

Oregon Deafblind Project



Building Effective Programs

Lyn Ayer, Ph.D., Grant Project Director. November 2016



Hello everyone!

I hope everyone had a wonderful Thanksgiving. As you can tell from the decorations — I wanted to send this out

when the leaves were turning! Too late for that. However, not too late to share information and news which may be useful to you. And I still think fall leaves are pretty and might cheer us up on some of these more gloomy days!

While we were at the Parent Weekend this August, our presenter, Robbie Blaha, reminded us all about how important it is to assess a child. So — the main article in this issue is on assessment. And assessment is not just for an educational team to do — it is for all of a child's "team" - parents and family members should definitely be involved in this process. It helps establish a good strong program for a child—beginning with an IEP that has appropriate and useful goals/objectives. Assessment doesn't just happen BEFORE we write an IEP either — but should be a continuous process. It is what will continue to guide a child's program, make it meaningful in a truly individualized way.

OHOA module 11 is one that I recently looked over and found that it contains some very basic guidelines for working with children who are deafblind (and others as well). It is what most of our series trainings start out with — or include.

The last part of this newsletter is our Facebook Share area — and also a brief overview of the Emergency Preparedness information from our 2016 Parent Weekend.

Take care.

Lyn



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"Autumn is a second spring, when every leaf is a flower." Albert Camus



OHOA Modules

Module 11 Intervener Strategies

This module is a MUST for anyone wanting some really quick and important information on techniques to use with children who are deafblind. As often happens, this information can also be used with other children as well. Here is an outline of what you will find on four really critical techniques that are truly "foundational" for our work with this group of children.



• Do WITH not FOR. The Takeaway at the end of the section summarizes it aptly: "'Do with, not for' is the foundation for all of an intervener's actions. It involves providing guidance and support (doing with), rather than taking over (doing for) and deciding everything for a student". We aim to make students as independent as possible — not dependent. It is important to recognize this technique since one misconception about interveners is that children will become dependent on them.



♦ Hand UNDER hand. This is a technique that helps us to "Do with not for". The child retains control and is able to gain confidence in themselves and in the persons around them. They learn to trust — and allow their hands to become their eyes and ears to discover the world around them. Hand under hand starts out as an "invitation" and not as a demand on the child. It ends in a child being more motivated to explore. Hand under hand also leads to better communication —because it lays the groundwork for tactile strategies, including tactile sign. I often think of hand under hand as a "comfort measure" — just as we have comfort foods! Use of this technique helps children relax and enjoy learning about new things. It definitely puts them in a "happy place"!



Be a BRIDGE not a BARRIER. This is a direct "address" as it were, to persons who become a child's intervener. It is also very important since another misconception is that an intervener becomes a barrier to a child learning about the environment and all the people in it that are significant. This section contains excellent slides and a handout that sums up all the key points on how to be a bridge—and how to figure out if we are actually being a barrier. The section also shows us ways in which we can determine what level of assistance a child really needs — so that we can step aside and let the child make progress on his/ her own. I like this question: "How can adult support be made invisible?" Sometimes we may not even realize we are being a barrier rather than a bridge. I believe that this section of the module will really make you think!



◆ Take your time: PACE, PROCESS, **WAIT**. We often start our workshops with this. It is almost miraculous what a difference it makes for our children who are deafblind — and it also makes a difference for children with other disabilities as well. And everyone who uses this technique has no problem changing what they do — when they see the positive results. The section defines the terms "pace", "process", and "wait". Initially, you may set the pace — but the end result you are looking for is that the student will set the pace for himself. Children process at different rates and indicate they are processing in a variety of ways. It is our job to learn to "read" that a child is processing — and WAIT while he/she does so. It is counterproductive to NOT do so. If you interrupt while a child is processing, he/she will have to begin processing again. Don't waste time by NOT following the child's lead in this.



So Much to Assess, So Little Time, So Many Directions....

Not really. And not if we do this continuously. Of course, we do need to begin the process before we begin a PLAN for a child – developing an IEP and a curriculum. But we also need to assess as the plan unfolds and as it is put into execution. We do need to remember that we cannot look at cookie-cutter assessment because each child we serve is so different. While there may be a few things in common, more often, there are many things that are not. For example, children with CHARGE syndrome have much in common, but they are also so different from each other – different needs, different motivation, different ways of understanding the world, different reactions to people and places, etc.

UNDERLINE THESE:

- ALWAYS involve families. They are a rich source of information. Just interviewing them, or getting a basic "history" of the child is not enough.
- Use standardized or formal evaluation tools only if you MUST and when you do, make quite sure that the tool is appropriate for a child who is deafblind not just a child who is visually impaired/blind, or deaf/hard of hearing.
- Use OBSERVATION when you assess. It always gives you the most practical pointers on how to enhance a child's program.
- Assess in REAL environments, not pull-out if you want a plan that reflects and emphasizes the functional aspects of a child's life.

ABOUT OBSERVING:

Even though this may seem "common sense", it may serve as a reminder. Preaching to the "choir"? Perhaps. But – even after years of practice, I find I have to remind myself of what I need to do when I observe.

- Observing should not be random. It is a LEARNED skill, even for what we call "informal" observation. Informal does not mean random. http://oregondb.org/ObservationHome.php
- You definitely need to document what you observe and be systematic about it.
- Involve parents in the process. If you are observing, you do not need a parent looking over your shoulder but if this is happening, you could involve them by having them also observe and document. It's a great way to compare notes later. Two (or more!) eyes are better than one.
- Before you observe a child, determine what the PURPOSE is. Is it to find out how much and how a child communicates so you can create a baseline? Is it to document information about specific behaviors that are seen as a concern? Is it to contribute to developing and enriching a movement goal in the IEP? Remember you cannot do everything all at once. If you do notice some significant "other" things just write a note to yourself to talk to another team member or the parents.
- You can use the child's IEP as a guide for your observations and make observations that relate to the child's goals. It is one way to determine whether there is something that is missing or needs to be tweaked.
- Observations should cover a wide range of:
 - ⇒ Locations (including home and community)
 - ⇒ Times (of day, of a week. Seasonal changes sometimes matter)
 - ⇒ Situations/Activities
 - ⇒ Interactions with a variety of people in the child's life

When you observe:

There are no hard-and-fast rules – but these are suggestions of what makes for a really thorough observation.

- Do this, WITHOUT DISTRACTION.
- Set some GROUND RULES with the people around you so they don't interrupt, comment, do something that will change the way a child normally behaves.
- Sometimes observing "COLD" is good i.e., not knowing a whole lot about the child ahead of time. That way, you don't start the observation with some pre-conceived ideas.
- If you already know a child and have worked with the child and team before, it may be good to remind yourself that you are OBSERVING and documenting and not comparing, discussing, or making suggestions at this time.
- No one lives in a void. So when you observe, observe:
 - \Rightarrow The child
 - ⇒ The child's physical environment

- \Rightarrow The people around or with the child
- ⇒ Interactions between the child and environment/people
- ⇒ The use or not! or specific techniques such as hand-under-hand, respectful touching/asking permission to touch, pausing, the following of a routine, and so on
- Sometimes you may need to interact with the child and then make notes on what you see.
- DON'T be a cheer-leader with the child, even if you see something really exciting. You don't have to "high-five" or be loud to encourage or praise! Interact if the situation demands this but do so gently, quietly.

WHAT do you want to - or need to - assess?

If you want to assess a number of things – I suggest you make a list. There is no way you can do it all; and you probably will need to space things out in a prioritized sequence. What is needed first? What next? Sometimes you may be looking for information from elsewhere – e.g., a doctor. You can start that process and move on to the next thing while you are waiting.

Here are a number of questions to think about:

About the child:

- How much residual vision and hearing does the child have? How are these used? Read and understand the medical records and the implications of what is documented.
- Is there any record of functional vision and hearing screening or evaluation? If yes, how does the information compare to the medical records?
- What about touch? Does the child use hands, feet, tongue, etc.? How often? In what way? Does the child have any touch preferences or aversions? Has an OT been involved in assessing a child's sense of touch? Have the parents used massage on this child? Did the child have "heel sticks" when in ICU? Does the child NOT want to use hands, feet, etc., to touch?
- Has anyone assessed smell and taste? What connection is there to any emotions where these are concerned especially smell?
- What about those really important vestibular and proprioceptive senses? David Brown calls them "The Forgotten Senses". See https://nationaldb.org/library/page/1940
- With whom does the child communicate? How? What modes are used? Why? What is the child's level of skill both receptive and expressive? What makes the child want to communicate?
- What motivates this child? Has anyone done an inventory of a child's preferences and aversions? See Open Hands Open Access module 5 at the OHOA site: https://moodle.nationaldb.org/
- Behavioral states. When is this child alert and ready to learn? Again check OHOA module 5. Here's a Sample form too: http://www.tsbvi.edu/example-form-assessment-of-biobehavioral-states-and-analysis-of-related-influences-1
- What is this child's sleep cycle? Is he an early-riser? Goes to bed late? Stays up all night?
- Is the child on any medications? What are they for? What do you know about the medications, possible side effects? You may not be able to prescribe but you can make notes if needed, and if you see something noticeable
- How does this child stay occupied especially when left alone? What do you notice about interests and preferences?
- Are there any self-stimulatory behaviors? Does the child stomp or drag his feet? Does he click with his tongue or snap his fingers?
- What are a child's social skills, competence? Does this affect what happens in school, at home, in the community?
- Can this child advocate for himself, even in subtle ways? What is this child's level of self-determination, self-confidence?
- What about mobility? Does the child have orientation skills?

About the environment – in relation to the child:

- Is there too much echo (e.g., bathrooms), loudness (e.g., cafeteria, mall), sound distractions or masking sounds (e.g., hum of a computer, heating vents)?
- Are carpets or flooring useful or not? Drapes? Does the child notice changes in floor, walls etc.?

- What about lighting? How is this child affected when in really bright light? Are there areas of a classroom or building that are too dim? Consider "glare" vs bright lighting in some situations (e.g., surprisingly, the lightbox may be better on a dim setting). Where and what type of lighting? Will additional individual lighting help this child? Does he/she wear a visor or cap; or tinted glasses to combat glare and enhance clarity?
- How does temperature inside (various rooms/spaces), and outside affect this child?
- How does space affect a child? Are large spaces or small spaces preferred? Cluttered, empty, organized? Is the shape of a space important? Is there anything that may be should or should not be in a child's personal space?
- How does this child make USE of the space and why does the child do this?
- What equipment does the child use? Where are these? How does the child make use of them?
- People. Which people does the child consider "his or her people" and some who are definitely not? Does this child perhaps think, "People are thieves" (Robbie Blaha) because we constantly take things away and they "disappear" or "appear" randomly? Why do you think this child thinks this way?

About the child's mobility, and orientation to surroundings:

- We usually focus on MOBILITY, BUT sometimes we need to focus on ORIENTATION (e.g., a child in a wheelchair or one who uses a walker). Orientation is what teaches and gives a sense of security in order to move. How does this child orient to the surroundings?
- ENVIRONMENTAL AWARENESS is a precursor to wanting to move or reach out or step out. Is the child motivated to reach out and touch something, or move towards something or someone?
- The child needs to understand his body parts and what they do (or what is possible) and THEN how the body fits in space (Kinesiology). Do you think this child really knows what his body looks like, how the parts relate to each other, how they move, what space they occupy, and what he can do with them?
- Reflexes and reactions, motor developmental milestones. An OT and PT can assist with this aspect. Where does this child fit on the developmental continuum?
- Posture, balance, muscle tone. Again, an OT, PT, PE or Adaptive PE specialist can assist with this.
- Assess from the point of view of concept development and how much a child grasps specific concepts. What does this involve? A child should be able to assess:
 - ⇒ What is the space around him?
 - ⇒ What can he do to "reach" into space?
 - ⇒ What does his body look like and what can the various parts do (or not do)?
 - ⇒ What information does he seem to get from muscles, joints and tendons?
 - ⇒ What does posture do to his understanding of his own body, space etc.?
- Note a child's concepts of:
 - \Rightarrow Shape
 - ⇒ Time (not just the clock time, but today, yesterday, tomorrow, etc.)
 - ⇒ Position (on top of, above, below, etc.)
 - ⇒ Direction (not just East, West, North, South; but also up, down, straight, across, vertical, horizontal, etc.)
 - ⇒ Movement effects (fast, slow, jerky, flowing, sustained, sudden, etc.)
 - ⇒ Common things around him, where they are, and how to get to them (doors, windows, desks, chairs, footpath, pencils, etc)
 - ⇒ Materials things are made of (cloth, paper, metal, sponge, glass, sandpaper, wood, stone, etc.)
 - ⇒ How things taste, sound, feel (bright, dull, muffled, echo-ey, sweet-smelling, yuk!)
- How do **combined** vision and hearing losses affect this child's ability to orient to the environment? And how might that be affecting mobility?
- Space itself what it "looks like" since all the child may know is within arms reach and even that may not be accurate
- What to the child -- are the differences between night and day, dull days and bright sunny days?



SELECTED RESOURCES:

Listen to this awesome webcast on assessment by Millie Smith: http://www.perkinselearning.org/videos/ webcast/strategies-assessing-and-teaching-students-visual-and-multiple-disabilities

Other selected Perkins videos on assessment:

http://www.perkinselearning.org/videos/webinar/assessment-that-informs-instruction

Assistive tech: http://www.perkinselearning.org/videos/webcast/assistive-technology-assessment

Dr. Jan van Dijk: Child guided assessment: http://www.perkinselearning.org/videos/ webcast/child-guided-assessment

Selected tools to use:

The Communication Matrix: https://communicationmatrix.org/ Also – join the Matrix Community – if you have questions to ask or solutions to share



- Assessing Communication and Learning in Young Children Who Are Deafblind or Who Have Multiple Disabilities (Rowland, 2009) https://www.designtolearn.com/uploaded/pdf/DeafBlindAssessmentGuide.pdf or use link from "Authentic Assessment". Pages 42-54 of this book has a listing of some formal assessment instruments and a page for each of these along with strengths and weaknesses of each.
- ♦ **Watch videos by Dr. Jan Van Dijk** and his observations and interactions. He says, "No intervention without assessment". Website: http://www.drjanvandijk.org/
- ♦ Of the videos he says, "Let the videos do the talking": http://www.drjanvandijk.org/index.php?
 option=com virtuemart&view=category&virtuemart category id=4&Itemid=285
- Especially look at: <u>Child-guided strategies: The van Dijk approach to assessment</u> (on the Perkins website. It is also a print publication: http://www.perkinselearning.org/videos/webcast/child-guided-assessment
- Project SALUTE (Successful Adaptations for Learning to Use Touch Effectively http://www.projectsalute.net/ index.html
- Assessment of Deafblind Access to Manual Language Systems (ADAMLS) http://documents.nationaldb.org/products/ADAMLS.pdf
- The SLK Guidebook and Assessment Forms (Millie Smith) (goes with the sensory learning kit book and use of the kit); Also see SAM (Symbols and Meaning). Kit information: https://shop.aph.org/webapp/wcs/stores/servlet/
 https://shop.aph.org/webapp/wcs/stores/servlet/Product_SAM:+Symbols+and+Meaning+Kit_1-08854-00P_10001_11051
- ♦ Every Move Counts. Learn more: https://www.youtube.com/watch?v=OV35UNwIZUU
- ♦ The Learning Media Assessment ask a vision teacher/specialist about this! Buy a copy? Go to www.tsbvi.edu
- ♦ Home Talk: A Family Assessment of Children Who are DeafBlind http://documents.nationaldb.org/HomeTalk.pdf
- Deafblindness: Educational Services Guidelines. Chapter 3 is on Assessment: http://www.perkinsproducts.org/store/en/perkins-publications/155-deafblindness-educational-service-guidelines.html#chapter3

Resources specific to Orientation and mobility:

The importance of learning to move (active learning). Discussion documentation and observations to document: http://www.tsbvi.edu/attachments/handouts/ActiveLearningStudyGroup/ActiveLearningStudyGroupHandoutOctober2014.pdf Also see sample forms you can use for active learning.



- ♦ Get the TAPS supplemental flash drive: http://www.tsbvi.edu/publications/3972-taps-flashdrive This contains:
 - * Comprehensive Initial and Ongoing Evaluation
 - * Inventory of Purposeful Movement Behaviors
 - * O&M Assessment: Early Years of Birth through Three Years
 - * Wheelchair Checklist
 - * O&M Data Sheet
 - Evaluation Report Template
 - * Spanish O&M Terms
 - * Spanish Vision Terms
 - * Analysis and Street Crossing Chart For The Traveler Who Is Functionally Blind
 - * Left/Right Scanning and Lane-by-Lane Scanning Chart For The Traveler Who is Functionally Blind
 - * Analysis and Street Crossing Chart For The Traveler With Low Vision
 - Left/Right Scanning and Lane-by-Lane Scanning Chart For The Traveler With Low Vision
 - * Types of Intersections Checklist

Resources on Functional Low Vision Assessment:

- Low Vision: A Resource Guide...:Chapter 3 talks about assessment; and the appendices have TX forms: http://www.tsbvi.edu/publications/1045-low-vision-a-resource-guide-with-adaptations-for-students-with-visual-impairments-2nd-ed
- Foundations of Low Vision: Clinical and Functional Perspectives: http://www.afb.org/store/pages/ShoppingCart/
 ProductDetails.aspx?ProductId=978-0-89128-883-1
- Functional Vision: A Practitioner's Guide to Evaluation and Intervention: http://www.afb.org/store/pages/ShoppingCart/ProductDetails.aspx?ProductId=978-0-89128-871-8 See chapters 4-6
 - * Chapter 4: Overview of Functional Evaluation of Vision
 - * Chapter 5: Evaluation Methods and Functional Implications: Young Children with Visual Impairments and Students with Visual and Multiple Disabilities
 - * Chapter 6: Evaluation Methods and Functional Implications: Children and Adults with Visual Impairments
- * Vision and the Brain (Amanda Hall Lueck & Gordon N. Dutton: http://www.afb.org/store/Pages/ShoppingCart/ProductDetails.aspx?ProductId=978-0-89128-639-4 Chapters 10-18 are on assessment.
 - * Chapter 10: Assessment of Children with CVI: Introduction and Overview
 - * Chapter 11: Assessment of Functional Vision: History Taking for Children with CVI
 - * Chapter 12: Assessment of Visual Function and Functional Vision
 - Chapter 13: Assessment of Functional Vision: Assessment of Visual Processing in Children with CVI
 - Chapter 14: Assessments Linked to Interventions: Observational Assessment of Young Children with Multiple Disabilities
 - * Chapter 15: Assessments Linked to Interventions: Literacy and Math
 - Chapter 16: Assessments Linked to Interventions: Independent Living Skills
 - * Chapter 17: Assessments Linked to Interventions: Orientation and Mobility
 - Chapter 18: Assessments Linked to Interventions: Computers, Tablets, and Other Assistive Technology

More Information on Functional vision assessment:

http://www.richmondeye.com/simulations-of-eye-disorders/

http://www.lea-test.fi/en/assessme/educearl/index.html — I love Dr. Hyvaarinen's materials and find them useful

http://www.ssc.education.ed.ac.uk/courses/VI&multi/assfva.html#1—MDVI

http://www.afb.org/info/programs-and-services/professional-development/teachers/assessment-issues-for-children-with-visual-impairments/specific-assessments-for-students-with-low-vision/12345

Videos on conducting a FVA: http://www.setbc.org/2006/11/functional-vision-assessment-2006/

FACEBOOK SHARE



- Introducing a braille-display to a child who is Deafblind -- from Paths to Literacy: http://www.pathstoliteracy.org/.../introducing-braille-displa...
- Teachers -- Need more storage, not enough space?
 Take a look at the dual duty teaching easel: https://www.youtube.com/embed/H9 ¡EQoL9Gw
- Learn from Wendy Buckley, AT specialist at Perkins --Webinar on Tech in Everyday Life: http://www.perkins.org/get-in.../.../learning-with-blindness-dec Tuesday December 6; 9-10 Pacific. PLEASE NOTE: IF INTERESTED, YOU NEED TO REGISTER
- Cool twins: Here's something of interest. http://www.cnn.com/.../cnnphotos-deaf-blind-twins-.../
 index.html
- I think I need a "focus fidget" myself!!! http://thefocusfidget.com/
- Some "gift ideas" from Parenting special needs: tiny talker -- hand-held size: http://www.thetinytalker.com/
- Would your child like to receive a letter from Santa -in braille? Take a look at what this site has to offer: https://brailleworks.com/santa-reads-braille/
- Beginning braille? Read more from Paths to Literacy: http://www.pathstoliteracy.org/.../tips-and-tools-teaching-be...

- Literacy for children with CVI: http://www.pathstoliteracy.org/.../adapting-literacy-material...
- Need a refreshable braille device that costs less?
 Take a look at this: http://www.pathstoliteracy.org/
 orbit-reader-20
- Any of you have children who are learning braille?
 Here is an excellent blog from Paths to Literacy:
 http://www.pathstoliteracy.org/pre-braille
- ◆ Tactile graphics: http://www.pathstoliteracy.org/.../ reach-out-and-touch-pictur...
- ◆ Seizures and Neurological Issues -- topic for the month with Complex Child: http://complexchild.org/
- ◆ Teaching children with CVI to write: http://www.pathstoliteracy.org/.../cvi-practice-strategies-de...
- Braille bricks they look like lego pieces: http://www.wonderbaby.org/resources/braille-bricks
- Interesting article about learning braille --- or not! http://www.wonderbaby.org/.../do-blind-kids-still-need-learn-...
- Thanks for sharing this information, Anne: http://www.perkins.org/st.../magazine/were-blind-not-invisible

EMERGENCY PREPAREDNESS for our families:

Parents who missed the Parent Weekend, here are the articles and handouts from our session in Auqust:



http://www.oregondb.org/Family/emergency.php

The following are links on the site above to resources you can use to keep yourself and your family safe in case of an emergency.

- ◆ Is Your Family Ready? Emergency planning and preparation for families of children with disabilities and access and functional needs This was the PowerPoint shared by our Marion County presenters, Sara Campos and Nicholas Burton. They were awesome!
- ♦ 7 Ways to Make Preparedness
 Cheaper
- Preparing for Emergency: A guide for families with special needs and considerations—Dave McCready took the time to find all these resources and links for us. Thanks Dave!
- Emergency Information Form for Children
 With Special Needs
- Emergency Communication 4 All...Picture Communication Aid This is really cool pictures of all kinds of emergency related messages. It also has outlines of figures so that persons can point out where they "hurt"; and gives instructions: "Ask me questions if you need to, but please wait patiently for my reply".
- ◆ Family Emergency Plan from FEMA





• Family Supply List: Emergency supplies



Emergency Medical Information
 Form: page 1



- <u>Emergency Medical Information</u>
 Form: page 2
- Preparedness Calendar
- <u>Links to Resources on Disability Inclusive</u>
 <u>Emergency Management</u> from FEMA
- Emergency Preparedness
 Tip for People with Service
 Animals or Pets



- ♦ Sheltering in Place
- Survive and Thrive: Personal Emergency Preparedness Plan
- <u>Emergency Plan Wallet Card</u> cool easy to carry
- <u>Possible Marion County Emergencies</u> This handout lists possible emergencies we could face—and not just Marion county!





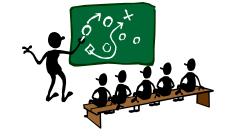


About ALICE training Informational flyer from Lyn about an alternative training/plan when there is a shooter. Western Oregon University has ALICE trainings from time to time—and Lyn will let you know. When these occur. The WOU training is free to anyone in the community.



THE OREGON DEAFBLIND WORK GROUP

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Amy Parker: NCDB representative, The Research Institute at WOU

Caitlin Shockley: FACT/PTI parent representative

Lyn Ayer: Oregon Deafblind Project, The Research Institute at WOU

WEB INFORMATION:

The Oregon Deafblind Project Website: www.oregondb.org

The home page has our newsletters, both current and archived, and a family section too.

Also get frequent information from our Facebook page:

http://www.facebook.com/pages/Oregon-Deafblind-Project/132672043449117

and our less active Pinterest page: www.pinterest.com/lynbayer

We also have our newsletters and other information on our web-page with our partner organization, the Oregon Department of Education:

http://www.ode.state.or.us/search/results/?id=185



Contact the Oregon Deafblind Project!

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