



# Oregon Deafblind Project



## Building Effective Programs

Lyn Ayer, Project Director • Spring 2010

June 2010

Hello to all Families and Service Providers! I feel like I only JUST sent out a newsletter — but it has already been a couple of months....



Thank you to all of you for the child registration forms that you sent in to us. If you are interested in the annual national information on children who are deafblind, please call an Information Specialist at DB-LINK with the National Consortium on Deafblindness. The phone number is 800-438-9376 (voice), 800-854-7013 (TTY) or write to them at [info@nationaldb.org](mailto:info@nationaldb.org). ( [www.nationaldb.org](http://www.nationaldb.org) ) You can also take a look at new graphic maps created from the database (a work-in-progress) [http://nationaldb.org/child\\_count\\_maps/age.htm](http://nationaldb.org/child_count_maps/age.htm)

Schools will soon be closing and summer vacation will begin. Hurray! Hope everyone has some wonderful-summer plans — whether traveling or not. R. Scheel has a list of things you might do — some of them right in your home, some in the garden, and others elsewhere. Take a peek at this three-page site: [http://www.funattic.com/game\\_summer.htm](http://www.funattic.com/game_summer.htm) In our "toolbox" section on pages 3-4, we share some ideas for how children who are deafblind might be meaningfully included.

SO — enjoy the fun of the last few days of the school year — with its field trips, end-of-year pizza parties, changing locations, rearranging rooms, and all the general vacation-anticipation activities. There will be a summer issue of the newsletter which will be re-sent in September to school-based group lists. Have a great summer!

Lyn

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### Child Registration:

The Oregon Deafblind Project completed a child-count for 2009. We now look forward to our next child-count on December 1, 2010. Keep in mind, the earlier a child is registered and can get services, the better the learning process. So don't wait until December to register your child, or pass this information on to someone you may know! Remember:

- The project offers its services to any child identified as deafblind — birth through 21 years. We work with Early Interventionists, just as we also work with Adult Services. In other words, we cover a large age-range (0-22).
- Once a child is registered with the project, you can call to find out about the Project's services — or e-mail Lyn at [ayerl@wou.edu](mailto:ayerl@wou.edu)
- The term "deafblind" can be misleading. Most children who are considered "deafblind" have some vision and/or hearing — and very few are totally blind and profoundly deaf. If in doubt — It doesn't harm to call and ask questions!
- Many of our children who are deafblind (estimated 90%) have additional challenging conditions, including orthopedic or cognitive impairments, autism, traumatic brain injury etc. So we are looking at a population of children with complex and multiple needs!
- Within this group, there are children who may have cochlear implants. This changes what educational teams do and how they need to approach these children.

The Oregon Department of Education continues to be a major partner in our grant efforts, and continues to assist us with family events and family-related project plans. Project information is at:

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

If you want to know more about "eligibility" — look at ODE's eligibility page:

<http://www.ode.state.or.us/search/page?id=339>

OR

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

and the PDF document titled "Student Eligibility".

## COMING EVENTS and ACTIVITIES



### An **Usher Syndrome Family**

**Conference**, July 9-10, 2010, will be held at Seattle Children's Hospital, WA. Please share this information with others. Information and registration is available at:

<http://www.hearseehope.com/>

Conference sponsors: Seattle Children's Hospital, Hear See Hope Foundation, and Decibels Foundation

AADB (American Association of Deaf-Blind) announces the **28th national symposium, "The Future is in Our Hands"**. Dates:

June 19th-23rd, **2011**. Location: Drawbridge Inn in Ft. Mitchell, KY — just across the river from Cincinnati, OH.

Check for details at: <http://www.aadb.org>

Closer to the time of the conference, AADB will be looking for SSPs (Support Service Providers) to volunteer for the conference.

**Hands & Voices of Oregon** is a non profit group serving families with deaf/hard of hearing children. Through our **Guide By Your Side** program, trained parent guides work with families from the time their child's hearing loss is identified, all the way through high school. The GBYS program is primarily funded through the Early Hearing Detection and Intervention (EHDI) initiative. Hands & Voices provides support, advocacy, education and resources to families across Oregon. Referrals can come through EHDI, a parent, and/or the school district. Please check the website to find out what is going on!

[www.handsandvoicesor.org](http://www.handsandvoicesor.org)

Helen Cotton Leiser is the Executive Director of the organization.

## THE TOOLBOX



### IDEAS Corner for Summer Activities

- Start a "collection" that is appealing to your child

If your child prefers to use touch — find out what might be a "collectible" of interest. For example, spoons might be fun. For one thing, there



are different sizes and shapes — ranging from large wooden ornamental ones, to tiny spoons meant to measure a "teensy" amount or to serve relish. Spoons are made of different materials and will differ in weight. Some are made of more than one material (like steel and porcelain collector coffee spoons).



There are ones that are large and decorative which can be hung on a wall. There are small collector spoons which have filigree work and various decorations — and come from various states in the US or from



other countries. Spoons can be sorted by shape, size — and use. Round "bowls" for soup, tiny coffee spoons, long-handled ice-cream/shake spoons, wooden spoons to mix a cake, sets of spoons to measure.... Of course, you will also need to figure out ways to store the collection. You could create a "spoon wall" in your child's room; or have a variety of boxes and tins that are stackable or can go into a large plastic storage container.



- 1, 2, 3 — Plan a Picnic in the Local Park — or your Backyard!

1. Make up invitations for the picnic and send these to friends. Siblings can pitch in too! Make the invitations out of small paper plates and stick "stuff" on these that can be felt and heard (bells? Beads?)



2. Decide what you want to eat and drink — and how much — and go shopping. Make sure your child "helps" with the shopping. Smell that cantaloupe. Feel the baby carrots. Handle a cold carton of ice-cream sandwiches. Feel the weight of a box of pop cans or container of water! A grocery store can be a "sensory heaven" for a child who is deafblind — and who "participates" in the shopping. Don't forget picnic plates, cups, spoons and napkins!
3. Gather other things together that you might need — blankets to sit on, cushions, a food basket, dog food (if you are taking Fido!), the right clothes to wear — and games or ideas for games that everyone might play. Of course, there are also things to do that you could just list — like "roll down the grassy slope", "splash in the pond", "feed the ducks", "play on the swings", "make mud pies — or make things out of clay", "walk barefoot through the sandy area", "jump on the trampoline". Think of some "artsy" things too — like decorating flat rocks with paint, beads, small stones, pennies. Organize a round or two of tug-o-war, or use a "parachute" — or just take a walk and collect things you find along the way. Be sure to take a bag with you!



All these are simple, but great sensory experiences!

Check out the latest "Deaf-Blind Perspectives" from NCDB:

<http://www.nationaldb.org/dbp/current.htm>  
Camping with Laci Faith (Matt Lowell)

## THE TOOLBOX



- **Redecorate your child's room WITH him/her**

Let's not break the bank!! Make a list of all the things your child likes to touch, hear, see, smell. For example, maybe he likes the rough feel of sandpaper or burlap, the "knobby" feel of bubble-wrap, the fun feel of corrugated cardboard or plastic, the "sticky" feel of non-skid shelf-liner. You can even find these in various colors! You could actually decorate walls, bed head-boards, outside or inside closets, sides of desks, night-stands, picture frames (or even create pictures) with these textures. You could add interest to a texture wall by gluing on 3-d objects such as nuts and bolts and other "stuff" you can get at a hardware store; Or you can go with shapes.



Check out <http://scrapaction.org> for cheap materials.

Maybe your child needs bright colors so he can see them — and contrast (e.g., a dark-colored, or single-colored bedspread might work better than a designed one — he will be able to see things he puts on his bed better). Or maybe "shiny" works best. Fabric stores may have sales where you could buy fabric to cover a comforter or bed-cover in a color-of-choice. Maybe he would be better off with simple drapes that can be pulled aside — than with blinds that can be visually disruptive.



Perhaps your daughter likes the smell of citrus fruit and would love a room freshener that has that smell — or a basket of potpourri that can be changed to match the seasons (e.g., pumpkin and spice for Thanksgiving).

You may know of a preference for high-tones or low-tones and can find a wind-chime or set of bells that your child can hear — and like. You could even put a wind chime on a door-handle so your child can hear when someone comes into her room.

What about lighting? If your child has limited vision, thinking about WHERE to position lights is important. It would also be a good idea to check HOW BRIGHT lights need to be. Sometimes dimmer switches will help.



## Did you know?

Wikipedia states that ECHOLLOCATION is a term coined to describe biological sonar (biosonar) — the ability to use echoes to locate, range and identify objects in the environment. It is used by bats, some marine creatures such as whales and dolphins, and some land animals such as shrews. Amazingly, some human beings can develop their biosonar abilities too! I remember one young man who was deafblind who could locate the playground equipment (including the obliquely-placed pipes), and avoid them — just through using tongue-clicks. So it is not "just hearing".

Take a look at the following youtube videos about Ben Underwood:

<http://www.youtube.com/watch?v=YBv79LKfMt4>  
<http://www.youtube.com/watch?v=MNKJ1diTxOE&NR=1>

Note: Dan Kish, Ben's O&M Instructor is also visually impaired.

Ben died from a recurrence of cancer just before his 17th birthday. Announcement:

<http://www.youtube.com/watch?v=zhtMXpNW1zc&NR=1&feature=fvwp>

Ben's website: <http://www.benunderwood.com>

### Other Readings you may find of interest

- "How Well Do We Know Our Own conscious Experience? The Case of Human Echolocation" (Sep 25, 2000. Eric Schwitzgebel & Michael S. Gordon). Citation below is on pg 21 of their paper. (Find this paper by googling "echolocation")
- "Facial Vision: Perception of Obstacles by the Deaf-Blind" — American Journal of Psychology 60 (1947): 502-553
- <http://www.sciencedaily.com/releases/2009/06/090630075445.htm> Scientists Develop Echolocation in Humans to Aid the Blind. Science Daily (July 6, 2009). Also look at the section, "Related Stories": Gene involved in Human Language Development Also Involved in Bat Echolocation (Sep 19, 2007) <http://www.sciencedaily.com/releases/2008/06/080625153404.htm>
- Sonar System for the Blind (Science Daily, June 26, 2008): Bats Use Touch Receptors on Wings to Fly, Catch Prey, Study Finds (ScienceDaily—December 15, 2005)
- Here's a website with a song about echolocation: <http://www.youtube.com/watch?v=5mwoOyOleGc>
- And some information about some marine creatures: <http://www.seaworld.org/infobooks/Bottlenose/echodol.html>  
<http://www.dosits.org/science/ssea/lb.htm>

## MORE DID YOU KNOW?

- News on gene therapy and congenital blindness (Thank you Kathy McNulty of NCDB!) [http://www.eurekaalert.org/pub\\_releases/2009-10/uops-oso102209.php](http://www.eurekaalert.org/pub_releases/2009-10/uops-oso102209.php)



• June commemorates the life of Helen Keller and June 27 to July 3 has been designated as Deaf-Blind Awareness week since 1984. DCMP (Described and Captioned Media Program) has done a super job — they created a new webpage in honor of her life and work: [www.dcmp.org/helenkeller](http://www.dcmp.org/helenkeller). Their message to students who are graduating: "It is important for you to have a perspective built on hope and achievement in order to succeed, whether in times that test you or reward you, just as Helen did, and remember that equal access to information is one of the many factors necessary to achieving and maintaining that perspective." The current DCMP newsletter is at: [http://www.eurekaalert.org/pub\\_releases/2009-10/uops-oso102209.php](http://www.eurekaalert.org/pub_releases/2009-10/uops-oso102209.php)



- And here is some litigation information about cochlear implants (Thank you, Kathy Zelaya from DBCI listserv): [http://www.eurekaalert.org/pub\\_releases/2009-10/uops-oso102209.php](http://www.eurekaalert.org/pub_releases/2009-10/uops-oso102209.php)
- Homeschool Rewards Zone still has their [Field Trip eBook](#) on sale.
- Read about the **Hearing Regeneration Initiative**: <http://depts.washington.edu/hearing/HRI.php>  
Virginia Merrill Bloedel Hearing Research Center (Thank you, Jim Brown, DBCI listserv, for sharing this information!)
- Read about Hearing Dog of the Month! [http://www.hearingdogs.org.uk/pships\\_dog\\_month.php?id=96](http://www.hearingdogs.org.uk/pships_dog_month.php?id=96)



## WEBINARS, WEBCASTS and TECHNOLOGY UPDATES



Webinar (archived from presentation held on February 25, 2010): "Sharpening Your Listening Skills with Hearing Aids or Cochlear Implants" by Carissa Moeggenberg, M.A., CCC-A <http://www.hearingloss.org/Community/transcripts.asp>

You can also download Ms. Moeggenberg's transcript in PDF format

For those of you who do not receive the e-news from Perkins, there are a number of very useful webcasts. The latest one by Barbara Miles is titled "**Conversations**". You can also download an adaptation of Chapter 4 from Miles and Riggio, eds. Book, "Remarkable Conversations". Look for this and other webcasts: [www.Perkins.org/webcasts](http://www.Perkins.org/webcasts)

NEW! Available for shipping in mid-June. Early bird discount for orders received before July 15. Regularly priced \$1,195.

**The PEARL** expands the features of OpenBook 9.0 to provide instant OCR. Press a key-stroke to snap a picture, and hear your book read back to you with Eloquence or one of the human-sounding voices from RealSpeak Solo Direct®. You control the reading rate and voice. Use the PEARL to read books, newspapers, magazines, and bills. OpenBook identifies columns and places them in logical reading order. Change the language setting to read foreign language documents with native speaker voices.

OpenBook converts your scanned documents into electronic text that can be read aloud. For the low vision user, text can be displayed on a computer monitor in large type, displaying your choice of text sizes, colors, and backgrounds.

# ANNOUNCEMENT

## Preservice Training Program in Deafblindness

A preservice online training program in deafblindness is now available through Utah State University. Based on the National Intervener Competencies, the courses are designed to prepare paraprofessionals to work as interveners with children and youth who are deafblind. It can also be useful to teachers, parents, administrators, and adult service providers. This coursework won the 2007 Blackboard Greenhouse Exemplary Course Award, which recognizes it as one of the top ten online courses in the country. The following options are available to interested students:

**Option 1:** Students can take the training program in deafblindness that consists of two 4-semester credit hour classes to be offered in the Fall and the Spring. Tuition is \$211/credit hour with no out of state fees. Upon successful completion of the coursework, students will be awarded a certificate of completion from USU. These courses can also be taken for graduate credit.

**Option 2:** Students can take the two course training program on a no-credit basis for \$110/credit hour with no out of state fees. Upon successful completion of the coursework, students will receive a certificate of completion from USU.

**Option 3:** Students can take the coursework as part of an Associates Degree program in General Studies with a Focus in Deafblindness. This online program includes 30 semester hours of general education classes and 30 hours of coursework that includes the deafblind classes and other related topics. Tuition is \$211/credit hour with no out of state fees.

Anyone interested in participating in this training, please contact:

Linda Alsop  
SKI-HI Institute  
(435) 797-5598

The announcement above is from  
the Ski\*Hi Institute



## Walking in Becca's shoes

Something or someone moving around, coming closer; suddenly "in my face", sounds flowing all around me. Mind racing to figure out who or what this is. Do I HAVE to look? Can I look away while I "take stock"? What do those sounds mean? Or are they meant to mean anything?

Someone grabs my face and turns it. .... Leaves an unpleasant sensation in my being. I try to look and listen; close my eyes; look again. No, I cannot absorb all the details. I turn my eyes away. The person's voice sounds unhappy — or is she mad? I turn my back on her, swing my arms to keep her away.

Someone else approaches. I try to make sense of the sounds pouring out from the person. I catch my name "Becca" from the flurry of words. So it must be about me. I slowly take a peek at the person. It is Eliza. I know Eliza. She is with me a lot — from the time I get off the school bus, until she helps me back on. So I know her — and I can look at her now while she says something to me — and I try to figure it out.

I get to my place at the corner table. Eliza turns on the light box. I turn my eyes away. She uses the dimmer switch to reduce the amount of light. I can now look at it. I absolutely love light, but not when it blinds me so I cannot look at it. Going outside into bright sunlight does the same thing! Eliza puts a grid on the light box. I can see the light peeking through each little square. Then she gives me a box with colored blocks. They are not all the same. I hold each one up and look through it. I like the blue ones best. So I put the blue ones in the lighted squares, until I have no blue ones left.

"Look at the words, Becca," Eliza

says. I wish I could tell her that the words read like a foreign language; that each letter hugs the next one. I cannot separate them. I cannot read them. I push the book away. Eliza takes out the magnetic board and patiently puts the words on there. The board is black; the letters are yellow. And she puts space between the letters. And she points and speaks the words. Now I can see them better — and maybe I'll read a bit. But I feel tired after about five minutes of this — and I turn away and close my eyes. Looking, listening, repeating — all seem to be separate tasks to me, and I am tired. Eliza waits patiently.

The noise level in the room increases as all my classmates return from elsewhere. They seem to whizz around me. It makes me feel like I am in a blender being churned to death! AHH! I put my hands over my ears and turn my face to the wall. Someone sits close to me, letting me feel that she is there. The person doesn't say anything — just lets me know "I'm here. When you're ready". She does not smell like Eliza. I peek at the person. It's Rita. Great! Maybe I get to take a walk outside today. Rita lets me walk on my own. I take my time. I sometimes twirl my body so that I can see the trees move. I like watching the traffic on the street. But I don't like the noises they make. I learned that it was the traffic and not the trees making those noises. I learned the trees make noises too — but those are different.

Time to go home. Eliza hands me a bunch of keys. I clutch these to my heart. They are my "proof" that I'm headed home. I keep the keys in my hand as I get on the bus, and as I ride home. When I get off the bus, I hand them over to Mom. I'm home. And I'm exhausted.



There are many children who are deafblind who have difficulty seeing or hearing because they

have some level of brain/nerve damage. It helps to work with them if we can make an attempt to understand what and how they might see or hear. It certainly helps if we keep in mind what their preferences are, what they avoid (and why) — and try to picture what their world might be like.

☞ It will help to create the right modifications if we take the time to "walk in their shoes".

☞ It will help us to be more patient with their "behaviors", cat-napping, hands-over-ears, and apparent disinterest.

☞ Many of these children may lack what we call "affect". Their faces do not show their emotions. So we must learn to read body language and behaviors better.

☞ We need to pace what we do so that we do not exhaust them to the point that they are no longer paying attention.

☞ We need to keep our speaking to a minimum — so as to not distract the brain from the "focus" of the task.

☞ Using hand-under-hand rather than "grabbing" the child's hand will help.

☞ Avoiding rushing through things, and hurrying the child will give the child have time to integrate all the sensory pieces. What is easy and automatic for us may not be so for the child.

Having cortical "issues" with vision and hearing can make a significant difference to how a child may perceive the world and people around him/her. Take a look at a music video, "Emmy's Song" that was created by a high school student — to present a picture of her friend, Emmy [www.ecb.org/wymf](http://www.ecb.org/wymf) in an attempt to help understand what her world is like — and to create a non-stereotypical image of her. Thanks, Alcy!



HAVE A  
WONDERFUL  
SUMMER!

## THE DEAFBLIND WORKING GROUP

**Marria Knight**— Region one, Eastern Oregon  
**Colleen McLaughlin**—Region two, Central Oregon  
**John Pierce**— Region three, Southern Oregon  
**Terry Cadigan** — Region four, Cascade Regional  
**Anne Olson-Murphy** — Region five, Willamette Regional  
**Kim Puckett & Stephanie Karpouzes**—Region six, Columbia Regional  
**Kit Staples**—Region seven, Lane Regional  
**Brenda Satter**—Region eight, Northwest Regional  
**Donna Schuyler & Anne Harrington** - Oregon School for  
the Deaf  
**Dennis Crepeaux**— Oregon Commission for the Blind  
**Paddi Davies**— NCDB representative, WOU  
**Tom Udell** — NCDB representative, WOU  
**Sue Mathisen** — Regional Services, Management Team  
**Sam Ko** — Oregon Department of Education  
**John Killoran** — Director, The Teaching Research Institute, WOU  
**Lyn Ayer** — Oregon Deafblind Project, WOU



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

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

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## Contact the Oregon Deafblind Project!



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The Oregon Deafblind Project is funded through grant award # H326C080036-09, OSEP CFDA 84.326C  
U.S. Department of Education  
Office of Special Education  
OSEP Project Officer: Glinda Hill

The opinions and policies expressed by this publication do not necessarily reflect those of The Teaching Research Institute, or the U.S. Department of Education.

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