



Building Effective Programs

Lyn Ayer, Project Coordinator • Spring 2008



Instead of saying "Good bye" to Jay, I think we would all rather use the old-fashioned, original version of "farewell" — **FARE-THÉE-WELL**. This means "May it go well with you". May you enjoy your new job — and not forget to think of all of us. We will surely be in touch!

"Farewell" from D. Jay Gense, Project Director

I want to take this opportunity to let everyone know that I have resigned my position with the Oregon Department of Education. As such, I am also leaving my role as Director of the Oregon Deafblind Project. I have served in this capacity for the past 11 years.

I find my resignation from the Department of Education to be bittersweet in so many ways. However, leaving the Oregon Deafblind Project is by far the most difficult aspect of this change. I am incredibly proud of the services and supports the Project provides to children and families across the state, and I've cherished the opportunity to work with the many talented and dedicated individuals (you know who you are!) with whom the Project partners to deliver our unique services.

I'm grateful to be moving to a position that will allow me to remain connected to the Project, although in a different capacity. I've accepted a position with Columbia Regional Program in Portland. This Regional Program provides services to students with low incidence disabilities residing in the greater Portland metro area, as well as those in Hood River and Wasco Counties in the Columbia Gorge. Students served include those who are deafblind; as such, I look forward to partnering with the Project in serving students and families.

I want to thank everyone for the support and passion extended to the Oregon Deafblind Project, and to me, over the years. I will always hold my "deafblind family" near to my heart. Remarkably, never did I have to ask for help more than once. Never did I receive a "no" to a request made on behalf of the Project. For that, you all have my deepest gratitude and respect. In particular I want to offer my sincere thanks to each of the present and past Deafblind Consulting Teachers, to Teaching Research Institute (and specifically to Lyn Ayer, Paddi Davies, Tom Udell, and John Killoran), to Sylvia Carnes (former but never forgotten Project Coordinator and friend), to Oregon PTI, to Jo Anne Robison and Dave Jones, both of whom supported me and the Project at the Department of Education, and to the Project's Advisory Council. You each helped ensure the Project's services always did and will remain of value and quality.

Please know that although I am leaving, the Oregon Deafblind Project continues in the *very* capable hands of Lyn Ayer, Project Coordinator, and her colleagues at Teaching Research Institute at Western Oregon University. Indeed, the Project is incredibly fortunate to have "nabbed" Lyn last year. She has assumed the Coordinator role with gusto, finesse, and grace. I have no doubts that the Project is both solid and secure. We anticipate that the Project will be submitting an application for another "round" of funding very soon, and I fully expect that the quality work of the Project will continue for many years to come. With that, I look forward to our paths continuing to cross.



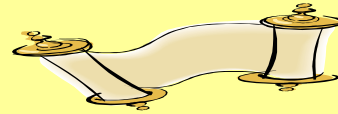


Overview of Services:

The Oregon Deafblind Project, funded by the U.S. Department of Education, is coordinated by the Oregon Department of Education through Western Oregon University. We provide technical assistance in support of mandated early intervention and special education services to children and youth who are deafblind, birth through age 21. Technical assistance and support is provided to IEP teams serving students who are Deafblind and to their families. Students eligible to receive services through the Project must meet the federal definition of deafblindness:

“Children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their education needs due to these concurrent disabilities”

Services are provided via each of the eight Regional programs, the Oregon School for the Blind, the Oregon School for the Deaf, and partner organizations such as the Commission for the Blind, and the Oregon Parent Training and Information Center. Each Regional program, and each of the special schools have a Regional Consulting Teacher working with the teams for children who are deafblind. Once children have been identified as Deafblind, a team is eligible for Team Training. The project also provides support, consultation and assistance to families of students who are deafblind. The project has a Parent/Family Consultant who is available to help us reach out to families. Technical assistance includes on-site consultation, inservice training, workshops, and assistance with program development.



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DB Project Summer 2008 Events

SAVE THE DATES!!

1. July 9-12 Summer Institute

Topic/s;

- Communication for children who are Deafblind/multi-disabled
- The importance of Movement
- School to Post-school Transition,

2. August 20 & 21 Tactile Sign Workshop

Where? Salem

Registration? Flyers will be sent out before school closes

Cost? Possibility of stipends

Cochlear Implants (CIs)



Here is a really quick way to find out (a) how we hear, and (b) how a cochlear implant works. Go to: <http://www.fda.gov/cdrh/cochlear/> and click on the picture titled "Cochlear Implant Device" to watch the short interactive "movie".

Things to note:

- Everyone does not get the same benefit from their CI. Hearing may vary in range from near normal ability to understand speech — to no hearing benefit at all! This FDA site documents things that determine the success of implantation, including the fact that the necessary bodily infrastructure (e.g., healthy cochlear and nerve cells) should support the CI:
 - Persons who have been deaf for a short time usually benefit more.
 - It also matters WHEN someone became deaf — especially whether deafness occurred at birth or before they learned to speak.
 - The age at which a person received a CI — as younger persons generally do better than older persons. However, adults will often benefit immediately, while a young child may learn to "hear" at a slower pace.
 - The length of time the implant has been used
 - The strength of the support services received to ensure that the CI user truly learns to use the system
 - The person's ability to learn (and tolerate some "annoyances" while learning!). It helps if the person documents what they hear, how they interpret this, and also whether they communicate this to the persons providing support services.
- The CI is, like a hearing aid, a device to help a person hear. It is not a "cure".
- The CI simulates natural hearing, but the result is not the same as normal hearing. However, even if a person cannot hear everything, if the person has sufficient vision, it will help lip-reading. Some persons can use the phone; others cannot. TV may be easier to listen to than radio — because there are visual cues with TV.
- Many CI users will find they can enjoy music.
- CI users can still participate in sports — but must be aware of when they need to remove their external equipment (e.g., during swimming, as the external parts may not be waterproof).
- Usually a CI helps the wearer to control the loudness of his/her own voice.

This site also documents what the risks are — during surgery or after:

<http://www.fda.gov/cdrh/cochlear/riskbenefit.html#a>

Here are a few other sites you might look at to get some information on Cochlear Implants:

<http://www.entnet.org/healthinfo/ears/cochlear-implant.cfm> (American Academy of Otolaryngology — Head and Neck Surgery)

<http://www.cochlearamericas.com/> states "Everyone has a different hearing fingerprint". This site has links to many other sites too. They also have some really interesting interactive ways of conveying information.



Family News



Last summer, the project was able to sponsor a small group to attend the CHARGE conference held in California. The group included Matthew, Stacey & Chris (his parents), and Shone (his IA). This proved to be a time of enrichment, bonding, expanding horizons, and fun for the whole group! They are already planning ahead to attend the next one — in Chicago. Here is a note from Shone:

This summer I was privileged to be given the opportunity to attend the International CHARGE Conference, in Costa Mesa, California. I am an instructional assistant in the public schools in Monmouth, Oregon. I traveled with my student, Mathew, and his parents.

I must admit to being a bit nervous about the conference. Mathew is the first person I've met with CHARGE. He has made such progress, and I was afraid that I'd be told that he was more fragile than I wanted to admit. Happily, our progress was to be celebrated and our expectations confirmed!

It was great to see families at ease with an instant camaraderie, chatting, eating, and doing what all families do. No one looked askance at children of all ages on the floor, being fed with a G-tube, or "talking" out of turn.

The presenters in the break-out sessions were all so well informed. David Brown and Maurice Belote really spoke to my heart. They were pragmatic, and compassionate in the delivery of their topics. Everyone left their sessions hopeful of the future with practical ideas to make each CHARGE person's life rich and full.

My favorite part of the conference? The Kids! Being able to talk to CHARGE children and young adults gave invaluable insight into the possibilities. The dance and carnival at the end of the weekend was pure joy — some kids "break dancing" on the floor, some sporting the latest moves. I know I slept well at the end of the night!

As for Mathew, he has become an ambassador. He is on the poster for the National Consortium on Deaf-Blindness. We also had a state Representative come to our school, and Sen. Smith's staff person came to Monmouth to meet him and Stacey! Mathew is teaching many about kids of all abilities.

Shone Stagg
Monmouth Elementary

ANNOUNCEMENT

Course for Parents of Children With Multiple Disabilities

<http://www.hadley-school.org/CourseDetails.asp?course=PMD111>

Unique challenges arise when parenting a child with a visual impairment as well as other disabilities, but having a basic outline and strategy could greatly assist a parent's approach to their child's learning needs.

Hadley's new course, Parenting Children with Multiple Disabilities, presents skills and techniques for furthering development in a child with multiple disabilities. This course is available in large print and online. This **tuition free** course helps parents meet their child's special learning needs.

In just seven lessons, this course provides empowering information to help their child learn and develop. Topics include an examination of basic concepts of learning; a description of professionals who may work with their child; communication, social development, and behavior issues; and an exploration of self-help skills and orientation and mobility. The course features examples of three children with different combinations of disabilities to present how individuals learn various concepts and skills in unique ways.

"Having the right information empowers the parent of a child who has multiple disabilities," said Ginger Irwin, Hadley instructor. "This course will give parents more confidence to take charge of their child's learning and development." This course is tuition free and open to students in Hadley's Family Education Program. To enroll in this course, visit www.hadley.edu or call (800) 526-9909.

CONTACT:

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Infant and Child Massage

In previous issues of the newsletter, there has been information on touch. We will continue that series, but thought that in this issue we would include some information on another aspect of touch — the ancient art (and science!) of massage for infants and children. It works!

A good place to start looking for information is the Touch Research Institute at Miami, FL., especially with information from Director, and long-time researcher, Dr. Tiffany Field:

<http://www6.miami.edu/touch-research/>

They have documented information that massage helps in a variety of ways. For example, massage:

- Facilitates weight gain in preterm infants
- Enhances attentiveness
- Alleviates depressive symptoms
- Reduces pain
- Reduces stress hormones
- Improves immune function (decreases autoimmune problems)
- Helps regulate sleep
- Reduces fussiness
- Improves sociability and "soothability" — and interaction behaviors
- Helps BOTH the massager and the massaged!
- Helps the bonding process for mothers AND fathers with their children

There is also evidence that

- Using oil helps enhance the effects
- Using firm pressure is better than light pressure

The Infant Massage Institute adds to the list:

<http://www.infantmassageinstitute.com/InfantOverview.html>

- It benefits the digestive system and stimulates circulation
- Massage improves sensory integration and encourages mid-line orientation
- It helps increase vocalization

Find out about the International Loving Touch Foundation, and its founder-director — in Portland, OR. The site will also guide you to trained massage instructors in other parts of Oregon. <http://www.lovingtouch.com/users/dianamoore>

At the URL below are a sampling of research studies documenting the value of massage (note: underlining and emphasis are mine): <http://www6.miami.edu/touch-research/research.htm#MTS>

Children with mild to moderate juvenile rheumatoid arthritis were massaged by their parents 15 minutes a day for 30 days (the control group engaged in relaxation therapy). The children's anxiety and stress hormone (cortisol) levels were immediately decreased by the massage, and over the 30-day period their pain decreased on self-reports, parent reports, and their physician's reports. [Field, T., Hernandez-Reif, M., Seligman, S., Krasnegor, J. & Sunshine, W. (1997). Juvenile rheumatoid arthritis: Benefits from massage therapy. *Journal of Pediatric Psychology*, 22, 607-617.]

Children in the massage group exhibited less stereotypic behavior and showed more on-task and social relatedness behavior during play observations at school, and they experienced fewer sleep problems at home. [Escalona, A., Field, T., Singer-Strunck, R., Cullen, C., & Hartshorn, K. (2001). Brief report: improvements in the behavior of children with autism following massage therapy. *Journal of Autism & Developmental Disorders*, 31, 513-516.]

Massage therapy helped children with CP reduce spasticity, gain more muscle flexibility, and motor function and have more positive social interaction. Hernandez-Reif, M., Field, T., Lergie, S., Diego, M., Manigat, N., Seonares, J., Bornstein, J and Waldman, R. (2005). Cerebral Palsy Symptoms in children decreased following massage therapy. [*Early Child Development and Care*, 175, 445-456]

Preschoolers were given WPPSI subtests before and after receiving a 15-minute massage or spending 15-minutes reading stories with an experimenter. Performance on the Block Design improved following massage, and accuracy was greater on the Animal Pegs in the massage group. [Hart, S., Field, T., Hernandez-Reif, M., & Lundy, B. (1998). Preschoolers' cognitive performance improves following massage. *Early Child Development & Care*, 143, 59-64.]

Infants showed more eye contact when adults, who were smiling and cooing, also touched them as compared to infants who received smiling and cooing without touch. [Pelaez-Nogueras, M., Gewirtz, J.L., Field, T., Cigales, M., Malphurs, J., Clasky, S., & Sanchez, A. (1996). Infant preference for touch stimulation in face-to-face interactions. *Journal of Applied Developmental Psychology*, 17, 199-213.]



PURPOSE of Hand-UNDER-hand

Children who cannot see very well do not really know how other people use their hands. They are often not aware of all that their own hands can do!

They may not know:

- How their hands relate to one another — i.e., how many movements need BOTH their hands
- That there are times when one hand can be used — while the other one “rests”. For example — one hand writes, while the other one rests on the piece of paper to keep it from moving
- How much force to use — when they need to push or pull hard, or when to be gentle
- Whether an action needs to be done fast or slow
- What the “shape” of the movement looks like (e.g., the twisting motion of opening a jar)
- About the “space” between their hands — and why it is important to know about this
- About hands and how their hands relate to direction.

We want children to learn about all of the above-mentioned points so that they can then begin to understand what they need to do with their hands to perform routine tasks, and to learn to do these independently of the hands of others.

They need to understand that they do not need the hands of others to do most of the routine tasks that are required of them. But they also need to know that the hands of others can be involved in some tasks that need joint action (such as lifting and carrying a heavy piece of furniture), or that have some “social” meaning (e.g., holding hands).

In encouraging Hand-UNDER-hand, we hope to

- Stimulate their curiosity rather than make them feel they are being “controlled”.
- Encourage the desire to be independent in the use of their hands.
- Reduce — even eliminate — the need for prompting for the various steps of a task.

HOW TO USE Hand-UNDER-hand

The best way to give students an experience of what THEIR hands can do will be to position yourself in such a way that they can feel the natural movements from their point of view. This will not occur if you sit opposite a child. Instead, you need to sit behind a child (if the child is small enough physically — and your arms are long enough!) OR sit beside a child (on the side of his/her “preferred” hand makes most sense). A very young child, especially a child who needs additional physical support could even sit on your lap. Things to consider:

- Make sure you are at the child’s level.
- Place your hands under the child’s hands — your right hand under his/her right hand, left hand under his/her left hand.
- For children who are “touch sensitive” and tend to withdraw their hands, you may initially have to gently “anchor” their hands with your thumbs — or allow your fingers to interlock with theirs. You will be surprised at how soon children will learn to relax once they know they are just being asked to “follow” and not to “do”.
- For children who are REALLY resistant, you may begin just with physical contact — e.g., arm to arm, hands beside rather than under or over a child’s hands. Play some movement games, or tap on the table. Make it evident that you are NOT going to force them to do something until they are ready.
- Initially find a task that is gentle and repetitive — such as stirring something in a bowl. Make sure there is some “resistance” to what you are stirring — so the child can really feel the movement of the spoon “stirring” the mixture — and how to hold on to the bowl too.
- When the child starts to show “curiosity” about the spoon, the bowl or the contents, allow his/her hands to slide down — or to feel “between” your fingers; at some point, gently encourage “joint” holding of the spoon, bowl.
- Examples of other activities to try:
 - Cutting food, scooping food, using utensils
 - Reading a Braille book
 - Zipping up a jacket; also, snaps.
 - Velcro fasteners on shoes, garments
 - Using a three-hole punch, paperclips



About Touch: Part 3 (contd.)

KEY CONCEPTS of Hand-UNDER-hand

The hands of a child who is Deafblind are not just "tools", or sensory organs deriving information from around them, but they are also the child's "voice". So, in Barbara Miles' words, "it is crucial for educators, parents, and friends of people who are Deafblind to become especially sensitive to hands. Just as they would never poke or control the sensitive eyes of a child who can see, they must learn not to control the equally sensitive hands of a child who is Deafblind, whose hands must function as eyes."

<http://www.dblink.org/pdf/hands.pdf>

So, what follows is that we think of hands in the same terms as eyes. The child needs TWO hands:

- To gather maximum information
- To know how to use them together — perhaps to do two different movements that are part of one total action
- To understand the "space" that is involved
- To understand that the world is three-dimensional; to acquire depth perception.

Keep in mind, especially if touch is the main learning mode for a child:

- That too much touch may become confusing to the child's brain. For example, touching the back of a child's hand (as in hand-OVER-hand guidance) may distract attention from what is under the hand. The child may pay more attention to your hand than what is under his/her own hand.
- Deep pressure massage to fingers and palm will help when a child continues to be resistant to touch. In most cases you will actually FEEL a child's hands become more and more relaxed.
- Talking constantly as one works with a child tactilely is also distracting to the brain. Use short precise words or phrases that describe the action or the concept — IF you need to talk. Sometimes, just working silently is best!

- Words are, more often than not, abstract and difficult — for some children, impossible — to understand. SO create contextual clues that have more meaning. Pairing these with words might ultimately give the words some "meaning".
- As always, repetition is very important.
- Slow down! Do this especially as you start out — so as not to alarm the child, or to make a child feel he/she is under pressure to feel something before it disappears.
- Work up to a normal rate of speed for that specific activity — because this is where you want the child to be. This might happen during the very first session, or it may take several sessions.
- Keep BOTH the child's hands engaged in the task. You will find that, initially, one hand (usually the non-dominant one) will tend to "wander" or not participate. The child may even need a tactile — or verbal — reminder of what each hand is doing. An example: holding a bowl while stirring something in it.
- You can use hand-UNDER-hand activities to emphasize what parts of a hand are needed to do a task — arm, wrist, fingers, palms. You can even teach the child more about what each of these parts are capable of doing.

You will KNOW you are making progress when:

- A child's hands feel increasingly relaxed while they "watch" what you do.
- The child begins to show curiosity about what is beneath your hands — and gradually begins to do more of the activity (e.g., joint holding of a spoon while stirring).
- A child becomes excited when you place your hands under his/hers — or when the child places his/her hands over yours indicating they are ready to "GO" — to learn something new.
- There is a "comfortable" feeling involved in joint tactile activities.
- A child actually does the activity independent of your hands.

I would like to thank Barbara Miles and Geraldine G. Larrington, for their "guiding ideas" on this topic.

The Project's DEAFBLIND WORKING GROUP

In each issue of this newsletter, we will introduce you to one or more members of our Deafblind Working Group:

Lyn Ayer: Coordinator, Oregon Deafblind Project

Susan McDonald— Region one, Eastern Oregon

Colleen McLaughlin—Region two, Central Oregon

Mark McKeirnan— Region three, Southern Oregon

[Terry Cadigan — Region four, Cascade Regional](#)

[Anne Olson-Murphy — Region five, Willamette Regional](#)

[Kim Puckett & Missi Hanson—Region six, Columbia](#)

Kit Staples—Region seven, Lane Regional

Brenda Satter—Region eight, Northwest Regional

Jennifer Orton —Oregon School for the Blind

Dennis Crepeaux— Oregon Commission for the Blind

Paddi Davies— NCDB representative, WOU

Tom Udell — NCDB representative, WOU

Wendy White — Parent

Sue Mathisen — Representing Regional Programs

We welcome our two newest consultants from the Oregon School for the Deaf:

Donna Schuyler and Anne Harrington



Terry Cadigan — Region four, Cascade

Terry is originally from New Jersey. He is the 10th child of a family of 14. The seed for his future profession was planted when his older brother returned from Vietnam blind.

Terry attended Kutztown State College in Pennsylvania to obtain a degree in Elementary Education and to become qualified as a Teacher of the Visually Impaired. He has been with Linn-Benton-Lincoln ESD since 1984.

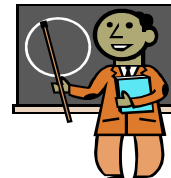
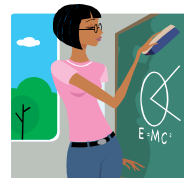
In 1989 he received his Master's degree from Western Oregon University in the area of Severely Handicapped. He has completed 12 hours toward an Orientation and Mobility certification. He became part of the Deafblind Working Group in 1984 and has made, and continues to make significant contributions to the training curriculum. Terry is an excellent teacher with a passion for what he does, a love for children — and a natural empathy with parents and families.

Anne Olson-Murphy — Region five, Willamette

Anne is a native Oregonian. She attended the University of Oregon and Portland State University. Her education qualifies her as elementary teacher, reading specialist, and handicapped learner and vision specialist. She has been a Teacher of the Visually Impaired for 10 years and a Regional Deafblind Consulting Teacher for 6 years. Anne believes the team training provided by Oregon Deafblind Project has helped teams design, implement and evaluate effective programs for their students who are deafblind. She states that all students in the classroom have benefited. Anne has involved outstanding teams in our Team Trainings. She continuously helps to identify changes to improve the quality and effectiveness of the training curriculum offered to teams by our Deafblind Project.

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

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



Kim Puckett — Region six, Columbia

Kim was born and raised in Milwaukie, Oregon. She attended Portland State University and Lewis and Clark. Her BS is in Speech/Hearing Science and her MS is in Early Intervention/Early Childhood with a focus on Deaf/Hard of Hearing Children. Her first job was as a Deaf/Hard of Hearing Itinerant at Willamette ESD. She now works at Columbia Regional as an Early Childhood Hearing Specialist and the Regional Deafblind Consulting Teacher. Kim appreciates how the Project helps to open the eyes of team members to new possibilities for each child.

Please let us know how we can be of service!

"IDEAS" CARD

This edition of **Building Effective Programs** was:

very useful somewhat useful not useful

SEND US YOUR SUGGESTIONS FOR TOPICS YOU WOULD LIKE TO SEE IN THE NEWSLETTER:

Lyn would love to hear from you! You can e-mail, or call her at:

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We would like to send you the e-mail version of our newsletter. It is colored and easy to read. So — if you are currently receiving a paper copy and would like to switch to an e-mail version, let us know by supplying your e-mail address to Lyn Ayer at ayerl@wou.edu

YOUR E-MAIL ADDRESS: _____

Phone Numbers for the Oregon Deafblind Project!


Director (vacant position)
Oregon Deafblind Project

David Jones
Deafblind Project Program Support
503-947-5731



Lyn Ayer, Coordinator
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Oregon Deafblind Project

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