Back and forth interaction………..

The foundation for all learning and healthy growth and development.

**Interaction Steps**

1. Notice-time, space, and intent.
2. Imitate-the sincerest form of flattery.
3. Affirmation-is the message received?

Video “Cam and Hollis”
Video “Shawn and Pamela”
Video “Kim and Luciana”
Video “Tish and Yesdy”
Rupture & Repair Cycle

Figure 2: A pie chart depicting 3 equal sections labeled Relate- Emotional Intimacy, Rupture and Repair- Trust and Resilience. A banner covering the pie chart reads “Making up is more important than messing up”.


Reciprocal Interaction “is a singular opportunity to promote the social-emotional, cognitive, language, and self-regulation skills that build executive function.” American Academy of Pediatrics (2018) The Power of Play: A Pediatric Role in Enhancing Development in Young Children Vol 142 No. 3

“The mutual joy and shared communication and attunement that we experience during nice interactions can help regulate the body’s stress response.” The Power of Play: A Pediatric Role in Enhancing Development in Young Children Vol 142 No. 3

Calendar: Words of wisdom from the Godfather…

Figure 3: Dr. Jan van Dijk, smiling.
What does your calendar do for you?

Figure 4: A monthly calendar hangs on the interior wall of a home.

Figure 51 A monthly calendar depicting the month of February. It is decorated with hearts and 2 images of a man and young girl sharing a bite of food.

**Calendars: Security**

Gives you assurance that an event is getting closer, so it is easier to wait.

Trustworthy information - it is in writing

Figure 5: A young girl wearing a hat and holding an umbrella, sits cross legged on stairs.
Calendars: Anticipation
Can lift your spirits by giving you something in the future to look forward to.

![Figure 6: A young boy wearing pajamas looks up the chimney. Stockings hang above.](image)

Calendars: Reminisce
- Supports the pleasure of reminiscing
- Enhances learning by reviewing events and fleshing out the facts

![Figure 7: Three ladies sit on a couch talking while smoking cigarettes.](image)

How can calendar conversations support our student’s learning?

![Figure 8: A young boy reaches out and explores a choice board while a teacher assists.](image)
Calendars for Our Students

- Mark the past from future, clarifies the present
- Teach time concepts and vocabulary and language forms
- Help our students establish a joint topic for discussion
- Provide opportunities for requesting, rejecting, choice making, volunteering new bits of information

Calendars for Our Students

- Provide for opportunities successful and clear conversations each day
- Provide an opportunity for a developing sense of control and autonomy
- Helps prepare for emotionally for significant events
- Provide a clear context for back and forth conversations

Symbols + Time Frames = Calendars

Figure 9: a vertical piece of cardstock with items overlaid: a photo of a man with his name in print. On top of the print there is clear strip of braille. Below the photo there is a tactile symbol representing the man’s name.

Figure 10: A calendar box with 4 slots. Left to right the slots contain: a bowl, a piece of egg crate, a big mac switch, a cup with toothbrush Inside.
Symbols

- Object symbols
- Tactile Symbols or Picture Symbols
- Braille or Print

Figure 11: an array of symbols representing spoon: real object, photo, print, tactile symbol, braille.

Time Frames

- Anticipation
- Daily
- Weekly
- Bi-weekly or Monthly
- Annual

Figure 12: shows a page out of the book Calendars by Robbie Blaha. A Guide to Selecting Time Frame for Calendar Systems.
Anticipation Calendars

Video: “Lucianna and Deanna”

Figure 13: Photos of various object symbols label in print: park, recycling, shopping, PE, relax with Music/headphones, technology.

Daily Calendar with Objects and Partial Symbol

Video: “Aaron and John”

Daily Calendar with Tactile Symbols

Video: “Tania and Pamela”

Figure 14: The written steps of “Tania’s Calendar Conversation Routine”.
Expanding a student’s calendar system

Figure 15: A calendar box with three slots. Slot one is covered with a flap. Slot 2 contains a towel. Slot three contains a small pillow.

Figure 16: A calendar box with 5 slots. Slots one, two, and three are covered with flaps. Slot four contains a tactile symbol. Slot five contains an apron.

Figure 17: A calendar box with five slots. Slot one is covered with a flap. The remaining slots are empty. On one of the two chairs there is a tactile symbol storage book. A finished box is under the calendar on a shelf.

Figure 18: A “two-week” calendar box, 14 plastic bins labled with tactile symbols for each day of the week. Each bin contains tactile symbols or real objects.
Weekly Calendar with Picture Symbols
Video “Yesdy and Katie”

Monthly Calendars

Figure 19: A teacher writes on a month calendar while 2 students look on.

Monthly Calendar with Tactile Symbols
Video: “Omar and Matt”

Why are routines important?

- Increase predictability while reducing stress and anxiety.
- Build anticipation for the next step as well as the end of an activity.
- They give structure and meaning to actions and events.
- Routines build memory; foundation for other learning.
- Gives kids a sense of purpose and feelings of success.

Things to keep in mind when planning a routine

- What skills are targeted? What IEP goals can I infuse?
- Have a clear beginning, middle, and end
- Use the same objects and materials and persons every time.
- Use short, easy and predictable steps.
- Provide enough support to assure success every time.
- Can be flexible and adaptive

Developing a Routine

Figure 20: A document titled “Likes/Dislike Inventory, a column to record “likes” and a column to record ‘dislikes’.”
Developing a Routine

Figure 21: A document titled “Activity Routine” with columns to record steps of the routine, modifications, IEP Goals, targeted vocabulary and comments.

Figure 22: A document titled “Omar’s dressing routine” with a detailed description of his routine.

Moments of Joy

Video: “Dr. van Dijk talking about moments of joy”

Wrap Up

Share any “Ah-ha” moment from this training?

Share an idea you want to try in the classroom or home on Monday?

REMEMBER TO COMPLETE AN EVALUATION!
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Figure 23 TSBVI logo.

Figure 24 IDEAs that Work logo.

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