



# Oregon Deafblind Project



## Building Effective Programs

Lyn Ayer, Ph.D., Project Director Summer 2016



Hello all!

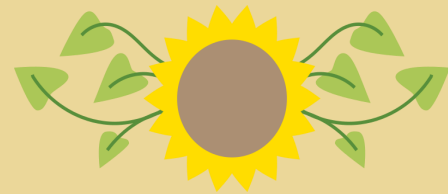
Ah! Summer vacation is here. Knowing that many on this mailing list will be on the sunny beaches of Hawaii or our own lovely (but sometimes chilly) Oregon coast — or elsewhere having fun — I will be sending this out again in fall.

Parents: We were so glad to see the quick response to our mailed invitations and RSVPs for the Annual Parent Learning Weekend next month. Thank you for paying attention! Registration is now closed since we have reached our maximum and have filled all hotel rooms now. We can still put you on a waiting list — if you would like to do that. Sometimes someone needs to drop out closer to the time of the event. So — if this happens — it will be short notice for anyone on the waiting list.

Kids and sibs: Hope you are all having a wonderful summer! Lovely weather too!

Educational Team Members: Have a super vacation — and see you in September!

Lyn



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“Summers had a logic all their own and they always brought something out in me. Summer was supposed to be about freedom and youth and no school and possibilities and adventure and exploration. Summer was a book of hope. That’s why I loved and hated summers. Because they made me want to believe.”  
—Benjamin Alire Sáenz, *Aristotle and Dante Discover the Secrets of the Universe*



## OHOA Modules

In the process of hosting the OHOA modules, I have found the content to be

really useful to parents and educational teams who have participated. I would like to highlight various modules in these newsletters—not necessarily in order. I am hoping these “overviews” will encourage you to go to the Oregon-hosted modules and look for something specific.

### MODULE 5: Availability for Learning

The focus of this module is to make sure a child is ready to learn. It is NO USE trying to teach a child who is not open and ready. This is critical, since within the population of children who are deafblind the large majority have additional disabilities.

The **learning outcomes** for module 5 include:

- ◆ Recognizing the internal and external factors that influence whether or not a child is ready and able to learn
- ◆ Learning more about “states of arousal” (to what extent awake/alert) to ensure that teaching only occurs during the times when a child can concentrate and learn — even if these are very small segments of time
- ◆ Creating “Likes and Dislikes” lists and learning how to make best use of the information this gives us—and how to use these as MOTIVATORS for your child to learn
- ◆ Knowing which senses are the most useful, most preferred — and putting that information to best use
- ◆ Learning how to recognize stress and stress levels in a child — and determining when to teach.

In the introduction to this module, Kathee Scoggin, the module lead, talks about ensuring a child is alert, attentive, interested (therefore, motivated), and NOT over-stimulated. She talks about “internal” and “external” factors. How do we KNOW or learn these things about a child? It is through careful and systematic observation—where we document as we observe. And if we ourselves participate in a simulation or two, it always helps. See Activity 1 for a suggested simulation experience. It’s FUN to do this and educational.

In Activity 2, there is a “discussion” relating to the “Box of Deafblindness” - and how to determine whether the lid is open or closed. (You will need to go back to Module 2 to know more about this “BOX”). This unique idea was contributed by a parent. When the lid is open, the child is able to learn; when it is closed, he/she has withdrawn attention and is not likely to learn. The questions within this set of slides make us think! Since STRESS is a key factor for the lid being closed, the reading for this section is “Stress—Good cop or bad cop?” by David Brown. David makes the point that “in time limited and manageable doses,

If you would like to register for the Oregon OHOA modules, please contact me (Lyn) and give me a) your name and e-mail address, and (b) the city you are from. Please also let me know your role/position (parent, teacher etc). [ayerl@wou.edu](mailto:ayerl@wou.edu)

stress is essential to life, a significant source of brain development and learning, of positive self-image, of effective problem-solving activities, and of good physical and mental health.” The human body can only react positively to the stress hormones for a limited time period. If this remains in the system, continues to be at high levels or does not get flushed out, then it becomes a problem. It can actually “damage brain cells, weaken memory, and block effective thinking”. This is a terrific article. David goes on to discuss what stress might look like so that you might have an easier time recognizing it — and you might be surprised at some of them. He also discusses what might help. You can also read the article on this page: <http://www.cadbs.org/articles-by-subject/medical-sensory/>

Activity 3. The first handout here is a bulleted handout listing some internal and external factors, and a short list of support strategies. In the next set of slides, Kimberley Lauger discusses—in more detail — what the internal factors might be, and what a student might be experiencing. And then — what we may be able to control in the external environment in order to balance things out.



The next slide/video with Kathee gives an example of how important it is to REALLY observe very closely.—and how past associations might influence the present. Memory can provide both positive and negative feedback—and this example of a child “acting out” when the table was wiped with disinfectant is a really good example. The slide/video of Kimberley has her talking about Dylan and hysterical laughing — which, in this case, was not an indicator of joy but of stress. She follows this with how she manages Dylan's stress. Melanie follows up with information on how her son's stress was reduced by having someone who taught him how to communicate — and so to be ready to learn.

The following set of slides begins with Kimberley—and then Caroline — stressing the importance of observation—and an opportunity to observe a series of video clips with various children—so you can practice.

I hope these snippets about and from Module 5 will tempt you to take a closer look and to go through the whole module. I don't know of anyone who has done this module who has NOT learned a ton from it. SO — GO FOR IT!!

There are 18 modules currently available, and two on Touch that will be available before the end of 2016. Read more about them at the following link so that you can decide if you want to learn more about a specific topic:

<https://moodle.nationaldb.org/mod/page/view.php?id=24821>



MANY organizations and individuals, including children and parents, were involved in creating the OHOA modules! Take a look at this long list: <https://nationaldb.org/ohoamoodle/contributors.html>



## ATTENTION PARENTS!



Have you seen the “FAMILIES MATTER” section of the National Center on Deaf-Blindness (NCDB) website? If not—take a look. You may.....

- Find a family you would like to connect with....
- Learn about the DB network's FAMILY ENGAGEMENT INITIATIVE
- Join an ongoing FAMILY DISCUSSION — or start a new one
- Find information in SPANISH
- Connect to the NATIONAL FAMILY ASSOCIATION FOR DEAF-BLIND



<https://nationaldb.org/families>

# MEMORY

“It is an important part of what makes us truly human, and yet it is one of the most elusive and misunderstood of human attributes.” <http://www.human-memory.net/>

## What is memory?

It is something that is much more complex than we can begin to imagine. To simplify things, it has been compared to a super-computer, or a complex filing cabinet. It would have been simpler if memory was located in one place in the brain; but it isn't. It involves a process that occurs all over the brain (Distributed Processing) in patterns that we really cannot fully comprehend and is reflected in our body's sensory and other systems. So, it might be better to imagine a really complex web of intrinsically connected threads that “symbolize the various elements of a memory that join at nodes or intersection points” to create a whole memory (<http://www.human-memory.net/>). Since memory is distributed, when there is damage to one or more parts of the brain, some memory is retained in the undamaged or less damaged areas. Let us look at some basic memory information and think about deafblindness and its impact on memory.

## Types of memory:

These three can be thought of as **levels** where one leads to the next:

**Sensory memory** → **Short term memory** → **Long term memory**

You need all three to have a really well-established memory of something. Because it completes the “storing” process, this will also give us some idea why long term memories usually persist when short-term memory fails. It is then reasonable to think if a child has a memory that is established in this way, we should try to connect other memories to it – so the “new” memory is added to and strengthened. Concepts are broadened in this way as part of the process.

◆ **Sensory Memory.** Our memories differ because of the way in which we receive input for them. So visual input from an event for one person will result in primarily a visual memory; while for another person who cannot see, the input from the same event may have been auditory. So the memory is auditory. These are two very different memories – but for the same event. For our children who are deafblind:

- How are they getting the information to store? Using a sensory integration inventory, or a functional assessment of the senses is important. Occupational Therapists will definitely have suggestions for this.
- Which sensory system is functioning the best?

To “jumpstart” your quest – here’s a sampling of Sensory Inventories:

- From the University of Iowa: [http://www.uihealthcare.org/uploadedFiles/UIHealthcare/Content/Services/Center for Disabilities and Development/UCEDD/Self-Advocacy/Behavioral\\_Support\(1\)/sensoryinventory.pdf](http://www.uihealthcare.org/uploadedFiles/UIHealthcare/Content/Services/Center%20for%20Disabilities%20and%20Development/UCEDD/Self-Advocacy/Behavioral_Support(1)/sensoryinventory.pdf)
- From OT Innovations: <http://www.ot-innovations.com/clinical-practice/sensory-modulation/sensory-assessments-for-adolescents-adults/>
- And then there’s Texas School for the Blind and visually Impaired – Learning Media Assessment: <http://tsbvi.edu/publications/1037-learning-media-assessment-a-resource-guide-for-teachers-2nd-ed> Want an overview of the LMA? Check our earlier article: <http://www.oregondb.org/news/Summer1-2014.pdf>

• What might all the pieces be? It would be important to note if more than one sense is involved. What would the combined input look like? These sensations, often stored as “emotionally” connected memories are sometimes known as “**Bodily Emotional Traces**”. See the section in this blog under ‘Is there a language of deafblindness’: <http://www.deafblindinformation.org.au/congenital-deafblindness/for-professionals/communication/> .

- ◇ Want to learn more and practice noticing these? Go to Open Hands Open Access module 7 on [www.nationaldb.org](http://www.nationaldb.org) . Click on the link to the OHOA modules and register so that you can take a look. No cost for doing this!
- ◇ And here's one more site that has an interesting section with a diagram of body maps connected with various emotions (Fig.2.) : <http://www.pnas.org/content/111/2/646.full> .
- ◇ Look at this study – which connects the emotional and physical pain: <https://www.psychologytoday.com/blog/body-sense/201204/emotional-and-physical-pain-activate-similar-brain-regions> .

Are there implications for our children who are deafblind? When a person's body "lights up" in a specific way to an emotion, the body-brain connection provides that emotional piece that only serves to strengthen what the child is learning. If all remembered emotions were positive – this would be so beneficial. But this is not always what happens. Perhaps if we knew or could guess what the less-than-positive ones were, we could work on connecting them to more positive activities and memories. For example, a child who had been a premature baby has emotional memories connected to heel sticks (for blood-draws). This child may not even consciously remember this, but the pain and emotional upset connected with them may remain, hovering in the background in his memory. He may react poorly to massage when someone touches his foot and heel – even though there is no actual pain – and display emotional distress. Even though infant-child massage dictates starting with the feet and legs, perhaps for this child, starting from a less vulnerable place on the child's body will help to relax the child. Doing the heels last may, in time, help transfer the emotions from negative to positive. <https://www.psychologytoday.com/blog/body-sense/201204/emotional-and-physical-pain-activate-similar-brain-regions> .

◆ **Short term memory** – also known as "working memory".

See the 'video-watch' section of our newsletter: <http://www.oregondb.org/news/Fall2014.pdf> I love that the website I am looking at calls short-term memory the brain's "post-it" note. It is not meant to stay and is more for instant and quick recall – unless it is processed and stored. [http://www.human-memory.net/types\\_short.html](http://www.human-memory.net/types_short.html) . The same article gives a couple of good examples. If you are reading a sentence, your short term memory has to keep track of the earlier part of the sentence so that the whole sentence can then be put together for meaning. I picked this example because so many of our children cannot keep too much information in short term memory. For example, they may hear and understand the first part of the sentence and lose the rest, or only make note of the tail end of the statement. SO – wouldn't it help to (a) shorten sentences – or even use phrases; (b) Look for comprehension (and storage of this) before moving on, and (c) Practice recall really soon after – and repeat, repeat, repeat? It is also helpful to figure out if we need to use one-step, two-step – or more – directions with a specific child. Too many steps all at once, and you may lose the child's attention and muddy his comprehension. Since the pre-frontal cortex (front of the head) is thought to be the main part involved in short-term memory, damage to this area of the brain results in poor working memory – and this will disrupt the process of memories being stored to be retrieved.

- What are some possible factors/techniques to help our children so that a short-term memory is stored in long-term memory?
  - ◇ Make sure the child is attending – and is relaxed.
  - ◇ Simplify what it is that needs remembering.
  - ◇ Repeat, repeat, repeat.
  - ◇ Attach it to a context.
  - ◇ Connect it to something that is of interest to the child and so provide motivation.
  - ◇ Try using Mnemonics with some children. Music mnemonics are interesting... <http://learningassistance.com/2006/january/mnemonics.html> . Remember "knuckle mnemonics"? <https://commons.wikimedia.org/wiki/File:Knucklemnemonic.jpg> . If you are a creative person, you can perhaps create some "touch mnemonics", based on the "likes" and preferences of a child, that might help "anchor" ideas and concepts.
  - ◇ Link to "old" and established memories – and provide cues (visual, auditory, or other sensory).
  - ◇ If a child is able to speak or sign—have them repeat, using words or signs – and not just passively listening to or heeding your message.

- ◇ Use “chaining” (an Applied Behavior technique)– both backward and forward – depending on what it is. It could be simple instructions, or a routine:
  - \* <http://special-ism.com/last-is-first-in-backward-chaining/>
  - \* <http://www.learningsolutionsmag.com/articles/325/last-things-first-the-power-of-backward-chaining> .
- ◇ Remember – reduce distractions because they will possibly erase the short-term memory and you will have to start over.
- ◇ Be aware that each child will differ in “memory span” – i.e., how many things in a row can be recalled. Miller’s Law suggests that the “magic number” is 7+ or -2. For our children who are deafblind and have additional severe disabilities, this will be less.
- ◇ The human memory website also reminds us that memory span can differ between cultures. For example, “..English-speakers can typically hold seven digits in short-term memory; Chinese speakers can typically remember ten digits.” The reason? “Chinese number words are all single syllables, whereas English are not.”
- ◇ “Chunking” or putting together in a group is one technique – the ideal being 3; but this may or may not be possible to use with a specific child. It’s okay if you only do ONE thing a time – a chunk of one!

In short – grab an important idea or concept from short-term memory – and find a way to help it stay!

- ◆ **Long term memory** No one yet knows enough details about long-term memory. It is possible that we never forget anything that gets stored there – but that the recall process may be affected and it may appear like we have forgotten. In the elderly, long-term memories often seem to come out of nowhere – and even seem more vivid than before. So they WERE somewhere – buried in the brain – resurrected by some association that seems random.

*To be continued in our next issue.....*

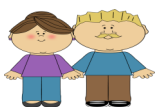
## FACEBOOK SHARE

- ◆ OSEP has a new user-friendly website. Take a look: <https://www.osepideastthatwork.org/>
- ◆ Heard of Epigenetics? This is very interesting: <https://www.youtube.com/watch?v=xVggHJbvJPA&feature=share>
- ◆ Here's a powerful statement from our early communication tutorial: According to Dr. Linda Alsop from the SKI-HI Institute, "children who are born deafblind may be unaware that formal communication exists. They may not know that they can exert power over their environment with communication...They may express wants and needs through behaviors, but be unaware that their actions are being observed and interpreted by others. They may not be getting enough information to understand that they have caused something to happen". Want to learn more? Go to the tutorial: <http://www.oregondb.org/CommunicationHome.html>
- ◆ A foldable, backlit keyboard? <http://www.pcworld.com/.../iclever-backlit-foldable-keyboard-...>
- ◆ The Helen Keller National Center has a new website and so does "Connections"! Take a look:
  - <https://www.helenkeller.org/hknc>
  - <https://www.helenkeller.org/hknc/news-letters/spring-2016>
- ◆ Comic books -- accessible? <http://www.pathstoliteracy.org/reso.../accessible-comics-blind>
- ◆ Do you know all about Helen Keller? Find out: <http://mentalfloss.com/article/81472/10-things-you-might-not-know-about-helen-keller>



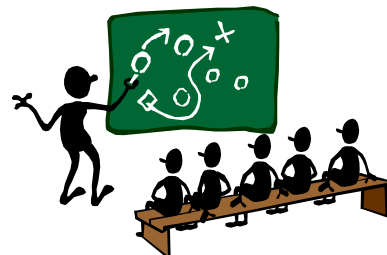
### PARENT LEARNING WEEKEND 2016 Only Waiting List status available

Dates: August 26-28  
 Location: Oregon Garden Resort, Silverton  
 Questions? Contact Lyn Ayer  
 E-mail address: [ayerl@wou.edu](mailto:ayerl@wou.edu)  
 Phone (leave a message): 503-838-8328



## THE OREGON DEAFBLIND WORK GROUP

<b>Malina Lindell:</b>	Region one, Eastern Oregon
<b>Nancy Abbott:</b>	Region two, Central Oregon
<b>Lynette Kleespies:</b>	Region three, Southern Oregon
<b>Terry Cadigan:</b>	Region four, Cascade Regional
<b>Anne Olson-Murphy:</b>	Region five, Willamette Regional
<b>Darlene Daniels:</b>	Region six, Columbia Regional
<b>Trish Orr:</b>	Region seven, Lane Regional
<b>Gina Fivecoat:</b>	Region eight, Northwest Regional
<b>Sharla Jones:</b>	Oregon School for the Deaf/RMT representative
<b>Linda Brown:</b>	Oregon Department of Education
<b>Kathy Eckert-Mason:</b>	Department of Vocational Rehabilitation
<b>Sarah Mora:</b>	Oregon Commission for the Blind
<b>Amy Parker:</b>	NCDB representative, The Research Institute at WOU
<b>TBD</b>	FACT/PTI parent representative
<b>Lyn Ayer:</b>	Oregon Deafblind Project, The Research Institute at WOU



### WEB INFORMATION:

The Oregon Deafblind Project Website: [www.oregondb.org](http://www.oregondb.org)

The home page has our newsletters, both current and archived.

Also get frequent information from our Facebook page:

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

and our Pinterest page: [www.pinterest.com/lynbayer](http://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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